# The needs of individuals and their families injured as a result of the Troubles in Northern Ireland

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In association with Northern Visions

Commissioned by WAVE Trauma Centre

Funded by the Office of the First and Deputy First Minister through the Community Relations Council

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"People who suffer from injuries are made to look like beggars if we need help. Doctors and government say it's our past and we have to move on. This is our present."

## Respondent in survey

Before you know kindness as the deepest thing inside, you must know sorrow As the other deepest thing. You must wake up with sorrow. You must speak it till your voice catches the thread of all sorrows and you see the size of the cloth.

Then it is only kindness that makes sense anymore, only kindness that ties your shoes and sends you out into the day to mail letters and purchase bread, only kindness that raises its head from the crowd of the world to say it is I you have been looking for, and then goes with you every where like a shadow or a friend.

## **Naomi Shihab Nye**



"This project has received support from the Strategic Support Fund for Groups Working with Victims and Survivors of the Troubles, which is administered by the Northern Ireland Community Relations Council ( NICRC) on behalf of the Office of the First Minister and Deputy First Minister. NICRC promotes a pluralist society characterised by equity, respect for diversity and interdependence. The views expressed do not necessarily reflect those of the Community Relations Council."

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#### Foreword

Reflecting on the challenges faced in my previous role as Chair of a Statutory Committee for The Employment of Disabled People, during the Disability Discrimination Act consultation period, along with my fellow injured group members at WAVE Trauma Centre; we were all truly delighted when our long search to secure funding for a unique research study to explore the needs of the injured and their families was eventually granted. We are therefore indebted to the Community Relations Council and the Office of the First Minister and Deputy First Minister (OFMDFM) for supporting this much-needed study.

Given the vision for the study and to ensure its robustness a twin track approach was adopted. The University of Surrey made the successful tender and was commissioned to carry out the research to deal with the intellectual aspect of the study. The research was also informed by an Advisory Committee made up of key stakeholders such as the seriously injured, the WAVE Injured group, various Victims Group representatives, the Commission for Victims and Survivors NI, OFMDFM, CRC, health and social care providers, WAVE Board members and employees See Appendix 1 for full list. The University of Surrey have been generous in their commitment to the study and we are grateful that their principal investigator, Professor Marie-Breen-Smyth was already conversant with the subject material, due to her earlier work on the Cost of The Troubles Study. Northern Visions documented the story of the study. It is also important to mention Damien McNally, WAVE's Management Board Chair who worked tirelessly and unselfishly to ensure the objectives of the study were met.

The study is needs focused and its primary purpose is to inform and advise Government, policymakers and legislators about current need and future provision.

Whilst acknowledging that the ultimate loss was experienced by those families who suffered bereavement, many of the seriously injured during our years of conflict felt that their needs were overlooked both in the past and now in more recent times as society makes the transition from conflict. In their view, "should a modern democracy or any responsible society not ensure that those most affected by the years of conflict and who live with the legacy of that conflict not have their needs met?"

We are hugely indebted to the founding members of the Injured Group at WAVE for their pioneering work and lobbying to bring about this study and our deepest appreciation go to the families of those who campaigned so hard on the needs of the injured and who are no longer with us.

Mark Kelly MBE

Chair- Advisory Committee

## **Executive summary- Short Form**

WAVE Trauma Centre commissioned this study following a competitive tendering process, with funding from the Community Relations Council for Northern Ireland through the Office of the First and Deputy First Minister. The resources for the study were augmented by the University of Surrey's contribution of the time of the Principal Investigator and the volunteered help of Dr Tereza Capelos and Stavroula Chrona.

The desire to undertake the study on the part of the funders, the commissioners, the University, and the researchers alike is driven by the recognition of the lack of attention to and knowledge of the consequences of the Troubles for those, who were injured over the decades, when violence was ongoing. Those disabled in the Troubles are a sub-set of all those injured. To date there has been no research on disability as a result of the Troubles, and the research on the population of disabled people is comparatively scarce. The goal of establishing a more complete, accurate and detailed picture of the issues facing injured people and their carers is a shared goal, as is that of improving the recognition afforded to injured people and their carers and developing more effective and sensitive services to support them.

## **Focus of the Study**

- The study focus is an examination of the needs of individuals injured in the Troubles and those of their families, particularly carers who are usually family members
- The difficulty of defining injury was identified and a working definition was adopted as the primary inclusion criteria for participants: 'life threatening or disfiguring physical injury'
- Psychological injuries were also included, but only when suffered by those meeting the primary inclusion above

## Scope of the Study

- Literature review
- Review of the numbers of Injured people in Northern Ireland
- In-depth interviews with Injured people, their carers and service providers
- Survey of Injured people
- Documentary film on the experiences people injured in the Troubles
- Archive of video interviews with injured people and their carers

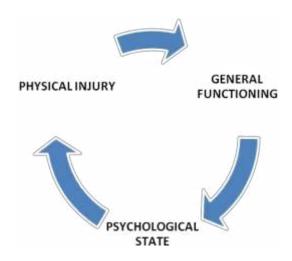
#### **Ethical Approval**

We obtained full ethical approval for the Study from ORECNI and from Belfast Health and Social Care Trust.

## **Summary of Findings**

The relationship between physical injury, psychological state, and functional capacity is complex and mutually interdependent. Physical injury will impact on functional capacity, reducing the person's ability to use their body. This in turn, affects morale and psychological state. Functional capacity similarly impacts on psychological state, and can lead to depression or conversely can give rise to a determination to recover lost functioning due to the injury. Psychological state will influence how the person functions physically and a determination to maximise functioning and live life to the full can greatly improve wellbeing.

## Relationships between psychological state, physical injury and general functioning



## The research identified the following functional impacts:

#### Need to manage complex medical needs

- 1. Chronic dependence on hospital/medical services, such as prosthetics
- 2. Restricted mobility and associated problems
- 3. Dependency on others for personal care and hygiene
- 4. Inability to ensure own personal safety
- 5. Intellectual impairment
- 6. Inability to represent own best interests
- 7. Inability to work
- 8. Difficulties or breakdown in family relationships

#### **Psychological state**

- 1. Phobias, agoraphobia
- 2. Social isolation
- 3. Depression
- 4. Anxiety
- 5. Post-traumatic stress disorder
- 6. Prescription drug dependence
- 7. Alcohol dependence
- 8. Illegal drug dependence
- 9. Loss of purpose
- 10. Chronic anger/belligerence towards others

## The Size of the Injured Population

No comprehensive census of those injured is available; therefore, it is not easy to provide a definitive estimate of the number of people who are living with injury as a result of the Troubles in Northern Ireland. This is because there is no obvious viable definition of what should be considered as 'injury' and existing estimates are likely to have been based on a variety of different definitions. The size of the population of those injured as a result of the Troubles will depend upon how 'injury' is defined. This report provides an overview of the current estimates of numbers of people injured which range from 8,383 to 100,000. Such a variation in figures is due to disparities in definition of what constitutes 'injury' and also to changing practices in record keeping over the period of the Troubles, including the destruction of some records.

## Health, Service Provision and the Complexity of Need

The majority of people injured in the Troubles are now experiencing deteriorating health and increased dependency due to the combination of ageing and the limitations placed on them by their injuries.

Many people sustained severe and traumatic injuries, which have had long-term effects on all aspects of their lives. Their injuries included blast and gunshot damage, loss of limbs, and loss of hearing and vision. Some people have injuries that are not visible, for example, as a result of embedded shrapnel or gunshot wounds, which continue to cause pain and distress. Those with injuries that are not as visible report a sense that they are suspected of malingering and a lack of sympathy with their condition.

While evaluations of initial hospital treatment were good, ongoing services and treatment were seen as inadequate in certain respects. This included limitations in current NHS

provision in terms of access to new technological developments in prosthesis and remedial treatment. The multiple health problems experienced by many injured people require attendance at a number of different services and hospitals. This often results in the injured person or carer having to coordinate and manage multiple health and social care needs. This is a complex and demanding process, which becomes more difficult with age. Thus, many injured people reported an abiding anxiety about how their future healthcare needs will be met as they and their carers get older.

Injured people expressed concern about both the lack of access to services such as emotional support, counselling, psychological treatment of trauma symptoms, family support, and care for carers. Their health problems such as drug and alcohol misuse and weight management issues have largely gone unaddressed due to a lack of service provision.

Despite advances in pain management, both injured people and service providers reported that pain management continues to be an unrecognized and under-resourced service. The psychological aspect of pain management appears to be insufficiently understood by health professionals outside the specialism. Service providers reported ongoing medical problems faced by those injured including pain management and a lack of trauma focused mental health service provision

The short term nature of funding contracts for victims' organisations who offer services to injured people and their families threatens the sustainability of such service provision. Short term funding undermines the ability of such organisations to attract and retain professional staff with the required skills. Injured people living in rural areas also identified lack of provision as a particular problem.

There is a lack of integration between victims' organisations offering services for those injured in the Troubles and disability organisations. Victims groups and disability groups operate in largely separate domains, with little coordination between them.

## **Economic and Financial Needs**

Injured people identified their economic needs and money worries as a major stressor. Initial compensation, where it was awarded, was based on income and not need, and life expectancy was underestimated. Those awarded compensation and unable to work were disqualified from benefit entitlement. Thus, injured people compensated in the early 1970s exhausted their compensation, since they had to live off it. They are now dependent entirely on benefits.

Limited life and career opportunities meant that those who returned to the labour market were not able to obtain the type of work and income they may reasonably have expected prior to injury, thus their occupational pension entitlements were drastically reduced.

Injured people reported encountering disability discrimination, some, even after the introduction of anti-discrimination legislation.

Since many injured people rely entirely on the benefit system, the current review of disability benefits is causing great anxiety, particularly the review of Disability Living Allowance. Their lack of employment history as a result of injuries sustained, and their lack of access to rehabilitation services, coupled with the current economic climate make it almost impossible for injured people denied DLA to find work.

Injured people also reported increased expense associated with their injuries and disabilities. Many of those interviewed identified the rising cost of heating as a major problem for those with mobility and neurological /circulatory problems, who find it difficult to keep warm.

On the positive side, The Northern Ireland Memorial Fund was widely highly regarded as a source of support and financial help and its uncertain future is a huge cause of concern to those who have benefited from its services.

#### Living in a Divided Society

In the context of continuing divisions in Northern Ireland, injured people have had to continue to adjust to manage their identity as a person injured due to the Troubles. Some people who experienced traumatic injuries due to the Troubles described continuing fear, distrust, and isolation and some reported feelings of resentment and bitterness that intensified after the Good Friday Agreement and subsequent broken promises of help for injured people. Several injured people described a sense that peace has come too late for them and their difficulties were compounded by a lack of acknowledgment of their suffering. This is illustrated by the remit of the Historical Inquiries Team which has no remit to investigate cases where "only" injuries have occurred. Where acknowledgement occurs it often focuses on death and bereavement, omitting injury, and this also contributes to the sense of injustice expressed by injured people.

Injured people interviewed in this study also reported their experience of invasive questions about how they were injured and encountering suspicion that that they were injured because they were "involved" in paramilitary groups. Significant numbers of injured people reported on-going concerns about their own personal security. These fears have an isolating effect and many injured people chose to stay within their own local communities because of such fears. Other injured people pass off their injuries as non-troubles related in order to avoid being drawn into awkward, invasive or anxiety provoking conversations. Injured people may live in close proximity to those who injured them, and this compounds the sense of injustice and isolation. The segregation of services between civilians and security forces also reinforces division and misunderstanding.

## Families of the Injured

Injured people and their carers reported that wider family concerns and needs, such as relationship difficulties, caring responsibilities, and financial strain were largely unaddressed by current provision. Carers described their social isolation and uncertainty about the future, and the restrictions on career and personal development as a consequence of their caring duties.

Overwhelmingly, partners and families, including children, are the primary carers of injured people and cope with the long-term physical and psychological effects of injury, disability and caring on both themselves and their injured relatives. For example, several families witnessed the attack or opened the door to the attacker who injured their family member, yet they reported that their trauma was neither recognised nor addressed. The impact of the injury and the circumstances surrounding it on the family is largely ignored in services for injured people and this has resulted in intergenerational trauma. This has significant implications for the future health and wellbeing of both the injured person and their family.

#### Recommendations

The following recommendations arise out of the research:

## Financial support for injured people and their families

- A dedicated benefits advice service should be developed for injured people and their families and carers;
- The service generally most valued by interviewees was the Northern Ireland Memorial fund. It is important that the expertise contained in their staff team is not lost to the sector. It is also recommended that the kind of service provided by the Memorial Fund is retained and expanded;
- It is recommended that CVSNI advocates that government guarantees that those injured
  in the Troubles and those who care for them are not financially penalised in the course of
  the current review of disability benefits. In pursuit of this, a system of a guaranteed
  minimum income safety net for those injured in the Troubles (similar to that operated in
  some civil service and security forces pension provision) be adopted;
- Pension rights for people injured in the Troubles should be reviewed as a matter of urgency. Urgent consideration should be given to the provision of a special pension for those injured in the Troubles, backdated to the date of the Agreement, in order to ensure their financial security and allay their anxieties about their ability to meet basic living costs;
- Urgent attention should be devoted to the ability of carers of those injured in the Troubles to acquire retirement pension rights commensurate with the value of the work of caring and the savings they deliver to the public purse in undertaking caring duties. Here, too, any provision should be backdated to the date of the Agreement;
- In the light of persistent and widespread disquiet about the inequities in past compensation awards, it is advocated that the government revisit the recommendations of the 1999 review of the scheme, in particular the recommendation of 'top-up payments' especially for the worst cases of inequity amongst those awarded compensation in the first decades of the Troubles;
- An additional heating allowance be introduced for injured people suffering from restricted mobility and who suffer from profound coldness as a result of circulation problems or neurological damage;

## Welfare, mental health, and wellbeing

- The welfare services relevant to injured people and their families that require development include:
  - Weight management
  - Drug and alcohol support
  - Support for couple relationships
  - Family support and counselling
  - Care and respite for carers
  - Training for carers /information days
  - o Improved access to pain management support
- We recommend that where these services exist, the service providers educate themselves about the specific needs of people injured in the Troubles and how these issues affect them and that they ensure that such services are delivered to injured people and are accessible to them;
- Psychological support appropriate for alleviating psychological trauma symptoms (trauma focussed Cognitive Behavioural Therapy and Eye Movement Desensitisation and Reprocessing) should be made available to injured people and their families from services capable of dealing with dual diagnoses i.e. people suffering from more than one condition, as well as conducting comprehensive multidisciplinary needs assessment and providing or signposting services on a multidisciplinary basis;
- The importance of improving mental health support and alleviating psychological trauma symptoms should be prioritised in their own right but also in terms of their significance in impacting physical health and rehabilitation. The evidence shows that depression and other mental illnesses compromise physical health and recovery;
- The most impressive model for service provision in the statutory sector was the Trauma Resource Centre currently operating within the Belfast Trust where a comprehensive needs assessment is followed by services that address a series of issues within one facility. This model should be evaluated with a view to extending a similar comprehensive multidisciplinary service in other Trust areas.

## <u>Justice</u>

- The Historical Enquiries Team remit should be re-examined to consider how people with serious physical injury can avail of the investigative capacity of the HET;
- Whilst most injured people interviewed in this study do not seek the punishment of those who caused them injury, a gesture of acknowledgement that those who caused injury understand the extent of the continuing suffering that their actions caused and some expression of that acknowledgement and sympathy would be welcomed by many;

#### <u>Integration</u>

- There is a need to address the fact that some injured people are still fearful for their safety. These fears militate against trust, partnership, and best use of resources in the sector. CVSNI should establish a working party on how fears of injured victims of the Troubles can be addressed in a manner that increases opportunities for integration and dialogue and lessens the expressed need for separate provision;
- Issues of accessibility to services and support for injured people in rural areas should be addressed by better transport provision, outreach provision and the use of new media technology;
- Disability groups should be more integrated into provisions for injured people and their families:

#### Victims' policy, service development, and acknowledgement

- Cross party support for a needs-based approach to all victims regardless of background or occupation is advocated;
- Care should be taken to ensure that all policies, services and gestures of acknowledgement should be inclusive of people injured in the Troubles, in order to address a widespread sense of marginalisation on the part of injured people;
- By putting the voluntary victims' sector onto a more secure funding cycle, services for injured people and their families could be planned on a more secure and systematic basis, staff retention issues could be addressed and services improved;
- Service provision in the form of rehabilitation and other human services for those injured in the security sector should be matched for injured civilians, and core funding for key services provided equitably for each sector.

#### Further work: measuring the size of the population of injured people

In order to arrive at a more definitive figure for the total population of injured people, a number of tasks should be undertaken.

Firstly there is a need to define the parameters of injury more clearly including differences between physical and psychological injury. This will require a consideration of setting a threshold below which an injury will not be considered sufficiently severe in order to warrant inclusion in the group of people considered to be injured as a result of the Troubles. This will result in policy and scientific challenges and may be an area of political contest, and will require direct engagement with victims groups themselves, involving them in informing decisions about how resources ought to be prioritised.

Should a satisfactory definition be arrived at; this could then be applied to a random sample of the population in a survey to establish the prevalence of injury in the wider population. This work will entail a considerably more resource intensive exercise than the one undertaken here.

## **Full Executive Summary and Recommendations**

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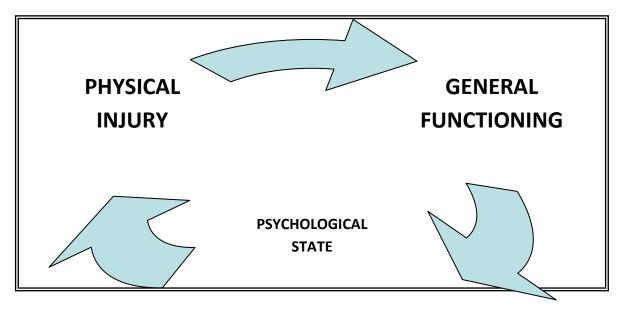
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## Relationships between psychological state, physical injury and general functioning



The research identified the following functional impacts:

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## The Size of the Injured Population

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There is a lack of integration between victims' organisations offering services for those injured in the Troubles and disability organisations. Victims groups and disability groups operate in largely separate domains, with little coordination between them.

#### **Economic and Financial Needs**

Injured people identified their economic needs and money worries as a major stressor. Initial compensation, where it was awarded, was based on income and not need, and life expectancy was underestimated. Those awarded compensation and unable to work were disqualified from benefit entitlement. Thus, injured people compensated in the early 1970s exhausted their compensation, since they had to live off it. They are now dependent entirely on benefits.

Limited life and career opportunities meant that those who returned to the labour market were not able to obtain the type of work and income they may reasonably have expected prior to injury, thus their occupational pension entitlements were drastically reduced. Injured people reported encountering disability discrimination, some, even after the introduction of anti-discrimination legislation.

Since many injured people rely entirely on the benefit system, the current review of disability benefits is causing great anxiety, particularly the review of Disability Living Allowance (DLA). Their lack of employment history as a result of injuries sustained, and their lack of access to rehabilitation services, coupled with the current economic climate make it almost impossible for injured people denied DLA to find work.

Injured people also reported increased expense associated with their injuries and disabilities. Many of those interviewed identified was the rising cost of heating as a major problem for those with mobility and neurological /circulatory problems, who find it difficult to keep warm.

On the positive side, The Northern Ireland Memorial Fund was widely highly regarded as a source of support and financial help and its uncertain future is a huge cause of concern to those who have benefited from its services.

#### Living in a Divided Society

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## Families of the Injured

Injured people and their carers reported that wider family concerns and needs, such as relationship difficulties, caring responsibilities, and financial strain were largely unaddressed by current provision. Carers described their social isolation and uncertainty about the future, and the restrictions that have been on career and personal development that their caring duties have entailed.

Overwhelmingly, partners and families, including children, are the primary carers of injured people and cope with the long-term physical and psychological effects of injury, disability and caring on both themselves and their injured relatives. For example, several families witnessed the attack or opened the door to the attacker who injured their family member, yet they reported that their trauma was neither recognised nor addressed. The impact of the injury and the circumstances surrounding it on the family is largely ignored in services for injured people and this has resulted in intergenerational trauma. This has significant implications for the future health and wellbeing of both the injured person and their family.

#### Recommendations

The following recommendations arise out of the research:

## Financial support for injured people and their families

- A dedicated benefits advice service should be developed for injured people and their families and carers;
- The service generally most valued by interviewees was the Northern Ireland Memorial fund. It is important that the expertise contained in their staff team is not lost to the sector. It is also recommended that the kind of service provided by the Memorial Fund is retained and expanded;
- It is recommended that CVSNI advocates that government guarantees that those
  injured in the Troubles and those who care for them are not financially penalised in
  the course of the current review of disability benefits. In pursuit of this, a system of a
  guaranteed minimum income safety net for those injured in the Troubles (similar to
  that operated in some civil service and some security forces pension provision) be
  adopted;
- Pension rights for people injured in the Troubles should be reviewed as a matter of urgency. Urgent consideration should be given to the provision of a special pension for those injured in the Troubles, backdated to the date of the Agreement, in order to ensure their financial security and allay their anxieties about their ability to meet basic living costs;
- Urgent attention should be devoted to the ability of carers of those injured in the Troubles to acquire retirement pension rights commensurate with the value of the work of caring and the savings they deliver to the public purse in undertaking caring duties. Here, too, any provision should be backdated to the date of the Agreement;
- In the light of persistent and widespread disquiet about the inequities in past compensation awards, it is advocated that the government revisit the recommendations of the 1999 review of the scheme, in particular the recommendation of 'top-up payments' especially for the worst cases of inequity amongst those awarded compensation in the first decades of the Troubles;
- An additional heating allowance be introduced for injured people suffering from restricted mobility and who suffer from profound coldness as a result of circulation problems or neurological damage;

## Welfare, mental health, and wellbeing

- The welfare services relevant to injured people and their families that require development include:
  - Weight management
  - Drug and alcohol support
  - Support for couple relationships
  - Family support and counselling
  - Care and respite for carers
  - Training for carers /information days
  - Improved access to pain management support
- We recommend that where these services exist, the service providers educate themselves about the specific needs of people injured in the Troubles and how these issues affect them and that they ensure that such services are delivered to injured people and are accessible to them;
- Psychological support appropriate (trauma focussed Cognitive Behavioural Therapy and Eye Movement Desensitisation and Reprocessing) for alleviating psychological trauma symptoms should be made available to injured people and their families from services capable of dealing with dual diagnoses, people suffering from more than one condition, as well as conducting comprehensive multidisciplinary needs assessment and providing or signposting services on a multidisciplinary basis;
- The importance of improving mental health support and alleviating psychological trauma symptoms should be prioritised in their own right but also in terms of their significance in physical health and rehabilitation. The evidence shows that depression and other mental illnesses compromise physical health and recovery;
- The most impressive model for service provision in the statutory sector was the Trauma Resource Centre currently operating within the Belfast Trust where a comprehensive needs assessment is followed by services that address a series of issues within one facility. This model should be evaluated with a view to extending a similar comprehensive multidisciplinary service in other Trust areas.

## <u>Justice</u>

- The Historical Enquiries Team remit should be re-examined to consider how people with serious physical injury can avail of the investigative capacity of the HET;
- Whilst most injured people interviewed in this study do not seek the punishment of those who caused them injury, a gesture of acknowledgement that those who caused injury understand the extent of the continuing suffering that their actions caused and some expression of that acknowledgement and sympathy would be welcomed by many;

## **Integration**

- There is a need to address the fact that some injured people are still fearful for their safety. These fears militate against trust, partnership, and best use of resources in the sector. CVSNI should establish a working party on how fears of injured victims of the Troubles can be addressed in a manner that increases opportunities for integration and dialogue and lessens the expressed need for separate provision;
- Issues of accessibility to services and support for injured people in rural areas should be addressed by better transport provision, outreach provision and the use of new media technology;
- Disability groups should be more integrated into provisions for injured people and their families:

#### Victims' policy, service development, and acknowledgement

- Cross party support for a needs-based approach to all victims regardless of background or occupation is advocated;
- Care should be taken to ensure that all policies, services and gestures of acknowledgement should be inclusive of people injured in the Troubles, in order to address a widespread sense of marginalisation on the part of injured people;
- By putting the voluntary victims' sector onto a more secure funding cycle, services for injured people and their families could be planned on a more secure and systematic basis, staff retention issues could be addressed and services improved;
- Service provision in the form of rehabilitation and other human services for those injured in security sector should be matched for injured civilians, and core funding for key services provided equitably for each sector.

#### Further work: measuring the size of the population of injured people

In order to arrive at a more definitive figure for the total population of injured people, a number of tasks should be undertaken.

Firstly there is a need to define the parameters of injury more clearly including differences between physical and psychological injury. This will require a consideration of setting a threshold below which an injury will not be considered sufficiently severe in order to warrant inclusion in the group of people considered to be injured as a result of the Troubles. This will result in policy and scientific challenges and may be an area of political contest, and will require direct engagement with victims groups themselves, involving them in informing decisions about how resources ought to be prioritised.

Should a satisfactory definition be arrived at, this could then be applied to a random sample of the population in a survey to establish the prevalence of injury in the wider population. This work will entail a considerably more resource intensive exercise than the one undertaken here.

## Overview of the study

#### Introduction

The Wave Trauma Centre, with financial assistance provided by the Northern Ireland Community Relations Council, commissioned to undertake this study in order to gain a better understanding of the lived experiences of those injured as a result of the Troubles in Northern Ireland. The study was commissioned from the University of Surrey.

The conflict in Northern Ireland, often referred to as the Troubles, lasted from the late 1960s until the mid to late 1990s, with violent attacks continuing beyond the formal ending of the conflict with the signing of the Belfast or Good Friday Agreement in 1998. Continuing, albeit lower, levels of violence are as a result of two things: the activities of dissident groups who do not support the Agreement; and internecine feuding, particularly amongst Loyalist paramilitary groups. The main protagonists in the conflict were the Republican paramilitaries and the loyalist paramilitaries. The republican paramilitaries largely focussed their attacks on the security forces, the police, the British Army including their local regiments, and on feuding with other Republican groups. The Loyalist paramilitaries who saw their role as 'taking the war to the IRA' but who also conducted random assassinations of Catholics and feuding with other Loyalist groups; and the security forces, whose attention was largely focussed on Republican paramilitaries and whose casualties were largely drawn from the Catholic population. From 1969 to 1998, in all, approximately 3,700 people were killed, putting the death rate on a par with that in the Israeli-Palestinian conflict, since the population of Northern Ireland is small, comprising between 1.5 and 1.7 million during the period of the conflict.

This research was informed by an Advisory Committee, which was comprised of representatives from the Recognition for All Injured, OFMDFM, Commission for Victims and Survivors NI, service providers from nursing, social work and rehabilitation services and WAVE.

## Focus of the study

- This study examined the needs of individuals who were injured in the Troubles and those of their families, particularly their carers who are usually family members;
- The difficulty of defining injury was identified and a working definition of 'Life threatening or disfiguring physical injury' was adopted as the primary inclusion criteria for participants in the study;
- Psychological injuries were also included, but only when suffered by those meeting the primary inclusion criteria above;

#### Methods

- A review of the literature;
- An examination of the numbers of injured people in Northern Ireland;
- In-depth interviews with injured people, their carer's and professionals who work with them;
- A survey of injured people;
- A documentary film about the situation of people injured in the Troubles;
- An archive of video interviews with injured people and their carers;
- Full ethical approval for the study was obtained from ORECNI and from Belfast Health and Social Care Trust. Applications to other Trusts were abandoned due to the onerous procedures involved. Fieldwork was curtailed as a result and the time and effort involved caused significant delays in the project;

## **Findings**

#### Size of the injured population in Northern Ireland

- Previous research (Cost of the Troubles (COTTS)/Smyth, 2002; Cairns and Mallett 2003; Muldoon et al 2005 CSVNI 2010) find figures between 3-600,000 people severely or very severely affected, or who consider themselves to be direct or indirect victims of the Troubles. The variation in figures is due to the use of a variety of definitions, or imprecision in definition, of 'injury' (see the further discussion on definition below);
- The NI Omnibus Survey (2010) found just over 100,000 people to be physically injured in the Troubles whereas police statistics suggest only 47,541 by 2003;
- A re-analysis of the NI Survey of Activity Limitations and Disability showed only 17 cases 6 reporting sight injuries and 11 hearing injuries, suggesting 8,383 people in the NI population suffering sight or hearing loss due to the Troubles;
- A similar re-analysis of COTTS data showed numbers of people exposed to physical attack, injured in a bomb, injured in a shooting or suffering ill health due to the Troubles peaking in the 40 -70 age groupings. The projected total population of people who met these criteria in Northern Ireland was found to be 52,153;
- There is no obvious viable or preferable definition of what should be considered as
  'injury'; existing estimates of numbers of injured are likely to have used different
  definitions. The size of the injured population will depend on how 'injury' is defined;
  given the very high levels of violence and the prevalence of large urban bombs,
  there is likely to be a 'bulge' of injured people in their late fifties, early sixties with
  blast injuries such as limb loss;

#### Findings from interviews with injured people

A sample of 30 injured people was interviewed, selected to represent the likely population of injured people in terms of type and date of injury, cause, religion, and location.

#### Health status, acute health care, and rehabilitation

- The population of those injured in the conflict are now experiencing deteriorating health and increased dependency due to a combination of the ageing process and the limitations placed on them by their injuries;
- Injured people report that their initial emergency medical treatment and subsequent acute hospital treatment was of a high standard. It is possible that some respondents experience a 'halo' effect in the early days of recovery associated with surviving a life threatening event;
- Low expectations of their health and longevity led to 'writing them off' as potentially economically active, political, creative, sexual people;
- Whilst physical rehabilitation was provided to injured people in the 1970s, and those
  provisions were consistent with standards at the time, no consideration was given to
  occupational or other forms of rehabilitation;

#### Current and chronic health and healthcare issues

- There was limited availability of the latest technologies of prosthesis, remedial interventions for those injured in the past. Current NHS provision is also often very basic and some injured people rely on the NI Memorial Fund or other charitable sources to obtain lighter wheelchairs, adaptations to their homes and other provision;
- Over time, the ageing process combines with injuries to produce additional health challenges. Some of these require continuous or repeated intervention, for example surgery to repair new problems, shorten stumps, remove scar tissue, on a regular basis for some injured people;
- Some injured people have multiple problems, requiring relationships with several different hospitals and departments. This requires the injured person and/or their carer to actively coordinate and manage their health care; this gets more complex and demanding as people get older;
- Many injured people reported serious worries about their health deteriorating over time, and anticipated that they would have increased needs in future. They worry if carers will be able to cope and whether additional services will be available when they need them;
- Comparably few resources were devoted to long-term provision for this group, including assistance with circulation problems, pressure sores, muscular-skeletal problems, chronic pain;
- Injured people who were severely wounded or who carry shrapnel report continuing problems with wound or scars re-opening or shrapnel travelling to the surface of the skin and breaking through;
- No provision was made in the past for the emotional aftermath of injury, including counselling, treatment of trauma symptoms, family support, caring for carers, and

drug and alcohol support or weight management for those with limited mobility. Some of the current provision in these areas is patchy, over-subscribed or non-existent;

- Trauma Resource Centre, Belfast, offers an integrated provision, multidisciplinary and in one location, which allows for comprehensive needs assessment and integrated provision;
- Those who lost legs reported considerable challenges in relation to problems with stumps (abscesses, need for further surgery etc), difficulties with prosthetics particularly their suitability for use over longer periods. For some, they need elbow crutches alongside prosthetics, which ties up their hands, and as a result some decide to use a wheelchair in preference;
- Those who lost two legs report issues with stability and safety in using prosthesis and they more likely decide to use wheelchairs for safety reasons as they get older or experience falls;
- Many of those with restricted mobility suffer from severe cold and require additional heating to mitigate this;
- Some injured people with no visible disability but, for example, carrying shrapnel as
  a result of gunshot wounds report a sense that they are suspected of malingering,
  and they sometimes feel a lack of sympathy with their condition, since it is not
  visible;
- Several injured people reported having significant problems with alcohol use, and having resorted to alcohol to manage emotional issues. None reported having had help with this issue. One man reported that religious practice helped him manage his alcohol use;
- Several injured people reported difficulty with weight management due to restrictions in mobility and the risks associated with being overweight being exacerbated by their overall deteriorating health situation. None reported that they have been offered help with this issue;

#### Pain management

- For some people with embedded shrapnel or gunshot wounds, or those who lost limbs and suffer phantom pain and severe itch, or those who lost mobility or sustained neurological damage, pain management is an ongoing problem;
- Injured people report an ongoing struggle with pain management, a sense of not having their pain taken seriously, of learning to live with pain, and 'Doing the best we can' to accept the pain;
- Pain and pain management continues to be an unrecognised and under-resourced issue and the psychological aspect of pain management is not always understood by e.g. GPs;

## **Criminal Injuries Compensation**

- The compensation system as it operated in the past was perceived to be highly problematic insofar that amounts were based on income and not on need, some individuals were ruled out because of eligibility rules that were perceived to be problematic, and amounts awarded were inequitable;
- In deciding amounts of compensation in the early period of the Troubles, there was a lack of foresight of longevity and future health needs of those compensated;

- People who received compensation in the early 1970s exhausted their compensation, since it disqualified them from benefits, so they had to live off it. They are now dependent entirely on benefits;
- Some used their compensation to buy a house, but now finding it hard to manage household bills;
- One injured person who divorced lost a substantial proportion of his compensation to his ex-partner in the divorce settlement;
- There seems no prospect of those compensated before 2001 getting any remediation for any of these problems or issues. The government rejected the recommendation of the review that historic cases be given a 'top up' payment. This is regretted by many injured people;

## Finances, income, and economic stress

- There is almost universal benefit dependency amongst those injured in the Troubles.
   A minority of those injured later in the Troubles have been able to work or build careers, and thus build up occupational pension rights, but this is not the overall norm;
- Some were able to work for a period of time after immediate recovery, but deteriorating health forced them to stop work well before retirement age, so they have reduced occupational pension rights;
- Some injured people sought work but faced disability discrimination and were unable to gain employment or were expected to look for menial jobs because of prejudice about disabilities;
- Current attitudes and legislative protections against disability discrimination were unavailable to those injured from the 1970s mid 1990s;
- Financial stress is exacerbated by the lack of ability to acquire pension rights for civilians and reduced pensions for security forces;
- There are enormous amounts of anxiety amongst those injured in the conflict about the current government reviews of benefits paid to injured and disabled people DLA which is seen to be threatening their already meagre income levels;
- Some injured people were unaware of the review of DLA and did not know where to go to get advice or advocacy if they needed it;
- The atmosphere surrounding the review of disability benefits was particularly
  distressing for some injured people given the press coverage and underlying
  assumptions that some people were claiming disability benefits who were capable of
  working, and that the suspicion was roused that injured people were somehow
  'swinging the lead';
- There was praise for WAVE's benefit advice service which was seen as very useful;
- Lack of employment history and rehabilitation, coupled with current job market would make it almost impossible for injured people who were denied DLA to get work;
- Financial assistance from Northern Ireland Memorial Fund was valued and welcomed by all who received it, but there is disappointment that the fund is ending, and anxiety about the loss of benefit its end may entail;

## Attitudes, identity, social integration

- Those injured decades ago described 'not being expected to live this long' and had lived with past attitudes to disability and this had shaped their social access, their expectations and self-image and their achievements were limited by it;
- Some of the older injured people described a kind of grieving process, which is
  ongoing for the life they could have had were they not injured. Several spoke in
  interview about regretting the loss of opportunity to use their talents, and the other
  losses that they sustained such as: careers, relationships, sporting activities and
  other opportunities that were inaccessible to them because of their injury;
- Some injured people talked of their awareness and guilt at what their injuries have done to their family;
- Some injured people talked about a lack of trust of other people, and fearfulness about going out or meeting people; others reported bumping into the person who attacked them or other people associated with their injury. This was particularly acute in rural areas;
- Opportunities to meet other people in similar situations through victims' groups were particularly valued, and people described how such involvement had ended their isolation;
- The research team noted that there is an almost complete segregation between
  disability organisations and victims' organisations, with disability organisations
  having little involvement with victims of the conflict and victims' organisations
  having little contact with disability groups. Those injured in the Troubles, therefore,
  who wish to avail of services in the voluntary sector must choose to attend a victims'
  group where their disability is not the primary focus of services, or disability groups,
  where their victim identity may not be acknowledged;

## **Current Victims services**

- In the statutory sector, although Cognitive Behavioural Therapy (CBT) and Eye
  Movement Desensitisation and Reprocessing (EMDR) are the treatments of
  preference for psychological traumatisation according to the National Institute for
  Clinical Excellence, these seemed difficult to access. Although CBT training had been
  bought for NHS staff, there were still waiting lists for treatment, much of this
  capacity ultimately ended up in the private sector;
- Some GPs do not seem to be able to access services on a timely basis for their patients, so some injured people were getting general counselling rather than specifically trauma focused appropriate treatment;
- Services in the Musgrave Park Hospital Limb Centre had been improved, and the role of the users group in achieving this improvement was recognised;
- The Northern Ireland Memorial Fund was generally acclaimed and the financial assistance given by the Fund was generally welcomed and appreciated. Help given was practical, adaptations, short breaks, assistance with costs of education etc;
- Disappointment that Northern Ireland Memorial Fund will be discontinued was expressed by several interviewees, and worry, about what, if anything will replace it;
- The short-term nature of funding for victims' groups has led to problems in some groups being able to plan in the medium to long term, staff being on short term contracts and a series of other problems associated with the lack of secure funding. This form of funding ultimately could undermine the quality of services in the sector;

- Groups not able to recruit professional staff such as psychiatrists on short term contracts and therefore unwilling to operate on a short term basis are forced to close e.g. NI Centre for Trauma and Transformation;
- Incrementally more onerous accounting requirements reported by some victims groups entail more resources spent on administration as opposed to front line services:
- Termination of funding and closure of some groups creates an atmosphere where groups are loathe to speak out or complain in case they become targets of attention;
- Procurement requirements means that groups must cope with more onerous and time-consuming processes, which place greater demands on their time. Attempts should be made to streamline these processes to relieve the pressure they place on groups.

#### **Identity management**

- People severely injured and disabled in the Troubles must adjust to a new identity as
  a disabled person in common with other people who acquire disability. This includes
  learning to deal with people staring at them, access issues, prejudice, and
  discrimination and so on;
- Some injured people, those with gunshot wounds, for example, can 'pass' without their injury being apparent, and some feel that the injury is therefore not taken seriously or seen as substantial;
- In addition, people injured in the Troubles must develop strategies to manage their identity as a visible victim of the Troubles. In small communities, how they came by their injuries will be common knowledge. Such knowledge can lead people to make wrong assumptions about the injured person, for example that they are well off financially because of compensation payments;
- Injured civilians reported encountering the 'no smoke without fire' prejudice if they
  disclosed that they had been shot in the Troubles, based on an erroneous
  assumption that they must have been doing something to deserve being shot or
  attacked;
- Some injured people reported prying questions if they disclosed how they came by their injuries, such as 'what does it feel like to get shot?'
- Former members of security forces habitually did not reveal their profession in social situations, and continued this when injured, often constructing fictional cover stories about how they came by their injuries, car accidents being the most common;
- Civilians, too, invent cover stories to protect the origins of their injury and thus manage to avoid dealing with the political ramifications in wider social encounters;
- Some injured people cope by restricting themselves to moving in social circles where they will not encounter the challenge of having to manage issues of identity;
- Some injured people do not see themselves as victims. Some of these people also do not see themselves as injured or disabled, even though they have substantial permanent restrictions on their health, functionality, and mobility;

## Troubles related injuries in a divided society

- Lack of contact between civilian and security forces alongside perceptions of different treatment and levels of services, compensation and financial support ensures that division and misunderstandings between the two sectors (former security forces especially former police, and civilians) persist;
- Actual material differences in levels of support and services (e.g. ex security forces
  provided with for example the Police Rehabilitation and Retraining Trust with
  recurrent funding out of central government funds whereas civilians rely on short
  term voluntary provision) reinforce some injured civilians' sense of being second
  class citizens and that provision is not needs based but preferential to former
  security forces (although there is a perception that PRRT largely serves the Belfast
  urban area);
- These divisions are exacerbated by the atmosphere of competition for ever dwindling resources, increasing scrutiny of groups and closure of some groups;
- The provision of financial support by government is interpreted by some victims as recognition of suffering and legitimacy of victimhood in some quarters, not merely as the meeting of need;
- Injured people and their families who live in rural areas face particular problems of rural isolation, making it very difficult in some cases to avail of suitable services to victims. Some victims groups servicing rural areas focus predominantly on former members of the security forces and civilians, particularly those who have not had a positive experience of the security forces may not feel able to avail of their services;
- Some injured people, former members of the security forces and civilians restrict their social activities and use of social facilities due to continuing fears, outlined above;
- Some injured people and their families live in close proximity to communities containing the organisation or individuals that attacked them. Often there has been no prosecution or justice obtained. This exacerbates victims' sense of insecurity;
- There appears to be few attempts and little success to date in addressing the fear, distrust and isolation that some injured people experience;
- Whilst segregation of spaces and single identity groups are ways of managing these difficulties in the short term, they also contribute to perpetuating the problem;
- Some of these divisions are reflected and therefore reinforced in political institutions, with certain politicians championing certain sectors of victims and displaying disinterest in others;

#### Justice

- As is the case with those bereaved in the Troubles, in many cases there were no prosecutions or convictions of those who caused the injury;
- In some cases, where collusion with Loyalist paramilitaries is suspected the injured person feels that their situation had not been dealt with fairly, honestly or justly. Even where there had been an inquiry in one case, there had been no acknowledgement of the injury caused and no prospect of prosecution;
- Where prosecutions had occurred, some injured people were disturbed by the length of sentence;

- Some were particularly upset by the early release of the perpetrator under the terms of the Good Friday Agreement and others found the Agreement roused strong and disturbing emotions, feelings that peace had come too late for them;
- Although there is a mechanism for dealing with Troubles related violence where
  justice has not been obtained, The Historical Enquiries Team (HET), located within
  the Police Service of Northern Ireland, only investigates fatal incidents, and will not
  investigate cases where 'only' injury occurred, which denies injured people the
  prospects of justice;
- In two cases examined in this research, a relative died as a result of the shock of the
  attack, but these deaths do not qualify the attack as a fatal attack in order to qualify
  under the terms of reference of the HET. This causes enormous distress to the
  injured person and their family, who are bereaved as well as having to cope with
  injury and trauma and yet are denied justice;
- The lack of regret on the part of the perpetrator, or in the worst cases the evident triumphalism or the success of perpetrator's organisation politically is also a source of bitterness for some injured people, perhaps more acute for some after the Good Friday Agreement;
- Other injured people disengage as a way of coping with these challenges, they do not think about what happened, 'because it would send you crackers';

#### **Acknowledgement**

- There was a widespread feeling amongst those interviewed that whilst death in the Troubles had been taken seriously and was acknowledged and memorialised, injury was not similarly acknowledged;
- Some injured people especially (but not only) in rural areas, and mostly civilians reported that they feel 'totally forgotten' in the public discourses about the Troubles;
- Benefits and financial payments, such as the Northern Ireland Memorial Fund, are not only valued for their practical use, but are also seen as a form of acknowledgement;
- The sense of neglect and lack of acknowledgement creates an abiding resentment that damages quality of life and health;

#### Family and Intergenerational issues:

- In some cases, the injuring attack was conducted on or near the family home with the family witnessing it. In these cases, the whole family suffers at very least the psychological aftermath alongside coping with the injured person. However often the needs of the family are subsumed in the concern for the injured person and the family's needs are not addressed;
- Families often reported feeling guilt for opening the door to the attacker, or somehow feeling unrealistically responsible for the injured attack, and this guilt can be corrosive and remain with family members;
- Some family members developed significant problems with alcohol use, which they used in unhealthy ways, in one case contributing to premature death and ill-health;
- There was no evidence of a family oriented approach to families who had been traumatised by the attack on the injured person, nor was there any evidence that a family based approach could potentially alleviate some of these difficulties;

- Some injured people were concerned about their children's mental health. Several injured people attributed the significant mental health problems of their children to the attack on them;
- Some injured people have other family members with disabilities or health needs. One injured person gave birth to a child with severe learning and physical disabilities, and so has now also got long-term caring responsibilities; however, as a disabled person she is not entitled to caring allowances for her child;
- Young children may have to act as carers or helpers for their parents. One person described how her young child learned very young that if she wanted a drink during the night, she had to get her mother's prosthesis to her mother's bedside first;

## Agency and advocacy

- An important part of the wellbeing of injured people relates to how able they feel to advocate for themselves and represent their needs and views to people in authority;
- The politicised nature of some victims' organisations and expressions of compassion fatigue relating to the victims' sector creates uncertainty and insecurity in the sector;
- Those plugged into social networks or victims' groups seem to stand more chance of getting needs met;
- Although a variety of social networks such as churches, disability groups, and voluntary sector organisations exist, not all are aware, able, or willing to serve the needs of injured people. Victims' groups will remain the most conducive environment unless awareness and sensitivity increases in these other sectors;
- Those who were active in advocating for victims and who participated in forums and other activities seem to enjoy a better standard of overall wellbeing and avoid some of the problems of isolation;

## Findings from interviews with carers

- Carers often made a positive choice to remain in relationship with the injured person and become a carer. Some marry the injured person after injury, and carers described this in a positive and proactive way, not as being 'trapped' as some injured people (and others) believe;
- Some partners do not remain in relationship with the injured person, some leave soon after the injury has occurred and divorce and separation are common;
- Couple relationships must bear considerable strain as a result of one partner being injured. Where relationship problems occur, there does not seem to be an accessible and appropriate service available to assist couples and families;
- Carers are often dealing with both physical needs and psychological issues of the injured person, and there is little recognition or support for this dual role;
- Carers often put their own life on hold whilst performing caring duties, so cannot avail of career or educational opportunities. This has long term implications for health, income and wellbeing of carers and the wider family, but this is not addressed in current pension provision, or in past levels of compensation and so on;
- These arrangements have meant that not only will the injured person, but also their whole family be dependent on benefits in the long run when compensation is used up (whilst compensation lasts, few benefits are paid). Given that benefits are set at minimal levels, injured people and their families not only suffer the physical and

psychological damage of the injury and the attack that caused it, but also endure impoverishment and financial strain in the long run;

- Carers can develop health problems, some of them severe. One carer of an interviewee had a series of strokes, for example. The reality and possibility of the carer developing such problems causes worry about carer's ability to continue and what will happen if they cannot;
- One injured person worried about what would happen to his wife who cared for him
  if he died, given that she had not been able to work since he was injured due to his
  need for care. In the event of his death, she would lose any caring allowances and be
  living on minimum benefits, given that their compensation had been used up long
  since:
- The injured person may not be the main or only person that the carer has to care for.
   Some injured people have other family members who are also disabled etc. Indeed sometimes, the injured person is also a carer but this is not understood or recognised financially;
- Male carers encounter particular difficulties in a society where males are usually not the carer. There are few if any context in which to normalise their work, and this can be damaging to self-esteem;
- In some cases, the identity of the person who cares is bound up with being a carer.
  Respite provision is important but carers may struggle with feelings of overresponsibility and trusting others to care properly for their relative, so be reluctant
  to avail of respite;
- Carers interviewed very much appreciated and benefited from social contact with other carers, with neighbours and with away days for carers;
- Carers reported great anxiety about the future, worrying about the increasing needs
  of their own and their relatives in the future and also the injured persons
  deteriorating health and ageing process. They worry whether additional services will
  be available when they need them;

#### Findings from interviews with service providers

- Service providers confirmed the range of ongoing medical problems encountered by people who had lost limbs;
- The inextricable link between good mental health and the ability to maximise physical rehabilitation was emphasised by several service providers;
- Resourcing of the Limb Centre was good, but more support for pain management services is required;
- Appropriate trauma-focussed mental health services are not always available to injured people and their families. Unmet mental health needs are seen as a public health problem, and the provision of such services is seen as an investment in the future;
- There is a need to develop commissioning structures on a cross departmental basis to address these needs;
- The value of comprehensive needs assessment and a suite of multi-disciplinary services delivered to injured people on one site was affirmed;
- The need for development of statutory sector provision in a manner that is sensitive to those injured in the Troubles is indicated;

- The comprehensive and multidisciplinary model used in the Trauma Resource Centre in North Belfast is capable of delivering services effectively in an area deeply affected by the Troubles;
- The transition to the new Victims and Survivors service has created areas of uncertainty amongst service providers;
- There is a recognition that some areas of Northern Ireland have experienced greater concentrations of the effects of the Troubles and require more support and intervention to address these effects;

# The survey

Drawing from the preliminary analysis of the interview data a short questionnaire was designed examine issues from the interviews amongst a larger number of people injured in the Troubles; A range of organisations working with victims publicised the survey and distributed the questionnaire;

## Survey Instrument - The Questionnaire

- A self-completion questionnaire was designed to elicit information about type of injury and its effect on physical and emotional health, economic circumstances and caring arrangements;
- A standard screening measure of Post-Traumatic Stress, the PDS (Foa, 1995) was embedded into the questionnaire;
- Pilot surveys were conducted to test the questionnaire and it was amended as a result;

#### **Sampling and Questionnaire Distribution**

- Respondents were self-selecting on the basis of receiving information and a copy of the questionnaire from one of distributors;
- Hard copies and prepaid envelopes were distributed and mailed in batches of 40 to 13 organisations operating in the victims' sector;
- WAVE conducted a mail shot to 1,000 people on their mailing list asking for participation in the survey;
- By the end of the fieldwork 76 completed questionnaires were obtained. Even though response levels were low, due to difficulties in accessing injured people, some significant trends can be identified; and support obtained for findings in the interview data;

#### The Sample

- There were limitations in the composition of the sample due to recruitment technique and low turnout;
- However the demographics of respondents in the sample can provide an indication
  of the networks in which injured people are included; for example, the sample
  contained disproportionate numbers of injured people from certain victims' groups

- (WAVE) or occupational groups, such as those for disabled former members of the security forces;
- The participation of particular networks in supporting the survey affected the overall demographic balance of respondents;

# **Findings**

#### **Demographics of sample**

- Gender: 54 male (71.1%) and 22 (28.9%) female participants. Total number of participants: 76; suggests that females are more likely than males to be in contact with victim organizations or with other injured people;
- 26 participants (34.2%) self identified themselves as Catholic and 46 (60.5%) as Protestant which suggest an under-representation of Catholics;
- 15 respondents (19.7% of total sample) identified themselves as members of the security forces;
- The sample is concentrated in the 41-50 years old group, 51-60 and the largest age cohort is the 61-70 age groups.
- Respondents were predominantly injured in the early period of the Troubles; over half were injured prior to 1986, and almost a quarter before 1976;
- The cluster of respondents between 50 and 70 years old were aged between 10 and 30 years old during the 1970s when deaths and injuries at their height;
- Half of the sample were between the ages of 11 and 30 at the time of their injury;
- The age demographic is likely to be broadly reflective of the real pattern of injury;
- In terms of area, 18 participants (23.6%) were injured in Belfast, 10 (13.2%) in 'Other Co Tyrone', 9 (11.8) in 'Other Co Antrim' and the same proportion in 'Other Co Fermanagh', 8 (10.5%) in 'Other Co Derry/Londonderry';
- 6 respondents (8%) reported more than one injury in the Troubles;
- The majority of respondents were married (56.6%) with a further 14 (18.4%) being divorced, 7 (9.2%) widowed, 9 (11.8%) single and 1 co-habiting;

## Patterns of injury in the sample

- Victims of Republican paramilitaries are over represented in the sample, whilst victims of Loyalist paramilitaries and victims of the security forces are comparatively under represented;
- Bomb injury and shooting were the most common cause of injury reported by 24 participants (31.6%);
- In addition 13 participants (17.1%) reported multiple gunshots and 12 participants (15,8) mentioned single gunshot as the cause of injury;
- Severe beating was also mentioned by 6 respondents (7.9%);

# Nature of the injury

• The most frequently reported injury was partial loss of hearing (33 participants, 43.4%);

- 28 respondents (36.8%) reported disfigurement other than facial (damages at hands, legs etc);
- 11 respondents (14.5%) mentioned facial disfigurement;
- Respondents also reported triple limb loss, double limb loss, loss of one eye, partial loss of sight, total loss of sight, total loss of hearing;
- About half the respondents reported multiple injuries as a result, for example, of being in a bomb explosion;

# Impact of Injury- Impaired physical function

- 23 respondents (30.3%) cannot walk as a result of their injury;
- 15 (19.7%) experience constant pain;
- 6 respondents (7.9%) reported brain damage, depression, anxiety and/or panic attacks related their experience of injury;
- 4 (5.3%) are paraplegic;
- 2 (2.6%) experience paralysis in one limb;
- Respondents reported that restricted mobility had severe impacts on their lives and self-perception;

# **Recovery since injury**

• Less than half, 31 (40.8%) reported a total recovery, with exactly half, 38 (50%) reporting a partial recovery and 5 (6.6%) reporting no recovery since injury;

#### **Current Physical health of the Victims**

- Whilst some respondents mentioned that they had made some recovery and their health state has improved; a large number reported severe or medium mental health issues and the highest proportion reported multiple health problems (61 respondents; 80.3%);
- A large number of participants expressed concerns about the impact of ageing on their already diminished health;
- A large number of respondents reported significant mobility problems that prevented them from participating in social activities;

#### Impact of the injury

- The most common response to the question about the impact of their injuries, was that it had totally changed their lives, followed by respondents reporting that it had meant the loss of employment and the loss of their home;
- Respondents reported that their injury had caused family stress, relationship breakdown, loss of education and restricted social life, and mental health problems;
- A number of respondents reported alcohol abuse as a result of their injury;

## **Experience of Hospital Treatment**

- Injured people had positive experiences of hospital, with 65% reporting 'excellent' or 'good' experiences, and only 9% reporting 'not good' or 'bad' experiences;
- Almost three quarters of respondents' hospital treatment was 20 years or more ago.

- In particular, for 15 respondents (19.7%) treatment took place 40 years ago, for 20 (26.3%) 30 years ago, for 22 (28.9%) 20 years ago
- The rest of the participants answers ranged between 10 years ago and the present day
- a substantial minority 23, (43%) of the respondents attend hospital several times a year, 9 (11.8%) attend monthly, representing a substantial demand on medical services, if taken over the period of time since their injury
- The main reason given for repeat hospital attendance was check-ups (17 or 22.4%) followed by complications due to the injury (15 or 19.7%)
- Degeneration of the injury accounted for a further 12 or 15.8% respondents' hospital attendance with only 2 respondents were attending for rehabilitation

### **Experience of health services**

- 34.2% (26) rate their GP or District Nurse as excellent, 42.1% (32 participants) rate them as good and 15.8% (12 participants rate them as not great but they did their best and 5 participants (65%) rate their experience as 'not good' and 'bad'
- Contemporary experience of hospitals is less likely to be ranked as excellent (13 or 17.1%) as opposed to past experience of hospitals (22 or 28.9%)
- About the same number (28 or 36.8%) ranked their present experience as 'good' as in the past (27 or 35.5%); negative rankings of hospital remained about the same - 3 respondents ranked their present experience as 'bad', whereas 5 had ranked it as 'bad' in the past

### Pain management

- Some 89.5% of respondents, 68 out of 76 reported that they suffered constant pain from their injury at present, but only 25 (32.9%) said that they attended a pain clinic;
- First preference for managing pain is clearly prescription drugs, but the next most popular is alcohol. Non-prescription drugs, complementary therapies and religion are much less popular as a first choice, but nonetheless respondents report using them for pain control; meditation and complementary therapies together with religion were as popular as a second choice;

## Help and support

- The overwhelming majority of respondents (68 or 89.5%) cited their family as their first source of support;
- 2 respondents (2.6%) reported no family and 2 (2.6%) reported that they have no help and support;
- Family and friends still feature prominently, alongside less prominent helpers such as churches, victims' organizations (such as WAVE) and employers;

#### **Counselling and Emotional Support**

• 62 respondents (81.6%) replied that would have been benefited from counselling or emotional support and 12 (15.8%) saying that they would not have benefited;

- Only 21 (27.6%) said that they had they had received counselling or emotional support at the time of the injury, with the majority 55 (or 72.4%) saying that they had not received any such support;
- Of those who had received such help (24 respondents), two-thirds 16 (or 66%) found it helpful.
- 44 respondents (57.9%) said that they had received counselling or emotional support later, whilst 30 (39.5%) said that they had not;
- Of those who got such help (46 respondents) 35 (76%) said that they found it helpful, whereas 11 (24%) did not find it helpful
- 29 respondents (or 60.4%) who were helped later were helped by the voluntary sector, compared with 19 or 39.4% who were helped by the statutory sector

# **Impact on Families and Carers**

- Nearly two thirds of respondents, 48 (63.2%) said that their injury had 'changed everything' and a further 16 (21.1%) said that it had had a strong effect on those around them
- Spouses and partners emerge as the most likely carers for injured people, followed by other family members, sons or daughters and then parents
- The 'other' category included friends (2), 'myself' (6) including one respondent who commented 'I look after myself, I don't have a choice'
- The pattern of the family being the primary source of care for the injured person emerges very clearly from these data.

## **Support for Carers**

- Only 24 respondents (31.6%) said that their carer received Carer's Allowance with 44 (57.9%) reporting that their carer was not in receipt;
- Out of the 68 respondents with carers, only 10 (14.7% out of 68) said that their carer gets the option of a respite break and 55 (80.8%) said that they did not;
- Asked if their carer can avail of emotional support, only 3 (4.4%) said that emotional support was available to their carer, whereas 62 (91.2%) said that their carer could not access emotional support;
- 20 (38.5%) said that their carer needed other support, whereas 32 (61.5%) said that they did not;
- The respondents said that their carers needed respite/ a break, emotional support, financial support, complementary therapy, practical support.

#### **Post-Traumatic Stress**

- The PD Sis commonly used as a screening measure for Post-Traumatic Stress Disorder. Scores are placed on a four point scale: 10 or less (mild); 11 to 20 (moderate); 21-35 (moderate to severe); and 36 and above (severe) with those who score at the mild end less likely to have PTSD and those at the severe end most likely to suffer from the condition. Patients scoring moderate or severe scores on this scale are those who would attract clinical attention.
- In total, 65 respondents completed the scale, and their final scores ranged from 3 to 51 on the scale.

- Less than 4% of the sample (3 respondents) scored at the mild end of the scale, 6.6% (5 respondents) scored as 'moderate';
- Three quarters of the sample, (75% or 57 respondents) scored as either 'moderate to severe' or 'severe' on the PDS scale.
- This rises to 87% of the respondents who completed the PDS scale, if we exclude the 11 respondents (14.5%) who did not complete the scale

### Ability to return to work in the aftermath of the injury

- Overall, 24 (31.6%) said that they were able to return to work, whilst 46 (60.5%) said that they were not. 54 respondents (71.1%) said that they wanted to return to work, and 15 (19.7%) said that they did not want to return to work;
- In asking the respondents what prevented them from going back to work, 42 (55.3%) mentioned their health, physical disability and issues of access prevented them, 20 (26.3%) reported that incidents of intimidation and fear preventing them, 39(51.3%) said that anxiety, depression and loss of confidence prevented them and 5 (6.6%) said that a lack of job opportunities prevented them.
- Over half of the respondents (43, 56.6%) were never able to work since their injury, with 6 finding employment elsewhere.
- In asking participants to provide the reason of not being able to work since the injury, almost a quarter (17 people or 22.4%) of the sample reported that it was primarily the physical limitations caused by the injury, that prevented them, 29 respondents (38.2%) reported that their inability to work was due to a combination of physical and emotional problems. Only 11 (14.5%) explained their inability to work as due to psychological causes alone.

## **Criminal Injuries Compensation payments**

- Of the total 76 respondents, 65 (85.5%) said that they had received compensation, with 10 (13.2%) saying that had not been compensated, or that they had not yet been paid.
- About 14% (11 respondents) of the sample thought that their legal advice was either good or excellent, whilst 38% (29 respondents) thought that it was 'not good' or 'bad'. A further 40.8% (31 respondents) thought that their legal advice was 'not great but they did their best'.
- In over 40% of cases, in the experience of 31 respondents it took between 2 to 3 years to settle their compensation case. Very few cases (4 cases or 5.3%) settled in less than this and 27 (35.6%) took longer, some up to ten years, to settle. Only 9 respondents (11.8%) thought that their compensation was adequate for their needs, with 56 (73.7%) seeing it as inadequate.
- 52 (68.4%) of respondents said that they received Disability Living Allowance, 21 (27.6%) said that they did not receive it;
- 36 respondents (47.4%) said that they received Incapacity Benefit and an equal number said that they did not. A further 22 respondents, said that they did not receive any other benefits or pensions, whilst 45 (59.2%) said that they did receive such pensions or benefits;
- 4 respondents received Ministry of Defence or army pensions, 6 received industrial injuries pensions, 9 received state retirement pension, 1 received a 'state police pension' and other responses were inconsistent;

- Only 7 (9.2%) said that their financial needs were well enough met, 35 (46.1%) said that their income was 'just adequate', 27 (35.5%) said that they struggled to get by and 5 (6.6%) said that they cannot survive on their current income;
- Respondents told us that the kind of financial assistance they would find helpful
  were pensions or benefits, compensation, medical and aids, any financial help at all,
  heating, financial support for carers, housing and household costs and help at home,
  emotional support, respite and breaks;
- Two respondents commended the Northern Ireland Memorial Fund and wished it to continue;

# Victims' groups

- Over 80% (61 respondents) were aware of victims groups in their area, and only 14 respondents (18.4%) were not aware of such groups;
- However, this result could be a product of our sampling strategy, which used victims' groups as one of the distribution mechanisms for the survey. This is supported by the fact that nearly three quarters (73.7% or 56 respondents) said that they were members of a victims' group;
- Those participants who were not members said that they did not join because of: negative views about the groups, access issues, and difficulties, not being aware of victims' groups, not attracted to the idea of groups and security issues.

#### The film

A subset of interviewees was selected representing the spread of experience and demographic in this study. Interviews were filmed by Northern Visions focusing on the issues raised in the other parts of this study. Footage will be edited into a feature documentary film and a short campaigning film for use by WAVE Injured Group. Footage will also be archived for historical and other purposes to be determined by WAVE.

#### Introduction

This is a participative action research study of injury due to the conflict in Northern Ireland, carried out in partnership with key stakeholders, those with professional and personal expertise in the matter of injuries and centrally with those who have, themselves sustained such injuries. These stakeholders participated directly in the research process as members of the advisory group, by assisting with the distribution of questionnaires, by reviewing methods and findings, some as interviewees and they also advised on all stages of the work.

Given the urgent need to raise the profile of this issue and secure improved services and provisions for those injured in the Troubles, the project also encompassed a film dimension, selected research interviews were filmed and the film was both archived and edited into a short film setting out the challenges and issues facing those injured in the Troubles. This work was carried out by Northern Visions, who have a track record of work with this group of people, and a personal commitment to supporting their cause.

There are a number of challenges facing anyone working in this field and seeking to provide robust and comprehensive research evidence. Chief amongst these challenges is the lack of a central, reliable database or census of all those injured in the Troubles.

Second, is the issue of the definition of what constitutes an injury – does it include physical, emotional, and psychological injury for example, and what is the distinction between injury and disability. These difficulties are addressed in this project and a number of decisions were made which necessarily limit the scope of the project.

#### The focus of the Research

The goal of this research project is to provide the first comprehensive exploration of the needs of those injured as result of the Troubles and their families through the provision of an account of the physical, emotional, and psychological effects of injury due to the Troubles and an evaluation of the support provision available. This is a long neglected area and one that urgently requires attention and documentation that can assist in building up political will to remedy that neglect. This research aspires to be a tool through which the situation of those injured in the Troubles is recognised and improved.

There are several issues that require clarification so that a useful and appropriately focused piece of research could be designed and delivered within the available resource limits. These issues are: issues of definition; issues of prevalence and incidence; the representativeness of any survey; the structure of the project; ethical considerations; and the nature of the outputs.

#### **Issues of definition**

The brief for the research project is 'the needs of the injured and their families'. At the outset, it is important to clarify how this population is defined. First of all the definition of 'injury', is clarified and defined for the purposes of this study.

### Definition of the population to be examined

During the Troubles, many injuries were sustained in the wide range of violent occurrences over the decades of violence. Some of those injured sustained only minor injuries, and some made full recoveries from their injuries. Others were less fortunate, sustaining severe injuries that led to disabilities and permanent loss of senses and bodily capacities.

At the outset of the research, the researchers spent time with the advisory group clarifying and defining the focus of the research and the parameters within which respondents were to be recruited. A number of factors influenced the decision about the focus of the study.

First, we were aware of another literature-based study focussing on the mental health effects of the Troubles. For this reason, and because of the difficulties in defining psychological injury, it was decided that physical rather than psychological injury would be the focus of the study.

Second, we are aware that the severity of injuries sustained in the Troubles varied enormously. Given the limited resources available for the study, it was decided that the research would discuss the various definitions of injury and disability including psychological injury in order to highlight the wider context before narrowing the scope of the project. It was decided that the primary focus of this project should be on serious physical injury, although we interviewed those with both physical and psychological injuries to explore the connections and interplay between the two. It was also decided that the land mass of Northern Ireland would be the boundary of the project which means that injured police will be included, but injured members of the British Army were not included except those who served in local regiments.

This tight focus rendered the project feasible within the time and resource limits, provide greater clarity and potentially greater impact on policy makers, since there is a lack of authoritative data on the subject.

### **Disability as a result of the Troubles**

Those disabled in the Troubles form a sub-set of those injured. There has been no specific research on disability as a result of the Troubles, and even the research on the general population of disabled people is not comprehensive or plentiful. Research carried out by the Northern Ireland Statistics and Research Agency in 2007 (NISRA, 2007) concluded that:

"There is a lack of good quality information on people in Northern Ireland with a disability, especially in terms of their multiple identities and their experiences across a range of social and economic contexts such as education, employment, transport and claiming of benefits."

NISRA went on to point out that "there are significant difficulties surrounding the definition (or definitions) of disabilities". Disability is not a homogenous concept. It can be conceptualised under three broad headings: physical disability; learning difficulties; and emotional disability. There are difficulties in setting out even this definition, and in delineating the various sub-categories. However, we will attempt to briefly sketch out each and their relevance to this research.

## **Physical disability**

Physical disability in Northern Ireland as a result of the Troubles takes on particular forms. Those who lost limbs in the Troubles, many during the bombing campaigns of the 1970s and 1980s, not only lost full function but the longer term impact of such loss is attritional on general health, identity, life chances, employment and financial status as well as on family and community.

Some others have suffered paralysis or damage to limbs, necessitating the use of braces, walking aids or wheelchairs. Another cohort of injured people suffered brain injury due to gun or bomb attacks. Gunshot wounds have caused particular forms of neurological damage that pose acute challenges for physicians in terms of pain management. Yet others were injured by missiles, fire or baton rounds in riot situations or street disturbances throughout the Troubles and this is a continuing feature of life in Northern Ireland.

The use of medication for injuries has also caused further problems in some instances, for example, the use of morphine for pain relief in cases of neurological damage due to gunshot wounds or the practice of prescribing psychotropic drugs now known to be addictive in the early Troubles.

The deterioration of health over time, and the increasingly complex needs of those with disabling physical injuries as they grow older points to the need to revisit levels of compensation, as well as to re-evaluate the suitability of support services to the changing needs of this population and their carers.

Coupled with the psychological issues related to victimhood, this may have led to further deterioration in physical and psychological health. Furthermore, the social aspect of

explaining the causation of disability presents difficulties for some of those disabled as a result of the Troubles, particularly those disabled whilst in the security forces. The necessity of managing identity has faced many people injured and disabled in the Troubles, particularly when the violence was at its height. This has had implications not just for the identity of the disabled person, but also for their perceived safety and that of their families.

# **Emotional disability**

Those emotionally traumatised as a result of the Troubles are not usually regarded as disabled. However, there are chronic forms of mental illness that can be regarded as disabilities. Evidence from the field of traumatology would suggest that those who endure repeated traumatisation over a protracted period might end up suffering from disabling chronic psychological conditions as a result. These conditions are not usually amenable to remission as a result of any known intervention at this time and therefore, arguably may be regarded as environmentally caused emotional disabilities. Given the available resources for this study, and the limits on the timescale, we will only examine emotional or psychological challenges or damage sustained by those seriously physically injured as a result of the Troubles by including an examination of their emotional and psychological needs. Those who have sustained a psychological injury without a physical injury will not be included in the study, for practical reasons. This is not to suggest that their situation is any less serious or urgent, but merely that our resources will not stretch to that extent.

# Literature Review and Review of existing research

Stewart and Jain (1999) in a study of war-related limb loss remarked gruesomely that:

'In all armed conflicts there is considerable advantage in maiming rather than killing one's foes. The injuries thus sustained occupy much time and medical resources which if the individual had died would not have been incurred, tying up manpower that could be used in a more "war effective" way.

The costs - financial, emotional, social, and political – of injury in the Troubles are addressed in a rather piecemeal fashion in the literature. In the following part of the review, both the academic literature as well as related research studies undertaken in the sector will be reviewed. Unfortunately there are only a few primary studies focused on those injured in the Troubles that have been undertaken; and the small number that have been conducted have largely focused on specific kinds of injuries, such as limb loss, and those on specific aspects such as health problems or the costs of, or access to, services.

Although the study's primary focus is on physical injury, the psychological injuries could not be ignored, given that many of those physically injured have also endured substantial psychological injury. For this reason, the review encompasses selected relevant material on psychological traumatisation. The review is organised under ten headings: health and wellbeing, with subheadings on physical and psychological health; services; identity management; social support and respite; trans-generational issues; individual financial support; compensation; agency; services in a divided society; and truth, justice and acknowledgement.

#### Health and wellbeing

Health and wellbeing among people living in a society where violence, death, and injury were a daily experience for three decades of conflict could not be unaffected. In Northern Ireland nearly 3700 people were killed, tens of thousands injured with the intensity of the violence being particularly severe in the early years, and unknown numbers of others were traumatised by bereavement, grief, incarceration, and witnessing violent events. Particular groups (predominantly male) and particular neighbourhoods (those of high intensity of violence) were most vulnerable to trauma and the negative consequences in terms of both physical and mental health (Fay, Morrissey, Smyth, & Wong, 1999, p. 77). Early estimates of total numbers of injured suggest that 40,000 people were seriously injured (Daly, 1999); this issue is discussed in more depth in Section 8.

#### **Physical health**

Although various studies have been conducted, often by clinicians working in accident and emergency departments, comparison of results and compilation of figures is prevented by variations in methodologies and definitions. Nonetheless, an overall sense of the pattern of injury can be acquired by reviewing some of these studies.

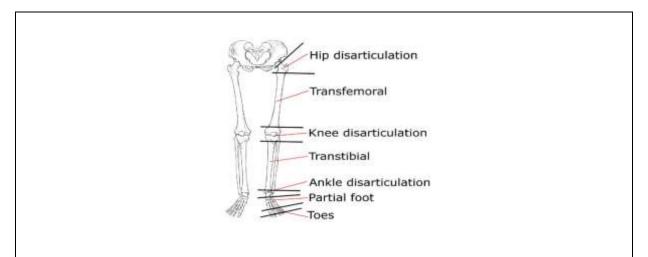
In particular, Hadden, Rutherford, and Merrett (1978: pp. 525–531) examined bomb injuries in 1,532 patients in the early period of the Troubles. Of the total 1,532 explosion victims, 9 died in hospital). They found that injury to the chest or abdominal organs was comparatively rare (10 patients of whom 5 died) as was primary blast lung (2 patients). In addition, 16 patients underwent major limb amputations 4 of whom died. None of the 50 patients with burns required skin grafts. Injuries were predominantly to the head, neck, and limbs, suggesting the protective effect of clothing. The study, however, includes a cohort of patients who suffered from emotional shock, most of these had no physical injury, and 82% of these without physical injury were female. This study pointed to a pattern that remained more or less consistent subsequently, with limb loss being the most frequent serious physical injuries due to bombs.

# **Limb loss**

As limb loss emerged as one of the most common, if not the most common serious physical injury due to the Troubles, Graham and Parke (2004) conducted a retrospective study of limb loss due to the Troubles. This study analysed patient demographics of the survivors of political violence in Northern Ireland who suffered limb amputations due to the Troubles between 1969 and 2003 of whom there were 129 patients (Graham and Parke, 2004: 255).). This, in itself is of interest in terms of calculating total numbers of injured people with limb loss in Northern Ireland. They report 9 deaths in the period 1969- 2003 (35 years) which gives a death rate of .0069 over 35 years. Using this rate, one could anticipate a further 2 deaths since 2003, leaving a total of 118 people who have suffered limb loss using their services, five of whom have left Northern Ireland. This would suggest a current population of 113 people currently living with limb loss due to the Troubles in Northern Ireland. Their analysis showed that in the total population suffering limb loss there was a predominance of males (110 or 85%) and civilians (72 or 56%). Of the total, 19 or 15% were police officers, 16 or 12% army personnel and 22 or 17% were assessed to be members of paramilitary groups. They found age injury ranged from 7 to 60 years with an average of 30.9 years. 11 or 9% of the patients were 16 years or below at the time of injury, 7 sustained upper limb amputation and 4 lower limb amputation. The number of amputations in each year is concentrated in the years 1971-1976 with further lesser peaks in the years 1991 and 1978.

Out of the total 93 (72%) patients underwent immediate amputation and 27 (21%) had a delay (1 day to 26 years) in amputation. Causes of delayed amputation ranged from non-healing of deep wounds, chronic osteomyelitis and failed arthrodesis. Booby trap, under car or car boot bombs were the most frequent cause of injury, followed by static bombs, then gunshot wounds. Of the 26 gunshot wounds, 13 were kneecappings. A total of 92 (71%) patients required amputation of one limb or part thereof, 35 (27%) required amputation of 2 limbs, 3 patients (one police officer, one army and one civilian) suffered loss of both hands. There were also 2 patients that (<2%) underwent triple amputation: one sustained trans-femoral, trans-tibia and trans-radial amputations, and the other bilateral transfemoral and trans-radial amputations. The interview data and survey analysis presented later in this report shed further light on the ongoing needs of those suffering limb losses.

Figure 1: Nomenclature-Lower limb amputation level



Source: Stuart. C.P.U. and Trimmings, N. (2008) Synopsis of Causation: Lower Limb Amputation. Ministry of Defence

Stuart and Trimming (2008) summarised the causation and prognosis of lower limb amputation providing a useful synopsis of the demographics of military amputees, but significantly the long-term effects, complications and side effects, which are also relevant to civilian amputees. The relevant points are that:

- [amputees''] life expectancy is similar to that of their peers, although it will depend on the severity of the overall injuries;
- long-term artificial limb use is associated with an increase in back pain although not specifically osteoarthritis, but the timescale for this development is unpredictable;
- lower limb amputation is associated with the premature development of arthritis in the hip on the amputated side (61%) and on the non-amputated side (23%) (expected incidence 11%) (Kulkarni et al 2005). This does not lead to an increase in the need for prosthetic hip replacement as compared to the non-amputee population;
- stump pain is common and can occur at any time after the amputation, even 20 or more years later; in some, this is due to the development of neuroma which may require surgical excision; however, in some cases this does not relieve the problem;
- stump pain can also occur from prosthetic use;
- the prosthetic socket imposes considerable pressure on the stump, which in turn
  was not designed biologically to function as a weight bearing structure;
- prosthetic advances have improved the comfort and function of artificial limbs;
   however, they are not perfect replicas of the natural limb;
- phantom sensation occurs in over 90% of all amputees. These phenomena can be in the form of simple sensation, or severe intractable pain;
- phantom pain occurs in about 30%-50% of amputees. There is some evidence that traumatic amputees have more pain than other amputees;
- the level of amputation has no effect on the phantom incidence;

- management of phantom pain is difficult; there is a huge range of methods that have been tried. In some, no treatment works totally successfully; ...
- prosthetic developments will hopefully reduce the secondary pathological problems that inevitably occur with long-term artificial limb use.

An international comparative study conducted by Frykberg and Tepas (1988) compared casualty patterns in bomb explosions in Northern Ireland with those in Israel, Beirut, Italy and the US. However, caution must be exercised since the size and targeting of explosions in Northern Ireland varied considerably over the period of the conflict, from the large city centre bombs to the individually targeted car bomb whereas bombing in other places, Israel, Beirut and elsewhere took other forms and this will have implications for the way casualties are caused. Frykberg and Tepas use their data to calculate a critical mortality rate of 12.4%, (that is the number of critically injured people who die) which is used elsewhere in this report to calculate numbers of critically injured in explosions in Northern Ireland.

A later study by Graham et al. (2006) examined the psychological state and physical rehabilitation of patients who suffered limb loss due to the Troubles. They set out to determine their satisfaction with 'the period of primary prosthetic rehabilitation and the artificial limb' (Graham, Parke, Paterson, Stevenson, 2006, p. 797.) Patients were screened using The Special Interest Group in Amputee Medicine (SIGAM) mobility grades, the General Health Questionnaire (GHQ12), and three screening questions for Post Traumatic Stress Disorder (PTSD). They obtained a response rate of 66%, where 52 (69%) patients felt that the period of primary prosthetic rehabilitation was adequate; 32 (54%) lower limb amputees rated their mobility as poor; 45 (60%) patients stated that they were still having significant stump pain and this was associated with poorer mobility. Over half the upper limb amputees could function with their prosthetic limb. In terms of emotional well-being and mental health, 33 (44%) patients showed "psychiatric caseness" on the GHQ12 and 50 (67%) had symptoms of PTSD. Poor mental health was associated with lower levels of satisfaction with rehabilitation and with stump pain.

Moving beyond from the realm of the purely physical and incorporating the mental health dimension is the work of van der Volk (1994) whose work on the psychobiology of post-traumatic stress focuses on the biological as well as the psychological aspects of traumatisation. According to this approach, the neuro-endocrine system is implicated in the psychobiology of trauma, calling for a comprehensive approach to treatment including the use of psychotropic medication, drugs that affect the mind. The research team noted that in a number of treatment facilities, there is a growing recognition of the mind-body connection in relation to traumatisation, and the use of physiotherapy (Trauma Resource Centre) aromatherapy; deep tissue massage, yoga and other forms of exercise are increasingly part of a suite of treatments offered.

Another study that bridges the fields of physical and mental health is Seff and Gecas' study of injury, pain, and depression. Using path analysis, they look at the direct and indirect effects of pain and work limitation associated with a job-related injury on self-efficacy self-esteem and depression. They found that self-efficacy, or what we refer to as 'agency' and self-esteem is negatively associated with depression, while work limitation and pain are positively associated with depression. They also found that limitation on the ability to work

has indirect effects on depression through its negative effect on self-efficacy and self-esteem. Furthermore, they found that pain has an additional indirect effect on depression through its effect on self-efficacy and its limiting effect on the ability to work. They concluded that self-concept has a significant effect on the relationship between physical injury and depression.

"The strongest relationship in the path analysis is between pain and work limitation. Individuals in pain frequently restrict their activities in an effort to avoid pain. Part of the effect of pain on depression is mediated by work limitation. This result confirms conclusions reached in pain treatment programs. When such programs are successful in returning patients with chronic pain to normal activities, success is related to reduction in functional limitations, often without any change in overall pain intensity (Swanson et al. 1979). Individuals who have learned ways to increase their ability to work in the face of pain are less depressed." (Seff & Gecas, 1992, pp. 584-5)

For many of those injured in the early phases of the Troubles, finding work, even if they were physically or mentally capable of doing so, was almost impossible due to barriers of discrimination against disabled people. Such barriers, then, according to this study could negatively impact on a cluster of factors, through the limitation of access to work, reflecting both bodily and psychological processes.

"It is highly likely that the direct relationships between pain and depression and between work limitation and depression reflect biological or behavioural processes, while the indirect relationships mediated by self-esteem and self-efficacy reflect cognitive processes. The presence of both direct and indirect effects suggests this view. We think behavioural and cognitive explanations are valid in considering these relationships. In conclusion, pain and work limitation (two frequent consequences of physical injury) clearly affect depression. Much of this effect is direct, but some of it is mediated significantly by self-esteem and self-efficacy." (Seff & Gecas, 1992, pp. 585-6)

Thus, the maintenance or restoration of self-esteem and self-efficacy is central to the resilience of the individual, according to this analysis.

# **Mental health**

Gilligan (2006) provides a useful and succinct overview of the mental health issues manifested in the Troubles. He points to the early studies, which linked street violence to increased admissions to psychiatric hospitals and increased use of tranquillisers by general practitioners (GPs) in Belfast (Fraser, 1973: 45–59). A more recent study has found a positive correlation between 'the extent to which people and areas were affected by the Troubles ... and the likelihood of suffering from significant mental health problems' (O'Reilly and Stevenson, 2003: 491 cited in Gilligan 2006). However, there is disagreement about the nature and significance of the psychological impact as Gilligan points out. On the one hand, some such as O'Reilly and Stevenson found a direct correlation between exposure and mental health outcomes whereas Fraser, however, found that serious psychiatric illnesses

'showed an increase only in areas adjacent to those affected by rioting' (1973: 59 cited in Gilligan). Nor was there a catastrophic social breakdown and according to Curran (1988)

"as well as can be judged from community surveys, hospital admissions and referral data, psychotropic drug usage, suicide and attempted suicide rates, and from assessment of the actual victims of violence, society has not broken down nor has the impact been judged considerable." (Curran: 1988, p. 474)

Gilligan points to Curran's distinction between mild psychological disturbance ('normal anxiety') and serious psychotic illness, arguing that the Troubles have led to an increase in the former, but not in the latter (Curran, 1988).

The literature, as Gilligan points out, points to other factors such as social support or lack thereof, alongside exposure to traumatic events that are implicated in mental health outcomes (Weisaeth, 1998).

Northern Ireland, whether as a result of the Troubles or other factors, has comparatively high levels of such networks at local community level, and there are strong community bonds in many of the areas worst affected by violence (Burton, 1978; Griffiths, 1978; Nelson, 1984). However, studies that are more recent suggest, and some interview data support the view that the peace process has undermined rather than strengthened such bonds and the peace process has led to increased levels of alienation and a sense of community fragmentation (Cairns et al, 2003). This provides another explanation for the reported increased demand on support services after the peace process.

A further complication is delayed onset of emotional or psychological symptoms. This means that assessments of the emotional or mental health in the aftermath may not pick up all of the mental health consequences since in some cases onset of mental problems is delayed. In a study of the survivors of the Enniskillen 'Poppy Day' Bombing in 1987, it was noted that:

"the intense attention and the cosseted hospital environment may protect the physically injured from PTSD and psychological disturbance in the initial stages, only to see it emerge when they are discharged from hospital" (Curran et al, 1990, p. 481).

Curran found that people often suffered a delayed onset of symptoms and frequently experienced enduring effects – both emotional and physical (Curran, 1988).

On the other hand although, perhaps indicative of the diagnostic trends of the time a quarter century ago, Loughrey et al (1988) found that "PTSD can be identified in a population stressed by civil violence" (Loughrey, Bell, Kee, Roddy, & Curran, 1988, p. 559). Also noted is the "danger in over-reliance on results from combat veterans is emphasised" since their findings indicated that marital disharmony and suicidal behaviour were most frequently reported as a consequence of civil disorder in Northern Ireland.

Furthermore, the ceasefires and the 1998 Good Friday Agreement did not eradicate tensions between the Protestant and Catholic communities. There was no significant

improvement in the psychological wellbeing of the population (Cairns, Mallett, Lewis, & Wilson, 2003). Despite a dramatic reduction in the level of violence, fear and polarisation remained the reality of everyday life. Peace-lines remain and segregation persists.

"Residential segregation has been a feature of NI since the nineteenth century increasing during the twentieth century, particularly in working class areas" (French, 2009, p. 888).

It is noteworthy that a third of the victims of politically motivated violence in Belfast were murdered within 250 meters of an interface (Shirlow & Murtagh, 2006).

French (2009) analyses the costs of hospital and community services for older people alongside the costs of prescribing psychotropic medication for anxiety and depression using measures of segregation and deprivation. He concludes that the effect of segregation on health is "pernicious". In particular, French reveals that:

"... the negative effect of segregation on mental health as indicated by the costs of prescribing for anxiety and depression has been identified and this result is robust to the sets of variables used to account for ease of access to services and is generally robust to the definitions of segregation employed. The effect of segregation on ill health is sure to be more pernicious than identified in this analysis. Societal division over the years has had a negative effect on socio-economic conditions, which have been seen to worsen health." (French, 2009, p. 895)

The consequence for people who had themselves been affected by the 'Troubles', or their families, has been exposed to high levels of stress, as is borne out by the findings of the 1997 and 2001 Northern Ireland Health and Social Wellbeing surveys (Murphy & Lloyd, 2007). Indeed the view from outside Northern Ireland was that:

"it is important to recognise that, as in most civil conflicts, there has been a significant proportion of those most seriously injured drawn from the poorest sections of our community." (Boraine: 1999, p. 13)

Murphy and Lloyd (2007) compared the levels of psychiatric problems across the UK, with the aim of assessing the 'impact of low-intensity warfare in Northern Ireland' by comparing psychiatric morbidity rates. They found varying levels of psychological morbidity across the UK with Wales scoring the highest mean General Health Questionnaire (GHQ-12) score, followed by Northern Ireland. The results from England showed the lowest mean score. The article concludes that 'psychological morbidity rates in Northern Ireland are comparable to other parts of the United Kingdom' and the authors believe that individuals in Northern Ireland use 'a range of coping strategies' to lessen the impact of conflict on their daily lives. These could include 'habituation to violence, denial, and social cohesion.'

While the literature could be interpreted as portraying a population and society fractured by decades of civil conflict, in fact the impact of political violence is unevenly distributed and is concentrated within specific groups, namely those severely injured, bereaved, and traumatised.

"The impact of civil conflict on the Northern Ireland psyche appears complex. Although the results from this current study suggest that this Northern Ireland population sample does not display significant levels of psychiatric morbidity, there is also some convincing evidence to suggest that particular subgroups of the population have suffered significant psychological distress as a result of the conflict." (Murphy & Lloyd, 2007, p. 405)

It is individuals who come from those particular sub-groups, namely those seriously physically injured and their families that this research is examining. Although previous studies have examined specific forms of injury such as limb loss, we have been unable to find any study that examines Troubles-related physical injury in general.

There have been, however, studies of the psychological impact of violence, which physically injured people also experience. Trauma and PTSD occur in communities, which are not in the violent upheaval and conflict that have characterised Northern Ireland, and these can be examined in terms of socio-demographic factors (Available at <a href="http://www.ptsd.va.gov">http://www.ptsd.va.gov</a>). Moreover, even where 'community violence' happens suddenly and without warning it is both discontinuous and rarely long lasting. Research on such community-originated trauma can illuminate policy and practice by identifying relative risk factors according to age, gender, ethnic or race identity, employment or marital status; and by constructing typologies of trauma and traumatic events, and indices of co-morbidity (Breslau, Kessler, Chilcoat, Schultz, Davis, & Andreski, 1998). In the case of prolonged civil conflict, like that in Northern Ireland, this is not an entirely viable methodology or paradigm for investigation, given the multiplicity of incidents and the long duration of the conflict. However, a recent study has taken account the both 'community' and conflict-related PTSD to examine the notion of complex PTSD, termed DESNOS. This research investigated:

"the psychiatric sequelae of interpersonal victimization, particularly those forms of victimization that occur early in the life cycle and involve multiple traumatic events and extended exposure" (Dorahy, et al., 2009, p. 72).

There were 81 participating adults, ranging in age from 19 to 73 who had:

"Troubles-related trauma histories (i.e., those referred as a direct result of exposure to the political violence in Northern Ireland known as the 'Troubles') ... not currently a suicide risk".

And, as if to illustrate one of the difficulties of this research into those 'Injured due to the Troubles' they find,

"Whilst somatic symptoms were well affirmed, the degree to which these represent true somatic expressions versus unknown physical complaints or a misunderstanding of the non-physical nature of the symptom is difficult to assess and therefore difficult to draw conclusions on." (Dorahy, et al., 2009, p. 78)

Research on a UK-wide basis was also conducted by the Tim Parry and Jonathan Ball Trust (2003). They examined the 'legacy' of the Troubles for the 'GB population', which encompassed a wide range of cohorts including exiles, British Army veterans and their families. The study focused on the psychosocial dimensions and effects of the Troubles using in-depth interviews and qualitative analysis. The major outcome of the study was the emphasis on recognising those affected by the Troubles living outside Northern Ireland, and involving them in emerging policies for victims and survivors. The study, which encompassed a wide range of groups, did not focus specifically on physical injury, although some participants fell into that category.

Studies have also been undertaken of the effectiveness of certain treatment approaches. A recent controlled study conducted by staff in the Northern Ireland Centre for Trauma and Transformation (NICTT) demonstrated the efficacy of cognitive behavioural therapy (CBT) for people suffering PTSD after the Omagh bombing of 1998 (Duffy & Gillespie, 2007). They identified four essential findings. Firstly, "the presence or absence of other psychiatric disorder did not influence the extent of the patient's reduction in [PTSD] symptoms" and secondly, "ongoing physical problems resulting from the trauma did not predict poorer outcome". This would indicate that CBT was effective for physically injured clients and those suffering chronic pain. However, they noted that "high levels of depression at intake were associated with poorer outcome. ... In our study, patients whose initial depression score was over 35 were particularly difficult to engage in the treatment, though notable exceptions occurred." Finally, they noted the importance of using CBT techniques "and the finding of a therapist effect" (Duffy & Gillespie, 2007, pp. 1147-8)

Duffy and Gillespie's findings are also supported elsewhere. Marshall et al (2010) in a longitudinal study found:

"evidence that anxiety sensitivity may affect, and be affected by, the severity of PTSD symptoms following traumatic physical injury. The reciprocal nature of the relationship of anxiety sensitivity and PTSD symptom severity shows how PTSD-related distress might be maintained in the aftermath of trauma. These results also suggest that anxiety sensitivity might be an important target for interventions aimed ultimately at reducing PTSD symptom severity." (Marshall, Miles, & Stewart, 2010, p. 149)

This suggest that physically injured people who experience higher levels of anxiety, which may be related to concerns about security or encountering the perpetrator, may be less able to recover from traumatic symptoms. Therefore improving levels of subjective security is an important aspect of overall wellbeing for this cohort.

Campbell (n.d) examined 'trauma, alcohol and drug co morbidity' for the Eastern Trauma Advisory Panel with a view to raising 'awareness and stimulate further debate' on the issue. They emphasise that those diagnosed with PTSD should also receive appropriate treatment for substance abuse, if needed, as the two conditions often accompany each other. Campbell points out that the communities that have suffered a disproportionate number of deaths also have high levels of poverty and ill health. The key challenge for the Health Services is to understand the problems posed by a 'dual diagnosis' of PTSD and substance abuse when 'two conditions are "playing off" each other.' A wide range of intervention skills

are needed, ensuring 'physical, emotional, and psychological safety' for individuals and the role of psycho-education where therapists should assist people to understand and manage the two simultaneous conditions. Campbell advocates an integrative treatment approach and "joined up" thinking between the Statutory, Community and Voluntary current providers.'

NICTT also published research on 'The Economic Burden of Psychological Trauma in Northern Ireland: An investigation into the health economic costs of mental health needs associated with psychological trauma and the specific impact of the 'Troubles''. This comprised a report on PTSD, on the ways it can be treated effectively, the prevalence of trauma related disorders in Northern Ireland's population and the economic and social impacts of PTSD (as an example of a trauma related disorder). They concluded that the assessments of the impact of the conflict are likely to be conservative as the needs of those affected by the conflict 'are increasingly chronic and complicated.' The study was also unable to account for the traumatic experiences that were the result of the 'sudden death of a loved one or trauma to a loved one.'

The NICTT jointly with the Psychology Research Centre at the University of Ulster published an epidemiological study which focused on 'Trauma, Health and Conflict in Northern Ireland' deriving from the Northern Ireland Study of Health and Stress (NISHS) on the number of people in Northern Ireland who have been exposed to conflict related and other traumatic experiences due to the Troubles. The report also focuses on those individuals who have developed 'psychological, mental, and physical health disorders'.

Through the use of qualitative interviews the research examines the experiences of individuals experiencing traumatic events, approximately 50% of which were conflict-related. They found a 12 month prevalence rate for Post Traumatic Stress Disorder of 4.7% and a lifetime prevalence rate of 8.5%. They also found that people with a physical impairment who also had PTSD were impaired for twice as many days as those without PTSD. Only 34% of those with PTSD had seen a medical doctor and only 50% of those received help that they found useful.

Probably the most relevant study is that conducted by the University of Ulster<sup>1</sup> and the Northern Ireland Centre for Trauma and Transformation and Compass working in partnership with the Commission for Victims & Survivors (2011). The research examines the relationship between conflict-related trauma and mental health issues in Northern Ireland. They cite the Northern Ireland Study of Health and Stress which found that 23% of Northern Ireland's adult population met the criteria for a mental health disorder in the 12 months preceding the NISHS interview report (Commission for Victims & Survivors, 2011, p. 70). The report delineates the key features of mental health issues with a view to assisting the development of relevant policies can be developed in order to establish 'fit for purpose' services and suitable training provided across different sectors (p. 3). The report makes the case for a 'better identification of trauma related needs' and for a 'routine and readily available access to effective specialist trauma services' (p.71)

<sup>&</sup>lt;sup>1</sup> Bamford Centre for Mental Health and Wellbeing based at the University of Ulster, Magee.

#### **Services**

The 2009 Consultation paper on Victims and Survivors Service produced by the Victims Unit of the Office of the First and Deputy First Minister outlines the proposals for the establishment of the Victims and Survivors Service. The proposal states that they will be more 'comprehensive and responsive to the needs of individual victims and survivors and the groups and organisations which work in this area' (Office of the First Minister and Deputy First Minister, 2009, p. 3.)

The planned Victims and Survivors Service will function to provide support for groups and individuals in response to 'assessed and agreed needs' (p. 5). While various needs assessments have been carried out by victims groups and Trauma Advisory Panels at a local level, a need of assessing the complete range of needs across Northern Ireland which is evidence based and stated in a comprehensive and coherent manner' remains prominent (p.5). The paper notes that there is no coherent system that helps identify and record the changing needs of victims and survivors in a manner, which can 'inform service delivery and funding decisions' (p. 5).

The paper argues that the comprehensive needs assessment is essential to enable the Commission in addressing its statutory responsibility to comment on the effectiveness of services provided to victims and survivors (p. 5). A comprehensive needs assessment would also be relevant to the work of the Commission for Victims and Survivors in order to create a 'sound basis for funding the work of victims and survivors groups' (p. 5). The paper anticipates that such an exercise would be complex due to the nature of the issue and that it will be an evolving exercise given the changing nature of needs over time (p.5).

Dillenburger et al (2008a) provide a detailed analysis of the community services available to people affected by violence during the conflict – including a typology of services (psychology, philosophy and education-based) and statistics on the number of groups and people for whom they have provided services (from befriending to advice through to psychotherapy). The analysis and recommendations are geared towards developing practice among social workers.

## They concluded that:

"these services were varied in quantity and quality. For example, some of the community groups were not very clear about the difference between group therapy and support groups or befriending and in some groups the range of services offered seem to be more related to available funding rather than an analysis of the needs of service users. Many groups felt that the most appropriate way of providing services to victims was through groups that were victim-led (Clio Evaluation Consortium, 2002), in which, by and large, members shared similar experiences and concerns. They felt that these groups understood them better than professionally led agencies. In general, service users seemed to prefer social support provided in form of befriending and support groups as well as advice and information." (Dillenburger, Ahkhonzada, & Fargas, 2008a, p. 21)

Dillenburger et al (2008b) investigated the effectiveness of voluntary sector services for victims of community violence in Northern Ireland in a study of 75 service users who completed a research inventory (including GHQ-30, BDI-II and PDS) up to four times over nine to twelve-months period. The results showed that despite detrimental effects of additional life stresses, psychological health and depression scores improved for all service users. Some community-based services (befriending) and some complementary therapies (reflexology) were significantly related to these improvements. Changes in PTSD symptom severity were not significant. Evalutions by users of such services were strongly in favour of voluntary sector services.

Dillenburger et al concluded that in terms of general psychological health and levels of depression, voluntary sector services did provide effective help, although PTSD symptom severity did not decrease. They point to a number of possible reasons for this. First, difficulties with the diagnosis of PTSD; second, chronic traumatisation due to the lack of appropriate support at the time of the traumatic event/s, and a need further professional input; third PTSD is highly resistant to treatment; fourth the context of an unstable political situation, post-ceasefire violence) and/or a lack of justice and recognition. Last, they point to the possible influence of other stressful life events. (Dillenburger, Fargas, & Ahkhonzada, 2008b, p. 1642)

Dillenberger et al 2005 highlighted a "hierarchy of services" for victims of conflict.

"Similar to Maslow's (1954) hierarchy of need, the hierarchy of service needs reaches from a broad-based need for social supports, [and] considered services provided by voluntary sector victims' organizations in four main categories: community-based services, such as befriending, support/self-help groups, respite care, youth work and narrative work/ storytelling; psychology-based services, such as psychotherapy, counselling and group therapy; philosophy-based services, such as complementary therapies (reflexology, aroma therapy, massage, etc.); and education-based services, such as advice and information and indirect services (IT or arts classes, practical skills groups, advocacy, etc)." (Dillenburger et al., 2005)

Dillenburger et al (2008b) identified four sets of factors that can impact on emotional health, arguing that a comprehensive assessment of these factors in order to discern which were significantly related to changes in psychological health, levels of depression and PTSD symptom severity (Dillenburger et al., 2005) The four were:

Death- (or trauma-) related variables, including comparison between participants who experienced a certain traumatic event and participants who had not experienced this event; Individual variables, including age, gender and changes in psychological health, levels of depression and PTSD symptom severity over time; social variables, including a comparison between participants who had received a certain service and participants who had not received the service; and social validity assessment of services, namely social importance and significance of services, appropriateness and acceptability of treatment goals and procedures, and perceived importance of outcomes (Foster and Mash, 1999); and culturally specific and environmental variables, including stressful political events (e.g. return of paramilitary leader to Northern Ireland or prison release of Troubles-related detainees),

injury or illness, intimidation and/or moving home, death of a close family member or close friend and other stressful life events." (Dillenburger, Fargas, & Ahkhonzada, 2008b, p. 1637)

The researchers propose that evidence-based practice is being impeded by the voluntary sector services' resistance to gathering statistics (Dillenburger, Fargas, & Ahkhonzada, 2008b, p. 1643).

The first interim report on a Comprehensive Needs Assessment of victims of survivors of the conflict, produced by the Commission for Victims and Survivors (CVS, 2010) is less critical of the services provided by the community and voluntary sector than are Dillenburger, Fargas and Ahkhonzada. Although they note that there is a need for monitoring and evaluation of this multi-million pound service provision, they stop short of drawing the conclusion that much of this work has been funded without rigour or questioning. However, in the survey component of this study, although some respondents raised issues of trust and politicisation in relation to victims groups, others expressed high levels of satisfaction with the services and support provided by victims' groups.

The Northern Ireland Centre for Trauma & Transformation (NICTT) produced a series of papers on the issue of services to victims in general. Their 2009 Briefing paper for the OFMDFM committee members includes an evaluation of the origins and development of 'trauma related services' for individuals who were affected by the Troubles in Northern Ireland (p1). The report identifies the establishment of 'an actual or virtual comprehensive service' as a key challenge recommending that it would be more cost effective to do so through existing structures and services that could be complemented by new services and developments where required. The report also highlights the potential for the expertise developed in Northern Ireland to be extended to help in other conflict-ridden societies. A further series of five papers were requested by the Department of Health, Social Services and Public Safety (Bolton and Rankin, 2008-2009) in order to map psychological therapies available to people in Northern Ireland. These reports identified large gaps in service provision, confusion about regulation of the sector, a lack of proper training in the voluntary sector, different work being undertaken in the statutory and voluntary sectors, and long waiting lists and a lack of availability in the statutory sector.

The Northern Ireland Centre for Trauma & Transformation (2004) report "Addressing and overcoming the problems of a troubled community" was prepared in response to the DHSSPS commission's report 'An Evaluation of Health and Social Services for Victims of Conflict' (2003). Its outlines the view of the NICTT 'on the development of policy and services in relation to those who have suffered psychological trauma related disorders as a consequence of the violence associated with the Troubles.'

The Troubles have led to substantial consequences for individuals and communities, 'resulting in an as yet unknown but undoubtedly major burden of disability, distress, grief and trauma.' These needs are major demands on the community, health and social services and other public services. With the emergence of 'better knowledge about the psychological impacts of traumatic events and their consequences, and the development of effective treatments, we are now in a position to make improvements to the nature of the

community's response and to make a qualitative impact on the lives of those affected by violence.'

The needs associated with the Troubles should be viewed as 'a-political (i.e. non-partisan).' This could be done by adopting a 'public health and well-being approach to the personal and community consequences of violence.' Finally, 'the suffering arising in the context of violence' associated with conflict, must be addressed 'as part of the political processes that seek to address the causes and legacy of violence and the underlying conflict.' The establishment and restoration of relationships, as well as the task of dealing constructively with the past, necessitate that the 'suffering and loss is duly recognised and addressed.'

The report makes three major recommendations:

- 1. Increased attention should be given within the political processes to the current and future human consequences of the violence associated with the civil conflict;
- 2. The psychological and disability related consequences of the Troubles should be addressed as a specific public health and well-being issue;
- 3. To ensure an integrated and evidence-based approach to the psychological and related mental health needs associated with the Troubles, an integrated service system, based on a managed clinical network approach involving all relevant sectors, should be established.

A joint paper by David Bolton of NICTT and Arlene Healey of the Family Trauma Centre in South Belfast, (Healey and Bolton, 2005) examined the feasibility of establishing a 'A Coordinated Service Network for Trauma Treatment and Related services.' The paper, was produced at the invitation of the DHSSPS to consider how the Department's 'investment in the Family Trauma Centre and the Northern Ireland Centre for Trauma & Transformation could be optimised.' The paper advances four recommendations:

- (1) the formation of a Regional Commissioning Support Committee (RCSC) to provide guidance, support, and set out expectation of trauma related services;
- (2) Trauma Advisory Panels should have specific function of coordinating developments in service arrangements and service integration;
- (3) in line with the RCSC's guidance the DHSSPS would set out its requirements and guidance for Boards and Trusts, and the Family Practitioner Services;
- (4) a forum for organisations specialising in the treatment of trauma (statutory and non-statutory) would be formed to agree referral networks and processes, to advance developments in treatments and to identify how best the collective skills and knowledge of specialist services could be maximised.

Dorahy et al (2008) evaluated services at the Trauma Resource Centre in North Belfast from the perspective of service users. The Trauma Resources Centre (TRC) was established in Belfast with the help of funding granted by the Belfast Regeneration Office in May 2005 and provides services to some clients injured in the Troubles. Its aim is to 'address psychological, somatic and functional needs of individuals' who were directly affected by the 'Troubles.'

Along with providing multidisciplinary clinical services, based on a comprehensive needs assessment, the TRC has developed a research programme to better understand the history of the problem as well as to contribute to the understanding of PTSD symptoms and the related difficulties. The report describes the 'extent of "Troubles-related traumas" among individuals from North and West Belfast areas', the history and symptoms of trauma experienced by these individuals and the extent to which 'they engage in destructive behaviours and dissociation to help them manage their difficulties.'

The report concludes that individuals suffering from 'Troubles-related' trauma not only displayed a complex array of posttraumatic difficulties, but they also engage in various coping strategies that are not helpful and express high levels of dissociation. The TRC serves higher numbers of men compared to women, a trend distinct from other services in North and West Belfast. However, it does not mean to suggest that their difficulties are different from the ones experienced by individuals attending other services in Belfast. The difficulties include 'problems with regulating strong feelings' as individuals may not have effective internal (mentally relaxing) or external (taking a warm bath or shower) coping strategies to soothe themselves. In the absence of 'adaptive strategies,' further aggression and self-harm may become 'plausible alternatives' as might 'chemical remedies' that include alcohol and drug use. Through treatment, individuals also go through major 'cognitive and emotional alterations in the way they perceive themselves.' Individuals felt that they were ineffective, permanently damaged along with feeling elements of guilt and shame. These problems in turn prevent the administration of 'short-term trauma-focused interventions.' Dorahy et al argue that there is a need to understand the distinction between 'chronic PTSD' and 'complex PTSD' so that these two are not confused with each other and used interchangeably. Those with complex PTSD exhibited more 'severe and diverse symptoms' than those suffering from chronic PTSD. Complex PTSD was also related to 'childhood exposure to "Troubles-related" traumatic events, childhood emotion, and sexual abuse, increased incidence of self-destructive behaviour... and feeling less emotionally connected with family and friends (i.e. relational disconnectedness).' The research found that dissociation (generally) and severe dissociative symptoms (specifically) were related to aspects of complex PTSD and not with chronic PTSD.

Individuals attending for treatment had experienced multiple 'childhood and adult traumas' including injury due to the Troubles. The result of these experiences is 'chronic and complex posttraumatic adaptation' that has effects on individuals' self-perception and the way they perceive the others. This in turn leads to major alterations in psychological, social, and vocational functioning and is followed by the responses related to 'self-harm, aggression and dissociation'.

Also in the statutory sector, Manktelow (2007) investigated the needs of people affected by the Troubles with a view to identifying the role that social workers could play in meeting those needs. He found that psychological experience of the Troubles is characterized by vulnerability to depression and anxiety arising from the internalization of negative feelings and loss — a sudden and violent bereavement and grieving which has had to be postponed or denied. Victims suffered ill health caused by long-term, attritional stress and the employment of coping mechanisms, which in themselves placed individual health at risk. The Troubles caused adverse social effects including an individual experience of anomie,

community fragmentation, and disintegration and a social culture of suspicion and segregation. He recommends that social work services for victims of the Troubles must be community based, offer safety and trust, recognize the right to campaign on human rights issues and offer a range of therapeutic responses including specialist social work services for individuals suffering conflict-related trauma.

# <u>Identity</u>

Identity management covers a wide range of issues, not least is the self-identification of those suffering PTSD, who do not see themselves as 'victims'.

"Many of those with symptoms suggestive of PTSD do not consider themselves victims of the 'troubles' and hence it is not surprising that some have resorted to self-medication instead of seeking professional help: our evidence shows a higher reported misuse of substances. Current government policy is targeting services towards 'victims of the troubles'. Our findings suggest that advertising or targeting resources towards 'victims' might act as a barrier to those who have been most adversely affected. Finally, holistic approaches that consider previous traumatic experiences and socioeconomic background are crucial to understanding the impact of any specific incident in conflict situations." (Muldoon & Downes, 2007, p. 149)

# Social support and respite

McGlone and Stinson (2006) examined a largely forgotten aspect of the conflict in Northern Ireland – those caring for victims. This study acknowledges the contribution of carers assesses their needs and the extent to which these needs are being met by service provisions. The report emphasises the need to quantify the size of the population of carers. McGlone and Stinson propose two methods for this: Contract Monitoring Returns within Board areas could be used to get data on service uptake by victims and their carers; and victim support groups across Northern Ireland could be funded to conduct local Needs Assessment of the Carer population within their membership. They argue that carers should be included at strategic level in the shaping and delivery of support services and for monitoring of carers' health status alongside programmes to educate Carers about Carer burnout, and remedies to alleviate burnout. McGlone and Stinson also advocate the development of 'support and self-help groups for Carers' to alleviate social isolation of carers. Respite breaks should also be provided for all family members on an annual basis as well as short breaks of respite for carers. They also point to a need for advice for carers on benefit entitlements and sources of help, advice and support. They highlight the importance of the economic impact of the trauma which must be addressed in order to improve the financial situation of the carers. They also recommend addressing the level of mistrust and frustration with the statutory sector among carers.

### **Trans-generational issues**

Trans-generational issues have been noted in relation to the decades of conflict in Northern Ireland.

"As in South Africa that suffering has taken place over an extended period of time, involving at least three generations of our people. For many families from both communities, the youngest generation has experience only of a society in conflict." (Boraine, 1999, p. 13)

Long-term effects have been noted among victims of the 9/11 bombing in New York, and compared with those experienced by those involved in the traumatic events of Bloody Sunday<sup>2</sup> and subsequent generations (McGuigan & Shevlin, 2010). Just as later generations of Holocaust survivors were found to 'carry the burden' of trauma, so it has been found that the children of war veterans have suffered nightmares, anxiety and near-death experiences. Similarly, people who were not directly involved in Bloody Sunday suffered long term psychological consequences. Despite the limitations noted and caveats, identified (McGuigan & Shevlin, 2010, p. 1147) the study concludes that:

"some participants were experiencing clinically significant levels of psychological distress in response to an event that occurred 37 years ago. Also, it was found that there were differences in the level of distress with those participants directly exposed to the event, or their family members, showing the highest levels. The level of distress decreased across time, possibly as a response to fewer reminders of Bloody Sunday."

A sample of 81 adults, aged 19 to 73 participated in a study of complex PTSD (DESNOS) in Northern Ireland. The study stresses that:

"Interpersonal traumas in the form of childhood sexual abuse, childhood emotional neglect, and childhood exposure to Troubles-related violence were associated with DESNOS. Perceived impact of political violence exposure was also related to DESNOS. DESNOS was associated with relational consequences in the form of interpersonal disconnectedness. PTSD avoidance may maintain and heighten DESNOS symptoms severity." (Dorahy, et al., 2009, p. 79)

It would seem that the trends and predictive probability of PTSD and DESNOS have common features in 'community' and 'civil conflict' situations, although the presence of violent conflict — whether directly or indirectly experienced — provides a 'tipping point'. (However, the evidence of child neglect and abuse among the Northern Ireland participants gives cause for concern — not least given increasingly high present-day rates of suicide among young adults in the jurisdiction.) In 2010, 313 deaths were registered as suicide in Northern Ireland, 240 males and 73 females, the highest figure ever recorded in the region. (NISRA 2011)

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<sup>&</sup>lt;sup>2</sup> Bloody Sunday, 31<sup>st</sup> January 1972 was the day when the British Army shot thirteen civil rights marchers dead and wounded a further fourteen.

## **Individual financial support**

Individual financial support has been subject to scrutiny and the compensation awarded to survivors in the 1970s and 1980s considered "derisory" (CVS, 2010) (Bloomfield, 1998). The work and efficacy of the Memorial Fund, set up in the wake of Bloomfield (1998) is yet to be assessed.

By February 2011, in Northern Ireland, the number of individuals in receipt of Disability Living Allowance was 185,599. Of these 52.3% female and 47.7% male and more than three quarters (76.7%) were in the 40+ age group. The main causes of qualifying disability were 'mental health causes' (22.2%), followed by 'arthritis' (18.4%). Some 15,355 awards were made in the 12 months ending 28th February 2011 and 12,153 had their benefit terminated in the same period so numbers are increasing. The biggest concentration of Disability Living Allowance recipients were in Belfast with 37,171 or 13.8% of eligible population in receipt of DLA, followed by Derry Londonderry with 14,238 or 13% of the eligible population in receipt (Department for Social Development: 2011).

There is a widespread consensus that individual financial support for those injured in the conflict and their families and carers is extremely varied and inequitable in certain cases. The evolution of welfare and social security benefits over the past four decades complicates matters, as disability and incapacity entitlements were not available in the 1970s, and entitlements have changed throughout this long period.

Furthermore, imminent changes to disability and other benefits are likely to have major implications for people injured in the Troubles. Creelman (2012) of WAVE Trauma Centre has argued that changes in incapacity benefits 'will be the single hardest hitting change that will affect our client group' (p 2). These changes involve retesting of existing claimants, and re-testing will be triggered by compulsory migration of incapacity Claimants over to Employment Support Allowance (ESA). This is planned for February 2011 – March 2014. Retesting involves a new medical assessment with tougher health and disability qualifiers, requirements to engage in work related activity and setting a time limit on entitlement to contribution based benefit. Creelman points out that someone suffering from Post Traumatic Stress Disorder might find it difficult to qualify for benefits under the test, because of the limited descriptors in the test. The new test is much tougher than the previous one according to Creelman who points to the pilots where 30% fewer people were found unfit for work and 70% fewer people were found eligible for the full-rate, unconditional support benefit.

At the time of most of the incidents, there were no victims groups or counselling support available. Their trauma affected not only their mental health but family life; careers were cut short often at a young age. Despite passing medical assessments in the past they are now facing cuts in their benefit, not because their health has improved but because of changes in the benefits system. This is a huge cause for concern and is causing untold anxiety. The problem is that for those who fail the new test, they are not sick enough to get ESA or are able to use their aids and adaptations and hence may fail the test because of their independence, but are not well enough to keep down a job or even find an employer willing to take them on in the first place.

A large portion of Creelman's client group were injured bereaved or traumatised in their twenties and thirties and are now in their fifties and sixties. They suffer long-standing health problems, have long been out of the labour market and stand little or no chance of getting a job in the current recession. Creelman argues that they would be competing with the many unemployed young people and those recently made redundant who have up to date skills and recent work experience. The increase in state pension age (to rise to 66 years for both men and women by 2020) means that some of this group will have a longer wait to qualify for state retirement pension. The government is also cutting payments for mortgage interest, winter fuel allowances, abolition of the discretionary social fund, cuts to housing benefit and the freezing of benefit levels also impact on injured people. In Creelman's view, there is a substantial risk that many of those injured in the Troubles now in their fifties and sixties could have their benefits withdrawn, not because their health or mobility has improved but simply because of changed government policy. Should this happen, she foresees many falling quickly into poverty, debt and even losing their homes before they reach retirement age. She cites cases where families have lost almost £400 per month in support.

Creelman points to another set of issues related to the differential effect of these benefit changes on civilians compared to former members of the security forces. The means test for Incapacity and Employment Support Allowance (ESA) means that 50% of occupational pensions above £85 per week are deducted pound for pound from benefits, so some injured people do not qualify for any of these benefits because their pension is too high, but they can claim a national insurance credit towards their state retirement pension. Other injured people will receive a reduced amount of benefit because of the means testing of their pension. This may include injured police officers or injured UDR whose pension entitlement exceeded the means testing rules for ESA or Incapacity benefit Injured police officers who claimed prior to 6<sup>th</sup> April 2001 before means testing for occupational pension was introduced can receive some entitlement to Incapacity/ESA and the financial loss of ESA under the new harsher test or through the 12 month time limit, may be 'made up' or compensated for by the way their pensions are calculated.

Thus, if they no longer receive Incapacity Benefit/ESA it will not be deducted as income in the calculation of their yearly pension entitlement. The Civil Service Injury Benefits Scheme is based on "guaranteed minimum income" and will ensure that some ex civil servants and prison officers will also be similarly protected. Similarly, many seriously injured ex-UDR and army veterans receive Un-employability Supplement from the Veterans Agency, which is an equivalent of Incapacity Benefit or ESA for veterans, but this is unaffected by the current reforms of benefit. However ex-UDR who do not qualify for Un-employability Supplement and who rely on Incapacity Benefit or ESA will be affected by the changes. Therefore injured prison officers, civil servants such as customs officers, and police offers will be protected from the effects of incapacity reform, since any potential financial loss to them will be compensated by a different government department. It is noteworthy, however, that part time members of the security forces and those injured in the early phases of the Troubles do not benefit to the same extent as some other officers, and some are acutely conscious of being less favourably treated.

The main effects of the changes will therefore be felt mostly by civilians and a small group of ex-servicemen who receive Incapacity Benefit and who will be denied benefit or have their benefits reduced even though their health has not improved and in many cases has deteriorated. Regular re-testing even when health is deteriorating and the context of an ongoing recession and a scarcity of jobs mean that these welfare reforms have taken on a punitive and draconian aura for many injured people and as Creelman argues, this has had a negative impact on their mental health in some cases.

# Compensation

Creelman's findings on the difference between civilians and service personnel are bourne out to some extent by a 2005 study of police widows, where one widow remarked that despite the availability of financial support, victims feel that there is 'Plenty of money but no husband' (widow, in Dillenburger et al 2005, cited in Dillenburger et al 2008b).

It is noteworthy, however, that not all injured police officers are entitled to the same level of benefits. Indeed the Patten report remarked on the unjust and unfair treatment of officers injured prior to 1982, and this situation remains unaddressed and a source of continuing grievance, as does, in some quarters, the differential between the treatment of widows as compared with injured officers. Dillenburger, Fargas and Ahkhonzada, (2008b) were pointing to the gap between financial compensation available to bereaved relatives and their undiminished and lasting personal loss.

"Today, individuals who have suffered as a result of the Troubles are compensated through the Northern Ireland Memorial Fund (NIMF), the Northern Ireland Police Fund (NIPF) (for police officers only) and the Northern Ireland Prison Services Trust (for families of deceased prison services officers only) (McDougall, 2006)." (Dillenburger, Fargas, & Ahkhonzada, 2008b, p. 1634)

In its early days, the Northern Ireland Assembly conducted a review of police injury awards arrangements in response to public and other concerns about the scheme, which was subsequently reformed. Awards will be made in one of four bands, depending on the severity of injury and the appeals process has also been reformed. This will affect the levels of compensation and injury pensions of injured officers henceforth.

In September 2011, The Police Federation for Northern Ireland announced their intention to ask the Libyan National Transitional Committee to extend the compensation scheme, which was originally agreed with Gaddafi to include the families police officers killed or injured. The Chairman of the Federation Chairman, Terry Spence called on the incoming Libyan Government:

"to recognise the injustice to the families of RUC and PSNI officers if officers who were on duty continue to be excluded from the compensation arrangements... Under the previous agreement Gaddafi had undertaken to compensate the families of civilians killed or injured through explosives and weaponry shipped to Ireland to supply the IRA. That agreement failed to recognise that the police here have always been a normal civilian based police service and not a paramilitary force. The officers

were civilians whether on or off-duty. I have therefore instructed our London solicitors to ask the NTC to relook at the existing Memorandum of Understanding and to include our officers. Since 1987 when the Eskund was stopped with 150 tonnes of Semtex and heavy weaponry 80 more officers have died and hundreds injured including PSNI officers a result of the earlier lethal imports. I fully understand that the NTC's priority will be the physical and civic reconstruction of Libya. Nonetheless it would be the mark of a more enlightened and benevolent regime if the NTC agreed to compensate civilians in Northern Ireland including all police officers, killed or injured as a result of Gaddafi's support for the IRA."

In October 1998, The Review of Criminal Injuries Compensation in Northern Ireland was established and Sir Kenneth Bloomfield was appointed to lead an examination into the fitness for purpose of the scheme as it had operated till then. The Report published in July 1999 made 64 recommendations for change, which led to the comprehensive reform of the system of compensation and the introduction of a tariff system but with no retrospective effect. The reformed scheme retained the current lower threshold for psychiatric injuries at £2.5K in contrast to £1K for physical injury. The old scheme disqualified people from receiving compensation if they had 'ever been a member of a terrorist organisation; ever been engaged in the commission, preparation or instigation of acts of terrorism; or failed to co-operate with the police in bringing the offender to justice.' In addition, other criminal convictions may result in refusal or reduction of compensation. The reformed scheme recognises that individuals may reform over time and dissociate themselves from their previous way of life and the principles of the Rehabilitation of Offenders Order apply in the new scheme and a penalty points system for disqualifying or reducing awards operates. Significantly, the Report recommended "top-up" payments to certain categories of victim who claimed compensation prior to the introduction of the 1988 Order. These recommendations were rejected in favour of 'financial support for a wider category of victims'. The report also claimed that the average time to process a claim for compensation in 1999-2000 was 45 weeks.

#### **Agency**

The idea of agency is the ability to advocate for oneself, self-determining with the power to bring about change effectively in one's circumstances. Some refer to successful transition from 'victim' to 'survivor'. The UN Convention on the Rights of Persons with Disabilities is taken forward and published in Northern Ireland jointly by the Equality Commission and NI Human Rights Commission.

Article 29 of the convention, stresses that participation in political and public life requires state parties to 'guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others'. In pursuit of this, they are obliged *inter alia* to:

(a) To ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others

- (b) 'To promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others
- (c) Encourage their participation in public affairs, including:
  - Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties
  - Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.

Fleischer and Zames (2001) have documented the shift from benevolence to a rights focus in the disability movement, which is reflective of a shift towards an agnatic approach to disability, as opposed to a dependency on benevolence. However, as they document, such a shift often stimulates a negative shift in public attitudes. In relation to those injured in the Troubles, it is perhaps predictable that the adoption of a campaigning stance may alienate those who would prefer a more passive and submissive constituency. Furthermore, those injured and victims in general have not been identified with the disability movement, nor do they necessarily frame their claims to acknowledgement and services as disabled people, but rather as victims of conflict.

### Services in a divided society

Services to victims operate within the confines of a society that remains divided in significant ways. Some of those services and their take-up patterns reflect those patterns of segregation and the fears that are both cause and consequence of the Troubles. Victims' organisations, with some notable exceptions, have operated in silos – bereaved families and people injured in the Troubles are segregated into organisations that serve the armed forces, civilians, Republican communities, and Loyalist communities.

A second problem is the policy (and actual) silence that has been maintained within statutory services about the Troubles until relatively late in the peace process. Healey (1996) and Gibson (1998) discuss this from the point of view of practitioners in the statutory social care system.

The continuous and seemingly intractable practice of public services and agencies working in silos – despite policy and reform to embed 'joined-up' operations across the whole of the UK has been commented on the work of Bundred (2006). This is as relevant in the arena of service provision for the injured and their families – just as much as the politicization of 'victimhood' and 'need', which Bundred is writing about. The solution is that:

"transformation of knowledge management is essential if the wider objective of substantial public service improvement is to be achieved. Quite simply, the radical improvement of public services requires the equally radical improvement of public service knowledge management." (Bundred, 2006: 130)

### **Truth and Justice**

A continuing debate on truth, or dealing with the past, or justice or acknowledgement has emerged and remained inconclusive in the period since the Northern Ireland peace process began. This debate is often polarised, politicised and highly emotive, characterised by completing claims to victimhood, accusations about past deeds and demands to reopen investigations or hold inquiries. Few of those injured in the Troubles have had successful investigations and convictions of those who injured them. Many feel forgotten, relegated to insignificance in comparison to bereaved families and denied the truth or justice. There is also an impatience in some quarters with the persistent demands for truth, justice, investigation, inquiry. Gilligan points to the language of 'healing' or 'forgiveness' that is preferable in some quarters as it steers away from challenges to the status quo. Gilligan describes how The Report of the Victims Commissioner, noted that those who had relatives killed directly by state forces, or killed by alleged state collusion expressed a 'firm view that revelation of the full truth of [these] controversial events was far more important for the victims they represented than any other consideration' (Bloomfield, 1998: 36 cited in Gilligan, 2006). Gilligan asserts that healing can be achieved through obtaining justice rather than undergoing therapy.

# **Acknowledgement**

Likewise, in policy on disability, the cause of disability of those injured in the Troubles often goes unacknowledged or ignored. This highlights the more general trend to address conflict-caused injury and its sequelae as identical to the issues of physical and mental health and well-being, and support, access and rights faced by the general population of people with disabilities. The policy and service provision for the injured and their families is similarly situated in silos — thus side-lining or ignoring the specific concerns and needs of those injured in the Troubles and how their particular circumstances affect their other needs and abilities to access help and services.

The Consultative Group on the Past, headed by Denis Bradley and Robin Eames was created in June 2007 to 'consult across the community on how Northern Ireland society can best approach the legacy of the events of the past'. They make recommendations on steps that might be needed 'to support Northern Ireland society in building a shared future that is not overshadowed by the events of the past'. Their report was published in 2009 (Eames and Bradley, 2009, p. 22).

A key principle in their work was that 'the past should be dealt with in a manner which enables society to become more defined by its desire for true and lasting reconciliation rather than by division and mistrust, seeking to promote a shared and reconciled future for all' (p. 23). Other working principles were: 'dealing with the past is a process and not an event; sensitivity towards victims and survivors is essential; recommendations should be human rights compliant; relationships matter and are the foundation for reconciliation; and consensual agreement is the ideal'(p. 24). They pointed out that, concerning 'the past,' two divergent opinions are present (p.24). Some believe that past should be laid out in front of everyone and truth should be 'sought and told' while others say that 'the past should be forgotten in the interests of the future' (p.24). Genuine conversations, concerning what the

truth is, 'should take place between those involved in the conflict, while recognising that complete truth is unattainable' (p.25). The Group recommended that an exercise involving a Commission for Victims and Survivors for Northern Ireland (CVSNI) should 'facilitate and encourage the telling of stories about the impact of the conflict on communities and of intra-communal difference' (p.26). The Group also recommended that the Legacy Commission, working with CVSNI through the Reconciliation Forum, should ensure the participation of young people in 'storytelling initiatives and that education programmes are developed which inform young people...about the nature and impact of the conflict' (p.27). The report also identifies 7 issues that are seen as crucial in identifying but also meeting the needs of victims and survivors:

- The multiplicity of services in some geographical areas, or areas of need, but in contrast, the gaps in others;
- The inadequacy of funding to meet the needs of, and provide services for, victims and survivors: the lack of strategic focus;
- The preference in some cases for local community, rather than statutory, interventions;
- The role of, and support for, carers now and in the coming years;
- The need for more to be done to relieve the burden of victims and survivors, while acknowledging the help afforded by the statutory schemes established to assist members of the security forces;
- The real and pressing concerns about the longer term future, of funding to meet the needs of victims and survivors;
- Understanding of, and responses to, trauma: more needs to be done to create a greater understanding of trauma, to ensure effective responses to it, adequate service provision and the accessibility of those services (p.30).

It should also be established whether certain victim and survivor groups are 'contributing to shared and reconciled future or whether they are compounding the division and suspicions' (p.31). Perhaps most controversially, the Group also recommended that the 'nearest relative of someone who died as a result of the conflict in and about Northern Ireland, from January 1966, should receive a one-off ex-gratia recognition payment of £12,000' (p.31). They made a range of recommendations about memorialising, using story-telling and rituals of remembrance (p.34) urging further efforts to develop ways in which the 'conflict and its impact are remembered' (-.35).

The report also acknowledges a tendency to 're-fight the conflict through the courts; to pursue truth through litigation; to deal with the past without a perspective for the future' (p.35). The Group proposed the 'establishment of a Legacy Commission, which would deal with the past by combining processes of reconciliation, justice and information recovery' (p.36). The mandate of the commission would encompass four strands: (1) help society towards a shared future; (2) review and investigate historical cases; (3) conduct a process of information recovery; and (4) examine linked or thematic cases emerging from the conflict (p.37). They also recommended the establishment of a Reconciliation Forum to promote the cross-sector activity on: sectarianism; remembering activities (including storytelling, memorialising and a day of reflection) at both an individual and community level; the provision of improved services to meet healthcare needs attributable to the conflict, including dealing with trauma, suicide, and addiction issues.

However, these recommendations were effectively shelved in the aftermath of the outcry about the £12,000 payments. There has been little progress on resolving the issue of how to deal with the past, outstanding justice issues, and related matters. A recent attempt to reopen the discussion made an unpromising start, with the First Minister pouring cold water on the idea of a truth commission: "What would be the purpose of having a truth commission when we know without a doubt that the terrorists will not be coming forward to tell the truth? All you would get, once again, would be the police and army in the dock and history being distorted. The DUP will not allow any talks to become a rewriting of history. For any talks to succeed, there must be an acceptance that part of the problem in dealing with the past in Northern Ireland is the refusal by some to accept the part they played in creating these problems" (Counihan, 2012).

A paper by the Victims and Survivors Pilot Forum (2010) *Dealing with the past: The experiences of meeting within the forum* outlines the experiences of meetings within the forum as an important medium for members 'to explore the past, acknowledge the present realities' and to find way 'to move forward into a more open future with a great common sense of one another' (Victims and Survivors Pilot Forum, 2010, p. 3.)

As a new relational space and a new institutional structure, the forum enables:

- the reality of victims and survivors to be acknowledged in civic and public life, the needs of ...injured and bereaved to be addressed through new public services and;
- the contribution of those who have suffered to be valued as part of this society moving beyond conflict (p.3).

The report refers to the work of Lederach who emphasised the need to bring together opposing notions of 'process' and 'structure' (p.3). The Forum can be seen as a space where the experiences are 'simultaneously *dynamic processes* between members and a *structure* with form and purpose' (p.3).

A further paper by the Victims and Survivors Pilot Forum. (2010). *Recognition for victims* aims to persuade the government address the needs of the victims/ survivors of the conflict as quickly as possible (Victims and Survivors Pilot Forum, 2010, p. 3.) The victims/ survivors fall into various categories including those who are 'physically injured, psychologically injured, bereaved,' those affected 'financially,' and those who suffered the loss of their family, social and community support (p. 3). The paper points to a lack of awareness among the public concerning their suffering and they have to often face apathy and stigmatisation (p.3). The report outlines multiple recommendations that the government should adopt (pp. 8-9).

# The framework: wellbeing as a central concept

This research is designed to inform the development of a comprehensive needs assessment of those injured in the Troubles. Therefore, it is important that the framework adopted is relevant and fit for its purpose. For this reason, we examined the approach taken by the Comprehensive Needs Assessment of the Commission for Victims and Survivors in their first interim report (2010). This utilised a seven-part framework within which to organise the assessment material:

- 1. Health and wellbeing
- 2. Personal and professional development
- 3. Truth, justice and acknowledgement
- 4. Social support and respite
- 5. Trans-generational issues
- 6. Individual financial support
- 7. Welfare support.

The revised framework no longer includes personal and professional development or welfare support. , In order to take cognisance of the difficulties faced by victims of the Troubles specifically, we added two further categories: identity and identity management and agency. We introduce those two categories and the reasoning behind their addition is outlined below in the items that this research explores.

#### Being a victim in a divided society

As discussed in earlier sections of this report, those injured in the Troubles must cope, not only with the physical and psychological sequel of their injuries; but they must also negotiate the politics of victimhood in a divided society (Breen-Smyth: 2007; 2008; 2010; Ferguson et al: 2010; Manktelow: 2007; Cairns and Mallett: 2003; Smyth and Morrissey: 2002; Fay, Morrissey and Smyth: 1999). This includes positioning themselves within a political dynamic where there is a risk that their suffering may be used to justify retaliatory violence (Smyth, 1998), and where competing claims to victim-hood provide fuel for continuing political contests. During certain stages of the Troubles, victims were portrayed in the media, often just hours after an attack, calling publicly for no retaliation, or calling for justice. As discussed earlier, some victims become icons of grievance for their entire community and their freedom to move beyond a victim identity, particularly where their suffering is bound up with the communal grievance. This is particularly true for those injured in high profile or multiple attacks. This dimension of injury in the Troubles demands of the sufferer a degree of self-management over and above that ordinarily required in injury due to accidental causes.

Others, such as those injured in punishment attacks, for example, may experience little social support from the broader community, and their injury may be perceived as a byproduct of an already stigmatised identity as a deviant of one kind of another. Those victimised by paramilitary groups for petty crime or anti-social behaviour may attract little social sympathy or support; indeed, local social attitudes may support their victimisation, with local opinion holding that they 'got what was coming to them.'

Some victims have been called upon regularly by the media, requiring them either to develop some mechanism for managing the media, or to surrender some aspects of their identity management to the media. In this process, some victims, more commonly those bereaved in the Troubles, have become quite well known public figures, whilst others – many of those injured - are ignored. Within the category of those injured due to the Troubles, some are judged to be more deserving of public sympathy than others. The victim of the punishment attack may attract little attention or sympathy compared to the victim of an IRA bomb explosion. The demands for prosecution of their assailant by a victim of a security forces shooting may be regarded as politically motivated whereas similar demands made by the victim of a paramilitary group, particularly in the past a victim of a Republican paramilitary group, may be represented as understandable and normative.

This political dynamic has both led to and been reinforced by the largely divided nature of the organizations operating within the voluntary sector who provide support for victims of the Troubles. With few exceptions, organisations providing support or campaigning on justice issues are associated with one or other side of the conflict. Those organisations that are providing support for members and former members of the security forces comprising a 'third sector' of their own, until the beginnings of the peace process largely remote from the rest of civil society, and indeed still maintain a degree of separateness. This means that to access services, even in some cases the mainstream health services, involved managing the social attitudes to one's injury and the identity issues raised by it.

## Services in a divided society

Up until the late 1990s, mainstream health services and, to a large extent voluntary services within the fields of disability, victim support and bereavement care operated in a policy context whereby the existence of the Troubles was not formally acknowledged or factored into policy and service provision. Whilst victims of the Troubles clearly accessed such services, at a policy level, they were treated on the basis of their injuries, largely without taking into account the justice, security, sectarian and other ramifications of their situation. Indeed to do so would have called for an acknowledgement that Northern Ireland was a divided society and that something untoward was taking place there, an acknowledgement that a Westminster direct rule administration was unwilling or unable to make. Thus, policy in the health and social services resembled that of Surrey or Yorkshire and the large voluntary sector often followed suit, with disability charities and others looking to their English counterparts for policy and practice developments. The corollary to this was the reluctance, if not fear, of attempting to open the Pandora's box of the reality of life in Northern Ireland. Thus, many Northern Ireland wide voluntary groups adopted a position of providing 'bread and butter' services - which by definition were apolitical. This position ill equipped them to deal with victims of the Troubles, whose situation inevitably exposed the deep divisions and dangers in the society. In turn, this led to a deep reluctance on the part of many voluntary organizations to engage with issues related to the conflict.

The more cynical view is that this only began to change with the advent of the European Special Support Programme for Peace and Reconciliation in Northern Ireland, following the

1996 ceasefires. The availability for the first time of substantial funding to address the issue of victims of the Troubles, in a financial climate where substantial new funding for voluntary activity was rare, began to stimulate voluntary organisations to reconsider their relationship with victims of the Troubles. Although the starkness of past divisions has diminished somewhat, the separation of functions persist to a large extent.

Relevant to this study, are the surviving divisions in the disability sector. Disability organizations in Northern Ireland in the past have not contained or represented the bulk of people disabled as a result of the Troubles. Rather, their focus has been on the mainstream of disability issues affecting disabled people and their carers throughout the UK and Europe. Those disabled in the Troubles, where they affiliate to any organization, have been more likely to gravitate towards a victims' organization than to one of the disability charities. This is replicated in the field of bereavement care, with Cruse providing general bereavement care, including to some bereaved in the Troubles, but many so bereaved opt for membership of a victims group in preference to seeking services alongside the wider population of bereaved people.

At a service delivery level, there may be good reasons for this. In psychological terms, an injury or bereavement due to the Troubles could be construed as a 'complicated' bereavement or injury. Insofar as the harm caused has been intentional or targeted for political or sectarian reasons, this differentiates to some extent the victim of the conflict from those injured in accidental ways. One could argue that the victim of a drunk driver has similar experiences. However, there are few in the community who would support the activities of drunk drivers, whereas the violence of the Troubles enjoyed support of one kind or another, as a consequences limiting sympathy to victims of one or other cohort using violence. This not only limits and shapes the social life of victims and where they can seek support, but it also may have consequences for their psychological coping. A 1995 study by Parson, for example, examined the complexity of effects of intentional harm or injury on victims of the Oklahoma bombing in terms of the victim's subjective evaluation of a harm caused by intentional human action. The consequences of this means that victims of the Troubles, certainly in the past, had needs that were unlikely to be met within the mainstream statutory or voluntary services.

The growth of the 'victims sector' and the development of a range of organizations specifically addressing victims' needs has mitigated this to some extent, although the limitations of this development are evident, as addressed above. Furthermore, the development of a victims' sector based to some extent on principles of self-help affords victims opportunities of self-development not readily available in professionally based services, particularly the statutory services. A study published in 2009 by Vollhardt examined the development of 'pro-social' behaviours in individuals suffering adverse life events, whereby victims deploy their suffering as a motivation to help others in similar circumstances. This trend is perhaps nowhere more evident than in the victims' sector in Northern Ireland. Whilst these opportunities have been life affirming and confidence building for many of the individuals involved, it has perhaps contributed to the separation of victims' organisations into a separate silo within the voluntary sector, one that is regarded with a smidgen of resentment by some other voluntary organisations as better resourced than the rest of the sector.

This landscape of voluntary provision has been summarized diagrammatically in the Figure 2 below.

....... Silence about the Troubles, absence from policy LARGE VOLUNTARY SOCIAL HUSTINE ORGANISATIONS DRIGANISATIONS STATUTORY HEALTH AND SOCI SERVICES, BENEFITS AND HOUSING VICTIMS: ...... GROUPS Troubles acknowledged and SMALL LOCAL ARMED FORCES VOLUNTARY addressed **ASSOCIATIONS** ORGANISATIONS

Figure 2: Silence about the Troubles and service provision during the Troubles

#### Victims in a divided society

Much has been written about victimhood in general and a good deal of material exists on victimhood and victim identity in Northern Ireland's Troubles (Breen-Smyth, 2007; 2008; 2010; Ferguson et al, 2010; Manktelow, 2007; Cairns and Mallett, 2003; Smyth and Morrissey, 2002; Fay, Morrissey and Smyth, 1999).

To access services in the voluntary and community sector also involves making decisions about which organization in which community and which affiliation to approach. Such decisions often had to take into account issues of perceived and actual safety, risk taking, loyalty, community support or censure and the reproduction of existing societal political divisions. In addition, the thriving community sector in Northern Ireland is replete with other, more localized politics within communities. Factional conflicts between various locally based organizations, including paramilitaries, church based versus secular groups, family and neighbourhood loyalties, amongst others, can mean that the simple decision to approach a particular group is not only a statement about one's identity, local allegiances and politics, but it also serves to either reinforce or undermine the political status quo within such groups. Thus, to access services, as with many other seemingly innocuous actions in divided societies, can be a political statement and a decision about identity management. The victim of the Troubles must not only deal with their injury, suffering, and disability. They must also negotiate the tricky terrain of service provision. Many do not seek services or join victims' groups. One suspects that for many, the stress and pressure of negotiating this terrain has a deterrent effect on their willingness or ability to seek such services.

The demands of this level of identity management and the tensions within the field of service provision have implications for the wellbeing of those injured. It is an added pressure, on top of the other pressures they must cope with. In the end, it may also compromise their accessing of services.

#### **Identity management**

Negotiating all of these factors and managing one's identity as a person injured in a political conflict can present considerable challenges to injured people, and this can have marked effects on their emotional well-being. Being injured in the Troubles raises a range of issues for injured people and those who care for them in terms of identity, management of that identity and representations of the self in the various arenas in a divided society. Some victims have had to conceal the real circumstances of their injury, whilst most injured people must make complex decisions about how much to disclose about one's injury or disability in the variety of circumstances in which they find themselves. For those injured people whose body and functioning has been substantially altered by their injury, the identity management issues facing them also face other people who have acquired disabilities through accidental or non-political means. The process of identity management in such circumstances has been well documented in the literature on disability, since Erving Goffman's 1986 anachronistically titled 'Stigma: notes on the management of spoiled identity'. However, the victim of the Troubles not only faces the actual management of their own self identity as a result of the disabling effects of the Troubles, but also faces the need to 'manage' or even conceal the reality of their injury or disability, particularly its causation, in a wider social and political context. This is akin to the process described by Pachankis (2007) in terms of the stressors caused by the demands of concealing stigma.

Similarly, the victim of a punishment attack approached to be interviewed for this study declined, because although his wife knew about the circumstances in which he had acquired his disability, his children were unaware of these. He did not wish his children to know that their father had been considered a 'hood' in his adolescence, nor that he had been severely injured, not in the relatively benign circumstances they had been told of, but in a brutal attack by a paramilitary group, intent on 'policing' him. People in these kinds of circumstances may invent alternative narratives to explain their injuries. In order to avoid the stigma of the reality.

The political dynamic in Northern Ireland (Smyth, 1998), whereby claims to victimhood have been used to justify retaliatory violence has, certainly in the past, created a political culture, based on competing claims to victim-hood. This can be a very difficult environment to negotiate for those worst affected by the violence. Furthermore, some such as Bloomfield (1998) have adopted very broad definitions of victimhood, pointing out that 'there is some substance in the argument that no-one living in Northern Ireland through this most unhappy period will have escaped some degree of damage' (Bloomfield, K. 1998, p14).

However, such broad, universal definitions of victims do not facilitate the targeting of humanitarian resources towards victims. Furthermore, they mask the way in which damage and loss has been concentrated in particular sub-populations and the enormous suffering of some people compared with minimal effects on others.

Where victims suffering is taken up as a cause by their community, it may be difficult for them to move beyond a victim identity. Victims have been called upon regularly by the media, and some become quite well known public figures, whilst others are ignored. The victim of a punishment attack may attract little attention or sympathy compared to the victim of a bomb explosion.

Finally, some victims have had to conceal the actual circumstances, which led to their injury. One police officer seriously injured in a gun and grenade attack used to explain his difficulty in walking as due to a road accident that he didn't want to talk about, because it involved his own drink driving. An earlier fictional explanation – that he had had polio – had to be abandoned because of his inability to respond to knowledgeable questions about polio by concerned interlocutors. Police officers routinely passed themselves off as 'civil servants' or some other occupation during the conflict. Indeed, as attacks on police officers continue, a continuing need for caution in the management of a police identity is apparent in Northern Ireland. Many former police officers feel that to reveal their affiliations with a particular organisation may render them vulnerable to further attack.

Negotiating all of these factors and managing one's identity as a person injured in a political conflict can present considerable challenges to injured people, and this can have marked effects on their emotional well-being. For this reason, we wish to add a category of identity management.

#### **Agency**

Elsewhere it has been argued (Smyth 2000; 2001; 2003) that victims are often represented stereotypically as helpless, passive, suffering, powerless, dependent and so on. Furthermore, there may be unintentional subtle or indeed overt social pressure on victims to conform to the stereotype, sometimes at the expense of their own wellbeing and interests. Yet the importance of personal agency and the ability to advocate on one's own behalf is an important aspect of mental health and wellbeing. Furthermore, the complex inter-relationship between physical and mental health and the transformative powers of a positive and empowered attitude form an important part of understanding well being in general. This is, perhaps, particularly important for injured people, some of whom may be living with challenging disabilities and must maintain a resiliently positive attitude in order to overcome the challenges of daily life. We therefore argue that possessing a sense of agency and personal power is an important part of wellbeing.

We therefore propose a framework that is based on a general notion of **wellbeing**, within which we identify the following component parts:

- 1. Health and wellbeing
- 2. Identity management
- 3. Truth, justice and acknowledgement
- 4. Social support and respite
- 5. Trans-generational issues
- 6. Individual financial support

## 7. Agency.

This framework informed the structure of interviews and survey instruments and data was elicited under these headings. These were analysed both, as discrete categories and as contributory factors to an overall assessment of 'wellbeing'.

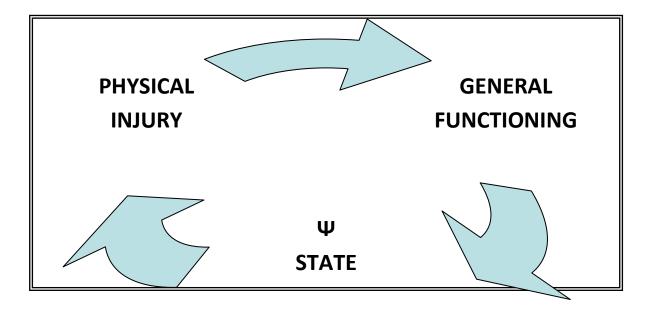
## **Categorisation of injury**

A further issue that faced the study was the need to operationalise the concept of injury due to the Troubles. Since our focus was to be on physical injury, we identified a range of physical injuries to begin with. These were:

- 1. Loss of upper limb
- 2. Loss of lower limb
- 3. Multiple losses of limbs
- 4. Brain injury
- 5. Gunshot wounds
- 6. Shrapnel wounds
- 7. Loss of sensory capacity (sight, hearing)
- 8. Multiple loss of sensory capacities
- 9. Disfiguring injury (burns etc)
- 10. Neurological damage

The relationship between physical injury, psychological state, and functional capacity is mutually interdependent. Physical injury impacts on functional capacity,NS This in turn, affects morale and psychological state. Functional capacity similarly affects psychological state, and can contribute to depression or conversely can stimulate a determination to recover abilities lost as a result of the injury. Finally, psychological state can also influence physical performance, as is evident in sports performance. Psychological disposition and adetermination to improve one's health and quality of life can greatly improve wellbeing.

Figure 3. Relationships between psychological state, physical injury and general



# We identified the following functional impacts:

# Need to manage complex medical needs

- 17. Chronic dependence on hospital/medical services, such as prosthetics
- 18. Restricted mobility and associated problems
- 19. Dependency on others for personal care and hygiene
- 20. Inability to ensure own personal safety
- 21. Intellectual impairment
- 22. Inability to represent own best interests
- 23. Inability to work
- 24. Difficulties or breakdown in family relationships

# **Psychological state**

- 21. Phobias, agoraphobia
- 22. Social isolation
- 23. Depression
- 24. Anxiety
- 25. Post-traumatic stress disorder
- 26. Prescription drug dependence
- 27. Alcohol dependence
- 28. Illegal drug dependence
- 29. Loss of purpose
- 30. Chronic anger/belligerence towards others

#### Research methods and ethics

## Research strategy

The tender document offered two options in terms of research design, one to include the making of a film and the other a more elaborated field research. WAVE opted for the design, which included making a film, and Northern Visions was sub contracted for this purpose. The research strategy for the project involved four stages:

- **Stage 1**: Review, evaluation and analysis of data sources available on levels of Troubles-related injury
- **Stage 2**: To record and archive personal experiences of a representative sample of those injured through the Troubles
- Stage 3: A field survey-A survey of people injured in the Troubles -Design Survey instruments
- Stage 4: Administer Survey
- **Stage 5:** The report
- Stage 6: The film

The stages have been explained in detail below:

#### Stage 1

# Review, evaluation and analysis of data sources available on levels of Troubles-related injury

This stage comprised a review of the available research on the topic, together with an evaluation of the available data sources on the size of the population of those injured in the Troubles. The output of this stage of the project was the production of a written report in which the various estimates and datasets purporting to define the size of the injured cohort are discussed and evaluated. This is included here as Section 8 of this report.

## Stage 2

# To record and archive personal experiences of a representative sample of those injured through the Troubles

Although the difficulties of obtaining a statistically representative sample of people injured in the Troubles are insuperable, "a representative sample" composed of people who broadly represent the range of injuries suffered by the population as a result of the Troubles, was drawn through the use of a carefully structured quota sample. Quotas for each gender, geographical locations, type of injury were drawn up and this is further discussed in Section 6 of this report.

A total of 45 semi-structured in-depth interviews were planned, 35 of these were to be with injured respondents and their families carried out in the interviewees own home. The remaining 10 interviews were to be conducted with service providers, policy makers or other relevant people identified in consultation with the steering group.

Interviews were planned to cover the nature, extent and circumstances of the injury, the short, medium and long term impact of the injury, both physically, emotionally and psychologically, together with the impact on relationships, economic circumstances, life chances in both the short and long term. Interviewees' needs resulting from the effects of the injury were to be explored, together with the methods, networks and agencies used (or not used) by the injured person and their family to cope together with the interviewees' evaluation of their effectiveness. In the case of service providers, interviews were to focus on the nature and level of service and issues of quality, accessibility and fitness for purpose.

It was planned that interviews would be digitally recorded for the purposes of transcription. Transcripts of interviews were to be provided to interviewees and transcripts were to be analysed using a manual system of textual analysis, identifying themes, commonalities across respondents and features that appear to be specific to certain categories of respondent. The outputs of this stage was to inform subsequent stages of the research. Analysis of interviews would identify the themes and topics for inclusion in the questionnaire.

#### Film and archive

A sub-set of interviewees was to be selected and interviews were to be filmed with them, in order to produce a film focussing on the short and longer term needs and situations of those injured in the Troubles. Northern Visions, a community based media company, agreed to provide this option. This film could be used for educational and advocacy purposes and also as a historical record. In addition, Northern Visions proposed to make the total filmed footage available to WAVE as well as the edited film, so that archiving can be facilitated. Following the conduct of the first phase of in-depth interviews, participants in the film were to be identified, and filming and editing was to be carried out alongside the other work of the project. Film editing was to commence when filming is complete, so that film participants and the steering group can view the rushes and have an input into the final shape of the film prior to post-production finalising.

# Stage 3 A field survey

#### A survey of people injured in the Troubles Design Survey instruments

Arising from the analysis of interview data, a pre-coded survey instrument was be prepared with an embedding standardised instrument that aim to measure disability as being a suitable method be found. As with the interviews, the instrument will also capture information – albeit in a more basic form - about the nature, extent and circumstances of the injury, the short, medium and long term impact of the injury, both physically, emotionally and psychologically, together with the impact on relationships and economic circumstances. It was planned to keep the instrument concise and simple, to ensure the obtainment of accurate responses; with completion taking no longer than 30 minutes, and questions in plain English.

## **Sampling**

Since randomised sampling was not possible, a snowball sampling technique was adopted, eliciting contact with potential participants from victims groups, service agencies and other suitable agencies. As before a structured quota sample was planned to ensure coverage of the injured population in as representative a manner as possible (see Section 6). Given that the distribution of deaths in the Troubles, (Fay et al, 1999) is likely to provide good indicative information about the likely distribution of injury, these data will be used to inform the construction of the matrix setting out the numbers of respondents to be recruited in each category.

#### Stage 4

## **Administer Survey**

It was anticipated that the networks of the Campaign For All Injured group, the steering group, Disability Action's Human Rights Group, WAVE and other victims groups (those that are interested and willing) would facilitate the distribution of the questionnaire and the recruitment of survey respondents. Survey data was to be cleaned and entered into SPSS, where initial descriptive statistics (frequency counts) will be produced. Cross tabulations showing breakdowns of the data by age, gender, location, date of injury, in terms of aspects of needs and experiences of services will be undertaken. A survey report will be prepared, including a description of the sample, and an account of the survey methods and the results in terms of the short and long term needs of the injured will be prepared for the steering group by the specified date.

# Stage 5

## The report and further Publications

The report was to incorporate data (including quotes) from the qualitative interviews in order to produce a more rounded account, exploring in more depth the physical, emotional and psychological effects of injury, the coping mechanisms used by the injured and their families and their experience of service provision and support or lack thereof. All reports were to be prepared to both academic publication and professional report standard. In consultation with WAVE, the preparation of one or more academic publications arising out of the research data was anticipated.

# **Methods: the interviews**

In total, 35 interviews with injured people were planned, with an additional 6 interviews with carers and 14 service providers. This is a small number of interviews with which to encompass the varieties of experience of injury.

We identified a number of important demographic characteristics which we wished to ensure were covered in the interview cohort. These were:

- 1. Gender
- 2. Age at injury
- 3. Location: site of injury/ home address
- 4. Community affiliation
- 5. Type of injury
- 6. Date of injury
- 7. Perpetrator

## **Gender**

Whereas those killed in the Troubles were overwhelmingly male (91.1%) estimates for injury indicate that the gender balance is similar, with roughly 80% of injured people being male. The nature of the conflict has an impact on this, and the large city centre bombs favoured by the IRA in the early 1970s arguably produced relatively more female casualties. However, we planned to interview both men and women.

# Age at injury

Again, there is no reliable data on age at injury. Data on deaths shows that more 19 year olds died in the Troubles than any other single age and the 18-24 age category contains substantially more deaths than any other. This would suggest that we needed to oversample people who were injured when they were in their late teens or early twenties.

# Site where injury occurred/ home address

Data on deaths shows that deaths were concentrated in North and West Belfast, which has the highest death rates, followed by the border counties and the Lurgan/Portadown area. It seems likely that injuries should follow the same pattern. Therefore we proposed to concentrate our sample in these areas where possible. We therefore identified four geographical categories: North and West Belfast; the border counties; Lurgan /Portadown; and the rest of Northern Ireland.

## **Community affiliation**

Analysis of deaths data shows that both relatively and absolutely, more Catholics than Protestants were killed in the Troubles. We therefore, planned to take this into account when selecting interviewees.

# Type of injury

As outlined above, we also identified a number of types of injury:

- 1. Loss of upper limb
- 2. Loss of lower limb
- 3. Multiple losses of limbs
- 4. Brain injury
- 5. Spinal injury
- 6. Gunshot wounds
- 7. Shrapnel wounds
- 8. Loss of sensory capacity (sight, hearing)
- 9. Multiple loss of sensory capacities
- 10. Disfiguring injury (burns etc)
- 11. Neurological damage.

The sample should include as many of these types of injury as possible.

## **Date of injury**

As mentioned above, the type of violence used varied over the decades of the Troubles. The 1970s were characterised by large city centre bombs in Belfast and other urban locations, whereas later in the conflict, assassination attempts using devices under cars or gun attacks were deployed. Street disturbances, shooting at moving vehicles, riots, and arson attacks also produced injuries. Each of these forms of violence subsequently led to the kinds of injuries sustained by targets, bystanders, and perpetrators. Blast injuries, associated with large bombs were more prevalent during the 1970s phase of the Troubles than during others. We identified two phases of the Troubles, pre 1985 and post 1985 as distinct phases of the conflict in terms of the type of violence used, with large bombs featuring in the early stages of the conflict, and gunshot wounds, smaller blast bombs and other types of injuries predominating in later phases. We also wished to include a range of people with a variety of experience of both recent and long-standing injuries.

#### **Perpetrator**

The final factor to be considered was the issue of the perpetrator of the attack that caused the injury. Again, using deaths data, we know that Republican paramilitaries caused around 56% of deaths, followed by Loyalist paramilitaries (27.4%), and the security forces caused approximately 10% of all deaths and these were mostly of Catholics. It seems likely that injuries would follow the same pattern, with one significant departure. Data from the PSNI database would suggest that public order incidents produce the largest number of injuries. Insofar as these data are reliable and record civilian as well as police casualties, this is a significant departure from the pattern seen in deaths data. In order to ensure a fair picture of the spread of injuries, we need to take these patterns into account when selecting interviewees.

## The interview sample

In selecting injured people, their carers and service providers for interview, a number of axes were considered in order to achieve a total interview cohort broadly representative of the population of injured people, their carers and service providers. These axes include: perceived religion, cause, and date of injury, age of injured person, home location, extent of injury, status of injured person and injuring agent.

There is no overall sampling frame for a study of injured people. Although there is a convergence of estimates about the total size of the population of injured people, the size of the population depends on how the definition of injury is determined. This issue is discussed in more detail in the full report. However, even if the size of the population was known, there is no detailed information about the structure of that population, its breakdown by age, religion, location and so on.

In structuring the sample, we were informed of what is known about the patterns of deaths due to the Northern Ireland conflict, and although the pattern of injury is unlikely to be identical, since there were many more injuries than deaths, a working assumption that the spatial, gender and religious distributions could inform the structuring of the sample. We know a number of things about deaths that are also likely to be true for injuries, namely:

- 1. The peak levels of deaths occurred in the first half of the 1970s; and
- **2**. The majority of deaths were caused by gunshots, followed by bomb explosions.

Thus, in drawing our sample of injured people for interview, we were informed by this pattern. Within the sample there is a concentration of people who were injured in the 1970s, and a concentration of people who were injured by gunshots, or gun attacks, followed by those injured by bombs.

Table 1: Injured Sample: Date of injury by cause of injury

	DECADE OF INJURY				
CAUSE OF INJURY	1970s	1980s	1990s	2000 onward	TOTAL
Premises bombs	6	1	1	0	8
Gunshots	7		1	0	8
Gun / rocket attack on person	6	1	0	0	7
Bomb attack on person	1	1	0	0	2
Plastic bullet	0	2	0	0	2
Punishment attack/gun	0	0	1	1	2
Army vehicle	1	0	0	0	1
TOTAL	21	5	3	1	30

## <u>Gender</u>

Whilst the overwhelming majority of those killed in the Troubles have been male (91.1%) (Fay et al, 1999), figures for injury are likely to include a larger proportion of females, because of the prevalence in the 1970s of large city centre bombs, and subsequent events such as the Omagh bomb, where relatively large numbers of random civilian casualties were injured and killed. Nonetheless, any sample should include larger numbers of males than females to reflect the likely pattern of injury in the wider population over the duration of the Troubles. Table 2 shows the breakdown of the injured sample by gender and religion.

Table 2: Religion and gender of injured sample

	GENDER			
RELIGION	Male	Female	TOTAL	
Perceived Catholic	12	5	17 (56.6%)	
Perceived Protestant	9	4	13 (43.3%)	
Total	21 (70%)	9 (30%)	30 (100%)	

#### Religion

The Cost of the Troubles Survey (Fay et al, 1999) found that percentage of Catholics reporting a lot (8.9%) and quite a lot (22.8%) of experience of the Troubles was much higher than that of Protestants (5.25% and 13.80/0 respectively) whilst only 5% of Catholics compared to 38.9% of Protestants reported very little experience of the Troubles. The survey concluded that Catholic experience of the Troubles is disproportionately high; of those reporting a complete change in their lives due to the Troubles, 90.9% were Catholic compared to 8.1% Protestant. Catholics overall, report having experienced more extreme effects of the Troubles, whereas Protestants report less overall change on a smaller scale; in spite of this, proportionately more Protestants than Catholics reported long-standing illnesses. Catholics also reported more painful memories, dreams, and nightmares about the Troubles, intrusive thoughts, losing interest in normal activities and feelings of insecurity and jumpiness than Protestants.

#### <u>Age</u>

The death risk in the younger 20-24 age group has been highest, and almost 26% of all victims were aged 21 or less. However, the impact of the conflict was also concentrated in the early 1970s, hence the need to over sample people injured in the 1970s, see Table 3. This would suggest that people in the age group from 59-63 are likely to be most numerous in the injured population. As is evident in Table 3, we structured the sample so that this was the most numerous age group in our sample. We included small numbers in the cohort older than that, but focussed on those younger, injured later and relatively recently in the Troubles, on the grounds that these are likely to be the most long-lived with continuing needs in the future.

Table 3: Age of injured person by gender

	AGE						
GENDER	<40	40-49	50-59	60-69	70-79	80+	TOTAL
Male	0	2	8	8	1	1	20
Female	1	3	1	5	0	0	10
TOTAL	1	5	9	13	1	1	30
TOTAL	(3.3%)	(17%)	(30%)	(43%)	(3.3%)	(3.3%)	(100%)

# **Status**

Civilians are the largest category of people killed in the Troubles, and account for 53% of the total (including the British Army) killed; with the British Army accounting for almost 15%. Republican paramilitaries account for almost 13%, the RUC account for 8% of those killed and the other groups including Loyalist paramilitaries each account for less than 6%. Our research did not include members of the British Army beyond those in local regiments, therefore the percentage of civilians included is higher (see Table 4);

**Table 4: Status by gender** 

		GENDER	
INJURED STATUS	Male	Female	Total
Civilian	14	8	22 (73%)
Former RUC	4	1	5 (17%)
Former UDR	1	0	1 (3%)
Former political activist	2	0	2 (7%)
Total	21	9	30(100%)

## **Injuring agent**

In relation to perpetration of killings, Republican paramilitaries account for almost 59% of all deaths, Loyalist paramilitaries for almost 28%, the British Army for 9%, the RUC for almost 2% and other groups each for less than 1%. Republican paramilitaries have killed 74% of all Protestants killed over 25% of all Catholics, and almost 96% of those who were classified as "Non Northern Ireland." Loyalist paramilitaries killed 19% of all Protestants killed, almost 50% of all Catholics and just 2% of the "Non Northern Ireland" category.

Table 5: Injuring agent by gender of injured person

		GENDER	
CAUSE OF INJURY	MALE	FEMALE	TOTAL
IRA	12	5	17 (56.6%)
DISS REP	1	1	2 (7%)
OTHER REP	0	1	1(3.3%)
UVF	1	0	1(3.3%)
OTHER LOY	2	0	2 (7%)
BRITISH ARMY	2	2	4 (13%)
LOY COLLUSION	3	0	3 (10%)
TOTAL	21	9	30 (100%)

## The spatial distribution

The spatial distribution of the sample was informed by what is known about the spatial distribution of deaths, where a concentration of deaths was found in Belfast ward areas, with only 15 of the 57 highest-ranking wards outside the Belfast area. Derry Londonderry and Armagh account for most of the remaining wards. This table shows the geographical location of residence of the injured person at time of interview. Some injured people were forced to relocate away from the area where their injury occurred, however, as the focus of this study is on the needs of injured persons, their geographical location of residence is where they are more likely to require services.

Table 6: Geographical location of residence of injured person by gender

GEOGRAPHICAL LOCATION		GENDER	
OF RESIDENCE	MALE	FEMALE	TOTAL
BELFAST	6	6	12
TYRONE	2	1	3
FERMANAGH	1	0	1
DERRY	3	0	3
CO LONDONDERRY	1	0	1
DOWN	3	1	4
CO ANTRIM	3	0	3
ARMAGH	1	2	3
TOTAL	20	10	30

## The extent of injury

Finally, and perhaps most importantly, the interview cohort design reflects the range and extent of injuries sustained by the broad population of those injured during the Troubles. To some extent, this is an unquantified range, and beyond what is known anecdotally by those providing services, there is no way to be sure that the cohort accurately reflects the range of injuries. However, given that the composition of the cohort is well composed on other axes, we are reasonably confident that the range of injuries reported by the cohort are typical of those suffered by the broader range of those injured in the Troubles.

In Table 7, an audit of the injuries of the cohort is set out. In some cases, where an interviewee could be included in more than one category, the interviewees' allocation was to the category that represented the most serious of the injuries sustained. For example, one interviewee had lost three limbs and had also suffered some loss of sight in one eye. For the purposes of the audit, her allocation was to the category of 'loss of more than two limbs'. A person who has lost two limbs was allocated to that category, even though they are also a wheelchair user, whereas those who were allocated to the category of wheelchair user have not lost actual limbs, but rather limb function. The severity of some injuries is not entirely captured by this tabulation, such as the interviewee who is paralysed from the chest down, using a stoma and catheter, is allocated to the same category 'wheelchair user' as the interviewee who uses a wheelchair rather than crutches, and has some movement in his legs and is fully continent. Nonetheless, the tabulation gives some albeit crude sense of the spread of injuries manifest by the cohort.

**Table 7: Extent of injury** 

		GENDER	
EXTENT OF INJURY	MALE	FEMALE	TOTAL
LOSS OF ONE LIMB	1	2	3
LOSS OF TWO LIMBS	4	1	5
LOSS OF MORE THAN TWO LIMBS	0	1	1
PARTIAL LOSS OF SIGHT	1	0	1
LOSS OF HEARING	1	1	2
GUNSHOT WOUNDS	6	2	8
DISFIGUREMENT	0	1	1
WHEELCHAIR BOUND / PARALYSIS	4	0	4
BRAIN INJURY	1	1	2
PARALYSIS OF ONE LIMB	2	0	2
PARALYSIS OF TWO LIMBS	1	0	1
TOTAL	21	9	30

## **Ethics**

This project required full ethical approval from the Office of Research Ethics Committees for Northern Ireland. A full ethical approval application, together with documentation which included a summary protocol, copies of all interview schedules, participant information sheets and consent forms each for interview, survey and film were submitted for approval, evidence of insurance cover, sponsorship, names and qualifications and CVs for all research staff and copies of the application forms completed on the electronic system. These were considered by the committee, who required amendments to the consent forms, which were duly amended and resubmitted. A favourable opinion was obtained with the requirement to submit the questionnaire for the survey for approval when it became available. However, we were also required to obtain ethical approval from each of the Health and Social Care Trusts in Northern Ireland in order to interview their staff about provision for injured

people. This process required criminal records checks in each trust area; which can take a lengthy period, honorary contracts with each of the five trusts, completion of different sets of paperwork for each trust, attendances at training courses on 'good clinical practice', and nominations of Chief Investigators who must be Trust staff for each Trust area. The study was designed without Trust involvement and a new set of application documents.

There were considerable difficulties in finding the relevant staff in most of the trusts, so responses were made to emails, and phone calls—with Trust staff revealing that some have never heard of their own Trauma Advisory Panels, or Research Offices. A member of staff in each Trust had to be found who was willing to act (or not to act, as the case was) as Chief Investigator, since without this, ethical approval cannot be obtained.

There is considerable doubt whether it is possible to apply for and obtain ethical approval to do research in Northern Ireland if one is working to a contracted time scale. In this case, we extended the period of the research by several months to compensate for the delay and in the end abandoned parts of the study, involving interviews with Trust staff, simply because the Principal Investigator could not meet these requirements of the Trusts within the cost limits and time frames of the study.

This is in the context of private companies commissioned by government ignoring the law in relation to obtaining ethical approval in carrying out research in the same field without any kind of ethical requirement. It seems to me that the system is inviting those who wish to abide by the law, to flout it in future. If the requirements are so irrelevant, inflexible, and onerous from the Trusts, and other commercial operators already flout these requirements without penalty, there is no incentive for researchers to try to do the right thing in future.

Copies of the ethical approvals are included in the Appendices.

# The size of the population of injured people

There is no overall comprehensive census of injured people, nor would it be easy to arrive at a definitive size for the total population of injured people for a number of reasons. These include the difficulty of arriving at a generally acceptable and operational definition of 'injury'; including setting criteria for inclusion and exclusion which will involve defining and measuring severity of injury; and changing approaches and practices in record keeping over the period of the Troubles, including the destruction of some records. Although, as we shall see, there is some convergence of estimates, others vary widely, and mainly issues of definition (which are previously in the report) drive much of this variation.

The Commission for Victims and Survivors in Northern Ireland (CVSNI) produced a summary of the findings of various studies by taking the percentage figure in each of the surveys and extrapolated this to the population of Northern Ireland using the 2009 population figure for Northern Ireland of 1,788,900 (Register General of Northern Ireland 88th Annual Report). The Commission for Victims and Survivors also commissioned the Northern Ireland Statistics and Research Agency (NISRA) in September 2010 to incorporate a module relating to Victims and Survivors of the Northern Ireland Troubles in the 2010 Omnibus Survey. Their summary of the findings of a number of studies on the issue of size of population alongside the findings of the 2010 Omnibus Survey is visible in Table 8 below.

**Table 8: CVSNI Summary of Previous Research** 

SURVEY/ RESEARCH	YEAR	FINDINGS	SAMPLE SIZE	SURVEY EXTRAPOLATED TO CURRENT POPULATION*
Cost of the Troubles Study	2002	25.5% of survey experienced severe or very severe experience of the troubles	1,346	456,169
(COTTS)		36% indicated a severe or very severe impact of the troubles	1,346	644,004
		16% of survey consider		
Who are the		themselves direct victims	1,000	286,224
Victims: Cairns and Mallet (NISRA 2003)	2003	30% of survey considered themselves indirect victims	1,000	536,670
The Legacy of the	2005	30% of the sample had		
Troubles:	2005	direct experience of the	3,000	536,670
Muldoon, O et al		troubles		
CVSNI Omnibus Survey (NISRA)	2010	30% of survey had been directly affected by the conflict	1,179	536,670

# **NI Omnibus Survey**

The CVSNI Omnibus Survey found 30% of survey respondents reported that they have been directly affected by the conflict is consistent with the previous research findings. On this basis, CVSNI concluded that approximately 30% of the current population of Northern Ireland consider themselves to be victims and survivors of the Troubles, giving a total population of approximately 500,000 people affected by the Troubles.

However, this is rather a general category, and the CVSNI 2010 Omnibus Survey module breaks this down into how respondents specifically describe their experience of the Troubles. This is summarised in Table 9 below.

Table 9: Experience of the Troubles: NI Omnibus Survey

Experience	Percentage of Respondents	Grossed up to 2009 population
Experience of trauma or	24%	429,336
caring for someone affected		
by a traumatic event		
Bereaved as a result of the	11%	196,779
Troubles		
Suffered Physical injuries	6%	107,334
themselves as a result of the		
troubles		

This narrower focus on injury, reduces the estimated number of those injured in the Troubles to 107,334 although The Cost of the Troubles Survey (COTTS, 1999) found that 100,000 people live in households where someone has been injured in a troubles related incident, implying that the actual number of injured is somewhat less than 100,000.

#### **Police statistics**

The RUC and subsequently the Police Service of Northern Ireland kept records of numbers of injury and these are shown in Table 10 below

Table 10: NI-SEC-05: Persons injured (number) due to the security situation in Northern Ireland (only), 1969 to 2003 Available at <a href="http://cain.ulst.ac.uk/ni/security.htm#05">http://cain.ulst.ac.uk/ni/security.htm#05</a>

Year	Police <sup>1</sup>	Army	UDR / RIR <sup>2</sup>	Civilian	Totals
1968	379	0	n/a	n/a	379
1969	711	54	n/a	n/a	765
1970	191	620	n/a	n/a	811
1971	315	381	9	1,887	2,592
1972	485	542	36	3,813	4,876
1973	291	525	23	1,812	2,651
1974	235	453	30	1,680	2,398
1975	263	151	16	2,044	2,474
1976	303	242	22	2,162	2,729
1977	183	172	15	1,017	1,387
1978	302	127	8	548	985
1979	165	132	21	557	875
1980	194	53	24	530	801
1981	332	112	28	878	1,350
1982	99	80	18	328	525
1983	142	66	22	280	510
1984	267	64	22	513	866
1985	415	20	13	468	916
1986	622	45	10	773	1,450
1987	246	92	12	780	1,130
1988	218	211	18	600	1,047
1989	163	175	15	606	959
1990	214	190	24	478	906
1991	139	197	56	570	962
1992	148	302	18	598	1,066
1993	147	146	27	504	824
1994	170	120	6	529	825
1995	370	8	5	554	937
1996	459	53	2	905	1,419
1997	357	136	14	730	1,237
1998	435	70	17	1,130	1,652
1999	395	20	16	552	983
2000	446	25	2	591	1,064
2001	876	44	11	667	1,598
2002 <sup>3</sup>	456	39	38	628	1,161
2003 (to 30/06/03) <sup>3</sup>	79	5	1	346	431
Grand Totals	11,212	5,672	590	30,058	47,541

# Notes:

- 1. Includes Royal Ulster Constabulary (RUC) / Police Service of Northern Ireland (PSNI) Reserve.
- 2. Ulster Defence Regiment (UDR) / Royal Irish Regiment (RIR) (Home Service Battalions)
- 3. 2002 and 2003 statistics are provisional and may be subject to minor amendment in the future. n/a: not available

<u>Sources:</u> Police Service of Northern Ireland (PSNI). (2003) Persons injured as a result of the Security Situation in Northern Ireland 1969-2003, (by calendar year);

available online at: http://www.psni.police.uk/index/departments/statistics\_branch.htm

Northern Ireland Annual Abstract of Statistics 2002; Table 6.3

These figures, would suggest a total population of injured people at 30/6/2003 of 47,541. The share of security force personnel amongst the injuries (36.8%) is somewhat higher than their share of total deaths (30%) (Fay et al,1999, p.159). Even if members of paramilitary organisations are included in the civilian total, its very large size suggests that civilians represent the majority of those injured. Moreover, the injury table further reveals the concentration of violence in the 1970s. Almost a third of all injuries were suffered between 1972-1977.

However, like all of those available, these figures do not rely on a specified definition. Furthermore the consistency of record keeping and definition over time, given changing methods and approaches to record keeping casts doubt on the reliability and validity of these figures. As explained in the survey analysis, the RUC are not likely to be comprehensive in that they will not record injuries not known to the police and will tend to record local security forces injuries more comprehensively than civilian injuries. Those reservations notwithstanding, it offers a specific figure for those injured of 25,405 by 1996, which can be seen in the context of other estimates.

## **NISALD** data reanalysis

In an attempt to define the size of the injured population further, the full dataset for the NISALD survey has been acquired and re-examined. The 2007 Northern Ireland Survey of Activity Limitations and Disability (NISALD) survey was a comprehensive survey on the prevalence of disability in Northern Ireland and the experiences and socio-economic circumstances of people with disabilities. The survey instrument elicited data on Troubles-related injury in the following questions:

Table 11: NISALD Survey Question A14 – sight

A14. What was the MAIN cause of your sight difficulties?					
Sight related condition (e.g. long-sightedness, shortsightedness, astigmatism etc.)	If <5 at A5, A8 or A12 go to A22, otherwise go to intecB				
Disease/Illness/Other medical condition (e.g. cataracts, glaucoma, diabetes, etc.)	Go to A15				
Work Conditions	Go to A22				
Stress	Go to A22				
Accident or incident	Go to A21				
Violence related to the troubles	Go to A22				
Other violence or violence-related incident	Go to A22				
Other cause	Go to A14oth				
Don't know, doctors still trying to find out	Go to A22				
Don't know	Go to A22				
No known reason	Go to A22				

Question B16 elicited information about hearing difficulties, incorporating a Troubles related answer, thus:

Table 12: NISALD Survey Question B16 – hearing

	B16. What was the MAIN cause of your hearing difficulty?				
	Disease/Illness/Other medical condition	Go to B17			
	(e.g. tinitus, arthritis, multiple sclerosis)				
	Work Conditions	Go to insecC			
	Stress	Go to insecC			
	Accident or incident	Go to B24			
	Violence related to the troubles	Go to insecC			
	Other violence or violence-related incident	Go to insecC			
	Other cause, please specify	Go to B16oth			
	Don't know, doctors still trying to find out	Go to insecC			
	Don't know	Go to insecC			
	No known reason	Go to insecC			
B16 oth	Please specify this other cause	Go to B17			

There were similar dimensions to Questions C11- communication; D11 – mobility; E11 – Lifting; F21 – pain; H11 – breathing; I 12 – learning; J8 – Developmental delay; K8 - social/behavioural difficulty; L5 – memory; M5 - mental health; N11- head injury; O6 - mental illness which might overlap with M5 but there is a filter question at O8.

The full data set for the NISALD survey was subjected to re-analysis. The re-analysis identified the respondents who answered positively to these questions, indicating that they

had a Troubles related injury. The aim was to create a subset of data, relating to those who had been injured and undertake a basic analysis of the demographics, benefits/income profiles of the sub-population, based on their responses to Sections Y and Z of the questionnaire.

However, an initial run showed that only 17 cases had responded positively, 6 of these reported sight-related injuries and 11 reported hearing-related injuries.

It is notable that none of the questions elicited information about limb loss, gunshot wounds, or other injuries that we know to be frequent amongst those injured. This is assumingly related to the construction and conduction of the NISALD survey instrument, which was focussed on disability, rather than injury. Nonetheless, it may tell us something about sight and hearing loss in the Troubles. However, if we take the responses to the question in terms of hearing and sight related injuries due to the Troubles, then 17 responses were obtained from within a sample of 3,543. Using NISRA total population estimates for Northern Ireland for 2007 (when the NISRA fieldwork was carried out), an incidence of 17 in a sample of this size grossed up to the total population would suggest that approximately 8,383 people in the total population could have suffered damage to sight or hearing as a result of the Troubles. Action on Hearing Loss (formerly the Royal National Institute for the Deaf) report that, a large share of their clientele in Northern Ireland have hearing loss due to the Troubles. We know from the interview data in this report, that some of these conditions went undiagnosed for years after exposure to Troubles-related trauma, and often came to light only when it was too late to save the person's hearing.

## **COTTS** survey reanalysis

In 1999, The Cost of the Troubles Study (COTTS) undertook a survey of the population of Northern Ireland aimed at establishing the prevalence of emotional and physical sequelae of the Troubles. The survey also aimed to identify the needs (health, emotional, social, financial) of those affected. No existing questionnaire was adequate to the task, since a wide range of data was required including; demographic data; data on the nature and frequency of their exposure to Troubles related events, the effects of those events on physical and emotional health; their use of medication and alcohol; how they perceived the impact on them; and their experience of help and support. Therefore, for the purpose of this research, it was necessary to develop an instrument. A database of deaths in the Troubles from 1969 to date was compiled. This database was used to calculate ward death rates, and an analysis of this database was published separately (Fay, Morrissey and Smyth, 1998). The database provided a sampling frame for the survey.

From the database of Troubles-related deaths, a calculation was made of the number of residents of each Northern Ireland ward who had died in the Troubles. This was achieved by

translating postal codes into ward locations. The procedure ignored the deaths of non-Northern Ireland residents to concentrate exclusively on the regional population. A figure for ward population was constructed by taking the average from each of the 1971, 81 and 91 Censuses in recognition that the deaths occurred over a 30-year period. From these two figures a ward 'death rate' was then constructed and wards were ranked in descending order. Three groups of wards were identified:

- Those with the highest death rates (7 or more deaths per 1,000 population) ten wards;
- Those with medium death rates (ranging from 2 to 6.9 deaths per 1,000) 122 wards;
- And, those with low death rates (ranging from 0 to 1.9 deaths per 1,000) 424 wards.

From each group, 10 wards were selected on a random basis. The sampling fractions were thus 1, .082, and .024 respectively. Sampling was thus proportionate to the intensity of politically motivated deaths. The end result was a sample of 30 wards stratified by death rates. Within each group of wards, 1,000 cases were selected. The number of cases in individual wards was proportionate to the ward's share of its group population, and these were also selected randomly from the 1997 electoral register. The fieldwork was completed in April 1998 so it does not capture people injured since that date.

This sampling procedure does not facilitate the generalisation of survey results to the population of Northern Ireland. The aim was to compare those areas, where the experience of violence was greatest, with those, which had no direct experience of it. It probed some of the worst experiences of people's lives, with just over a third or respondents drawn from those areas where the Troubles were most intense. The selected wards represent about 6% of the region's population. For the purposes of a study of those injured in the Troubles, it also offered the possibility of providing a picture, albeit one drawn in 1999, of the views and experiences of those injured.

This was achieved because the following questions were included in the questionnaire:

36. If there is a change in your health over the past five to ten years what, in your opinion, caused this change? (Complete all items – if answer is negative circle "No")					
		Yes	No	No Response	
(a)	Troubles related trauma: e.g. bombings, shootings, intimidation, attacks	1	2	3	

43.	Can I ask if you have had any of these experiences and if so how often:					
		Several times	More than once	Once	Never	
(i)	Being physically attacked due to the troubles	1	2	3	4	
(j)	Being injured in a bomb explosion	1	2	3	4	
(k)	Being injured in a shooting	1	2	3	4	

The data was re-examined and:

- 233 people were found to have answered positively to Question 36a, that changes in their health had been caused by Troubles related trauma.
- 439 answered positively to Question 43i, that they had been physically attacked in the Troubles
- 241 answered positively to Question 43j that they had been injured in a bomb explosion 39 answered positively to Question 43k that they had been injured in a shooting

A filter variable was set up to identify everyone who answered positively to any of these questions. However, this does not give a total of 952 people since there is some overlap. Checking for overlap, there are 376 who answer positively to one of the questions, 170 who answer positively to two of the questions, 68 answer positively to three and 8 answer positively to all four questions.

The true total, allowing for overlap is 622 participants, which comprises 46% of the total sample of 1,356. This might seem high, but the sample was stratified to oversample, as described above, in areas of high violence, and therefore it is in line with other findings. This created a new group of people within the sample, who had identified themselves as having been physically attacked, injured in a bomb or a shooting, or had their health affected by exposure to traumatic events. When this group was identified, the data was re-examined to compare this group of positive responders to the rest of the sample.

Having divided respondents into an 'injured' and 'non-injured' group, we then compared their responses to a number of questions. Question 3 asked about the age or respondents. Table 13 shows a comparison between the injured group and the rest of the sample. Fieldwork was completed in 1998 so respondents are now 14 years older, so the age at survey is shown in column 1 and a calculated current age is shown in italics in column 2. Of course, numbers will have been decreased by mortality and migration, but nonetheless the figures give some indication of the prevalence of injury in the population.

Table 13: Age of Injured and non-injured Respondents

Age at survey	Current age	Number injured (percentage of age	Percent of injured group	Number Non-injured	Percent of non injured
	(2012)	category)			group
17-20	31-34	32(38.5%)	5.1	51	6.9
21-24	35-38	49 (41.8%)	7.8	68	9.3
25-29	39-43	66 (45.5%)	10.6	79	10.7
30-39	44-53	128(48.5%)	20.6	136	18.5
40-49	54-63	114 (48.5%)	18.4	121	16.5
50-59	64-73	94(50.5%)	15.1	92	12.6
60-69	74-83	75 (46.5%)	12.1	86	11.7
70-79	84-93	33 (41.7%)	5.3	46	6.3

80+	94+	7 (21.9%)	1.1	25	3.4
Total		598	96.1	704	95.9
Missing		24	3.8	30	4.1
Total		622	100	734	100.0

The peak share of injured people is in the current 64-73 age group (50.45%) with shares of around 48% in the 44-53 and 54-63 age groupings, and slightly less in the 74-83 age group. Shares of injured people in the younger age groups are also high, but lower, than in these older groups. Clearly, these high percentages of injured people do not apply to the general population, since this survey over-sampled in areas where conflict was concentrated. Nonetheless, the pattern rather than the shares in this age distribution is likely to be indicative of an age distribution in the wider population.

Projected Age distribution of injured and non-injured group

160
140
120
100
60
40
20
31-34 35-38 39-43 44-53 54-63 64-73 74-83 84-93 94+
Age

Figure 4: Projected Age distribution of injured and non-injured group

Table 14 shows the gender distribution in the sample between the injured and non-injured groups.

Table 14: Gender of injured and non injured groups

GENDER	Injured	Non-injured
Male	308 (49.6%)	316 (43.5%)
Female	312 (50.3%)	410 (56.4%)
Total	620 (100%)	726 (100%)

In both injured and non-injured groups, there is a majority of females, with the differential being greater in the non-injured group. In the overall sample, out of 1,346 respondents, 624 (46.4%) were male and 722 (53.6%) female. This would suggest that there are fewer females than one would expect in the injured group.

Table 15 below shows the religious breakdown (where religion was stated) of the injured respondents compared with the non-injured respondents.

Table 15: Religion of injured and non-injured groups

	STA <sup>-</sup>	TUS
RELIGION	Injured	Non-injured
Catholic	496 (80.25%)	412 (58.5%)
Protestant	109 (17.6%)	283 (40.1%)
Other	13 ((2.1%)	9 (1.2%)
Totals	618 (100%)	704 (100%)

Catholics comprise 68.7% of the overall sample and Protestants 29.7% with 1.7% of 'others' Therefore the 80.25% of Catholics in the injured group is a higher share than in the overall sample and the 17.6% of injured that are Protestant is a lower share than for the overall sample, suggesting a higher proportion of Catholics in the injured group.

We then calculated that the total population in the ten 'high violence' wards which was 50179. Of these, a sample of 471 were interviewed giving a sample proportion of .94%. Of these, 65.3% (307 respondents) answered positively to Questions 36a or 42i, j or k. This incidence rate generalised to the total population gives a total of 32707.

A similar calculation for the 'medium violence' wards whose population totals 28726 shows that a total of 475 respondents from those wards were surveyed (a proportion of 1.65%). Some 159 or 33.5% respondents answered positively to the filter questions. Grossing this up to the total population gives a figure of 9616 out of a total population of 28726.

Finally, in the 'low violence' wards, whose total population was 29788, 475 respondents were sampled, of which 156 or 33% responded positively to the filter questions. This incidence rate generalised to the total population gives a total of , 9830 individuals.

Therefore, in the total projected injured population for Northern Ireland would be: 32707 + 9616 + 9830 = 52153 (based on the 1991 census figures).

When the numbers of injured were identified, they were disaggregated into three groups according to the three strata, areas of high, medium and low violence. The share of the population that total sample comprised was then calculated and the share of each that were injured and this was applied to the total population figures for each strata. This resulted in total figures of 32707 for high violence wards + 9616 for medium violence + 9830 for low violence wards giving a total estimated population of injured people in the population of Northern Ireland of 52153. This figure reflects only those who answered positively to the selected questions, namely that there had been a change in health due to the bombings,

shootings, intimidation or attack, that the respondent had been physically attacked as a result of the Troubles, or had been injured in a bomb explosion or shooting. It does not capture other forms of injury, nor does it address the issue of type of injury or its severity.

The COTTS analysis confirms indications from elsewhere, including the deaths data, that the population of injured people are likely to be in their sixties and older, with lesser numbers of injured people in the younger age groups.

#### Other sources

Further clues to total numbers of injured is contained in Graham and Parke (Graham and Parke, 2004, p. 225) on amputees. They identify a total of 129 amputees using their services in the period 1969-2003. In order to determine the likely current numbers of amputees, we calculate a death rate of .0069 over 35 years (they report 9 deaths in the period). Using this rate, one could anticipate a further 2 deaths since 2003 leaving a total of 118 people who have suffered limb loss and using their services. Of course, there may be additional people who do not use their services, but were treated elsewhere. Given out-migration from Northern Ireland, this would suggest a current population of 113 people currently living with limb loss due to the Troubles in Northern Ireland.

Hadden, Rutherford and Merrett examined bomb injuries in 1532 patients in the early period of the Troubles. Of the total 1532 explosion victims, 9 died in hospital. This gives a death to injury ratio of 1:170. By 1999, COTTS had counted 3650 deaths in the Troubles, of these 1075 were deaths by explosion. Applying this ratio, this would mean that 20,305 people were injured. However, we know that 84% of those injured were treated as outpatients, leaving an estimated 3,248 treated as in-patients as a result of explosions. It is possible that some of those treated as outpatients were quite seriously injured. However, from another international comparative study (Frykberg and Tepas 1988) we know that Northern Ireland triage practices were accurately targeted in comparison to other locations studied. This study offers the possibility of a similar calculation. Frykberg and Tepas calculate a critical mortality rate of 12.4%, namely that 12.4% of those critically injured in explosions die. Since we know that 1,075 people had been killed by explosions in the Troubles up to 1999, this would suggest an overall total of 8,600 killed and injured and therefore 7,525 surviving injured. However, this is bomb injuries alone, and similar research would require to be undertaken in relation to other causes of injury, such as gunshot wounds, grenade attacks, beatings and so on.

To summarise, whilst there is some convergence in some of the estimates of the total population of people injured during the Troubles, certain characteristics of the population of injured people emerge in terms of their gender, age, religion as well as occupational characteristics and their location throughout Northern Ireland.

However, the total size of the population is still a matter of estimation rather than calculation. Available figures for the total population (including those made previously by the author) are best estimates, based on an ill-defined variety of notions about what should be included in the category of 'injured'. In order to arrive at a more definitive figure for the total population of injured people, a number of tasks require to be undertaken.

First, it will be necessary to define the parameters of injury more clearly, including the differentials between physical and psychological injury, issues of co-morbidity, multiple injury and so on. This will involve some consideration of issues of severity, and the setting of a threshold below which an injury will be considered not sufficiently severe to warrant inclusion in the group of people injured in the Troubles. There are measures used by the World Health Organisation (see for example, International Classification of External Causes of Injuries at ICECI Ver 1.2; July 2004) and others that could be adapted for this purpose. However, this is not only a scientific and policy challenge, it is also likely to be an area of political contest. Therefore, should such a task be embarked upon, it, should be approached on the basis of establishing common understandings of what threshold of injury due to the Troubles should requires policy attention. This common understanding could be developed by engagement with victims groups themselves, involving them in informing decisions about how scarce resources ought to be prioritised for this long neglected group.

In the context of Northern Ireland, it also seems likely that some consideration of the relationship between injury and disability is called for, since much of the current work is driven by a need to develop policy and services. This raises the issue of the extent to which the environment of the injured person supports them to lead a full life, and is central to process of service development. Again, some of the tricky concerns are raised by issues of disability in the context of injury defy the desire for black and white answers, or for absolute clarity of definition.

Should a satisfactory definition be arrived at, that definition could be applied to a random sample of the population in a survey, which could test the prevalence of injury due to the Troubles in the general population. This would entail a considerably more resource intensive exercise than the one undertaken here.

# The Survey

Another part of the study was the conduct of a survey of people injured in the Troubles. The difficulties in arriving at a viable definition of injury have already been discussed and the methods of formulating a working definition for the purposes of this study outlined. Interviews of those under that definition, and of their carers and service providers were conducted in the first phase of the research and are analysed later in the report. The themes and issues raised in these interviews informed the design of the survey.

Following the preliminary analysis of interview data, a short questionnaire was drawn up. Since resources did not permit an elaborate survey, a questionnaire suitable for selfcompletion was designed to elicit information from a larger cohort of injured people about the issues emerging in the interviews. Since emotional trauma was one of those themes, a standardized screening instrument for Post-Traumatic Stress (PDS, FOA, 1995) was embedded in the instrument. The PDS is a 26 item self-report instrument whose purpose is to aid in the detection and diagnosis of posttraumatic stress disorder. It is often used as a screening questionnaire in clinical settings. It is suitable for administering to individuals aged 18 to 65 years old with basic literacy skills, and it comprises 49 items and takes 10 - 15 minutes to complete. Respondents are asked to indicate on a list of symptoms which they experience 'not at all or only one time'; 'once a week or less/once in a while'; '2 to 4 times a week/ half the time'; '5 or more times a week/ almost always'. Items are scored from 0 -3 with 0 being 'not at all' and 3 being '5 or more times a week'. It can be scored manually, although in the case of this survey, this was done electronically. Scores of 10 or less indicates mild PTS, 11-20 moderate, 21-35 moderate to severe and 36 and above severe post-traumatic stress.

# The pilot surveys

The questionnaire was piloted with members of the WAVE injured group for ease of clarity, ease of completion but the PDS measure was not scored. The wording was amended as a result to achieve greater clarity. An amended version of the questionnaire was piloted a second time and without further amendment was deployed in the survey.

One of the major difficulties in surveying people injured in the 'Troubles', is the lack of an adequate sampling frame within which a random sample can be drawn. Whilst certain hospital departments might have lists of those with limb loss, for example, they do not necessarily differentiate between those whose loss was due to the Troubles and other patients. Equally, the Compensation Agency will only have records for those who sought or obtained compensation and the older records dating back to the earlier part of the Troubles no longer exist, even though the injuries still have a direct affect on people's lives. Whilst with greater resources and within a longer timeframe it might be possible to compile a list of those injured in the Troubles, within the constraints of this study it was not possible to contemplate such an approach. However this study had a major resource at its disposal, namely the knowledge and expertise of the WAVE Injured Group, who has a wide network of relationships with other injured people and who have been conducting an ongoing campaign on injury since 2011 which brings them into contact with more and more injured people. This campaign was inspired by a widespread feeling of participants of a lack of

acknowledgement of those injured in the Troubles and aims to have their needs recognized and addressed. Those participating in the campaign were an enormous resource for the researchers, and their commitment to making the research as success greatly facilitated our work.

For these reasons, it was decided that a survey using a snowball approach to sampling, using the extensive contacts of the WAVE Injured Group, whereby the questionnaire would be distributed to victims' groups and injured individuals throughout Northern Ireland, and to government agencies supporting victims, and responses would be elicited accordingly. Whilst this approach has severe limitations in terms of the ability to generalize to the total population of injured people, or to estimate the total size of the population of injured people, it affords a picture of general trends amongst those who respond. It can also suggest some directions for future research.

Moving to the shortcoming of the research approach, one of the main limitations is that a strict definition of injury cannot be formulated, and the survey participation criteria was decided upon by people other than the researcher. This meant that the research team had no control, as they did over the interview sample, of the demographics of the survey sample. We could not ensure that representative numbers of men and women, Catholics and Protestants, age groups, locations and so on were included. Nor could we ensure that participants met the criteria of having a life threatening or disfiguring physical injury in the Troubles. However, clear briefings were provided to all individuals and organizations participating, with the Principal Investigator personally contacting all the participating organizations, and where possible having face-to-face meetings with them. On the other hand, injured people who would not or could not be included in the interview phase of the research could participate anonymously in the survey, without any direct contact with the research team.

Questionnaires and supplies of prepaid return envelopes were distributed to the following organisations: the Commission for Victims and Survivors; Coiste; Cunamh; the Injured Officers and Families Association; The Memorial Fund; The Pat Finucane Centre; Relatives for Justice; South East Fermanagh Foundation; Survivors of Trauma; the Trauma Resource Centre; and WAVE offices in Belfast, Armagh, Derry Londonderry, Ballymoney and Omagh.

An ambitious goal of 300 completed questionnaires was set. Hard copies and prepaid envelopes were distributed and mailed in batches of 40 to the organizations listed above, alongside electronic copies of the questionnaire for distribution by email. In addition, WAVE conducted a mail shot of 1,000 people known to them, but in spite of mail shots from WAVE to their lists of contacts, the fieldwork had to conclude with 76 completed. However as mentioned above, irrespective of the lower than anticipated response rate, we can still identify some significant trends and draw some important conclusions from the data in hand. The results of the analysis of the survey data are presented below.

## The sample

The composition of the sample was determined by the outcome of the snowballing process by which respondents were recruited and can perhaps tell us something about the nature of the networks in which injured people are included, especially any particular focus or blind spots in these networks. For example, those injured people who belong to victims' groups or occupational groups for Troubles-related injury, such as some of the organizations for disabled former members of the security forces. Some of these networks are particular to certain groups and thus if one of these networks participated actively in the survey, whilst other groups were less active, the overall demographic balance of respondents may be affected. For the purposes of the exercise data on patterns of death (Fay et al, 1999) were used to guide the desired demographic balance of the survey.

## <u>Gender</u>

Out of the 76 people who responded to the survey, 54 were male and 22 female. If we can take the gender ratio of deaths as a guide, (and that might be open to challenge) Table 16 below shows that the sample has a 10% bias in favour of females.

Table 16: Gender of sample

		GENDER	
	Males	Females	Total
Sample	54 (71.1%)	22 (28.9%)	76 (100%)
Deaths in Troubles	91.1%	8.9%	100%
Skew in sample	-10%	+10%	

This could suggest that females are more likely than males to be in contact with victim organisations, with other injured people or to be known to them.

#### **Religion and status**

The religious composition of respondents was found to be 26 (34.2%) Catholic and 46 (60.5%) Protestant. These ratios were compared, first of all, to the religious composition of the population and to the religion of those killed in the Troubles. Table 17 shows that in comparison with both the population ratios and those killed in the Troubles there is a distinct bias (+14.94% and +30.9% respectively) in the sample in favour of Protestants.

Table 17: Religion of sample

	RELIGION			
	Catholic	Protestant	NNI/ Other	Total
Sample	26	46	4	76
	(34.2%)	(60.5%)	(5.3%)	(100%)
Population of NI <sup>3</sup>	40.25%	45.56%	14.1%	100%
Skew in sample compared to population	-6.05%	+14.94%	-14.1%	-
Deaths in the Troubles <sup>4</sup> (crude %)	43%	29.6%	27.4	100%
Skew compared with deaths	-8.8%	+30.9%	-	-

There could be a number of possible causes. Perhaps it reflects the level of attention paid to issues facing injury amongst the various victim groups, some of whom work predominantly in one or other community. It suggests that those groups working with predominantly Protestant populations have more connections with injured people than those working with Catholic populations. This could be a reflection of the proportionately large number of injured former members of the security forces in the population and historically the security forces have been overwhelmingly Protestant until new arrangement for recruitment were instituted after the peace agreement. So, the religious balance could be a reflection of the civilian - security forces breakdown of the sample, since we know that there are several organisations (Injured Officers and Families Association, Disabled Police Officers' Association), focused on representing and servicing the needs of injured members of the security forces, and who have been very active in doing so. A similar concentration is not visible amongst victim organizations focusing on the needs of injured civilians. This is perhaps related to the strong bonds formed between members of the security forces during the Troubles and their limited engagement with the civilian world, due to their concerns about their own security. With the exception of the WAVE injured group, we found no organization specifically focused on injured people.

#### Civilian- security forces composition

In all, 15 respondents (19.7% of total sample) identified themselves as members of the security forces, all but 2 as police officers (see Table 18 below). However, police officers and other members of the security forces do not always identify themselves as such, due to fears about their safety, or the habits of a lifetime of living with risk of attack. A further two respondents identified themselves as civil servants, one described his occupation as 'MOD' and five did not respond, so it is possible that the share of respondents who were members of the security forces is even higher.

<sup>&</sup>lt;sup>33</sup> NISRA Population of Northern Ireland by Religion Table UV018: RELIGION (BASIC DETAIL) Available at: http://www.nisranew.nisra.gov.uk/Census/Census2001Output/UnivariateTables/uv\_tables1.html#community background

<sup>&</sup>lt;sup>4</sup> Fay, Morrissey and Smyth, 1999: 164.

Table 18: Ratio of Civilian to Local Security Forces; Balance of responses compared with COTTS deaths ratios and RUC injury ratios

	STATUS			
	Civilians	Local security forces	British Army	Paramilitaries
Sample	61 (80.3%)	15 (19.7%)	-	-
COTTS Deaths data (Fay et al, 1999: 159)	54%	15%	15%	16%
RUC Injury Data (cited in Fay et al 1999:160)	68%	19%	12%	-

Comparing the civilian to local security forces ratios, with those found in the COTTS deaths data, the sample is composed of 19.7% identified members of local security forces. The deaths data shows a ratio of 15%, which means that if deaths are a reliable surrogate, then the number of injured security forces personnel are over represented in the sample, if deaths are a reliable surrogate. Royal Ulster Constabulary (RUC) data on injury shows a higher ratio of local security forces injury (19%), although slightly lower than our sample. However, it is likely that these data compiled by the police are not comprehensive, and will tend to record local security forces injuries more comprehensively than civilian injuries, since the security forces compiled said data. The sample did not differentiate former paramilitaries from civilians, nor did it include members of the British Army, so other comparisons are of limited value. However, since the sample contains 15 members of local security forces, it is likely to represent their proportion of total injuries. However, as already stated, the number of security forces personnel may be higher than 15, with some not declaring their previous occupation due to concerns about their security, or simply the habits of a lifetime.

#### Age

Table 19 below shows the sample by age of group, indicating a concentration in the 41-50, 51-60 and the largest age cohort in the 61-70 age groups.

Table 19: Age

	RESPONDENTS		
AGE	Number	%	
20-30years	2	2.6	
31-40years	2	2.6	
41-50years	16	21.0	

	RESPONDENTS		
AGE	Number	%	
51-60years	21	27.6	
61-70years	23	30.2	
71-80years	6	7.9	
81-90years	5	6.6	
Missing	1	1.3	
Total	76	99.8	

# Year of injury

A breakdown of the data on year of injury shows that respondents were predominantly injured in the early period of the Troubles, a pattern that is consistent with the pattern of deaths. As it can be seen in Table 20 below, over half were injured prior to 1986, and almost a quarter before 1976.

Table 20: Year of injury compared with distribution of deaths

RESPONDENTS				
YEAR OF INJURY	Number	%	% of deaths in period <sup>5</sup>	
1970-75	18	24	43.7	
1876-80	12	16	20.0	
1981-85	9	12	12.5	
1986-90	10	13	12.1	
1991-95	10	13	10.0	
1996-2000	10	13	1.5 <sup>6</sup>	
2001-05	3	4	n/a <sup>7</sup>	
2006-10	4	5	n/a	
TOTAL	76	100	99.8	

If we read the age data alongside the data on year of injury, the cluster of respondents between 50 and 70 years old were between 10 and 30 years old in the 1970s when the peak numbers of deaths and injuries were being caused.

<sup>&</sup>lt;sup>5</sup> Fay et al 1999: 137 <sup>6</sup> To 1998 only

<sup>&</sup>lt;sup>7</sup> Not available

# Age at injury

When we examine how the sample report their age at the time of their injury, half of the sample were between the ages of 11 and 30 at the time of their injury, as is shown in Table 21 below. This is likely to be broadly reflective of the reality, since we know that younger people composed the majority of those killed in the conflict, it is likely that injury follows the same pattern. The pattern in the deaths data shows that:

- More than a third of fatal victims were in their 20s
- More than half were in their 20s or 30s
- The risk to the 20-24 age group was more than twice as high as for any other group over 40
- One in six victims were 19 years old or even younger<sup>8</sup>.

Table 21: Age at injury

	RESPON	IDENTS
AGE AT INJURY	Number	%
1-10years	3	3.9
11-19years	7	9.2
20-25years	13	17.1
26-30years	18	23.6
31-35years	4	5
35-40years	8	10.5
41-45years	9	11.8
46-50years	3	3.9
51-55years	5	6.5
56-60years	5	6.5
Missing	1	1.3
TOTALS	76	99.3

Thus, the sample manifests the pattern that those in the sample sustained injuries when they were young and are now ageing.

#### **Current geographical location of residence**

The survey aimed to concentrate in areas that had been worst affected by the Troubles, where rates of injury are likely to be highest (Fay et al, 1999). Table 22 below shows the geographical location of residence of respondents at the time of the survey.

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<sup>&</sup>lt;sup>8</sup> Fay et al 1999: 161-2.

Table 22: Geographical location of residence

GEOGRAPHICAL LOCATION OF RESIDENCE	RESPONDENTS	
	Number	%
Belfast	18	23.7
Derry/ Londonderry	4	5.3
Lurgan/Portadown	1	1.3
S Armagh	7	9.2
Omagh	4	5.3
Other Co Antrim	9	11.8
Other Co Derry/Londonderry	8	10.5
Other Co Tyrone	10	13.2
Other Co Down	5	6.6
Other Co Fermanagh	9	11.8
Missing	1	1.3
TOTAL	76	100

In the case of deaths due to the Troubles, although many people were killed close to their home, others were killed in other locations. This is likely to hold for patterns of injury also. We know from interview data that some injured people later moved away voluntarily or had to move at the time of the injury from the location where they were injured, or they were injured at a location distant from their home.

## **Location where injury occurred**

Table 23 below shows the geographic distribution of injury by location. Immediately we see a greater concentration in Belfast and South Armagh, than the data on home address would suggest. This would indicate that there might be a pattern of people injured away from home in these locations, or re-locating out of them after their injury. Again, these trends are also evident in the interview data. Omagh emerges as a location of injury rather than a home address for injured people and possibly the 1998 Omagh bomb could account for this.

Table 23: Location where injury occurred

	RESPONDENTS INJURIES			
LOCATION	First injury	%	Second injury	%
Belfast	25	32.9	2	2.6
Derry/ L'derry	4	5.3	<del>-</del>	=
Lurgan/P'down	1	1.3	-	-
S Armagh	3	3.9	-	-
Omagh	7	9.2	-	-
Other Co Antrim	5	6.6	-	-
Other Co Derry/L'derry	8	10.5	1	1.3
Other Co Tyrone	8	10.5	-	-
Other Co Down	5	6.6	1	1.3
Other Co Fermanagh	10	13.2	2	2.6

		RESPONDENTS INJURIES			
LOCATION	First injury	%	Second injury	%	
Belfast	25	32.9	2	2.6	
Missing	-	-	70	92.1	
Total	76	100	76	100	

A further 6 respondents (8%) of respondents reported more than one injury in the Troubles, and second injury location is also provided in Table 8. Location is a significant factor in designing services and although the data here cannot be taken to be definitive, it would appear that injured people are located throughout Northern Ireland, with higher concentrations in Belfast and Co Tyrone. However, given the size of the data set, the location data could be spurious. Nonetheless, evidence elsewhere (Fay et al, 1999) would support the finding that some people have been injured more than once in the Troubles.

#### **Relationship status**

In terms of relationships status, the majority of respondents were married (56.6%) with a further 14 (18.4%) being divorced, 7 (9.2%) widowed and 1 co-habiting.

**Table 24: Relationship status** 

	RESPONDENTS		
STATUS	Number	%	
Single	9	11.8	
Married	43	56.6	
Widowed	7	9.2	
Divorced	14	18.4	
Co-habiting	1	1.3	
Missing	2	2.6	
Total	76	100	

A total of 9 (11.8%) were single. This is significant since it is often spouses and those living with the injured person who become long-term carers.

#### Responsibility for injury

The other significant factor in dealing with the aftermath of injury and which directly impacts on issues such as: truth, justice, segregation and community division, is the issue of responsibility for acts of violence. Respondents were asked to identify the organisation or faction responsible for their injury, and Table 25 below provides a summary of responses compared to the COTTS data for responsibility for deaths in the Troubles. From Table 10, we can see that the victims of Republican paramilitaries are over represented in the sample,

whilst victims of Loyalist paramilitaries and victims of the security forces are significantly under represented.

**Table 25: Responsibility for injury** 

	RESPONDENTS		
PERPETRATOR	Number	%	COTTS %
Republican Paramilitaries	50	65.8	55.7
Loyalist Paramilitaries	8	10.5	27.3
Security Forces	3	3.9	10.7
Civilians	2	2.6	0.3
Other response	6	7.8	6.0
Nobody caught	2	2.6	-
Paramilitaries	4	5.2	-
Missing	1	1.3	-
Total	76	99.7	100

Even if the responses that do not correspond to COTTS categories were reallocated to COTTS categories this pattern would still be maintained. This is consistent with the earlier findings of some over representation of certain groups in the sample. Thus, experiences of those injured by Loyalist paramilitaries, and by the security forces are under-represented in this survey. This will need to be borne in mind, particularly when analyzing responses to questions about justice, since this missing cohort may have different views to those in the sample.

#### Nature of injury

The next category of questions asked respondents about the nature of their injuries. Table 26 below describes s the breakdown of the responses obtained. Unfortunately, there are no data that are directly comparable against which to check with the spread of the sample. However, from COTTS data, we know that gunshots are the primary cause of death, followed by explosion, and this seems to be consistent with what the sample told us about patterns of injury.

**Table 26: Nature of injury** 

IAILLIDY	RESPONDENTS		
INJURY	Number	%	
Single gunshot	12	15.8	
Multiple gunshot	13	17.1	
Bomb	12	15.8	
Beating	6	7.9	
Bomb and shooting	24	31.6	
Other	4	5.2	
No injuries	1	1.3	
Missing	4	5.3	
Total	76	100	

We allowed respondents to write in their own words the response to the question 'What injuries did you suffer (e.g. gunshot, bomb, beating etc.)?' further responses are categorised in Table 27 below.

Table 27: Other injuries (a)

	RESPONDENTS	
INJURY	Number	%
Single gunshot	17	15.8
Multiple gunshot	5	17.1
Bomb	33	15.8
Beating	6	7.9
Bomb and shooting	5	31.6
Other	9	5.2
Gunshot and beating	1	1.3
Total	76	100

The predominant pattern here is the one of bomb injuries followed by gunshot injuries, reinforcing that these two were the primary cause of injury in this cohort, and this is likely to be the pattern for the broader population of injured people.

We asked respondents to tell us the specific nature of their injuries in the following question:

"As a result of your injury what physical problems have you experienced? Please circle all that apply to you:		
loss of one leg	loss of both legs	
loss of one arm	loss of both arms	
loss of one hand	loss of both hands	
loss of one eye	loss of both eyes	
partial loss of sight	total loss of sight	
partial loss of hearing	total loss of hearing	
facial disfigurement	disfigurement other than facial	

Table 28 below shows the results for this question.

Table 28: Other injuries (b)

	RESPONDENTS	
INJURY	Number	%
Loss of one leg	7	9.2
Loss of both legs	6	7.9
Loss of one arm	3	3.9
Loss of one hand	2	2.6

Loss of one eye	3	3.9
Partial loss of sight	8	10.5
Total loss of sight	1	1.3
Partial loss of hearing	33	43.4
Total loss of hearing	3	3.9
Facial disfigurement	11	14.5
Disfigurement other than facial	28	36.8
Total		
(These figures reflect the number of times a particular injury was reported, with some respondents reporting more than one injury.	105	137.9

The responses shown here are the totals for each category of injury, and the total percentage is more than 100%, indicating that some respondents reported injury in more than one category.

# Impact of injury

We asked respondents to explain about any "impaired physical function like ability to walk, bowel function, breathlessness, sexual function etc" and the responses to this question are displayed in Table 14 below.

**Table 29: Impaired physical function** 

	RESPONDENTS	
IMPAIRMENT	Number	%
Cannot walk	23	30.3
Cannot see	1	1.3
Pain	4	5.3
Breathlessness	3	3.9
Sexual dysfunction	3	3.9
Cannot drive	1	1.3
Other	21	27.6
No response/ not applicable	7	9.2
None	11	14.5
Missing	2	2.6
Total	76	100

Unlike earlier questions, this question did not allow for multiple responses, which, on reflection may have provided better data. Over a quarter of respondents used the 'other' category and a further breakdown of the 'other' responses is shown in Table 30 overleaf

**Table 30: Other physical impairments** 

	RESPONDENTS	
'OTHER' PHYSICAL IMPAIRMENT	Number	%
Paraplegic	4	5.3
Paralysis in one limb	2	2.6
Brain damage/ depression/ anxiety/ panic attacks	6	7.9
Pain	15	19.7
Other	30	39.5
Not applicable	1	1.3
None	8	10.5

The 'other' narrative responses clustered around a number of themes, and they are provided in detail below:

## Walking difficulties

"not able to walk unaided (wheelchair) crutches small distances.. bowel, urine, personal"

"Ability to walk, breathlessness, sexual dysfunction, loss of confidence"

"Ability to walk far due to gunshot wound in hip, sore back due to leg being shorter"

"arthritis, osteoporosis, pain;"

"back problems, ability to walk, got brick thrown at me"

"breathlessness, not good at walking"

"Can walk only short distance without pain, loss of use of right arm;"

"Inability to walk, bowel and bladder function, sexual function, paraplegic T11 lesion;"

"leg injuries, walking problems, lost muscle;"

"leg injuries, walk problems;"

"My legs are very painful, I only can walk short distances;"

"not able to walk far left leg badly hurt;"
"left lower leg limited movement;"

"hard to walk due to my injury, bowel and stomach problems;"

"unable to walk more than 15 feet, incontinence, balance, no sexual drive, panic attacks, nightmares, avoidance;"

"walk with a stiff leg, leg ½" shorter than right leg;"

"walking slower and ...(missing rest of response);"

"Walking, breathlessness, bowel function, burns;"

"Walking, Lifting, Sexual Function, Constant Pain of Joints;"

"wheelchair bound, psychologically injured;"

#### <u>Pain</u>

"back and knee pain from gunshot wounds, negatively impacts on walking;"

"back pain, headaches, depression;"

"Cannot stand for long period, pain in lower back at all times constant pain";

"constant pain;"

"severe pain in legs and arms;"

"constant pain, breathlessness, occasional bed wetting because of nightmares, panic attacks, don't trust people";

"mobility problems, back pain, widespread pain (muscles, joints, legs, feet), multiple symptoms;"

"severe leg injuries, back injuries make walking or standing very painful;"

"stump pain, sciatica, shoulder injury;"

# **Medical problems**

"bladder problems, gynae problems"

"Bowel colostomy/shrapnel in hips and tummy, diabetes"

"bowel function, chest injuries"

"bowel problems, angina, multiple schlerosis, heart problems"

"Bowel, Pain;"

"Bowels are not great and I suffer with impotence:"

"Dislocated shoulder";

"dizzyness, arthritis, cannot go anywhere unaided can't even fill in this form";

"impaired physical function, ability to walk, bowel function, breathlessness;"

"left leg 3/4 shorter badly scarred, affects walking, asthma Chronic Obstructive Pulmonary Disease, diabetes, high blood pressure, renal failure, severe depression;"

"leg injury, arm injury, fractured skull, lost hearing in left ear;"

"breathlessness, unable to have sound sleep, bronchial trouble, glaucoma,polymyalgia rheumatica (on steroids, eyedrops, inhalers)"

#### Mental health issues

"Depression, anxiety, memory loss and brain damage";

"flashbacks- nightmares;"

"gunshot wounds (arm shoulder, back and legs) stress and flash backs";

"Irritated bowel syndrome, PTSD;"

"mental health;"

"no physical problems, but mental ones;"

"panic attacks;"
"PTSD, cannot walk;"

"Disorder (PTSD) affects all human contacts, panic attacks, nights terrors, sexual contact and touch very difficult;"

"severe tinnitus, PTSD, clinical depression;"

"sexual dys, heart bypass, ear injury, stress, PTSD now over 30 years;"

"spinal injury, impaired physical ability, PTSD;"

"wounded across the spine, still suffering back pain after years, depression, blamed myself on 2 others who were helping me being killed."

## <u>Shrapnel</u>

"Bullet close to heart, shrapnel close to spine, constant pain, limited use of left arm, balance problem"; "I have two bullets still lodged in my right hip which has caused arthritis;"

"right food badly injured, left breast shrapnel, burned;"

## Loss of function, sensory capacity or organ

"loss of hearing, right ear and some loss left ear, mental. facial twitch, right side;"

"loss of memory, right hand has no feeling, loss of balance, mumbled speech, sexual function, no feeling in right side of face bed soiling;"

"loss use of one arm, loss use of one hand;"

"lost one kidney, other leg and back injuries;"

"part of arm blown away;"
"residual back, hand pain from injury;"

"right leg was severely damaged, mobility problems, deformation and pain, balance as right foot didn't grow and is misshaped;"

"short walks, lower back pain;"

"shot across the spine on the right side affecting ability to walk;"

"shoulder, wrist, hand arm pain;"

"tinnitus positional, vertigo bad back, walk with stick, cannot stand very long;"

"whip lash, two fingers fractured, as a result now suffer from Complex Regional Pain Syndrome;"

These narrative responses, together with other narrative comments made by respondents on the questionnaires, provide a vivid picture in the case of many respondents which lives were severely affected and also reveal the struggles they had to go through in order to live with the consequences of their injuries. In several cases, we were very concerned about the welfare of the respondent. Although many of the questionnaires were anonymous, several respondents signed their names, perhaps indicating a desire for recognition of their situation. Where a concern arose, a check was made to find out if a respondent was known to WAVE and if so, contact was made to find out if they wished to be put in touch with a support agency.

#### **Recovery since injury**

We then asked respondents if they had made any physical recovery since they were injured. Table 31 below shows their responses.

Table 31: Physical recovery since injury

	RESPONDENTS	
LEVEL OF RECOVERY	Number	%
Total	31	40.8
Partial	38	50
No/ none	5	6.6
Not applicable	1	1.3
No response	1	1.3
Total	76	100

Less than half, 31 (40.8%) reported a total recovery, with exactly half- 38 (50%) reporting a partial recovery and 5 (6.6%) reporting no recovery. However, it is difficult to square these accounts with the reported level of injury in earlier question. It is possible that respondents were referring to their initial survival from a life threatening injury rather than 'total recovery' as it is more generally understood. Again, this could be a function of the questionnaire design. Narrative comments, below, which are organized under thematic headings about respondents' current physical health provide a fuller picture.

#### **Positive**

"[A] lot better;" "apart from the obvious my general physical condition is normal for my age;"

"Good but not as it was before this happened;

"good but you never forget (mental problems)"

"Great;"

"its moderate;"

"not too bad for my age and Injury;"

#### Mental health issues

"attempted suicide 2008 and have daily thoughts of suicide"

"Depression, anxiety, memory loss and brain damage;"

"due to shooting i am unable to work as i now suffer mental health;"

"getting worse, have suicidal thoughts;"

"I attend a doctor weekly at the moment for my PTSD;"

"I suffer from extreme pain and depression;"

"Relive the experience, can't seem to let go;"

"severe pain in legs and arms, panic attacks, depression;"

"very bad. lost both legs and an eye. severe depression;"

#### **Problems**

"arthritis, osteoporosis, pain;"

"bronchial syndrome, polymyalgia rheumatica, on steroids, eyedrops, inhalers:"

"can't walk, personal needs still affected, require assistance – domestically and personally;"

"get tired very easily, balance impaired;"

"getting acupuncture at present, regular heart beat (unreadable);"

"I am reminded everyday of my injuries as I never forget I was electrocuted, lost all the skin on my hands I suffer cramps on my legs;"

"I have never really recovered. Going to Musgrave Park every year for issues relating to shooting;"

"in recent years have undergone specialized spine surgery;"

"My left leg gives me problems every day, my bowels don't function well and I have medical hernia(unreadable);" "my physical health has got worse, at times goes by; my dependence on others increases;"

"not good;"
"not very well;"

"Not very good;"

"Poor- completely deaf in the left ear now;"

"Poor:"

"poor, numerous medical Problems;"

"Poor, paid off on medical;"

"Poorly;"

"severely hindered;"

"still have both IBS and PTSD;"

"Suffering from acute arthritis of hands and upper limbs, ongoing bladder and bowel problems;"

"use of arm still impaired;"

"Various Problems;"

"very poor, fatigue worn out non stop pain, discomfort (physically and mentally);" (disabled son), blood pressure high since bomb explosion;"

"very poor, high blood pressure caused renal failure in pregnancy child born cerebral palsy

# **Acceptance**

"as good as it will be";

# **Concerns about ageing**

"as I age and due to the nature of my disability and time that I have been disabled";

## <u>Pain</u>

"tiredness and pain waking up from the bed (? unreadable);"

"constant pain, limited use of left arm, balance problem;"

"up and down, always pain in some area;"
"shoulder, wrist hand arm Pain;"

"Constant pain, severe Limp, unable to lift anything Heavy;"

"still have a lot of pain in my hip and knee.I had to have a knee operation as well;" "I am on constant pain, I am on daily medication have very bad arthritis in my legs and feet;"

"my injury still causes great Pain;"

"I still live with pain in my leg and arm and take very bad headaches;"

"back pain persists and requires physio on a regular basis;"

"still lot of pain in lungs and head, had operation to my ears;"

#### **Mobility problems**

"find it very hard to walk long distance and hard to get up and downstairs if there is no lift;"

"I still find it had to walk I need help with shopping, my family see that I am unable to go out unaided;"

"had a strook (stroke?), my left hip joint will not permit me to;"

"inflammation of joints, arthritis, even less mobility;"

"Hard to walk and the further I walk the slower I get suffer depression;"

<sup>&</sup>quot;declining each year;"

<sup>&</sup>quot;I recovered some but have deteriorated in recent years;"

"legs and back walking, stress, worries about going in to crowds;"

"no longer in wheelchair but can't walk unaided;"

"not good walking, bad control of right side of body, pain really bad, depression bad;" "still the same but now add on the effects of getting older, making pushing the wheelchair harder;"

"trouble walking and need a carer;"

"walking impaired, problems with back increased, hearing deteriorated;"

# **Current health status**

As it is evident from a further question about current health status, very few respondents regard their present status of health as being good, but rather report multiple problems, with pain, with deteriorating physical health, complex medical needs, mobility, and mental health.

Table 32: How is your physical health now?

	RESPONDENTS	
HEALTH	Number	%
Good	4	5.3
One Problem	9	11.8
Multiple Problems	61	80.3
No response	1	1.3
Missing	1	1.3
Total	76	100

Table 32 above shows that 61 of the 76 respondents (80.3%) report multiple health problems, supporting our earlier analysis which cast doubt on what respondents meant by 'total recovery'.

#### Impact of Injury

We then asked respondents about the impact of their injury.

"Question 29. What changed immediately after your injury? (For example, did you have to move home? Did this affect your work? Did this change your family circumstances?). Responses are summarized in Table 33 overleaf

Table 33: Impact of injury

	RESPONDENTS	
IMPACT	Number	%
Little or none	2	2.6
Moved home	13	17.1
Lost job	20	26.3
Lost relationship / marriage	2	2.6
Lost health	2	2.6
My whole life changed	22	28.9
Impaired school attendance	1	1.3
Not applicable/ Other	2	2.6
No response	1	1.3
Missing	1	1.3
Total	76	100

The most common response to the question about the impact of their injuries, was that it had totally changed their lives, followed by the loss of employment and the loss of their home. These last two are major stressors in their own right, which coming alongside the impact of the injuries place the individual in an overwhelming situation. Reading the narrative responses affords a more detailed picture. Again, here, too, had multiple answers bee permitted it might have provided a more complete picture. However, respondents also provided narrative comments, as follows.

#### Work

"affected my work, I was a butcher and could not lift heavy weights of beef or lambs, could not stand for long periods

"affected work for 1 year

"could not go to work because of my injury, family upset

"could not work doing job I was doing"

"could not work, failed medical for employment, yes father and mother became carers to me

"effect to work unable to, and adjustments had to be made to my house

"everything, ability to work, physical ability, mental wellbeing, family immediate care;"

"had to leave my job;"

"had to leave my job, my life and my family life has suffered;"

"had to leave work, home adapted, family mentally;"

"have been unable to work;"

"I could not work anymore and having not lived in N.Ireland I had to stay in the Province I was living and working in London;"

"loss of work, esteem, family in trauma, mother had to leave her work, financial loss"

"lost job as a lorry driver, no wage coming in causing a lot of friction, debt a big problem;"

"lost job, had to get help to look after family

"lost my work and financially found things very difficult;"

"off sick then paid off;"
"never work again, moved home;"

"retired, sold farm and bought bungalow in village;"

"unable to carry on farming (work), did not move;"

"unable to work, changed family way of living and where we visit

"was not able to work again

"was unable to return to work, family changed forever

#### **Family**

"affect work and family circumstances

"affected family circumstances;

"as a young girl, our home was not home anymore, we had bulletproof glass fitted intercom to our house and mom and dad were always fighting- caused a lot of stress;"

"family walked on eggshells around me;"

"I had young children and my mother cared for my children. my life was destroyed. I also had to move house;" "I lost my son in a farming accident in 1981, I moved house then my children were traumatized they didn't get any treatment either my life changed that night forever;"

"unable to drive, had to move house, wife had to work full time, cone child in middle of 0 levels at the time

#### **Alcohol issues**

"alcohol abuse, marriage break up;"

"yes under sled, medically discharged from work, divorce and then alcoholised;"

# **Loss of home**

"all of above except I did not have to move home

"already moved through SPED (2003) unable to, 'ucric' socialize (unreadable) involved in family activities due to depression and physical injuries;"

"had to move home and have not been able to return to work

"had to move home, family circumstances were affected by mood swings

"had to move home, had to leave work

"had to move home, lost job as a driver, lost my son indirectly

"home destroyed by blast bomb, move to a new home, ongoing loyalist, sectarian attacks there since 2006;"

"me and my family had to move house after pipe bomb and it made my tech life very difficult

"move home, sell family farm, change job, stress impact on children

"move home, unable to work, affected everyone in the family;"

"moved home twice:"

"lost my home and my career;"

"moved home, moved job;"

"moved to another army base in UK against my will;"

"my family had to move house within 3 days and a few years later my father had a bomb under his car but luckily did not go off;"

"we had to move house and it was still not ideal, relationship breakdown and loss of house;"

"we had to moved home;"

"where i live 1 mile from the border I have been asked to move home about 10 times, house is all bullet proof windows etc;"

"Unable to access 1st floor accommodation at home so had to have major Building and renovations done to facilitate wheelchair and equipment

# Relationship breakdown

"broke up with wife, now live on my own;"

"moved home, lost my partner;"

"my marriage fell apart;"

## **Education and social life**

"I was 9 and did not attend school for more than 1 year, this had result which affected the future:" "my going out changed, stayed in all time

#### **Mental health**

"my memory is disturbed basic chronic ear four heart attacks 1995 (unreadable);"

"my mental health, unable to cope with family life;"

"off work for 6 months, mentally very detrimental."

## **Experience of hospital treatment**

Next, we asked people about their experience of hospital. Table 34 below provides results obtained

Table 34: Experience of initial acute hospital treatment

	RESPONDENTS	
EXPERIENCE	Number	%
Excellent	22	28.9
Good	27	35.5
Not great, they did their best	14	18.4
Not good	4	5.3
Bad	5	6.6
No response/ not applicable	4	5.2
Total	76	100

Overall, injured people had positive experiences of hospital, with 65% reporting 'excellent' or 'good' experiences, and only 9% reporting 'not good' or 'bad' experiences. People were invited to record their other comments on their experiences of hospital, and these are categorized below.

## **Positive experiences**

"caring helpful;" "they saved my life;" "excellent treatment in both hospitals;" "Tyrone County saved my life and local preserved my life;" "I was the first person John Robb (surgeon RYH) used micro survey on, otherwise my "was in the hospital for 3 and 1/2 months leg was to be amputated;" and the care was excellent;" "nurses and doctors were great;" "the staff was very good;" "looked after well;" "were good at the time;" "Reasonably good;" "did not have long to wait;"

## **Prejudicial attitudes**

"being a prison officer meant my GP wasn't interested, local are good but my main hospital not interested due to job;"

"felt mistreated when they found out why was in hospital;"

#### Limited capacity, pressure on resources

"facilities were limited at the time;"

"Good considering the time and circumstances;"

"so much happening at the time 1970-1998;"

"staff were dealing with drama, they did their best but they had no training;" "there was nothing could be done about hightone hearing loss, have just received hearing aid for same;"

#### **Poor treatment**

"in the absence of my consultant there was a failure to diagnose ostemyelitis a huge abscess that nearly killed me;"

"not very updated on my case;"

"Kept in cells for hrs before I had treatment. After treatment RUC took me to Shankill Rd. Said they leave me there;"

"once discharged no care at all;"

"payed off and forgot about;"

"medical help at the time was non- existent;"

"they had no idea how to deal with PTS;"

"couldn't work with members affected;"

Respondents were also asked about the recency of their hospital treatment, in order to establish which of these issues were current. These results are shown in Table 35 below.

Table 35: Years since initial acute hospital treatment

	RESPONDENTS	
PERIOD	Number	%
40 years	15	19.7
30 years	20	26.3
20 years	22	28.9
10 years	6	7.9
Less than 10 years	9	11.8
No response/ not applicable	4	5.2
Total	76	100

Almost three quarters of respondents' hospital treatment was 20 years or more ago. We then asked if they still attended hospital for medical treatment, and 50 respondents (65.8%) said that they still attended hospital for their injuries. Table 36 shows how frequently they attend.

**Table 36: Frequency of hospital attendance** 

	RESPO	RESPONDENTS	
FREQUENCY	Number	%	
Monthly	9	11.8	
3-4 times a year	24	31.6	
Each year	5	6.6	
Every 2-3 years	5	6.6	
Less than that	2	2.6	
No response	7	9.2	
Not applicable	22	28.9	
Other	1	1.3	
Total	76	100	

A substantial minority 23, (43%) of the respondents attend several times a year, 9 (11.8%) attending monthly, representing a substantial use of medical services, if taken over the period of time since their injury.

We then asked why they attend hospital and Table 37 provides their responses.

**Table 37: Purpose of hospital attendance** 

	RESPONDENTS	
PURPOSE	Number	%
Regular checkups	17	22.4
Degeneration of injury	12	15.8
Complications due to the injury	15	19.7
Rehabilitation	2	2.6
Not applicable	21	27.6
Other	7	9.2
No response	1	1.3
Total	76	100

The main reason given for repeat hospital attendance was check-ups (17 or 22.4%) followed by complications due to the injury (15 or 19.7%). Degeneration of the injury accounted for a further 12 or 15.8% respondents' hospital attendance. Only 2 respondents were attending for rehabilitation.

Respondents were also invited to explain further in narrative answers. A number of additional comments emerged in these:

"artificial eye clinic" "COPD;" (Chronic Obstructive Pulmonary Disease)

"bowel blockages;"

"degeneration of injuries;" "mental health;"

"having treatment for lower back pain;" "pain management;"

"I am to get a knee replacement;" "physio/ counselling;"

"Injections to face;" "sometimes for x-rays;"

"limb fitting;" "still on medication."

# **Changes in health needs**

Respondents were asked if they thought their health needs had changed since they were injured, and 71 (93.4%) said that they had, with only 2 (2.6%) saying that they had not.

# **Experience of GP and District Nurse**

Respondents were then asked to evaluate their GP and district nurse. Table 23 below shows their responses.

**Table 38: Experience of GP and District Nurse** 

	RESPONDENTS		
EXPERIENCE	Number	%	
Excellent	26	34.2	
Good	32	42.1	
Not great, they did their best	12	15.8	
Not good	3	3.9	
Bad	2	2.6	
No response/ not applicable	3	3.9	
Total	76	100	

Respondents were then asked to rate the medical attention they currently received from their hospital or clinic. Their responses are shown in Table 39 below.

Table 39: Current experience of hospital or clinic

	RESPONDENTS		
EXPERIENCE	Number	%	
Excellent	13	17.1	
Good	28	36.8	
Not great, they did their best	16	21.1	
Not good	1	1.3	
Bad	3	3.9	
No response/ not applicable	15	19.7	
Total	76	100	

Contemporary experience of hospital is less likely to be ranked as excellent (13 or 17.1%) than their past experience of hospital (22 or 28.9%). About the same number (28 or 36.8%) ranked their present experience as 'good' as in the past (27 or 35.5%). Negative rankings of hospital remained about the same, with 3 respondents ranking their present experience as 'bad', whereas 5 had ranked it as 'bad' in the past.

## <u>Pain</u>

Some 89.5% of respondents, 68 out of 76 reported that they suffered constant pain from their injury at present, but only 25 (32.9%) said that they attended a pain clinic. We then asked respondents how they managed their pain. Table 40 shows their first responses and Table 41 shows their second responses.

Table 40: How do you manage your pain? (a)

	RESPONDENTS		
EXPERIENCE	Number	%	
Alcohol	9	11.8	
Non-prescription drugs	3	3.9	
Prescription drugs	42	55.3	
Meditation or complementary therapies	3	3.9	
Religion or faith	2	2.6	
Accept my pain	3	3.9	
No response/ not applicable	13	17.1	
Missing	1	1.3	
Total	76	100	

First preference for managing pain is clearly prescription drugs, but the next most popular is alcohol. Non-prescription drugs, complementary therapies and religion are much less popular as a first choice, but nonetheless respondents report using them for pain control.

Table 41: How do you manage your pain? (b)

	RESPONDENTS		
EXPERIENCE	Number	%	
Physiotherapy	1	1.3	
Non-prescription drugs	1	1.3	
Prescription drugs	10	13.2	
Meditation or complementary therapies	10	13.2	
Religion or faith	5	6.6	
Accept my pain	3	3.9	
No response/ not applicable	2	2.6	
Missing/ No second response	33	43.4	
Total	76	100	

However, although prescription drugs are still prevalent, meditation and complementary therapies were as popular as a second choice. Religion was more popular as a second choice whereas alcohol does not feature as second choice. Clearly, pain is a significant problem as a major and ongoing challenge for those injured in the Troubles. The prominence of alcohol as a way of managing pain (and for managing other symptoms) is also a concern, given the known health risks of alcohol use and the hazards of mixing prescription drugs and alcohol.

#### **Help and support**

The next section of the questionnaire asked people about their sources of support in the aftermath of their injury. Table 42 below shows responses to the question 'Who helped you in the aftermath?'

Table 42: Who helped you in the aftermath? (a)

	RESPO	RESPONDENTS	
SOURCE OF SUPPORT	Number	%	
Family	68	89.5	
Friends	2	2.6	
Other	4	5.3	
No one	2	2.6	
Total	76	100	

The overwhelming majority of respondents cited their family as their first source of support. This is consistent with the respondents' earlier reports of the impact of their injury on their families, who, in most cases rallied round the injured person, certainly in the immediate aftermath. Two respondents reported having no support. Neither respondent provided contact details so could not be contacted in order to offer support.

Respondents were also invited to write their own explanations of other sources of support, and these are shown in Table 43 below, ranked in order of their frequency.

Table 43: Who helped you in the aftermath? (b)

	RESPONDENTS		
SOURCE OF SUPPORT	Number	%	
Family and friends	20	26.3	
Family	18	23.7	
Other support	12	15.8	
Family, friends and church/faith	10	13.2	
Family friends and WAVE/victim support	5	6.6	
Family and work	3	3.9	
Family & wife/girlfriend	2	2.6	
No one	2	2.6	
Friends and WAVE	1	1.3	
Work	1	1.3	
No comment	1	1.3	
Total	76	100	

Family and friends still feature prominently, alongside less prominent helpers such as churches, victims' organisations, and employers. It is possible that a branch of the security forces employed those who found employers helpful, since they have dedicated services to assist injured officers.

#### **Counselling and emotional support**

In response to the question, 'Would you have benefited from counselling or emotional support?' 62 respondents (81.6%) replied in the affirmative, with 12 (15.8%) saying that they would not have benefited. When asked if they had received counselling or emotional support at the time of the injury, only 21 (27.6%) said that they had, with the majority (55 or 72.4%) saying that they had not received any such support. Of those who had received such help (24 respondents), two thirds (16 or 66%) found it helpful. When asked if they had received counselling or emotional support later, 44 respondents (57.9%) said that they had, whilst 30 (39.5%) said that they had not. When asked if this later counselling was helpful, of those who got such help (46 respondents) 35 (76%) said that they found it helpful, whereas 11 (24%) did not find it helpful.

We then asked respondents where they had received their help from, and Table 44 below summarizes their responses.

**Table 44: Source of later support** 

	RESPONDENTS		
SOURCE OF SUPPORT	Number	%	
Voluntary sector	23	30.3	
Statutory sector	18	23.7	
WAVE Trauma Centre	3	3.9	
Psychiatrist	1	1.3	
No response	4	5.3	
Not applicable	27	35.6	
Total	76	100	

If we add the 3 respondents who named WAVE to the voluntary sector figure,26 respondents received help from the voluntary sector. If we add the 1 respondent who was helped by a psychiatrist to the 18 respondents who got help from the statutory sector, 29 respondents or 60.4% who were helped later were helped by the voluntary sector; compared with 19 or 39.4% who were helped by the statutory sector. This highlights the prominence and importance of the voluntary sector in providing help to people injured in the Troubles.

# **Impact on families and carers**

We then asked respondents about the impact of their injury on those around them, including their family. Nearly two thirds of respondents, 48 (63.2%) said that their injury had 'changed everything' and a further 16 (21.1%) said that it had had a strong effect on those

around them. A further 7 (9.2%) said that their injury had 'quite a lot of effect' on those around them, and a further 4 (5.3%) said that it had some effect, and only one said that it had no effect on those around them.

We then asked respondents to identify their main carer. Table 45 summarizes their responses.

Table 45: Who is your main carer?

	RESPONDENTS		
SOURCE OF SUPPORT	Number	%	
Wife/husband/partner	46	60.5	
Son /daughter	11	14.5	
Other	9	11.8	
Parent	4	5.3	
Brother/sister	3	3.9	
Not applicable/ no response	3	3.9	
Total	76	100	

Spouses and partners emerge as the most likely carers for injured people, followed by other family members, sons or daughters and then parents. The 'other' category included friends (2), 'myself' (6) including one respondent who commented 'I look after myself, I don't have a choice'. One respondent said that his carer was his wife until she died in 2006' and another said 'when my husband was alive he was looking after me.' One respondent said that social services were looking after him. The pattern of the family being the primary source of care for the injured person emerges very clearly from these data. This points to the importance of providing support for, not only the injured person, but also of providing support to their family, given the centrality of families in ongoing care and support for injured family members.

We then asked respondents if their carer was receiving a Carer's Allowance. There are eligibility requirements for carer's allowance and not all respondents' carers may meet these. To qualify, a carer must regularly spend at least 35 hours a week caring for someone who receives a middle or higher rate Disability Living Allowance, Attendance Allowance or Constant Attendance Allowance (which is an addition to War Disablement Pension or industrial disablement benefit). Carers cannot earn more than £100 per week, they must not be in full time education, and they must be over 16 years old. Those who qualify are paid £55.55 a week. Only 24 respondents (31.6%) said that their carer received Carer's Allowance with 44 (57.9%) reporting that their carer did was not in receipt.

When asked if their carer gets the option of a respite break, 8 respondents said that this did not apply to them, and out of the 68 remaining respondents only 10 (14.7% out of 68) said that they did, and 55 (80.8%) said that they did not. Similarly when asked if their carer can avail of emotional support, of the 68 to whom this applied, only 3 (4.4%) said that emotional support was available to their carer, whereas 62 (91.2%) said that their carer could not access emotional support. (A further 3 respondents 4.4% did not respond.)

We also asked respondents if they thought their carer needed any other kind of support, and 15.8% or 12 respondents said that the question did not apply to them, and a further 10 (13.2%) did not respond. Some 52 respondents answered the question, and 20 (38.5%) said that their carer did need other support, whereas 32 (61.5%) said that they did not. The respondents were then invited to explain what their carer needed in terms of support. Responses to this question can be grouped under a number of thematic headings, thus:

# Respite, a break

"A rest from the daily routine;" "respite / time out;"

"break away would help her;" "respite break;"

"break from been around myself;" "short breaks etc;"

"maybe some respite;"

"Respite;"

## **Emotional support**

"emotional support;"

"more support from anyone who helps;"

"perhaps someone needs to advise of them what they need, after listening to me every day for the last 20+years, anything would help;" "someone to ask how she is now and

"support my son- he has gone through a

again;"

lot with me;"

# **Financial support**

"don't have any financial cover;"

"Further financial would be helpful;"

"financial, having to bring me to places etc;

# **Complementary therapy**

"respite or complimentary therapy to relax;"

"complimentary therapy such as massage

etc;"

#### Practical support

"help with domestic appliances and cooking;"

Some respondents wrote comments indicating significant problems in caring. In particular, one woman wrote, "My husband then suffered a breakdown and I am now his carer." All too often, respite has not been available to carers. One man wrote, "It's too late, she is dead now." Yet another wrote, ""my family don't or can't deal with it," indicating family conflict focused on the injury. One other respondent wrote that his carer "will have nothing to do with it," pointing to a further problem which can develop, whereby carers are reluctant to let go of caring responsibilities in order to rest or look after their own needs, even if and when respite and support is available. This trend also emerged in the interview data.

#### **Post-Traumatic Stress**

We embedded a standard screening measure of Post-Traumatic Stress, the PDS (Foa, 1995) into the questionnaire. This measure is commonly used in clinical settings as a screening measure for Post-Traumatic Stress Disorder. PDS is scored on a four point scale, 10 or less (mild); 11 to 20 (moderate); 21-35 (moderate to severe); and 36 and above (severe) with those who score at the mild end less likely to have PTSD and those at the severe end most likely to suffer from the condition. Patients scoring moderate or severe scores on this scale are those who would attract clinical attention.

In total, 65 respondents completed the scale, and their final scores ranged from 3 to 51 on the scale. Table 46 below displays the distribution of scores amongst the sample.

Table 46: PDS score

	RESPONDENTS		
SCORE	Number	%	
Mild (<10)	3	3.9	
Moderate (11-20)	5	6.6	
Moderate to severe (21-35)	23	30.3	
Severe (>35)	34	44.7	
Missing	11	14.5	
Total	76	100	

Less than 4% of the sample (3 respondents) scored at the mild end of the scale, a further 6.6% (5 respondents) scored as 'moderate' but three quarters of the sample (75% or 57 respondents) scored as either 'moderate to severe' or 'severe' on the PDS scale. This rises to 87% of the respondents who completed the PDS scale, if we exclude the 11 respondents (14.5%) who did not complete the scale (because of no response provided). Although scoring on the PDS is not the same as a PTSD diagnosis, it is indicative of post-traumatic stress. The joint study by the Bamford Centre for Mental Health and Wellbeing and NICTT has found lifetime and twelve-month prevalence rates for PTSD in the general population of Northern Ireland of 8% and 5.1% respectively. In the light of this, the prevalence rate for PTSD in this population is likely to be much higher.

A further breakdown of these scores by age is shown in Table 47 below. There is a clustering of scores in the 'moderate to severe' and 'severe' categories and in the 40-70 age range, suggesting that these age groupings experience more psychological difficulties in terms of traumatic symptoms.

Table 47: PDS scores by age

	SCORE CATEGORIES				
	Mild	Moderate	Moderate to	Severe	Total
AGE			severe		
20-30years	0	0	0	2	2
31-40years	0	1	0	0	1
41-50years	1	1	1	10	13
51-60years	1	0	7	11	19
61-70years	1	1	10	8	20
71-80years	0	1	3	0	4
81-90years	0	1	2	2	5
Total	3	5	23	33	64

Typically, PTSD and, by association, PDS are found to be higher in females. (Various reasons are advanced for this, to do with female psychology and gendered styles of managing stress.) Table 48 shows the comparison of male and female scores.

Table 48: PDS scores by gender

		sc	ORE CATEGORIE	S	
	Mild	Moderate	Moderate to	Severe	Total
GENDER			severe		
Males	2	3	17	26	48
	(4.2%)	(6.2%)	(35.4%)	(54.2%)	(100%)
Females	1	2	6	8	17
	(5.9%)	(11.8%)	(35.2%)	(47%)	(100%)
Total	3	5	23	34	65

Although the raw scores show fewer females than males scoring in the moderate to severe and severe groups, it has to be mentioned here that there are fewer females than males in the sample. When percentages of total male and female sample are calculated, the prevalence of high PDS scores is higher amongst males than amongst females. This could be related to severity of injury, nature of exposure to trauma, isolation or it could be due to the limitations of the sample or other factors.

# **Occupation**

We asked respondents to tell us their occupation at the time of their injury, if they were working. Table 49 below shows their responses.

Table 49: Occupation at time of injury

	RESPOND	ENTS
OCCUPATION	Number	%
Police	13	17.1
Farmer	4	5.3
Taxi / bus driver	4	5.3
Sales assistant/ manager	3	3.9
Lorry driver	3	3.9
Secretary/ PA/ clerk	3	3.9
Factory worker	3	3.9
Labourer	2	2.6
Joiner	2	2.6
Student	2	2.6
Butcher	2	2.6
Chef/ catering	2	2.6
Civil servant	2	2.6
Child minder	1	1.3
Fence erector	1	1.3
Buyer drapery	1	1.3
Cleaner	1	1.3
Crane driver	1	1.3
Soldier PT	1	1.3
Bricklayer	1	1.3
Engineer	1	1.3
Painter	1	1.3
Housekeeper	1	1.3
Kitchen assistant	1	1.3
Lecturer	1	1.3
Own business	1	1.3
Milkman	1	1.3
MOD	1	1.3
Mortgage Broker	1	1.3
Plasterer	1	1.3
Prison officer	1	1.3
Steel erector	1	1.3
Stock controller	1	1.3
Dog warden	1	1.3
Unemployed	2	2.6
No response	5	6.6
Not applicable	3	3.9
Total	76	100%

We then asked respondents, if they were able to return to work after their injury. Responses given were as follows:

- 24 (31.6%) said that they were able to return to work
- 46 (60.5%) said that they were not
- 4 (5.3%) made no response
- 2 (2.6%) said the question did not apply to them

#### When asked if they wanted to return to work:

- 54 respondents (71.1%) said that they did want to return
- 15 (19.7%) said that they did not want to return.

#### We asked people what prevented them from going back to work:

- 42 (55.3%) mentioned their health, physical disability and issues of access prevented them
- 20 (26.3%) reported that incidents of intimidation and also fear prevented them
- 39(51.3%) said that anxiety, depression and loss of confidence prevented them
- 5 (6.6%) said that a lack of job opportunities prevented them.

We also invited respondents to write in further comments on this issue, and their comments can be categorised thematically in two main groups- health and security. Those narrative comments can be found below under each of the two categories:

## **Health and disability obstacles to work**

"could not work was in pain;"

"Failed medicals to go back to work due to injuries;"

"was too ill;"

# **Security**

"fear of people who worked with me;" "got shot at work."

One other respondent wrote, "I was told not insured."

## Respondents were asked:

About your ability to work since your injury, please circle the option that best describes your experience:

Never been able to work since [1]
Only able to work part-time or reduced hours [2]
Can work sometimes but not others [3]
Had to leave my job but have other employment [4]
Other (Please state details) \_\_\_\_\_\_ [5]
Table 50 below summarises their responses.

Table 50: Ability to work since injury

	RESPONDENTS	
SOURCE OF SUPPORT	Number	%
Never been able to work since	43	56.6
Only able to work part time or reduced hours	8	10.5
Can work sometimes but not others	2	2.6
Had to leave my job but got other employment	6	7.9
Other	8	10.5
Not applicable/ no response	8	10.5
Missing	1	1.3
Total	76	100

Over half of the respondents were never able to work since their injury, with 6 finding employment elsewhere. Further narrative comments from respondents' remarks:

"had to leave work because of intimidation by someone who was in the IRA, He picked on me all the time had to leave work because I being singled out (intimidated);"

"had to return to work as had no other source of income;"

"went back to work ten years then worked ten years got ill;"

"worked full time;"

"medically retired 2009;"

"only able to do supported work;"

"I am a volunteer in WAVE."

Respondents were asked the following question:

About your inability to work since your injury, please circle the option that best describes your experience.

Due to the results of my physical injury I cannot work, even though I want to [1]
Due to the results of my physical injury and also the stress and trauma, I cannot work [2]
Due to the stress and trauma after my injury, I cannot work [3]

Table 51 below summarises their responses.

Table 51: Ability to work since injury

	RESPONDENTS	
SOURCE OF SUPPORT	Number	%
Due to the results of my physical injury I cannot work, even though I want to	17	22.4
Due to the results of my physical injury and also the stress and trauma I cannot work	29	38.2
Due to the stress and trauma after my injury I cannot work	11	14.5
Not applicable	15	19.7
No response	4	5.3
Total	76	100

Whilst almost a quarter (17 people or 22.4%) of the sample reported that it was primarily the physical limitations caused by the injury, that prevented them from being able to work, 29 respondents (38.2%) reported that their inability to work was due to a combination of physical and emotional problems. Only 11 (14.5%) explained their inability to work as due to psychological causes alone.

#### Compensation

The next questions related to Criminal Injuries Compensation payments to people injured in the Troubles. Of the total 76 respondents, 65 (85.5%) said that they had received compensation, with 10 (13.2%) saying that had not been compensated, or that they had not yet been paid.

We then asked respondents to evaluate the legal advice they were given in connection with their compensation. Their responses are shown below in Table 37.

Table 52: Quality of legal advice about compensation

	RESPO	RESPONDENTS	
QUALITY	Number	%	
Excellent	2	2.6	
Good	9	11.8	

	RESPONDENTS	
QUALITY	Number	%
Not great but they did their best	31	40.8
Not good	14	18.4
Bad	15	19.7
No response	1	1.3
Not applicable	4	5.3
Total	76	100

About 14% (11 respondents) of the sample thought that their legal advice was either good or excellent, whilst 38% (29 respondents) thought that it was not good or bad. A further 40.8% (31 respondents) thought that their legal advice was 'not great but they did their best'. Seen alongside the levels of satisfaction with their medical treatment, the level of satisfaction with legal advisors is lower, although perhaps the nature of the negotiations for compensation and the process which some of the interviewees saw as humiliating, protracted, alienating and unfair ensures that those associated with it will be less well regarded.

We then asked respondents how long it took to settle their cases of compensation in or out of court. The responses are provided in Table 53 below.

Table 53: Length of time to settle compensation case in or out of court

	RESPONDENTS	
LENGTH OF TIME	Number	%
Not yet settled	2	2.6
2 years or under	4	5.3
Over 2 but under 3 years	31	40.8
Over 3 but under 4 years	3	3.9
Over 4 but under 5 years	2	2.6
Over 5 but under 6 years	6	7.9
Over 6 but under 7 years	4	5.3
Over 7 but under 8 years	8	10.5
Over 8 but under 9 years	2	2.6
Over 9 but under 10 years	1	1.3
Over 10 but under 11 years	1	1.3
Can't remember	3	3.9
Other	9	11.8
Total	76	100

In over 40% of cases, in the experience of 31 respondents it took between 2 to 3 years to settle their compensation case. Very few cases (4 cases or 5.3%) settled in less than this and 27 (35.6%) took longer, some up to ten years to settle. Only 9 respondents (11.8%) thought that their compensation was adequate for their needs, with 56 (73.7%) seeing it as inadequate.

We then asked some questions about benefits, and 52 (68.4%) of respondents said that they received Disability Living Allowance, 21 (27.6%) said that they did not receive it, 1 did not respond and 2 said the question did not apply to them. On the question of Incapacity Benefit, 36 respondents (47.4%) said that they received Incapacity Benefit and an equal number said that they did not, with four respondents not providing a response. A further 22 respondents, said that they did not receive any other benefits or pensions, whilst 45 (59.2%) said that they did receive such pensions or benefits and 8 did not respond. When asked to describe their other sources of income, 12 (15.8%) respondents declined to reply, and out of those that did, 4 received Ministry of Defence or army pensions, six received industrial injuries pensions, nine received state retirement pension, one received a 'state police pension' and other responses were inconsistent.

When we asked respondents how well their financial needs were met, only 7 (9.2%) said that they were well enough met, 35 (46.1%) said that their income was 'just adequate', 27 (35.5%) said that they struggled to get by and 5 (6.6%) said that they cannot survive on their current income. 2 respondents did not reply.

We also asked respondents to tell us what kind of financial assistance they would find helpful. All but 6 of the respondents wrote a comment or suggestion and they are included here in full, to provide a sense of what people think might help. Their responses can be organized under the following headings, thus:

## **Pension or benefits**

"A pension that provides a reasonable standard of living;"

"have no private pension, would have conflict injury related pension;"

"some pension to allow me to do things;"

"serious disability as a result of conflict (NI) should be acknowledged in the formof the related pension;"

"High rate DLA;"

"to be given the proper DLA, if I had not been injured I would not need it;"

#### **Compensation**

"A relook at early compensation pre' 82;"

"Compensation for future;"

"Compensation;"

#### Medical and aids

"An artificial limb of good quality would have helped;"

"help to get therapies;"

"I would like assurance for payment for any medical requirements physical exercise assistance to maintain a quality of life - this includes payment to footwear specialists, exercise providers, physio and any other services;"

# Any financial help at all

"Any;"

"Any assistance would be helpful;"

"Any financial help would be helpful have received financial help from the NI memorial fund;"

"Any other financial assistance would be helpful;"

"Anything would be good;"

"Anything;"

"Anything at all:"

"I would be grateful for any financial

assistance;"

"money assistance;"

"in the current economic state any help

would be helpful;"

# **Heating**

"Any additional assistance would be welcome, help with heating would help greatly;"

heating and general housing costs;"

"heat, electricity, food, clothes;"

"Heat/ Fuel Payment and household financial assistance;"

"help to buy heating oil, help to buy things that break down, and help to pay for work that needs done around the house;" "help with fuel (home heating and

electricity);"

"payment in winter and at xmas;"

"home heating costs;"

"home heating, maintenance;"

"rent allowance, heating allowance, my wife does not get job seekers because I

get a pension;"

## **Financial support for carers**

"Anything, some assistance for my wife as my main family earner but also my carer;"

"Care allowance;"

# Housing and household costs and help at home

"Casual day to day costs;"

"Cheap loan in times of need;"

"Covering routine domestic bills such as rates etc and respite breaks;"

"Free rates for seriously injured troubles survivors, free TV licences;"

"help with rates;"

"helping to pay mortgage;"

"I would benefit with help in the house and upkeep of my home maintenance;"

#### **Emotional support**

"Emotional [support] and training to go back to work would benefit me;"

"For special needs;"

"more help and support;"

## **Respite and breaks**

"just more time at police home;"

"money towards breaks, me and my wife to get away;"

"lump sum payment yearly, also trust fund for holiday and other payments, added to yearly if unused in year awarded;"

"short breaks away;"

"respite/short break;"

Two respondents commended the Memorial Fund and wished it to continue, in particular one said, "I am grateful for what I get through the support and reconciliation scheme:" In reviewing what respondents said they need, people who, in many cases live with severe and disabling conditions should respond that 'anything at all' would be helpful was particularly poignant. This seen together with the other finding that 35 respondents (46.1%) said that their income was 'just adequate', 27 (35.5%) said that they struggled to get by and 5 (6.6%) said that they cannot survive on their current income.

#### Victims' groups

Finally, we asked respondents about victims' groups. Over 80% (61 respondents) were aware of victims groups in their area, and only 14 respondents (18.4%) were not aware of such groups. However, this result could be a product of our sampling strategy, which used victims' groups as one of the distribution mechanisms for the survey. This is supported by the fact that nearly three quarters (73.7% or 56 respondents) said that they were members of a victims' group. We also asked the participants to tell us if they were not a member to say why. Reviewing the responses can be categorized under the following headings:

# Negative views about groups

"all groups useless, included PSNI, MLAs, Medical, Law, no help at all, to so ongoing hatred;" "don't trust the people who run them;"

#### Members of victims groups

"I am a member of WAVE;"

"I am a member of WAVE in Ballymoney but to frail travel;"

"I am a member of WAVE since 2011;"

"I am a member of WAVE trauma centre;"

"WAVE member;"

"I am so glad to WAVE for the help they are giving me as a group;"

"I have good support from WAVE;"

"I wish I have been with WAVE earlier;"

"Thanks to WAVE for what they did for me when I needed help;"

"WAVE has been very good for PTSD and a great help to me and my family;"

"WAVE has been very good, as has NIMF;"

"WAVE is proving to be invaluable to me, wish I had been referred sooner;"

# **Access issues**

"I can't walk very far;"

"I find groups hard and would rather look to the future and try to forget the past

"I get the monthly news...a WAVE (unreadable)

"It took 25 plus years to seek for help;"

"Just one that I know is Trauma WAVE;"

"Cannot drive;"

#### Not aware of victims' groups

"None that I know of;"

"Not aware of victim groups;"

# Not attracted to idea of groups

"Not for me at present;"

"Not my scene;"

#### **Security issues**

"Security reasons as being ex-police;"

"Victims group are outside my area and in an area I would not feel safe in WAVE;"

"Mixed community;"

# Other comments

"Thank God to be alive;"

"I am happy and lucky to be alive;"

"I am in pain constantly and I will be in and out of hospital for operations for the rest of my life;"

"I have been attending all kind of doctor the last 35 years;"

"I have tried to answer these questions as well as I can, and with the help of my husband;"

"I just want to leave; I don't want to be in N. Ireland;"

"I was hospitalized 2 weeks and recovered - less than 400 pounds compensation. That was bad;"

"In 2010 I took a breakdown and was in hospital for 5 weeks;"

"In the 1970, little was available so it was up to family to take care of me;"

"Many children were injured and one of our greatest losses was that of potential. Even though I work, why should I pay for the criminal acts of others? I pay with pain. Government makes me use my money to (unreadable).

"People who suffer from injuries are made to look like beggars if we needhelp. Doctors and government say it is our past and we have to moveon. This is our present;"

"this has affected my temperament/patience -grumpy and moody

"too many groups;"

"treatment useless from PSNI, PSYCH hospital, yet benefits stops while problems worsen= sick!"

"victims just treated very badly NI always anything been given always been grudged (unreadable);"

At the final part of the questionnaire respondents were asked to provide any comments, they would like to leave as a final note. The narratives of those comments can be found below.

#### And the final comments:

"Because I can't get the minimum police pension, me and my wife cannot claim most benefits:"

"Due to injury find it very hard to associate with strangers (FEAR);"

"I am sitting in my home freezing because I don't have oil, that's my comment."

## The interviews with injured people

### **Introduction**

In all 30 injured people, 6 carers and 14 service providers were interviewed. All those interviewed have experienced serious, life-threatening or disfiguring physical injuries – often with the psychological sequelae – from which they cannot expect to make a full recovery. They live everyday with the consequences, pain, and complex problems that the injury has produced.

Most of the interviews with injured people took place in their own homes, with a small number conducted in the premises of a local victims' organisation or in the Northern Visions studio, by the choice of the interviewee. This was also true for the interviews with carers. Interviews with experts and service providers were conducted either in their offices or in places of work, in one case in the university, and in one case in the studio. Most interviews were sound recorded, although a small number of interviews were simultaneously filmed and sound recorded after asking the permission from the interviewee.

Interviewees generally seemed to appreciate having the opportunity to talk about their experiences, and although the interviews focused on traumatic and sad events, interviewees willingly cooperated with the researchers. The motivation for doing so was explicitly stated in a number of cases; the desire to have the situation of people injured in the Troubles better understood, and the desire to improve the levels of support and service for injured people and their families.

All interviewees were asked whether they wished their contribution to the research to be anonymous or whether they wished their name to be used. In the analysis of the interviews that follows, therefore, in some cases, names are used, with the consent of the interviewee and in other cases, the contributions, and situations of interviewees are anonymous. In the preparation of the report, where an interviewee wished to be named and quotes of a particularly personal or sensitive nature were to be used in the report, interviewees were contacted by phone to confirm that they wished to be named.

The Commissioners of the study, Wave, had concerns about some names being used, However, on advice from ORECNI, having offered interviewees the choice to be named or anonymous, the choice of the individual had to be respected. Every effort has been made to ensure that the interview material is presented in a responsible manner that fairly represents the views and interests of participants in the study.

The material gathered in these interviews is reported under three main headings: (1) Interviews with injured people (2) interviews with carers and (3) interviews with professionals. Within each category, sub-headings are used to identify the themes that arose. The analysis here can only be indicative of the rich and complex information, which the people interviewed, gave to the study. This will not fully reflect the unique circumstances of the people who have explained their situation in careful, intricate, and often painful detail. Certain themes recurred, and although one person is quoted, often the

point was made by many people. Some interviewees are quoted several times and some not at all. This does not reflect the value of their contributions that people made to the study, but rather that the form of words they used usefully sums up the issue under discussion. The themes here are those that appear to be of greatest significance; and have been set out where possible using the words of injured people, their carers, and the professionals who work with them. The richness of the data would support a lengthier analysis than can be embarked upon here, so the themes relevant to the aims of the research have been focussed on.

## <u>Health</u>

This study focused on those who had sustained a life threatening or disfiguring injury in the Troubles. Therefore it is, perhaps, inevitable that the health of the injured person was a major topic within the interviews. The state of health of the injured varied according to their injury, the loss of function or limb, the complications arising from that injury, the injury-precipitated additional conditions, the duration of the physical trauma, and their age.

### Ongoing physical health problems

In 1972, at the age of 5, Martine Madden was knocked down by an armoured personnel carrier (APC), driving at speed on the wrong side of the road in a quiet side street off York Road in Belfast. The line of vision in APCs meant that it was not uncommon for them to hit children in the street during the Troubles. Martine was given emergency treatment on the spot, while they waited for the ambulance to arrive, by a patrol of the Ulster Defence Regiment who were parked nearby, as the army vehicle sped on. She spent the next 2 years in the Mater Hospital at first in intensive care and then in an isolation cubicle with her foot in plaster. She underwent numerous skin grafts and lost her toes, one by one, as attempts were made to save her badly crushed foot. Had the APC struck her higher up her body, she would have been killed, according to doctors' reports. The repeated skin grafts taken from her thigh for her foot have left her permanently scarred.

"I was losing toes one at a time and had hundreds of stitches. I'd maybe get home the odd weekend. And after the 2 years, they decided they wouldn't be able to save it and they transferred me to the Royal – and they tried another two grafts in the Royal. And the consultant called my Mum and Dad in and told them that they felt the best way forward was to have the leg amputated. He told them it was their decision, but that he didn't think I'd ever have any use of the foot. I'd be on crutches forever and they couldn't guarantee it wouldn't break down – the skin just wasn't taking. So my parents had to decide – something they carried to their dying day because my Dad died ten years ago and he told me on his deathbed that only because of the way I had accepted it – which helped Mum and Dad. They'd never have forgiven themselves if I had blamed them for making that decision. In my eyes, it was the right decision. Although it is still very difficult but it was the right thing to do."

Her parents' distress at having to take such a decision as a parent of a young child was clearly long lived. Martine Madden now has serious on-going problems with her amputated leg.

"I was great until I hit about the age of 16 when I started to have recurrent abscesses and infections. I have been practically every year ... to have surgery to have these removed. When I was in my 20s you'd be in for 2 or 3 weeks because they used to pack [the wound] but now you're out within a few days and you have to convalesce at home – they can't get you out guick enough."

Having suffered limb loss and normally using prostheses, this entails periods when Martine cannot use her artificial limb, following surgery on the stump.

"So I would be out of my limb 8 to 10 weeks at a time, and that's not counting for the time before the operation when the leg has flared up. ... I would suffer from chronic back pain and pressure on the spine due to the constant wearing of the limb. And now I suffer terrible pains in my neck and shoulders, which I put down to having to use crutches so much over the years. I'm dreading it — I have to go in and have my leg shortened because I'm having so much trouble. I don't know how I'm going to come out of that I'm worried about having to use the crutches due to the pains in my arms and elbows."

Martine, like others who have suffered limb loss, attends the rehabilitation and limb fitting at Musgrave hospital regularly.

"I go there all the time to get a new limb made because as a child you're growing. That was another thing that happened. After I had my leg off I was in every few years having a bone chip because there's one bone grows more quickly in your leg than the other so it used to poke through the skin. So, I used to have to go in and get that bone cut back even after I had my leg amputated until I stopped growing. And I thought that's great – that's the end of the operations, but then all the other trouble kicked in – all the abscesses. So it has really been continuous surgery since I had my leg amputated."

The most recently injured person interviewed was W. Thomas was shot in 2009, by Republican Action Against Drugs in a case of mistaken identity. Armed men arrived at his sister's house asking for his nephew and Thomas was visiting from London. They shot Thomas 5 times in his torso and legs. Thomas has severe abdominal and leg wounds, he also almost lost a leg. He still has shrapnel in his wounds and he has been diagnosed as having PTSD. As a single man, visiting Northern Ireland, he has had to manage both physical and mental health needs of an acute nature. He was discharged from hospital in a wheelchair with a stoma and a urinary catheter and was 8 ½ stone when he left hospital when he had been over 13 stone at the time of the shooting. He had recurring stomach infections for which he was prescribed repeated doses of antibiotics, which depleted his immune system. In the end, he contracted both MRSA and C Difficile. He is awaiting an appointment for

further surgery to insert mesh into his abdomen in order to strengthen his abdominal wall to counteract the damage done by two bullets and to repair a hernia.

SR was shot in the centre of Belfast by men on a motorbike as he was working on a market stall:

"I was 100% fit before this ever happened to me. ... Even if you walk up that road - I'm stuffed – I can't walk up that road. I'm slow now – you have to sit and rest."

Many of those injured, such as Peter Heathwood, very nearly did not survive, and narrowly escaped death.

"... I had a lot of complications – I was actually dead twice. I had infections in my lungs, emphysema and all sorts of side issues. My body weight went from 15 stone to 7 stone – my thighbone was sticking out through the skin. Anne was told twice come up because we think he'll be dead by the morning but I pulled through. The doctor told me I was a dead man walking – I remember waking up and thinking 'I'm not going to die – I am going to see my kids grow and I'm going to see my grandchildren'".

Davey Kavanagh was shot by the IRA by mistake in crossfire, lost an eye and suffered wounds to the jaw, ear, and teeth, and his sight was damaged.

"I was shot and lost an eye – a lot of other damage too in my ear, jaw, teeth, and a lot of damage. It was the IRA – they weren't shooting at me. They ambushed the army and I happened to be in the way – I was in line with the shot and they hit me, sort of skimmed me. If it had hit me, I wouldn't be here. It went past here [side of face] and damaged my eye, my jaw and ear, and my teeth – loosened a lot of my teeth and they weren't able to save them. 1975 but it's still like yesterday – the whole half an hour – because I can remember everything. I used to have flashbacks all the time but ... it's very rarely I get them now. It's when you're sleeping ... you actually get the impact and you jump. It used to be all the time but it's very rarely now. ..."

He has recurrent eye infections, and is still attending hospital after 36 years, has since developed heart problems, and is still undergoing reconstructive surgery. Of his medical treatment, Davy says:

"I've never finished – I'm still going to hospital. That time I was in the hospital about a week – but it's never finished. I've had about 13 or 14 operations, plastic surgery. ... They want to do some more work on my face...There are new procedures – improved. ... I've had loads of operations – and then you've operations and they are not successful so they have to take the stuff out – back and forth. It's been on-going. There was a break for about 6 or 7 years where I didn't attend the hospital... It's to do with this eye – they were saying 'you're getting a lot of infections and it doesn't do you any good for your heart and all this'... So, I'm expecting any time now. ... They don't want to start making an eye for me until it's all finished. It's all about the eye – if they do a wee bit of work then the eye won't fit. So, they want to get everything cleared up first

and then they'll make the eye... After 13 or 14 operations, you give up. .... The guy who started the work, he's retired now – he was a young whippersnapper when I went and now this fella [his current surgeon] is a young whippersnapper..."

In 1998, B, who was in his early thirties, was attacked by three men who accused him of attacking a member of a Loyalist paramilitary group. He was held for 12 hours, beaten unconscious and threatened with death then taken outside and shot. He woke up in hospital months later having had a heart attack on the operating table – during the amputation of one of his legs. He was in intensive care and relocated to a side ward where he contracted MRSA. He had his second leg amputated and moved on to Musgrave Park Hospital. He has not used the prostheses for years, because the limbs are heavy and a wheelchair is easier to use. Although he says he is in constant pain, "the doctors have cut all my medication down". He takes mild painkillers sedatives and anti-depressants. He has trouble in sleeping.

Paul Kinnear suffered serious gunshot wounds in Belfast in 1978.

"As the years go on other things happen and is not as simple as being left on wheelchair. Other things, complications all directly linked to being paralysed. Lot of physical complications .I had to get significant surgeries, major surgeries over the years. They were all complications linked to my initial injury. It just continued on from 78 until the present day."

AM was shot in the head 31 years ago by a plastic bullet fired by the army. She was taken to hospital by car and on her way to the hospital she was hit a second time by a live round fired by the RUC. The car window shattered and the bullet skimmed her head. She was fifteen years old at the time. She was on a life support machine and spent four weeks at the hospital:

"I remember waking up, I was in the emergency place, I couldn't talk... I couldn't remember anything. People came to see me and I didn't know who they were. I didn't know why I was there. I didn't really know what was wrong with me. I couldn't talk and had to stay in bed. I couldn't remember anything...The nurses would come down and tell me bedtime stories, because I couldn't talk or anything, you see...they wouldn't let me out of bed... I climbed out of the bed and looked in the mirror, I had no hair and a hole in my head..., I had a big steaker [black eye], and I said, 'Oh, my God, you must have been a rascal!' .. I think I cried a wee bit... then the nurse came and said that I had to stay in bed... Another time, the nurse put me in the bath and forgot about me, the water got cold... but I didn't think about getting out of the bath... I didn't think about things like normal people would... my mummy came up but I didn't really know who she was... I was in hospital for four weeks... then they let me home. Then the Brits came to our house and the RUC and all them people, and they were going to arrest me, and I was only out of the hospital and all the time I still didn't know what had happened... I couldn't talk still, I was going to that speech therapy, I was paralysed... on the right side, my handwriting was appalling and I was a good writer before... I had to go to the hospital five days a week. You wouldn't look at me and know... Anything..."

Una McGurk was injured on 15 August 1998 in the Omagh bomb planted by the Continuity IRA. She was 14 years old.

"I am still attending the Royal Hospital for the burns unit, but I'm also attending the Ulster Hospital for laser treatment to reduce the scarring. I was there 3 weeks ago and I'm going in another 4 weeks' time. The service I get — and the burns unit — it's brilliant - they are so understanding... I will always have to attend the burn unit for my face. My scar keeps growing — they cut it away and it keeps coming back. I'll need work done on my skin grafts at a later time."

Her injuries continue to impact on Una's health. Although in 1996 she tested negative for celiac disease, she tested positive after the bombing, and has been told this is a direct result of that trauma. She has also developed thyroid problems.

#### She reflects:

"I didn't think 13 years ago that I would still be going to the hospital and I would still be having to have treatment. ... I do seem to have quite a stressful life but I am determined that I will get my Master's finished, like I did with my degree. ... But if I had known then what I know now – to take a bit more time to recover – not to push myself so hard. ... It's had an impact on my health."

Angela Mercea was injured in a bomb explosion during a bank holiday, Monday 14th July 1986, while she was working in a fish shop in Castlewellan:

"I was blown right back to the back of the building... After the explosion, I don't remember anything until I woke up in an army barracks. I probably was there for a minute or two and there was a soldier talking to me. I thought I was lucky and didn't think I was injured. Mum called the local GP. He looked at my ear and he said it was just a wee a graze and that probably was going to ring in my ears for a few days. He gave a few Valium. I didn't even go to casualty... After that, I notice that this ringing in my ears was not going away. People sounded distant. I felt embarrassed about it. Went back to my GP and he said to give it a few months and it would probably stop it. Reno didn't want to live in Ireland after that so we went back to Malta, Reno's country. I didn't go to the GP. I was getting more embarrassed about it, trying to hide it. I was in Malta 18 months than came back to London and just carried on like that. I was embarrassed about the fact that I was in my 20s and couldn't hear people clearly. It took a long time for me to go and say to a doctor and say 'Look, there's something wrong here!" When I did, the doctors in London didn't seem to know how to deal with me. I wasn't never even referred to audiology or anything."

Angela suffered significant disabling hearing loss, causing her to lose confidence in her ability to communicate and to become increasingly socially isolated and her condition went untreated. Recently she has had a cochlear implant surgically inserted and this has significantly improved her hearing.

A second interviewee, a male from Cookstown, also sustained hearing loss as a result of a bomb blast, which affected his ability to interact socially, and led to depression:

"When I go to bed and take my hearing aids out I go into a big lonely world. And toss and I turn and I toss and I turn. If I'm lucky, I get three, four quality sleeps... I am not taking anything away from the Police, Army, and UDR. But when those people put on a uniform there was a risk. I only went out of own gate... I feel I am one of the forgotten injured people of the troubles. I feel sad about that and when I look at the future with this tinnitus... I don't feel that there is a future."

Action on Hearing Loss, formerly RNID and report that significant numbers of the people seek their services in Northern Ireland have sustained hearing loss in similar circumstances. This is supported by the reanalysis of the data from the NISALD survey presented in Section 8 of this report...

### <u>Limb loss</u>

Within the population of injured people, there are significant numbers of people who lost limbs, particularly lower limbs in the IRA bombing campaign of the 1970s and 1980s. Traumatic limb loss raises particular issues for those who sustain such injuries, only one of which can be the need for ongoing surgery and recurring infections.

Jennifer McNern lost both legs in the IRA bombing of the Abercorn in Belfast in 1972 and wore prostheses until relatively recently. She explains why she now uses a wheelchair.

"Much later I got new state-of-the-art prostheses by way of the Memorial Fund. But they were so sophisticated I couldn't use them, too much time had passed, and I was much older. [I was now in my early fifties]. One day I was going out to the car and I fell. It was a terrible fall. After that, I decided I didn't want to use them. I preferred a wheelchair."

The needs of those with lower limb loss can vary for a number of reasons as Dr Roger Parke, a specialist in prostheses, explains that although some people who have lost limbs may want the latest technology, it is not necessarily the best option. Others may prefer not to wear prostheses at all and use a wheelchair.

Roland Pollock lost both his legs and arm function in an under-car bomb planted by the IRA in 1981. Although he has used the limbs for "about 8 years", he now feels much more comfortable in a wheelchair, and explains:

"this way I can wheel myself into the toilet, out of the toilet – up to the bed – more convenient. But if I go out ... I have to think 'will things be suitable for me?' And without the legs if there is not suitable accommodation you have to try ... but without the legs, I'm all right. Without the legs on I have to think 'how am I going to get them on again?'"

His wife and carer, Georgina explains further:

"And he needs a crutch and a stick to walk. ... So, what can he do when his two hands are tied up? So he's better in the chair."

So although prostheses may allow the person to 'look whole' as Jennifer McNern put it, they may not always be practical. Martine Madden explained the difficulty of getting up in the night to attend to her daughter and having to strap on her prostheses:

"she knew if she wanted a drink she had to go and get my limb when she was 2 years old for to give me my leg, put it on, for her Mummy to get her a drink."

For Martine, however, managing the stairs in her home meant that the prosthesis was her only option.

### Adjusting to the injured body and loss of capacity

Paul Kinnear who sustained suffered serious gunshot wounds in 1978 explained:

"The first thing when I was told that I was never going to walk again. It was the first Shock; and then having to deal with rehabilitation and learning to adapt to a life in a wheelchair. That was the first major thing you had to overcome. Thankfully, I was quite lucky that I had a strong family behind me, which helped at the time. Great parents! Possibly, it took well over a year before you come to terms that life is changed forever. It's changed completely."

Una McGurk, who suffered case injuries the Omagh bomb, describes her experience:

"I am scarred on the left side of my face, I broke my right leg, some fingers on my right hand, and I also have nerve damage to my left upper arm. I'm left handed so I can't lift a full kettle of water. I also have a lot of scarring down the left side of my body. There's not one limb that doesn't have any injuries on it. The scar I have on my face — it was very, very close to severing the jugular in my neck. I had to have my ear sewn back on and also one of my fingers sewn back on. I broke my leg but I also have skin grafts where the bone came through. At the time, there was talk about my losing my leg. They thought I'd lost my lips because the hair came round my face and was all matted."

Brendan Curran was shot by the British Army in 1989 in Lurgan. As result, he has a punctured lung, very limited use in the left hand and no use of left arm. He still has problems with a shoulder, one lung and eyesight difficulties:

"There's things I can do. You can't button a shirt, or tie shoelaces - even going through some doors. People sometimes don't realize that you would need help in these situations. These things are annoying because they remind you that you are not complete."

W fought to maximise his physical capacities:

"They said I would never walk. Eventually I got out of the wheelchair and walked. I fell 3 times but I walked. ... They said my left leg was dead – it was pointless even working with it. I just done my exercises every day – I had nothing else to do – I was lying in bed and couldn't move so I'd wiggle my toes – so simple things to get the tendons and the nerves back working again. My physio gave me tips ... It's still is painful walking – it's not as painful as it was but it's still is painful now. It can be dull and it can be really sharp to the point where I have to lie down."

He explains the background to his battle to walk:

"I was actually quite a fit bloke – that's what actually saved my life the doctors said, 'you should have been dead – because you're fit, it saved your life'. ... I worked out a lot for years. I can't train anymore and I loved to do that. I've tried – I've been back to the gym.... I've a lot of pain in my hips so training's out the window now.

As a single man, W faced the challenge of forming sexual relationships, a challenge that he has overcome, he is now in a relationship; but his injuries have affected his ability to engage in sexual activity.

"Making love that's a no-no. [He is now in a relationship.] I'm surprised she's still here."

This may well also be an issue for other interviewees who were unable to openly discuss their intimate lives as Thomas did.

Although Davey Kavanagh lost an eye and had other injuries and is dealing with complex and serious physical health problems, he considers the emotional difficulties are the worst.

"It used to be my looks. When you're about 30, you get depressed about the way you look. When you get the older it's a different type of depression — what might have been — things might have turned out better for you.

Several interviewees reflected in interviews about a kind of grieving for the life they might have had were it not for their injuries. Reflecting sadly on the loss or restriction of career, relationships, leisure pursuits, and ability to take up other opportunities is a process which several injured people reported they were engaged in, particularly as they grow older. But Davy Kavanagh balances this, with the realisation that however bad it is; there is always someone worse off:

"Of course, it might have turned out worse! And you see people a million times worse than you do. .. I go to hospital and see people and go, 'don't you complain!"

#### **Deteriorating health and weight issues**

Nor is the condition of injured people static. As time passes, the ageingprocess also affects the health and level of disability of the injured person.

KE lost both legs in a bomb in 1972 when he was 18. He has had continued problems with his two stumps.

"The future? I just would like to know as my condition deteriorates - it is deteriorating I know, I'm trying to manage it. So I try to keep myself healthy, 'cause if you put weight on then you limbs need adjusted and then you are up and down ... it's a constant battle you know to manage your condition."

P G is paralysed from the chest down, after his family was taken hostage in 1994 at their home by the UFF, who shot PG as they left. PG worries about his health prospects:

"Just basically deteriorating health: putting weight on over the years and not getting exercise. That worries me."

A recurring issue in the interviews with injured people are the often-linked problems of mobility and weight gain. And such weight gain, inability to exercise, continual medication, and stress often mean that other complicating conditions develop and are exacerbated. Davey Kavanagh developed heart failure:

"I had....They explained to me heart failure doesn't get any better whereas if you've a heart attack you can improve yourself by changing your lifestyle – but heart failure [means that] your heart's damaged. ... Every time I go they tell me off because I've put weight on – I've put about 5 stone on and they're on at me all the time 'you're going to have to lose weight'. There again there doesn't seem to be a big lot of help. ... I would need somebody to talk to me."

None of the interviewees mentioned were offered the services of a dietician or psychological support in order to address these concerns.

## <u>Traumatic memory and mental health issues</u>

Many of the interviewees reported experiencing emotional problems, sleep disturbance, depression and other mental health issues. Davy faced emotional challenges following his injury:

"There was a time when I was very, very depressed for about 5 or 6 years. Initially I was glad to be alive – the first month you were just so glad to be alive. And then you look in the mirror – I've had a lot of work done – it was really, really bad..."

One male interviewee from Derry was shot by the IRA in a mistaken identity attack when he was driving his car in 1984. He lost a lung and has urethral problems:

"You say, Jesus Christ, what's it all about? I was an innocent bystander – passing by – driving the car ... driving home ... and was shot for nothing. I'm going 50 now and I'm even surprised ... I've lasted this long. ... I am just a nervous wreck, on 3 different types of tablets, 2 or 3 times a day – they're high dosage – a bucket of tablets a day, for my nerves. I tried to get off them a few times. ... I was suicidal for a start, and bouts of crying ... and anxiety. I was very, very touchy, had nightmares, sleepwalked - used to do a lot of sleep walking, not so much now. I'd be found 3 or 4 streets away with just my boxer shorts. I didn't know where I was when I woke up – How did I get here? And getting up and kicking walls ... in my sleep. I woke up one morning, I was just married 2 years and I had a fractured ankle – I must have been kicking the wall all night. ... I have problems getting to sleep. I'm on diazepam."

Following the gun attack on him, W has nightmares and cannot sleep. He was so fearful it took him a year to go to his own bed – he'd sleep on the sofa. He has been diagnosed with Post Traumatic Stress Disorder. However, accessing mental health services has proved to be impossible and he gets no help other than private counselling:

"Psychiatrists won't take me on because there's a legal battle going on about my claim. They say they can't take me on until this claim is settled...This is the third year and the claim is not yet settled."

A former RUC officer who lost the use of one arm following a gun attack reported:

"In the early days I stuttered very badly. ... When I get anxious or nervous I will stutter... When I was being discharged from the police, they did send me to a psychologist. ... And when I was doing my compensation claim, they sent me to a lot of doctors and one of them was a psychiatrist... there were so many issues I tried to get out... I don't know if it helped because when I came back from [treatment] I think I was a little bit worse."

Paul Kinnear described how he copes with continuous medical treatment that he requires:

"I don't focus on it. I look at it as related to my injury and I have to accept this because if I dwell on it, I will send myself crazy. So, when they tell me you need an operation, I say OK. It's just the way I have to deal with it. I wish it would have been as simple as being paralysed, the rest of your life in a wheelchair which obviously you have to adapt to "quickly". But these other things could drive you insane, if you would focus on them. I just accepted it, it is part of my condition, and I have to accept it."

KE described his own struggles with emotional health:

"I also got counselling after that, not through WAVE ... And it was about forgiveness and letting go ... but these things need to be worked through. My issue probably was in some way ... with having lost the legs and I wondered if my marriage failed because of that even though I was sharp, and I would cook and clean and go to work. I thought I was quite the modern man. So that would have angered me, so I had a number of issues that I needed to talk through and the benefit of counselling for me is real. It's

like going to the gym. It's like a fitness suite. If you want to learn a skill you need to coached through it and there are life management skills and how to cope with some sort of crisis, I believe that is important."

PG places his traumatic experience in the context of his family's experience.

"... For [the family] it was a big thing too, so they were going through some trauma too because they were all in the room at the time I was shot. I was lying unconscious but they had to watch me bleeding, so it was far worse. I think that probably hit them more than me to actually see it, witness it - while I was oblivious to a lot of it. They didn't really get any help."

#### Alcohol use and abuse

Significant numbers of injured people use alcohol to manage anger, fear and a cocktail of other difficult emotions. They turned to drink as a solution, often with problematic consequences.

The male shot by plastic bullet feels that his faith and his mother helped him got through his experience. He lives alone, and admits to taking to alcohol for several years, perhaps as self-medication. However, he now only drinks once a week, and on other days goes to Mass every morning, and this helps to structure his day.

KE, too, realised that the use of alcohol might be problematic:

"But I do remember at one point where I was abstaining from alcohol a bit and a boy said to me, you know, you are an awful nice person - much nicer person without the alcohol. Maybe somebody didn't want to tell me that when I was going mad and taking too much drink and I think that's another side of it too... I went through a bad period over that divorce where I drank way beyond what I should have done and really did put myself in danger of health issues and whatever else. I got counselling then..."

One family described their experience after the husband was injured in 1976 and fragments of the bullets remain lodged his spine. His wife said:

"We used to go out as family all the time. Saturdays we would go to Dungannon. But then it stopped. I tried to get on with my life, and then as he started feeling better he started going to pub and that was not a good idea because he couldn't handle it ... there was no talking to him. That went on for a long time. It was awful, horrendous. That was his way of dealing with it. He would be home, and would be angry. Everybody was to blame. ... It was us who were the baddies. The children were very upset. It wasn't easy but we struggled on. This is what the drinking was about: trying to forget. But it just made it worse."

Their daughter felt the trauma has caused him to binge drink.

"Daddy wouldn't have drunk that much until he was shot. I never remember Daddy coming home drunk."

#### **Ageing**

As injured people get older, they face the challenge of ageing and its complicating effect on their physical condition. At the age of 22, alongside her sister Jennifer McNern, Rosaleen Murrin, lost both legs and an arm as a result of the 1972 Abercorn bomb in Belfast, and she has impaired vision in one eye:

"I think I've coped very well but it will be harder as I get older. I think I'll be lonelier. We were very young when it happened and then a lot of people would just get on with things, which is what we did. But I think as time goes on it will be harder."

Martine Madden also notices changes due to wear and tear and the demands placed on her body by her injury becoming more problematic as she ages:

"And when I was younger I didn't have the worry – you could fly about on crutches but as you get older your body is just not the same and you can't fly about on crutches. And even going about on my hands and knees, I've damaged my good knee and it's not so easy to crawl about the house on your hands and knees. ... They done X-rays on my wrists and that, and he says, 'they are quite a lot of years older than they should be, Martine, but that is expected because of your crutches and stuff like that.'

Martine cares for her daughter, Jessica, who has a learning disability and is in a wheelchair:

"but I still get older and Jessica's needs are never going to go away, either..."

Martine's husband provides her with assistance, but she worries about what will happened when he, ages.

"And you say 'how are you going to cope?' You know my husband is not always going to be helping me into baths or showers."

Injured people reported significant difficulties in getting help from outside the family.

## **Difficulty in accessing help**

Interviewees often reported difficulty in getting the help they needed, not knowing what was available or where to get it, or in some cases having needs that services did not cater for. A Belfast woman now in her 60s was injured in a no-warning bomb attack by the IRA in 1971. She described the hidden problems of people like herself in accessing help.

"People should be aware of the long terms implications and acknowledge the widespread trauma that there is in the province. It is hard enough for those of us who were injured in the first line to get the help we need..."

Although he was born and raised in Northern Ireland, prior to his injury, W had been living in London. After he was discharged from hospital he lived with his sister who looked after him, but after her illness six months later, he moved into an unfurnished flat on his own. He did not know where to go for help and support, and got no help from organisations or government, "so I just got on with it". He wants to go back to London and "loads and loads of friends there. I've no friends here."

#### **Accessing Services**

Although the physical health needs of the injured are met by the statutory sector, voluntary organisations are increasingly being asked to shoulder responsibility for other needs. Complementary therapies, benefits advice and social contact and activities, respite and other services are provided by many voluntary support groups throughout Northern Ireland. Annette Creelman spoke of the inherent problems in this approach, as she has experienced them as Welfare Advisor in WAVE.

"The statutory agencies are transferring people to us for counselling and support. They have no money. It's hard even to get OT (Occupational Therapist) assessment sometimes, for people because of the waiting lists. To me the NHS is pretty much on their knees as it is. Expecting people to be transferred over and that everything is going to be dandy is not living in the real world. The mental health service is terrible. I don't think you can really say it's going to be a good transition over."

The resourcing necessary to meet the needs of the injured is therefore in need of critical review. Jennifer McNern sees shortcomings in the way services are organised and needs met:

Service delivery is not joined up – and needs to be. It is crucial that the long-term effects ... are recognized by service providers. These may be physical due to ageing and exacerbated post-injury pain or psychological – and may be related to the change from conflict to a peace process that fails to recognize the injured or acknowledge that they and their families have lasting needs that are not met."

KE described how he managed to get help for his psychological difficulties after failing to do so through the usual channels:

"I was actually in hospital because I was very sick and I said, "I'm not coming out". My sister, who is a nurse, said to me that they have to have a care plan agreed. Don't come out. I said I can't get any assistance, psychiatric or whatever" "Just tell them you are not coming out" (sister said), so I got speaking to a psychiatrist in the hospital."

MK pointed not only to the difficulty in accessing services, but also of injured people's awareness of what is available:

"... I think that's failed to be delivered over time. Now if I chose to access those services they would have been available and funded through OFMDFM and the Peace money

that came through Europe so you can't say it hasn't been happening. It's whether people are aware that this is available to them."

A Belfast woman now in her 60s lost a leg in a no warning bomb on the Ormeau Road in Belfast in 1971 described her experience of services in the early days:

"My father was from England, from Manchester. We had never been involved in any sides. He was a very reserved English man. He went out in the Castlereagh Road looking for a farmer to get a barrel that I could use to shower. Because we had 10 minutes with a social worker who said, "I don't think you need anything" and went away. So we had to look for things ourselves."

#### **Identity and identity management**

Those who were injured in the Troubles face an additional challenge in terms of how they account for their injuries to strangers, or in social situations in a divided society. This was particularly apparent when the violence was ongoing, but has by no means disappeared as an issue. Civilians have less of a problem explaining openly how they were injured, in contrast to those with a security forces background. A former RUC officer explained:

"The only people I ever told I was shot were people I knew who were security. ... People I didn't know — 'car accident'. Isn't it terrible that we taught our children to lie because if people asked what does your Daddy do? He's a postman. ... You didn't tell people that you were in the police. ... It's a combination of both — the fact that it's so ingrained ... in the police ... it leaves its footprint inside of you. I don't go into detail ... because it all comes back again and you have to get over it. My wife notices it. My children notice it. My mood changes apparently."

A disabled police officer shot by the IRA in 1972, who lost one leg and wears a calliper, described how he managed his identity:

"It's got a serious side to it and a humorous side to it ... it's either you must have been knee-capped or you're a member of the security forces or you've done something wrong. The easy way out of that is just to say 'I'd a car accident — I was drunk and I wrote the car off'. And usually people feel a right fool and they don't want to talk anymore."

Brendan Curran was shot by the British Army in 1989. He still has problems with a shoulder, one lung and eyesight difficulties.

"I wouldn't usually tell people that I was shot. It surprises me that some people don't realize it immediately. If I look at a picture, to me that's the first thing I notice. If people mentioned to me, I'd say I had an accident, I would brush it off. If they press me on it, I just say that I was shot. I suppose you can be very conscious about it, I believe that I am more conscious about it than people who are with me."

After Rosaleen Murrin lost both legs and an arm in the 1972 Abercorn bomb, the family moved to England. For her telling strangers what had happened to her was not an option.

"We moved to England as Brendan (husband) was already working there. Well the move was horrific ... a completely new place, new people. I made some lovely friends and we are still friends – but it was horrific.... Most people there would assume you had a car accident. Most times I would just say, especially to a stranger, that I had an accident. It was probably difficult to explain. You were in a different country and they had no real understanding, not through their own fault, of what was going on. They just assumed that most people who were injured in the Troubles were people who were instigating the troubles. So it was a lot of explaining of years of history."

The stigma of being injured and suspicion of being labelled inaccurately has made Davey Kavanagh reluctant to talk about the cause of his injury.

"Sometimes you started saying you had a car accident because you didn't have to go telling people... That was during the '70s and '80s for work – you had to be a bit streetwise. And then sometimes you said 'I had a car accident' ... and the people would come back to you and say 'but I heard you were shot'. Somebody else had said. I thought maybe you should just tell the truth. I tell you it was a worrying time – people getting shot at work. I never liked that business where people sort of branded you as a terrorist - because you got shot, and I'm a victim."

For PG managing his identity as an injured person disabled in the Troubles was more of a problem for friends and family than for him.

"It's one of those questions which is hard to answer. Some of the friends didn't cope as well. They just couldn't look at you in the wheelchair. They felt bad about themselves for whatever reason, but others just got on it with it, maybe they were just a bit more mature."

W does not wish others to sensationalise his injuries and gets irritated when people mawkishly ask 'what was it like getting shot?' And he is conscious of the 'no smoke without fire' type of conclusions that people jump to when they know he was shot:

"Getting shot is not a celebrity status but these people ... and they say you must be shot for something – that's another reason I don't tell anybody. They label you right away – what did you do? If I was in London, I'd get my trust back right away. I don't trust the people in this town."

Una McGurk, too, says she prefers to keep a low profile, and is resistant to being labelled.

"I don't like being tarred 'a victim'. ... The reason I don't go to those groups is because I'm still alive. My perception is that some of those who have been bereaved feel that their loss is more important. Nobody's ever said that to me but that's the perception I get. ... People who have lost a relative feel that their loss is more important and that

their voice is more important and that their voice should be heard more. Bereavement is terrible but every day I look in the mirror I have a constant reminder and every time my parents look at me they have a constant reminder."

Another male interviewee who lost a leg in an under-car car bomb in 1981 is self-conscious about his appearance and lack of mobility, so he does participate in social events on offer to him. He can't walk far so would need a wheelchair but is resistant to using one so doesn't socialise much. In terms of his identity, he explained: "I wouldn't like to think myself as disabled — I'm registered as disabled but I don't want to be seen as disabled." In order to explain his limb loss, he puts it down to "a car accident — I lost my leg".

Michael Patterson, who lost both his arms in a rocket attack on his land rover when he was serving in the RUC, attracts attention and stares, which he has had to learn to deal with:

"I remember the week after I got out of hospital, I hadn't got my set of artificial arms at this point and a few colleagues from the police station... were assigned to me to take me to appointments and we stopped at this video shop and I was walking across the road to pick a video. Now you can imagine this, I didn't have artificial arms so the sleeves of my jacket were dangling, just flopping about. I was in a cast brace so I was hopping across the road. People were standing at a bus stop staring. I thought, 'what are they staring at?' I was turning round to see what they were staring at, then I realised it was me; I must have looked an unusual sight going across the road. So at that point I realised people are going to stare, I now look a bit different, and then I have the hook on this side, the plastic hand on that side ... people will stare, that's OK as long as they aren't over the top. Kids are fine, adults will have a sneaky look ... some people if they are quite rude about it, I'll be pleasant enough but be assertive and say, just back off."

For a complex of reasons, presenting their injured selves to others is a challenge for people injured in the Troubles and entails emotional work and effort. The wider society is experienced as not a safe or sympathetic place in which to reveal what has truly happened and so that wider society may often be oblivious to the legacy of suffering in its midst. It is as if injured people shield the rest of us from the worst consequences of our political pasts. As a result, they may carry their burdens alone, unsupported, and in the worst cases where they reveal the cause of their injuries, blamed, suspected and shunned.

## **Truth, Justice and Acknowledgement**

Acknowledgement of the suffering of those who were injured and that of their families in 'post-conflict' Northern Ireland is part of the broader debate about acknowledgement, recognition, truth recovery and dealing with the consequences of the past. Some of those who suffered in past violence have been voicing feelings of pushed to one side. Jennifer McNern considers that victims and survivors are not getting the political support they merit.

"Many victims and survivors feel justifiably ignored or that they have been side-lined in the peace process. The post-1998 events such as early release of prisoners were not matched by the emergence of services for the injured and their families. Expectations of the Memorial Fund, set up after the (very welcome) Bloomfield report, were high and have not been met."

Some of the injured and their carers feel there is no justice when the perpetrators have not been convicted for their crimes. Peter Heathwood has tried and failed to have his case reexamined by the Historical Enquiries Team, who will not do so because they only look at cases where someone was killed, and Peter survived. The death of his father at the scene of the shooting, on seeing Peter, his son being carried out in a body bag (they could not get the gurney into the room) does not count in those terms. Peter continues to feel that justice is denied.

Brendan Curran, a republican who was shot by the British Army in 1989, is less focussed on these issues:

"My attitude and belief is that at that stage there wasn't a police RUC but a quasimilitary force operating here. There was a war going on. I didn't expect anything different. I was on the other side of the war."

Others achieve some kind of solace from their religious faith. For Florence Stewart, whose husband Jim was seriously injured in the Abercorn bomb in 1972, justice is a matter for her maker and not a matter of earthly retribution:

"No, nobody was ever found. We just never think about it. They will stand before the Lord to be judged if they don't repent for what they have done. That's the way we leave it"

There is a continuum of views of fair treatment and opinions about what 'justice' means. Asked her views on 'justice' the former part-time police officer said:

"In the bigger picture I couldn't give a toss about justice because there've been so many injustices in my experience that I find it hard to get my head around all of those. ... They [who shot her] were charged with the attempted murder of two police officers and the charges were reduced to attempted murder of one police officer and the wilful wounding of his wife. That cut me up very badly because I was being demoted."

For her, as a woman, she was not treated in the same way as other injured officers, and the justice system was prepared to plea bargain away her prospect of justice.

After the police officer who lost one leg was shot, his mother took a heart attack at his hospital bed and died. He spoke about his thoughts on justice:

"I still want to meet the person who pulled the trigger and I'm convinced I know him. ... There's not a day that goes by in life that I don't think of that person. ... And the following day when my Mum dropped dead beside my bed, did he think, 'I've gone too far here – I didn't mean an innocent person to suffer?' I was a legitimate target in his

eyes but ... did he think, 'here's a family left without a Mum?' Or did he think 'that's even better – I went out to get 2 cops and I got 3 people'. I want to sit eye to eye and talk with him. I understand that mightn't happen because he might implicate himself. ... I'm not sitting seething with anger that I want to strangle him or see him put in jail... Time moves on."

SR who was shot whilst working on a market stall said:

"They never caught them and my clothes are still at the cop shop... I wouldn't trust any Protestant at all now. I used to work alongside Protestants and they were dead on. See now, it's made me very bitter ... but you can't take it out on all Protestants... I don't think the cops ever tried to get them to tell you the truth. It's not just for me. They have got away with murder. I just take it day by day — I don't think about the future at all."

He suspects collusion and would like to see the perpetrators brought to book and would cooperate with the HET if his case was to be re-opened. He has never joined a victim's group. "I'm a very shy person. I wouldn't want to mix." He does not see himself as a victim.

Another Catholic male who was shot in a pub spoke about his attitude to justice:

"I'm not really angry at the boys themselves – the bastards that shot me. And they're still walking about today – I know they are. Everybody – the dogs in the street know who they are – the police know who they are. ... They were from the UVF. ... "Some of them [are still walking about] but some of them got gaol for it – four of them." [There was a trial] "I got a letter from the doctor to say I wouldn't go. ... I had to go to the trial because they subpoenaed me. ... These people only live 2, 3, 4 miles away – at the furthest point away. I had to go to court in Belfast and all those people were there – all their families. I was in full view of them. I asked them – the police officer 'how can I give evidence against them when they're sitting there?' I went to court and they pulled out this brown envelope with these photographs – I didn't want to say. I went out – just as I went out, they pleaded guilty.

He did not have to testify after the guilty plea but noted that today a witness would had their identity protected unlike his experience:

"still and all we were left sitting in the public gallery – and all the UVF men and their families sitting there. ... I didn't want to go but they made me go – they subpoenaed me."

He feels the perpetrators are more leniently treated than was appropriate, and that the police were insensitive to the threats to him from his local community. "And it's still going on today – you can see it yourself."

The Historical Enquiries Team have taken up his case:

"Yes, it's on-going. ... I'd rather they'd just let it die. They started this peace, which is a great job — but it's stirring the whole thing up. Why didn't they come and say to the people [injured] 'look here's a few pounds to make yourself comfortable in your old age' instead of spending millions of pounds [on inquiries]. Some poor old person sitting in the house struggling to get a bit of heat and a wee bite to eat — would that not have been more sensible? ... I got £2,200 compensation. For the time I was on the sick they took the sick money off me, which amounted to — I think it was £1,200."

The Omagh bomb has been the subject of a protracted campaign for justice. Una McGurk has her own views about this:

"It's not about the injured. It's all about the bereaved. I've never been to the court and don't read about it because again it gives them the light of day. ... I know what happened on the day. I don't need some judge or barrister to tell me what happened. ... I think if I did go back into court it would have a really negative impact on my life and bring me back to scratch again".

The issue of acknowledging the position of victims in the peace process is also an issue for many of those interviewed. Annette Creelman, the welfare worker for WAVE, commented on the change in the political environment and how it is related to victims' prospects for acknowledgement and acceptance:

"I think that the political climate is changing. I think that there is less sympathy for victims. And that's a problem... The sympathy in Northern Ireland has drastically moved on very quickly. I think it's going to be a problem with funding and sustaining the help that is going to be needed, because people are going to say 'why has that person moved on and this one hasn't?' The way that people tried to get over it is very different. I don't know if that is going to be factored in detrimentally to those who didn't rehabilitate as much as others."

A Belfast woman now in her 60s echoes the sentiments of many of those injured in the early years:

"Obviously I would like people to be aware of specific problems of those who have been injured and particularly those who have been injured in the early days. We've been a little overlooked. I was never invited to do anything. Some years ago, they were putting up a plaque about the Bloody Friday people in the Belfast City Hall. For some reasons I was invited. They unveiled the plaque and it said "for all those who were injured in Bloody Friday and since". Now Bloody Friday happened in 1972. Somebody turned to me and said. 'what are you doing here B...? You were before that!" So there's no awareness of those of us who got very little compensation and who have struggled on and maybe have particular needs at this stage of their lives."

KE, like many other injured people, wants recognition for injured people:

"A real understanding of the size of the problem from a number perspectives, the complexity of the issues in and around it, that solutions can be addressed, if they are honest as an Assembly, to look at their opportunity to govern Northern Ireland as a

transition from conflict to the ultimate objective of a shared future. I want to share my future but I want to know that I am sharing it and I am not a second-class citizen. I want to be a real part on it and want my kids to have a meaningful part of that too."

PG's injuries were inflicted in 1994, just before the first cease-fires. Like many others injured in the Troubles, the peace process was a very difficult time for him.

"When the peace process came to be known, with the IRA ceasefire that was a hard day for me - because I'm from West Belfast you are sitting looking out. I'm only out of hospital say 3 months. You do want the war to be over but people are running about and celebrating and all. I sort of felt bitter sweet about it. Why did that not happen a year ago? Do you know what I mean? That's how I felt about it. People were out celebrating but the likes of myself are still with wounds, the bandages are still on. It was a really bad time for me, I think. Over the years, you were just looking at the peace and you just wouldn't want anybody else getting killed. Or to go through what I went through, me and my family. There needs to be a bit more (acknowledgment to the needs and experiences of those who were injured)."

For a male interviewee in Cookstown, the time was very poignant: "I feel I was totally forgotten."

For Paul Kinnear and other injured people, the issue of acknowledgement is tied up with services and financial support, and he recognises that all victims need to be considered.

"Sometimes I feel that the financial side pales into the insignificance that we have, because it is terrible that a person has been bereaved. At the same time, this is what I said at a meeting a few years ago: nothing can take away the hurt of somebody who has been bereaved, but could you please also include the injured when you are speaking? Please just mention them, because there are so many. You should keep mentioning the bereaved, as they live with that hurt day in and day out, but so do the injured. I know that I'm lucky and I hate to say about money 'cause I'm not money oriented, I'd be happy with 10 pounds in my pocket or with nothing on my pocket. But to have a recognition that there's still injured out there living with the day to day. It would be so nice to hear that now and again. There's still people living out there with terrific injuries far worse than mine. It still would be nice to hear that mentioned. So the financial side does pale into that."

Paul also addressed the thorny issue of forgiveness:

"Nobody was ever convicted and after this length of time I have accepted that it was part of the "so called troubles". I don't see what good it would do me. I moved on. I know it's not up to me to forgive but I forgive because it would have only driven me down to have bitterness and hatred. I just want to live and enjoy life as much as I can. I've just put it to bed, I am happy that I forgave what happen to me. Nobody was caught. After 33 years, I'm not interested in that side anymore. I know it would be important for some people and I would never argue against that. We are all different."

Although some seek 'justice' many are practical about its limitations, particularly when pursuing the investigations of the PSNI Historical Enquiries Team. As Peter Heathwood commented, "It won't give me back my legs".

### **Impact on family**

The impact of the injury and the event which caused the injury, on the injured persons' wider family circle was raised by many of the interviewees. W described how his family in Derry have been divided by the trauma, blaming one another for what happened, when clearly the responsibility lies with the person who pulled the trigger. However, since his nephew was the intended target, they argue about their failure to prevent the attack on Thomas. He doesn't want them to fight but understands they do feel very guilty. He works with his counsellor on these family issues but is anxious to put it behind him.

Martine Madden describes how her oldest daughter acted as her carer and the other impacts on her family.

"You become a disabled family. It's not just me that is disabled. My whole family have been affected too. ...Things like people saying things to them in school, like 'your Mummy has only one leg'. Kids can be cruel. So it just doesn't affect me – it affects them and it actually hurts me more when it affects them than when it affects me because they can't help what happened to their Mummy and they are my children."

SR separated and then divorced. SR has never remarried.

"My daughter ... was a baby when I went into jail and I was on remand for a year. When I came out, I saw her once. Her mother took her out and I said I'll see her again and she said 'no'. I never saw - never spoke to my daughter for 30-odd years. I never see her. [He has a daughter of 33.] My sister brings her — I see her every Friday and then I take her home... Now I go to my sister's for food and all, and I come over here about 8 o'clock. I like sitting on my own — like being on my own. I used to love mixing with people — now I can't do that at all. If I go out, I'd sit facing the door. I'd be scared — I'd sit watching the door and I'm watching every person — the door opens and I imagine and I jump. ... If I am sitting in company, I wouldn't talk. This is the first time I ever spoke to anybody [about the injury and its impact]. If I hear a motorbike in the distance, I look to see where it is coming from and I try and get out of the way. I'm shaking, sweating and my heart's going like a train... If I see a motorbike behind me when I'm driving I have to pull in. Asked if he would take help now SR says, "no, I really wouldn't be interested."

B, who lost both legs in a so-called punishment shooting, described how his family fell apart: "My ex-wife got me threw out of [Town]." According to B, her behaviour caused UVF to expel the entire family. B's younger son "he was 10 or 11" saw him being abducted. "He followed on his bike and got lost so he couldn't find me." This son is currently serving a 10-year prison sentence for robbery. B does not often visit, as he doesn't have a car. His marriage finally failed and B left, with his daughter, E whom he raised. His ex-wife was addicted to prescription drugs and E then started to take prescription drugs. B was an

absent parent much of the time. E fell pregnant and was forced to move back with her father but was taking drugs so Social Services got involved. Eventually after his grandchild was born, B took responsibility for the care of the grandchild four days a week. The remainder of the time, the child is in care. The Housing executive has adapted his kitchen so he can cook his meals. He can use the upstairs bathroom, both in the lift and using the stairs.

"There's days I would be down, depressed, but I just have to get on with it, I have a grandchild to look after. I am in constant pain... the doctors have cut all my medication down... I have been trying to get off certain tablets; I have got off two types of tablet. But I am taking the main ones for the phantom pain in my legs. That's all I take. And I take two wee anti-depressants and three other tablets to calm me down at night. I don't really sleep, I lie and watch TV, and I sleep maybe for an hour or so... I just keep thinking about what happened to me and all... The Memorial Fund have been good to me — with a new washing machine and fridge-freezer. I got a cheque from The Memorial Fund today that'll help me with Christmas. I go to WAVE all the time — I like WAVE."

Being there, he feels less isolated since he is not the only amputee.

At times, the injured person can feel enormous pressure knowing the demands and sacrifices that their families have had to make. For example, Una McGurk, who was injured in the Omagh bomb in 1998, at the age of 14 says she feels her family lost out a great deal and were neglected.

"I was treated very well, but I think they forgot about my family. I have 2 brothers and a sister – they missed out so much in their life. My 2 brothers got a trip away to Downing Street but it was because I said I wouldn't go. I know it had an impact on everybody's life but it had a massive impact on Mummy's life. Mummy was off work for a long time and her whole life now is mental health, trauma and her whole focus has changed in her life. She's even changed career path. For the whole ten weeks, I was in hospital my parents would come up. Every day Mummy would drop the kids at school and be up for 10.30 in the morning, left at 2 or 3 o'clock – the child minder lifted them so she was home at 5 for them. My Dad finished work at 6, went home to get a bite to eat and up the road to Belfast, stayed the night with me in the hospital – they gave him ... a relative's room. He then got up at 6 in the morning and drove back down the road to Omagh and went to work. For 10 weeks, they had enough of it. Even now, I do get support from the Northern Ireland Memorial Fund who are giving me the money towards my fees. ... If I had died, my brothers and sisters would probably be entitled to far more. And even my parents, because I survived, wouldn't be entitled to as much. My family have made such sacrifices for me and that's the difficulty ... although they weren't physically injured, their life has been shaped by what happened - and the trauma they suffered seeing me in the hospital after the bomb. Things like that aren't really accounted for."

The Protestant woman from Belfast who lost a leg in a no warning bomb on the Ormeau Road described how she has relied on family support and a changing circle of friends in the past 40 years.

"Well, the family coped very well. I must say it was mostly my mother and father. They were magnificent, given the situation. They have always had Catholic friends and family. My mother had always been involved in organizations like the Towns Women's Guild. It's cross community and she was the president. She continued with that, and we continued with cross community activities. So they were never bitter and that affected me as well."

Not all her family members were equally involved:

"My family abroad (sister) were never told how serious that whole thing was. Even to this day they don't have an appreciation of what happened to me and what I went through 'cause their lives have been very different."

She also struggled with over-protectiveness, well meaning but potentially restrictive:

"My friends tended to be within the church. They were very nice to me but they nearly wouldn't let me forget what had happened to me and for the sake of my sanity, I moved to a different church. That's not to say that they hadn't been kind but they were really over-kind. Thus, I gained new friends and there were also friends from work. Some people couldn't cope as well as others."

Finding the balance between sufficient support and enough motivation to recover some degree of independence is a continual process for many of those we interviewed.

#### Financial support and income

Financial worries are second only to those about physical health and survival for almost all of the injured and their carers.

Peter Heathwood was gunned down by the UDA in his home in front of his wife and children; in 1979 in a case of what Peter claims was Loyalist-Special Branch collusion. It was a case of mistaken identity; the target was his lodger who lived in the flat upstairs. Peter was in hospital 50 weeks and is an incomplete paraplegic, confined to a wheelchair. He described the impact of his injuries on his financial circumstances and career.

"It was an absolute disaster. At 26, I hadn't even begun to build a pension, which is something you maybe begin to think about after that. I didn't have a chance to build a pension – all of a sudden, I was on benefits. From a guy that was earning £1,000 a month – teachers were only earning £500 a month – I was on benefits and nobody wanted to give me a job. Life changed completely. I had a small private health insurance policy I'd taken out in case I broke a leg so it would cover me. I never

thought I was going to need it for life. It was written up till I was 55. When you're 26, 55 seems like it's never going to happen. Even that was a problem ... The company, who I worked for, refused to pay it! They said the terrorism in Ireland was an act of war, so I had to take them to court. We won that case, so they had to pay. It's amazing! You are one of their employees and they treat you like that – but it was a point of law that was under consideration."

But for Peter, this was little consolation for what he had lost in terms of his career and financial prospects at the time:

"So I got the extra, but it was nothing to what I could have been. In the court case they talked of '50 grand a year man'. When they said that in 1980, that was big. I was offered to go to Canada ... to open a branch of a new company. The potential was enormous – potential absolutely unfulfilled. Two little assholes ruined it all and they didn't even ask me my name. If they'd just said, 'what's your name; I'd have said "Peter Heathwood!" – "That's the wrong guy!" They didn't even ask, they just started firing."

Many of those injured - and the people who often had to give up work to care for them - have not been in employment since the traumatic event. As Dr Roger Parke explains later in this report this is in part due to the severity of injury, but is also heavily dependent on the person's level of education and qualifications. Whether the injured person is in a professional/clerical job or in manual labour often (though not always, as we shall see) determines their opportunities to continue in employment.

Davey Kavanagh was 29 at the time of his injury and in employment, "Painting and decorating, and I'd do special effects too." Since being shot 36 years ago, Davey has managed to find employment, but has faced discriminatory treatment because of his disability:

"Off and on but you weren't able to do the jobs you could before. I had problems hanging paper ... the eyesight's not the same. And lately it's just deteriorated. .. It's a mental thing at work when you've lost an eye. People look at you almost 'you've lost an eye, how can you paint?' ... If there's something amiss on a wall and I'm working with another fella I'd get the blame of the miss on the wall and 9 times out of 10 it wasn't me, because I'd be double checking it ... in case there was a miss. I found that so depressing at times — annoying and depressing. Some people say rotten things you know, especially people in authority. I remember one time the foreman on a building site — and here was something wrong with the door and he says 'aw it's probably him — that one over there'. I heard him and it wasn't me. It wasn't me but you get blamed on things. And I says 'No it wasn't me' — that's really demoralising."

Because of these difficulties, Davey has had to give up work: "I'm not working now ... as it affected me - losing the eye." The financial implications for him and his family were challenging:

"You see I was out of work for a long time and you use all your savings up, and then I was in work and tried to build up again – but I'm not going to complain, I look around me and there's a lot worse off. ... You mightn't like it at the time but they should hold something back for you or the family in later years that you can fall back on. ... I've a house and am fairly comfortable, thank God. That's why I don't like complaining too much. It's just independence. It's independence really."

Linda is extremely concerned about the changes to DLA, and the reassessment of Alec. This causes great worry to them both. "I haven't slept for worrying." Alec still needs nursing at home and she cannot realistically work full-time. For the Buntings, the financial impact was enormous and immediate as he was self-employed and Linda gave up work. She was not entitled to more than £33 a week while he was in hospital. Only on appeal did Alec get Mobility Allowance. The solicitor got interim/advance payments from potential compensation. Her brother bought her petrol and sisters bought meat from the butcher. They relied on handouts from family. They used the compensation to buy a house — it is a pension, as they have none. "We have no pensions — that worries me now."

The Pollocks are content that they are financially safe in that they expect their finances to last them through their 80s.

One former RUC officer who was shot whilst on duty left the police and had a struggle to get back to work, where he also experienced discriminatory treatment:

"When I left the police I was determined that I was not going to let my disability get the better of me. I went for training – education – got qualifications ... in computers. ... I went to the technical college. I had no help from the police. ... I was 35 and determined to do well. ... I took a placement – in a section of 12 guys and took an extra 6 months to do this ... but I still needed a lot of help to do things – I could move computers ... They said 'it didn't work out' so I left. ... Several years later one of the guys who worked in the section told me something that devastated me completely. ... He said, 'oh yes there was a vacancy, but they wanted someone in a wheelchair'. So they needed someone disabled, but they wanted them to look disabled. ... If they had to have the inconvenience of someone disabled, they wanted – when the visitors come in, they can say we've got someone disabled ... I don't look disabled.

Some former members of the security forces were afforded support to retrain or given desk jobs. Michael Paterson, who lost both hands in an attack on his land rover, went to university, acquired two doctorates, and re-trained becoming a distinguished psychotherapist who provides treatment for, amongst others, those suffering the psychological effects of the Troubles.

For others, retraining or employment was not an option due to their health situation, and those in manual jobs could not continue in their employment path easily if at all. For those who were injured whilst still of school age — with some exceptions - they were almost completely deprived of educational and employment opportunities. This has implications for their ability to meet their own financial needs, and places many injured people in the

position of living off their compensation till it is exhausted and then becoming dependent on benefits.

Peter Heathwood, who sat on the Victims and Survivors' Forum, offered a series of practical suggestions for the way the financial worries of injured people might be addressed, but is most concerned about his future finances particularly if he has to go into residential care:

"The big thing is getting older and financial worry. I dread the idea of someday being stuck in a nursing home. I just dread that. I'd like to see those of us in that particular bracket ... you have to grade injuries to a certain extent ... I think in the modern world we will have to look after the most severely hurt first — and then spread the rest over the others. I would like to see the worry taken out of it — for example, rates rebates ... free TV licenses — if it can't be done in a pension thing, you can do it in kind... to recognize that the failings of this society, which is responsible for your injury... Society here was a joke... We do get the car tax, which is a good one. Those are small savings...I brought that up at the Forum."

Some injured people live with particularly challenging circumstances, such as M M who also cares for her disabled daughter.

After a mid-1970s out-of-court settlement for the injury she sustained at age 7, she had no further injury-related financial support until recently:

"About 3 years ago was the first. Somebody told me I was entitled to the Memorial Fund. I was never aware of anything ... even DLA – I was in my 20s before I was awarded that - all down to never having a social worker. ... Counselling was never offered. Back then, you were left to get on with it. ... On one occasion I had asked for help in the home when I came out of hospital and was told, 'well you husband works so you'll have to pay them yourself'. I don't get a carer's allowance for my daughter either, because I am disabled. And I'm not fit to look after her. Sometimes I have to do it on my hands and knees because I am not in my limb. I think I've just got to a stage where I accept that that's a way of life – I'm sick fighting the system."

After four decades of pain, surgery, and disability and caring responsibilities for her daughter, with no end in sight, there is little prospect of an end to Martine's frustration.

The Memorial Fund has assisted most of the people interviewed – both the injured and their families. Opinions were generally positive, but some, such as Una McGurk, have had a negative experience. She ran into problems when she had financial support for chronic pain management and the Fund did not pay the therapist. An inexperienced assistant billed wrongly and this caused a problem with the Fund administrators. However, on the positive side, Una travelled to Malawi, supported by the Memorial Fund to work building houses for Habitat for Humanity, and they funded her Master's degree fees in 2011.

#### Welfare reform

Current changes to the incapacity and disability criteria and entitlements are an urgent issue facing those who are dependent on benefits. Interviewees reported high levels of anxiety

about changes in disability benefits, uncertainty about their future entitlements, delays in getting financial assistance and a range of problems with the system of compensation. A former part-time police officer has serious financial concerns:

"If DLA is removed from me I have nothing, very little. My pension is so small because I had little service. I've been put in this position that I'm in and I feel I've no way out of it."

This former police officer does not agree with the popular view that the police got, and still get, preferential and better treatment as a result of their injuries:

"I had a visit from an OT at the Police Fund. I was asked to open and close the door, which I did, with difficulty and with pain. Then she came into the house and she asked me what weight I was. I would have understood if it was a wheelchair or some (injury) for which weight is relevant. But I felt as if she put me down as a big fat woman who couldn't help myself. She came into my home and didn't give me any consideration of having been ripped apart by a rifle. I would never want that for anybody. That's appalling and I'm still trying to fight it."

Another former police officer is grateful, however for the financial support that is available to him as a former officer and as a victim of the Troubles:

"Now there are some good funds. There's the police fund – if you need a special shower they'd put it in for you. And the police dependents' fund ... but you don't like asking ... I heard about the Memorial Fund but I didn't really take advantage of it – but we got the holiday grant – the short break – very, very good indeed. I've heard a lot of good reports about the Memorial Fund. [Q: And the Police Rehabilitation and Retraining Trust?] I was on a pain management scheme. I didn't really find it beneficial... I am happy. I've got a wee car. I've got a nice house. And we can afford a wee holiday a year. ... We can afford heating, light and the telly...If I had had a decent claim I wouldn't have a mortgage. Give us a decent pension. Don't let us rely on state ... benefits ... there's a stigma attached."

For some former members of the security forces, any reductions in benefits will be offset by their pension conditions for those that are on the guaranteed minimum income pensions. This also applies to certain public and civil service pensions. For others, however, there is not such a safety net. Those injured in the Troubles have huge anxiety about the implications of changes in disability benefits for them. Mark Kelly, a member of WAVE Injured Group spoke for many injured people when he said:

"We would like to see assistance with that and not to feel under threat and the worry of money which is huge worry for everyone in society, I accept that, but If you are carrying a disability which you weren't responsible for I think that any decent society should address those issues in a proper meaningful way".

One man interviewed had been shot in the head by a plastic bullet in 1981 and sustained brain damage. Has a platinum plate, has lost sight on his left eye, had restricted left side

movement making it difficult for him to walk and he can't use his left hand. He has also suffered from epilepsy since the injury. He underwent breast reduction surgery as a result of side effects associated with some medication that he was given to treat epilepsy. Like many injured people with limited mobility, he requires additional heating, particularly in cold weather. He is under retirement age, so does not qualify for heating allowance.

"I could do with a lot more. The compensation I got run out very quickly and it was at the early stages. Even now, with help of the Memorial Fund, there's not so much money I have as a disabled person. See last year with the snow? I didn't even get money for heating. I was here in the house and had to keep the heating on all day to keep warm. Something like that would be good."

For many people with gunshot wounds or restricted mobility, getting cold brings on sharp pain and a profound sense of cold, even when the winter is relatively mild. Others report an increased need for hot water, which is used to alleviate pain, and in some cases incontinence requires an increased supply of hot water in order to maintain personal hygiene.

Paul Kinnear spelled out the effects of living on benefits:

"At the same time I hate to complain about it because at the end of the day I am able to live in my own home. I'm lucky. I do have a care system that is paid for me. But then I also feel so many of the politicians don't have to save every week, put some amount of pounds away for electric, for heating etc. And then when you have all the budgeting done, you see what is left. I don't think we should live in this way. For what I went through there should have been money in the pot to make sure I wasn't left in a limbo in that way. Sometimes I feel that I'm lucky too 'cause I can live in my own home. Not that money can change anything, but certainly can make you comfortable. You don't wonder, 'Will I go out tonight?' - 'cause you can't afford it."

AM sustained brain damage and subsequently had surgery to insert a steel plate in her skull. She currently lives with her mother, who has had breast cancer and subsequently a cerebral aneurysm, which has caused short-term memory loss. AM attends a day centre and has received support from the Memorial Fund.

"They helped me with my holiday. Gave me a couple of pounds (£20 a week) towards things I need. They help me with chronic pain cause I have arthritis in both my knees.... If they would be a bit more flexible, it would help. But they are not. Cause it's me that has to do all the running around..."

The financial assistance available from the Northern Ireland Memorial Fund was universally appreciated, although not everyone knew to apply, as Davey Kavanagh explained:

"Although the Memorial Fund have been good to me. I never knew about till this year — I got a short break and went to see a football match and they're helping work at the staircase. I really appreciate that they were able to do things for me."

#### **Compensation**

The Bloomfield report recognised that the compensation awarded to the injured and bereaved in Northern Ireland in the 1970s and 1980s was derisory and that the criteria have changed in an apparently ad-hoc fashion over the years. This often results in older survivors being left in poverty. Even comparing the Omagh bomb Fund to the London July 7th Funds, there are invidious differences. As Annette Creelman of WAVE points out:

"The Omagh Bomb fund lacked transparency, and was not very efficient compared to the July London Bombing Fund. People who got funds through the Omagh Bomb fund were brought in by Social Security Services, and some had to go through fraud investigations. It was horrendous actually, after what they had come through ... compared to the July Bomb Fund, where legislation was passed so that the fund was exempt from Social Security. It is unfortunate that the same political heads were not put together to deal similarly with the fund here."

The myth that those injured in the Troubles are financially secure for the rest of their lives because of their compensation awards was exposed by several injured people. When compensation is awarded over a certain amount, it disqualifies injured people from receiving certain other benefits, and many have had to live off their compensation.

Paul Kinnear, injured in 1978, was awarded compensation in 1980. It seemed a substantial figure at the time, but it didn't last very long:

"I never thought I would have been living on benefits. But I think it's quite difficult to live on benefits for anybody. I wasn't able to hold any job because of the health complications. Nobody would give you work because you couldn't hold it down. Then after 1986, I had another major operation and I got other complications I felt that the government could have looked again at it [compensation].

Paul voiced an opinion held by many injured people, that they had outlived their expected lifespan:

"I think that there's no way that they expected all the people who were injured to live as long as they live. I think that's what the problem is. They should have re-addressed some people who were injured and see if their compensation had lasted. Unfortunately, it turned out that the money was not as much as it looked at first and it didn't last as long, didn't see me through the rest of my life. I think the government could have looked at some of these cases. It's been 30 years for some."

Indeed, the review of compensation, headed by Sir Kenneth Bloomfield and published in 1999, recommended that: "Financial assistance should be provided to those inadequately compensated in the past." However, this recommendation was rejected in favour of additional financial support for past victims of the Troubles through various channels including the NI Memorial Fund. See:-

http://www.ofmdfmni.gov.uk/report of the review of criminal injuries compensation in ni.pdf

Davey Kavanagh exemplifies the situation for many of the injured who have struggled against all the odds to maintain financial independence:

"I got compensation but it's now I'm feeling the financial side of things. I thought it was enough at the time but you go through it – especially when you're rearing ... 5 children, and a house. You sort of go through it."

Davey Kavanagh explained the situation of his family:

"We find it a wee bit hard now – especially as my wife's been made redundant. ... I suppose if I'd been in constant employment over the years, you'd have money by you. And then if you do have a wee bit of savings and you fall into that grey area where you don't get help. It's unbelievable how they expect you to live. ... It does away with your independence."

The benefits system can be complicated and bewildering to injured people, who often fear doing the wrong thing.

"And see those forms they send out ... you say 'maybe if I make a mistake here they'll bring me to court' or something like that. You should have someone ... who sits and helps you talk it through – but you don't get that. ... [After 36 years] This is when you'd need a back up. ... If you did get a claim or something they should hold some of it back for you and give it tax-free when you're about 60. That's when you need it for heating, food, and whatnot. ... You're afraid to ask ... to say too much and you need a bit of privacy sometimes to discuss those things. ..."

Former members of the police also reported difficulties with adjusting to living on reduced income, even though their levels of compensation and pensions have tended to be higher than the amount for civilians. One ex RUC officer said:

"I was given compensation but it's not as clear cut as you think. When I was in the police you got overtime – you relied on overtime. I was not aware of the benefits and financial help available when I was on sick leave. I had to wait 4 years for compensation, and it was not enough for a young man with a family – I still have a mortgage. At my age I shouldn't have a mortgage."

Like other injured people who claimed compensation, this former RUC officer found the process of claiming compensation very difficult. He described how his solicitor called him and his wife to the High Court and he was unaware that it was for his compensation case. They were offered £12,000:

"and he [the solicitor] shrugged his shoulders and said 'we'll take it, we'll take it'. The most embarrassing thing of my life happened. He asked me to strip. I had to take off my shirt. ... [my wife] was crying. Only when they seen the extent of the injury that they put the price up."

His barrister said there was an unsympathetic judge on that day:

"so the case was settled out of court. This was quite common ...my solicitor kept the money – someone said in his own account, I don't know if it's true, but it was about 6 months after when I got the compensation. ... There was a lack of advice, understanding, and everything. You were just left to your own devices. It's all changed now I'm glad to say. ... The pressure of waiting for 4 years not knowing what is going to happen is terrible..."

Some interviewees felt that the courts and the legal system were humiliating or even unfair in their treatment. For the first 8 years after the shooting, a male interviewee from Derry said:

"I was in bits – fucking crazy. I got compensation for it – buttons compared to what you'd get now. I got £60,000 back in 1989. I was grateful for it but you look at what they're getting now – it's a joke. ... The compensation was a nightmare – the degrading of the Northern Ireland Office. They made you feel like you were a fucking dog. I remember going up into the High Court in Belfast, in Chichester Street. I was put in a corner wasn't allowed to look round me, I was stripped down to the waist, and they came – and they were looking at my injuries with metre rulers, and touching you... The way I was treated at the time!" [MBS: 'You were like a carcass?'] "Yes. I was put in a corner, spread-eagled – and I remember the rulers... These were medical people from the Northern Ireland Office, along with the lawyers... I never got introduced to anybody... I'll never forget it till the day I die – you're just like a block."

Florence felt aggrieved that Jim's compensation was so meagre. He got compensation

"Yes, but Jim was robbed. All he got was £38,000 – for losing two legs and knowing that he'd be the breadwinner. I don't think it was adequate for what he lost."

Jim was advised by the lawyer at the time not to mention that he had a girlfriend. The family later found out that this might have worked at his disadvantage (i.e. the court should have taken into consideration that Jim was going to be the head of the family).

Any suspicion of connection to paramilitary forces automatically debarred a person from compensation for injury. And to make matters worse, this male interviewee was accused by an informer:

"In 1989 there was a fellow who implicated me in – I don't know how – but I was lifted out of my home and taken to Castlereagh [interrogation centre in Belfast], four years after I was shot, for no reason. I was held for two days. That April I was awarded £60,000 and my solicitor told me 'that case was worth £100,000 all day long'. Four

months later, I was lifted and taken to Castlereagh on the word of a super-grass who said that I knew where guns and ammunition were. The held me 2 days and threw me out with no charges. My solicitor wasn't back in Derry an hour and he phoned me and told me, 'you'll have to take that £60,000 that you're offered'... 'They'll come back for you.' And I had £20,000 borrowed from the bank on the strength of the money."

Despite the fact that there were no charges, and the case was worth £100,000, he had to accept lesser compensation in order to pay the bank loan, which his solicitors had guaranteed. He had no option but to continue working with the solicitors, "I had to work with them — they took my money." The super-grass named 38 people —"half them didn't know him .... He was a Walter Mitty, you know. There was nothing there." The super grass case later collapsed, but the interviewee had settled for substantially less, because of the threat of criminal charges, which threatened the entire amount.

WAVE members have expressed mixed views to Annette Creelman, their welfare worker, on the fairness of their compensation:

"It is a very complex issue. Some people were happy with their awards. So it's not just everybody was poorly compensated. Some people were happy enough and they felt ok. Of course they had to leave with their disability and trauma but they felt that overall the compensation was okay."

Outside of WAVE, some experiences of the compensation have been difficult. As an injured child of about 7, Martine Madden knew nothing of the compensation process at the time, but she later found out the details:

"My father had pursued this and again it is a thing he never forgave himself for. He'd never been involved in nothing like this before and ... it went to court. In those days, you couldn't really take the army to court and they weren't willing to admit liability even though they were on the wrong side of the road. They were on active duty and the bottom line was they said they would award me £10,000 as to-keep-you-quiet-money. That is what was made for the loss of my leg and when you consider what the awards are now – that was an out of court settlement. They told my father if they took it into court he'd come away with nothing and to the day he died he regretted that he never took it into court – because he said at least he'd taken it further. But it was the first time they were faced with anything like that. I had just had my leg amputated when this came about. And I don't blame him because they were going through a hard enough time."

Martine feels there is now little possibility of redress.

"From when I was 16 my health has deteriorated so when they awarded compensation they didn't consider I was going to go through surgery virtually every year for the rest of my life. ... They made my father sign something that it couldn't be re-opened, even though I was a child. And when we enquired about the files, they are not there. ... And they might say your father signed that but my father didn't know what lay ahead for me – or the wee daughter that I love to bits, that I did have, which adds extra pressure to the home alone without my disability."

W is in his third year waiting for compensation and the claim is not yet settled. P G, severely injured in 1994 endured an even longer delay in receiving his compensation, during which his family had to cope as best they could with his extensive daily care needs:

"Compensation came 9 years after from the NIO. There were all those years of waiting. My brother and sister got £ 10,000 each. Looking back, I think they should have got a lot more. I was working at the time and I haven't worked since, I was on incapacity benefit throughout those years. Times were tough enough. My mum just finished a degree at Queen's a couple of years before and then she was out of work. My dad was working as bar manager and after what happened to me, he lost his job. There was a bit of hardship about money. There was no real support, it was hard enough, but then 9 years later I was given a significant sum."

The compensation awards for those on good incomes prior to their injury were higher than for others who earned less. Peter Heathwood told us:

"I got criminal injuries agreed damages— I got what was a record for agreed damages at the time. The reason was at that time I was earning £1,000 a month, in insurance. I was a unit manager. I was commission paid. I was a very good salesman. I'd six guys working under me and I had a percentage of their wages. It was very hard driven job but I was 26 at the time."

Rosaleen Murrin looks to the future hoping that the injured will get the appropriate recognition, and she might well be speaking for everyone we interviewed in this study.

"I would hope that the injured are assessed to see what their needs are, what they will be in the future. I know that I keep coming back to money, it's not that I am a greedy person, but you can't expect people to be able to help you in the way they have done because they get older — practically and emotionally. They have their own problems too. I personally would like to have enough money to pay for my needs. I would like to be able to go out if I want, go, and visit someone. Simple things really but you need to have a way of doing it."

The evidence points, to a clear need to address the financial problems faced by people who could not have predicted that their injuries would endure, and become more complex and difficult over the years. For some others, they were not expected to live as long as they have; their compensation is long since exhausted. Those left unable to work have been denied the opportunity to build up savings, let alone a pension. The complex health and care needs that have been a consequence of their injuries has not been reflected in those early awards of compensation.

For Jennifer McNern, one of those injured in the 1970s, the practical, financial, and personal needs of the injured must be met if there is to be justice and fairness.

"My only experience of the justice system was the compensation process. No one claimed responsibility for the bomb. The police took a statement when I was in the hospital but I never heard anything else. I am not interested in a legal justice process for myself. But I do, as a form of justice, want my financial needs to be dealt with and specific educational awareness in place for those working with individuals who have experienced trauma by way of conflict."

For Jennifer and many others, living on reduced incomes without proper pension provision is not merely a financial matter; it is a matter of social justice and acknowledgement. Injured people interviewed here have been clear in asking for a financial response of more substance and decency than has been forthcoming until now. They see it as part of a peace process that has delivered benefits to other people. Yet the benefits to those who, together with their families and carers, live with the daily consequence of past violence have been delivered slowly, if at all, and when they are they seem thin on the ground.

## **Agency and advocacy**

Many of those interviewed for this study that have been seriously injured have been active advocates for their own cause and that of other people, lobbying and raising issues that press on the lives of injured people. The ability to 'stand up for yourself' is an important part of avoiding the worst aspects of victim identity, namely passivity and dependency; and is also important for mental health and well-being. But for some people, too many years have passed; and they have not the ability, networks, or confidence to represent their own interests, even at an individual level. Yet others have — many decades later — challenged the view of survivors as passive people without the capacity to act as advocates for injured people.

MK is now an active advocate and lobbies for injured people - but was not always so.

"Many years ago somebody suggested that I'd get involved in the organisation in the early days but I avoided that. Then it was a personal need so I decided to find out what was available. ... Some people might not feel comfortable with it, because if you?? come to attend the Wave group there's a certain stigmatisation that comes with it. It is how an individual feels about that... Some [victims' groups] are not cross-community, some are very polarised in their view, but they still offer beneficial services ..."

PG is active in the Wave Injured Group and Chair of aictims organisation.

"It's only been 2 years that I have been involved with the Injured Group. Basically, it was just seeing people on TV. There's always been injured and we would get on with it. Then there was the Good Friday Agreement and there was peace. So I went: ok people are getting out of jail and nobody ever got lifted for what happened to me. There was an arrest, but nothing came out of it. There was no contact whatever since. So ok we have the peace, people are getting out of jail and we said we'll let it go, as a family. Maybe about three years ago my brother and my sister have children now and we just don't want any of this happening to them. So I tried to become a bit more politically active and that's how I thought I would get into the injured group. The Bradley report

was out and I saw bad reactions to it from a lot of injured groups who were just politicizing it. I said I need to get in here and give a different opinion. ... so I got involved in the Wave injured Group and this group.. I started taking part in the alternative therapy, joined the committee, and became the Chairman."

Belonging to victims' support organisations does not suit everyone, as MK also acknowledges. It works for some but not for others. Rosaleen Murrin is one who has not joined a group:

"I am not a member, Jennifer is. Up until now, I thought I was okay and I had a different life compared to her. She's just more involved in it. I suppose, I don't want to say I'm lazy but I heard from her all that was going on, so I kept in touch and kept up to date. I haven't been involved but I might do. Organizations are not for everyone."

A Belfast woman now in her 60s worried that groups might be too problem focussed, too negative:

"I have never been a member of Victim Support Group. There were none existing in my day. I also feel that they tend to dwell on the problems, rather than moving people on and out of the group. I just wonder what their purpose is but I was never a member so maybe that's a bit unjust, unfair.

However, as someone who lost a limb, she has been active and successful in working for better service provision:

"I became a member of the Limb fitting Centre Users group. That gave me a vehicle to try and influence things but we always try to work with whoever it was rather than score points on them. We would try to bring them along. It wasn't large-scale influence but where I was, I tried to say there's another way of doing things. But it wasn't in the political scene or anything like that. The group was formed 20 years ago. They contacted all the amputees (there's 1800 of us at the moment in the province) and asked for volunteers. We have lobbied through the civil service and through the politicians and we have managed to double the money for the Centre."

Along with others interviewed for the purposes of this survey, Peter Heathwood Jennifer McNern and Alec Bunting were members of the Victims and Survivors' Forum, which advised government on the services necessary for dealing with the legacy of the conflict specifically for the injured and their families. This advocacy has been recognised widely. It has also impacted positively on the resourcing of services such as the regional rehabilitation unit at Musgrave Park Hospital – for which Dr Park credited MK and others.

Although many of the injured are not able to engage in advocacy and lobbying – for reasons of age, severe disability, financial and physical mobility, and social networking – substantial evidence exists verifying that the injured are not prepared to be relegated to the category of passive victim. The range of advocacy and the length of commitment shown by them in their range of voluntary activity, leads to the conclusion that people injured in the Troubles are active informed and articulate their needs clearly and powerfully.

## **Social support and relationships**

As we have seen from the survey results, the biggest source of support for injured people comes from their families. Belonging to victims' and other groups, including churches and occupation-based support has provided further help.

When Martine Madden was in hospital – from the age of 5 until she was 7 – her parents had businesses to run as well as looking after Martine, so her aunt looked after her three brothers. So "it was family that helped … Back then you were left to get on with it and your family was left to sort it."

When Martine has been in hospital, her oldest daughter or her husband have to be at home with Jessica, her daughter with special needs, or at the hospital with Martine. Pulled in so many directions, has an emotional effect, and frustrated Martine. Until 10 years ago, her father and mother were daily support to them all, but they died within a year of each other, and their absence is sorely felt. Her brothers have their own families and responsibilities. It is particularly difficult for her to manage the household with her injuries.

"You're the one that does the cooking, the cleaning. When the mother's affected it really does affect the whole home, where if it is the man affected the wife will automatically do everything anyway for the children because it's their mummy. ... My husband has to work as well."

While there are many options in terms of social support, the injured and their families have almost entirely "just got on with it".

MK has a wide social circle, through his voluntary activities and connections with professional musicians:

"I was an 18 years old and I was just "let me get out of here! I want to get back into circulation. I was a voluntary youth worker at the time and leader in charge of the youth club in Glengormley. It was as if ward 42 of the Royal Hospital had turned into a youth club."

As a result of a bombing in 1991, a male interviewee, X, from Cookstown suffers progressive hearing loss and tinnitus, anxiety and depression. He relies heavily on his wife for social support and confessed to being very isolated:

"Since the bombing, to be truthful, my wife had to take a lot of back seats on things that she enjoyed doing because of me. She felt that but I didn't feel that, because being such a loving and caring wife it was always X this and X that."

JF was shot bloody Sunday and social support came entirely from family and friends who 'just got on with it':

"Well it was the troubles. Everybody took it as if this is another event, in 1972 with all the shootings and bombings. And then Bloody Sunday was just another event ... tragedy after tragedy. More or less you would get on with your life. That's what happened to a lot of people. If you dwelt on the things going on around you would, as I said, crack up. So you would just get on with it and so did my family."

For some the injury or its aftermath led to the breakdown of relationships. KE described the breakdown of his marriage and its consequences for him:

"You know I was married and I have four children. I had a break up of that relationship...I kept saying to the courts ... that a large part of the compensation I receive is tied up in the marital home. And therefore if you have to give that to the wife what's there for my future? ... I think that there were different failings in the system: in the protection of rights and fairness and it might [not] have been usual for the male to take the rearing of the children on his own, and that's exactly what happened in the last 7 years of my life. Now my youngest is in university in America but ... you know there is an anger about that, once again the system has failed I think the system failed to assess my issues around the divorce."

Another male interviewee was shot by a plastic bullet in 1981 and lucky to be alive. However, he came home from hospital to an empty home – his wife had left and taken the children.

"How can I be lucky when my wife got up and left me and I'm on my own? I haven't had any steady relationship since. I don't know if it's 'cause I am disabled and I can't get a girl or what? And things got playing in my mind stuff like that ..."

For some of these injured people who suffer from isolation, and who are sometimes not known to groups or fearful of participating for a range of reasons, the availability of social support is one issue, the ability to use such support is quite another.

# **Intergenerational impact and need**

Both Linda and G spoke poignantly about the traumatic impact of their husbands' injuries on their children. Linda now acts as a carer not only for Alec her husband but also for her son. The trauma of his father's injury is the underlying cause of her son's difficulty, she believes. Linda feels she should not have brought the children to see their father in the hospital at such an early stage after he was injured.

"I think I shouldn't have let the kids see what happened although I thought Alec was going to die and they needed to see their Daddy."

The oldest son gave up going to university to stay at home with his parents. Now the oldest son is a drugs and suicide prevention professional, and is married with two children. The other son was 10 years old at the time and was in a bad emotional state. He developed epilepsy and has since had two nervous breakdowns.

"He couldn't cope at all – he suffers from post-traumatic stress disorder. Everything to do with Alec he can't get it out of his head. He has dyslexia and he doesn't sleep well. He doesn't cope at all. He's attending the mental health. ... I had to take control of his money to pay his rent. He's always agitated. ... He was doing well and Alec had to have another 4 inches off his leg and it seemed to set Colin away back."

Linda manages both the impact of her husband's injury and her son's PTSD and feels some guilt about this.

Georgina described the wider impact on the Pollock family:

"They sent young Ron and me for counselling – to a specialist. I asked the doctor for a nerve tablet, the morning after it happened and I hadn't cried the whole day, and then it all just hit me. I said I didn't want to be crying in front of him. But my son – it nearly wrecked him. It nearly wrecked him and I do think that's the reason he is the way he is today. He'd a clot and it went to the brain, and it damaged the brain, and he was only 48. He couldn't have stood unless he had a wall at his back. And I had to let that boy sleep with me until he came out of the hospital. He couldn't even lie in his own room. And he was on nerve tablets I'm sure for years ...."

Peter Heathwood, who was gunned down in his own home in 1979 and this had a long-lasting and devastating effect on his wife and also other members of his family.

"Unfortunately we had problems with Z – he was badly affected by what he seen. He was 7 at the time, at primary school. We had trouble with him. He was obstructive – stole things. Nobody then talked about trans-generational effect. We got him to the psychiatrist at the Royal at the time and even then I found that upsetting because they wouldn't let me or Anne in – like we were abusing him – the secrecy about it – they weren't telling you anything. [His daughter] was in primary school they would send for us – she would have broken down and cried a lot, but she seemed to grow out of that. She's a teacher now herself and has 3 children. The other wee one that I was rocking that night was a nightmare baby – wouldn't sleep, but we put that down to the trauma, although she was only 2 at the time – the noise - the gunfire. ... We got two of them to university. Z never went – rebelled against everything – rebelled against society. He's the father of 4 sons now and he's not the same as he was but he was hard work."

R P lost both legs and the use of his arm in an under-car bomb in his car outside his home in 1981. There was an immediate impact on the family, which has persisted, particularly on his younger son. The same drastic impact hit the Bunting family when Alec was injured in 1991 when a bomb was placed under his taxi, with his younger son suffering extreme trauma. These instances of inter-generational impact highlight an often neglected feature of the legacy of the conflict in Northern Ireland. Children and grandchildren may suffer considerable emotional trauma. They may also find themselves in a caring role — either as child carers or as a necessary part of the support that keeps families together.

A former part-time police officer spoke of the inter-generational effect of her own and her husband's injuries. She fears for her daughter's emotional health as she is unable to discuss her mother's injuries.

"I have been fortunate, I have learnt skills,. I have friends from my childhood who really know me and they can give you so much and be so much to you. I have been surrounded by people who have been an enormous support to me, psychologically. My son and I can talk about it. My daughter is like her dad so we won't really go there. Just like her dad, I fear for the future I would like that they would be able to talk about it."

Ann Scott, injured in 1972, is heavily dependent on her daughter and admits:

"I don't think it is fair on her (daughter) as she is studying. It is not fair on her to see her mummy here in her pyjamas. I don't go out unless she's with me or unless I have to."

Martine Madden relies on support when it is available, but tries not to overload her older daughter.

"If I'm not in my limb I can't help or carry Jessica upstairs on crutches, so I have to do it and I bring her downstairs on my knee and come down on my bum. I do have a 20 year old daughter but she works. Another thing I would say is my attitude is 'yes I have a 20 year old daughter and she's great and when I'm in hospital from she was very young she has always had to take on the role of Mum' – I'm talking at 12 or 13 had to put her sisters to bed and do things for them'. She also teaches dancing in a special needs group and also dances herself and my attitude is 'she needs a life as well'. She is far too young to be tied down with my problems."

Martine's daughter, Jessica, suffers from life-threatening epilepsy for which she is often hospitalised.

"My husband fortunately is in a job where the church have been very good but he can't just take time off all the time. At the end of the day you need wages to be coming in. And you can't take advantage when the church says 'go' because Jessica can be quite ill at times. So I need him to keep that time for when she's ill rather than for when I'm ill "

The issues that emerge from the Madden family raise some important issues about the inter-related and complex relationship between the demands of the carer role particularly when an injured person is also a carer. The notion that the injured person or the person caring for them are separate and distinct – that they can be seen as requiring separate needs assessments is not sustainable when the interrelatedness of family units are taken into account.

## **Concern for carers**

Finally, the injured people we interviewed repeatedly voiced their concerns about the people in their families who cared for them on a daily basis. A Belfast woman now in her 60s, who lost a limb as a young woman, said:

"at the time my mother never got an ounce of help. She just struggled on. She was expected to do it. I think it is a pity that they haven't offered a holistic needs-assessment. You wouldn't expect your GP to do that, but you would need some sort of general form where you could put what your needs were."

W's widowed sister looked after him in her home for over 6 months, as well as their Downs Syndrome brother [recently deceased] until she herself had two strokes. His concern about his sister's health is mixed with the humiliation having to ask his sister to help him with his catheter and stoma and the pain that these processes caused him. His sister also had to deal with his screaming nightmares.

The former RUC officer described his relationship with his wife who cares for him:

"I've become more and more dependent on [his wife]. She does all my medications – fiddly things, buttons for example – I just can't do it anymore. ... It's too sore to write so I depend on the computer. ... If [his wife] wasn't here I couldn't be on my own. [And friends will help out]... ... The money didn't last long ... We had children ... and you try to do the best you can. ... One thing that really worries me is that if I die tomorrow [his wife] would get £250 a month from the police – that's all my pension is. ..."

For Linda Bunting's husband Alec, there is no pension for Linda to collect if he predeceases her, as he was a self-employed taxi driver when he lost his leg. Alec worries about Linda's future if anything should happen to him, as they spent his compensation, as many others did, in buying a house. However, a future living without the carer's allowance that Linda currently gets and without Alec's benefits, is a big worry for Alec.

### The interviews with carers

For the purposes of this study, 6 interviews were conducted with people who are primary carers for seriously injured people interviewed in the previous section. Five of the interviewees are female and one male. These five carers have been caring for a family member for between 17 and 39 years.

All six carers were close family members who were placed into the role of carer through traumatic injury. For some, they had no warning that their lives were about to change fundamentally. For others, such as Guais Malcomson, and Florence Stewart, they married their husbands after they were injured. For others, such as Linda Bunting, it was different.

On 21 October 1991, Alec Bunting was blown up in a car bomb planted at his home. He and his wife, Linda Bunting have two sons. She has been his carer ever since:

"My husband was a taxi driver. He had picked up a passenger. I was setting off to work and was waved down on the Crumlin Road. I'd heard on the radio in the car that there had been a car bomb. ... Alec had been in an accident. ... When I got to the City Hospital I was told that Alec was in theatre and he was fighting for his life – that he'd lost one leg and part of his other leg was missing."

Georgina Pollock has also been caring for her husband since the day he was blown up in an under-car bomb outside their home on 12<sup>th</sup> November 1981.

Guias Malcolmson has been her husband's carer since she married him following his injury in 1972.

Florence Stewart has been caring for her husband Jim since he lost both his legs in the Abercorn bomb in Belfast in 1972.

Mrs D has looked after her husband Y since 1976 when he was shot as he sat in a local pub.

Finally, the one male carer, R is the main carer for his brother, S, who was injured 17 years ago in 1994. R was held hostage with the rest of the family in their living room and watched S being shot.

"I was 17. The house was taken over by the UVF and as they were leaving they decided to shoot S on the way out. They burst in and shot him... That night we discovered that he would be in a wheelchair... He got out of hospital 3 or 4 months later and after that I've been basically looking after him."

At the time, R was doing his A levels and did not return to school as he could not focus. He began drinking but got his exams and subsequently completed a degree in American Studies at the University of Ulster. He then took a year out in the US.

His mother is in constant pain and cannot share the caring duties, although his father provides some respite for R when he requires it. R married and has three children. He looks

after two households – his own and S's. He also looks after his three children as his wife works. He 'multi-tasks' which includes looking after S's intimate personal needs, which his wife could not do.

All 6 care for injured people who suffer chronic pain, and have experienced emotional turmoil in the aftermath of the injury, and some well beyond that period.

### Physical needs

R said of his brother S: "His toilet needs are constant – he's got a bag – he's incontinent." S needs daily enemas, each of which may take 2 hours or more. R gets S out of bed, and dresses him. He needs help to get onto the shower pad. R will also clean the house. He will help S into the car and, if there is no-one at the other end to meet him, he will go with his brother to help him in and out of the car.

Linda said it was agreed by all that Alec needed counselling:

"Both of us went to counselling – to a psychiatrist – the man was great. ... When he brought me in and spoke to me I realised that things were just the way they should be. Over the next couple of months Alec got very aggressive – would lose his temper and would swipe the dinner off the table. He got nasty. We went to a doctor in the Mater Hospital – he said 'Alec, have you ever been diagnosed with diabetes?' ... He had developed diabetes with the shock of the bomb to the system, they said. Once they got the diabetes under control that all stopped. He changed back to what he used to be."

Linda dresses her husband's wounds and manages his medications – and he still takes infections. He has ongoing surgeries on his stump. Since their home was not wheelchair accessible this causes huge problems with sleeping accommodation and the bathroom.

"The OTs that came out said we needed a bigger bathroom [but] we wouldn't be entitled to any help with the bathroom. The Memorial Fund helped us with that."

F looks after J who has developed Huntington's disease. They are both in their 70s and have strong Christian beliefs which are the foundation of their coping mechanisms:

"We could not complain. We have carers coming in each morning and if I need any more the social worker says it is there for me – just ask. ... When we can't cope we will ask for help. ... The only thing is that I pray that the Lord takes Jim before me."

As carers age or fall ill, the delicately balanced arrangements on which the daily life of the injured person depends, can be in danger of collapse. The carer is the essential lynchpin on which all else depends.

### Respite breaks

The demands of constantly caring for another human being may take its toll on carers. Fatigue, isolation and a depleted social life can jeopardise the health of the carer. Some

organisations offer 'caring for the carers' packages and the Memorial Fund has supported respite breaks for carers. The Buntings got a four day break, with funds from the Memorial Fund.

"At the start they had a break for the carers to get away on their own for a couple of days ... I took my sister with me. It was brilliant – because Alec won't do the shops."

R has now made arrangements so that he can get respite breaks:

"If I need a holiday with the kids then my Da would look after S. So we do share it between us. Holidays [for S] are a nightmare ... because there's a lot of waiting about and he is in a lot of pain."

They have had several experiences of difficulties and hours of waiting on planes, or being stopped for lengthy periods at security points, so travelling long distances for an injured person is not always the best option.

Asked about respite for carers, WAVE welfare worker Annette Creelman said:

"My experience is that some carers wouldn't take respite because the person who they are caring for has nobody else. They are the ones who are kind of stuck. I think that if respite could be more flexible in maybe getting an extra carer for a few hours on top of what the statutory is allowing. Maybe it would help them more."

Both the injured person and the carer often need much greater flexibility than the standard respite package.

Carers are often also the close family member or partner of the injured person, with their own trauma about the circumstances of the injury. Carers' psychological and emotional needs may be substantial, but tend to be subsumed in those of the injured person. Carers may also be witnesses to the traumatic circumstances of the injury, as in the case of R whom saw his brother shot. He said:

"I tend not to think about it. ... What's the point — it happened. I look at it from the point of view 'What's the point, you might as well just get on with it.' ... I have to deal with the real issue which is coping with S every day ... I'm not indulging myself."

Nonetheless, in the immediate aftermath, R "was drinking quite heavily after it – to sleep – 'cos I was quite angry and feeling quite hateful".

PH's wife never recovered from the shock of his shooting and her guilt at opening the door to the gunmen:

"My wife developed problems with her mental health. She never forgave herself for opening the door that night. I would have told her 'it wasn't your fault – they'd have kicked the door in!' But seeing me gunned down and seeing her father-in-law die she

felt to blame for it. She did try at one time to overdose and was in the City Hospital – under Dr Alderdice before he became a politician – and then her father died. I asked him why she couldn't cope, because Anne had been a great wee battler. And he said, "Well, within a couple of years the two strong men in her life have gone." [Her father] was an amputee – he had diabetes and then he died after that. ... He said everything that was reliable in her life has been taken off her and she just can't cope with it. She started drinking a lot – an alcoholic basically – being dry a lot of the time, but then something would set it off. I could tell this mood. It was like you were looking at a stone with nothing behind the eyes. She'd be away in this wee world again and blame it on herself. And that could last a week. But there were more times that she wasn't [like that]. She was in ... all those places that help people – but at the end of the day it ended her life. She died, at only 51, upstairs here. She said she didn't feel well one night – that was 10 o'clock and I was watching a movie – I said, 'that's alright I'll be up later.' I went up at one and found her dead. ... They did an autopsy ... she had basically taken a heart attack – but she'd been warned by all the doctors, 'you're taking years off your life'. And God love her ... when she was sober and talking about it she said she hated doing it – just something drove her to it to get the pain out of her head... She couldn't get rid of this guilt thing, 'if I hadn't opened the door none of this would have happened'. In many ways Ann suffered more than me. I acknowledge that. My mental health is strong. I'm a fighter. But it destroyed my wife. And she's not even a statistic."

R, too, showed signs of struggling with the trauma that he and his brother and family had been through. He became upset during the interview and admitted that he does suppress his feelings by focusing on Christmas, holidays and so on:

"...rather than focusing on what's going on. I do have issues and I can be a wee bit dark. ... If I was talking to you when I was drunk you'd be talking to a different person because I am capable of expressing my dark side. I'm not violent — it's more just ... I would be a bit weepy sometimes. It annoys me to be emotional and that's probably why I do it. I'm a functioning alcoholic. ... There'll probably come a time when I break down ... but there's no point worrying about it — if it happens, it happens."

On the other hand, Guias Malcolmson feels she can get sufficient respite for her needs and has support from her daughters but adds:

"It's difficult to say as we're so used to coping on our own but more support for carers – just listening to the disabled is the main thing, as that helps the carers".

Fear remains a significant factor for the injured and their families, who may fear a repeat of the original attack. The Bs:

"decided to move house because the police told me that although it was a mistaken identity that address could still be on IRA records – and they could come back to the house."

Although it is 30 years since Roland was blown up, he and Georgina remain very vigilant and have more than the usual amount of home security; with additional lighting outside and a device that pulsates when there is any person or vehicle outside the house. They still live in a degree of fear. Guias also deals with the fear her husband experiences when travelling.

For those on whom a caring role was thrust unexpectedly, their perception of themselves and their relationship may change. From the preceding interviews with injured people, we know that some spouses walk away, and other marriages break down. For others, on whom the role is thrust, their role and how they perceive themselves may change to accommodate the caring responsibilities that are now part of the relationship. For those who marry an injured person after they acquired their injuries, the changing nature of their health needs, will also add a degree of unpredictability to the balance in the relationship.

### Personal and social needs and impact

Carers, particularly those with long-term responsibilities live under considerable pressure and restrictions. Janine McCann who specialises in the needs of carers pointed out, "There are key problems with levels of isolation, and rates of depression and ill-health being very high among carers." As R said, the carer's needs take a back seat, "Your ego takes a knock and you do lose confidence."

S is Chair of a victims organisation, and has made the family aware of support such as the Memorial Fund – and other entitlements of which they were not previously aware. Now, R can get free massage and respite holidays, for example at Easter and the 3-monthly cheque helps. He has now paid off credit card debts.

Pain-management drugs gave Alec Bunting hallucinations and bad moods so the couple would fight and Linda would feel guilty. They both now get a day each week at WAVE, and now they live a more enjoyable life.

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"We're getting out among people now."
[Q: So the extra support has let him let go of you a wee bit?]
"Yes."
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### **Coping mechanisms**

The coping mechanisms used by carers and wider family networks faced with long-term caring and the results of the serious injuries are consistent. All accept that a dreadful wrong was done to the injured person and their loved ones, but they try not to dwell on the past – either because they have found it possible to forgive, or because they think that revisiting the trauma will jeopardise their emotional health, or both. Florence and the whole family have taken strength from their faith:

"We never had any bitterness. We are Christians and we believe in forgiveness and that's what we taught our children. It is not the answer because it will just destroy you."

## Carer's relationship with the injured person

R and S don't discuss his capacities/disability "I pander to him ... I would feel guilty as well." He feels that as S is only going to get worse, he should take a course in care or nursing. He has mixed feelings about 100% commitment to nursing S for life, yet he shows signs of some co-dependency.

"I did worry about him as I didn't want him just doing nothing – so he could put his talents to good use and feel good about himself. ... At the moment I don't have a lot of confidence but I starting driving lessons and I've never driven before. ... It's all small steps."

# Georgina feels that:

"it's actually ruined my life completely – for I don't want to go out and leave him. I'm even nervous when I'm out shopping. And he can't drive now. It used to be, could drive the automatic car would take me shopping. Now I have to depend on neighbours and friends and other people."

Georgina: "If I get a couple of hours I can usually pick up what I need – but so long as I have for a couple of days."

Roland: "If she's out of the house she has all sitting ready for me – you've only to warm this and you've only to do that ... and I say to her 'forget about me, I'll look after myself'."

Georgina: "There's time my outings would be to church on Sunday mornings and that's it. He likes people coming in."

Linda's life became dominated by caring for her husband when he took an overdose and she had to get the sons to help her with him. Linda was very angry at that time. He often told her she could leave "that he didn't want to be ruining my life". And yet despite these tensions the marriage has seen them through and they both now have a better social life and independent social relationships.

# <u>Financial needs – past and future</u>

R and S had to manage, as their mother was very ill, with support from their father, and much help from the wider social circle.

"A lot of people did gather round at the start and were constantly looking out for you – especially when it came to getting the house done up, wheelchairs and getting adapted. We did rely a lot on charity because it was only 6 or 7 years ago that S got money from the government to help him. Before that we were completely skint. People raised funds to help him get his first wheelchair ... because he is quite big and needs his own wheelchair specialised."

R started going part-time and then gave up work as he could look after both his children and S and his wife could not look after S and his father could not look after the children. This has had the predictably negative financial impact — although R feels people see him as a parasite living off S.

"I would see it as symbiotic relationship — I have him and he has me. We are helping each other. ... We are lucky enough that we are a good family and communicate with each other — and we do constantly."

In this he includes mention of the normal family and sibling fall-outs. Aside of the nursing care for S, R prepares all the meals and does all the house-cleaning for S and for his own family.

R is sanguine about the future:

"At the moment it's upbeat. A lot of it's to do with the kids getting to a good age. ... Where S's concerned he seems to be in a good place, where he's working with victims organisations and he's up at university. I'm happy about that. His philosophy - we had a think tank and tried to work out a couple of ideas. And I was able to help out with that as I read a wee bit myself. I don't know where it's going to take us but I envisage S as a very good counsellor. ... So he's got good focus and that's helpful. ... I did worry about him as I didn't want him just doing nothing — so he could put his talents to good use and feel good about himself. ... At the moment I don't have a lot of confidence, but I starting driving lessons and I've never driven before. ... It's all small steps. Maybe I'm deluding myself but I think I will be able to work." (R)

Linda worries about both Alec's and her own lack of pension entitlements, and is concerned about the increasing cost of rates and home maintenance, if they are to be able to stay in their house. She feels help with paying rates might make the difference between keeping and losing their home. Clearly continuing social support is vital to the quality of their life.

Guias feels that Samuel's psychological needs and fears will not change and that he won't accept help for his claustrophobia. "I suppose its pride as much as anything else."

# As time passes

As time passes, both the injured and their carers are ageing. This creates its own problems. Janine McCann summarises the situation:

"... elderly carers... have needs. They have illnesses. The stress of being older, unwell, and trying to care for someone is a lot tougher than for someone who is fit and 30 years old.

Appropriate support for carers is essential to ensure that they are able to maintain good physical and emotional health. Isolation, depression, and ill health are very common among carers. Over the past four decades, they have been the silent sufferers alongside the seriously injured.

# The interviews with professionals

In addition to the interviews with and their carers, a number of interviews were conducted with service providers. There were two principal restrictions on this 30 injured people and 6 carers, so the numbers of interviews with service providers were limited by the resources available. The second limitation was the difficulty in obtaining ethical approval from the Health and Social Care Trusts to interview their staff, as detailed in the discussion on ethics in Section 7 of this report. The first of these was the size of the study itself. The tender specified 45 interviews in total, and we had already interviewed 30 injured people and 6 carers. These factors limited the extent to which we could interview experts and service providers. However, through the interviews with injured people and their carers, we developed a sense of what the key issues were and this allowed us to focus our remaining resources carefully.

In the end, we interviewed 14 service providers and experts. Interviews focused on those with expertise in limb loss, prostheses, pain management, psychological trauma and mental health, the provision of financial support for victims of the Trouble, welfare benefits, psychological and mental health difficulties, funding of the sector and provision of support services for victims.

# **Limb loss and prostheses**

Dr Roger Parke is recently retired, and was a surgeon and consultant in rehabilitation at Musgrave Park Hospital.

"I was a surgeon. I trained in many branches of surgery – general surgery and orthopaedic surgery in particular, so I'm very familiar with limb conditions of all sorts. During my career in rehabilitation, I had reason to work closely with orthopaedic surgeons, and work effectively, and I had to understand the nature of orthopaedic surgery, which understanding I felt my previous training had given me. That understanding was very important in making decisions and giving advice to orthopaedic surgeons and also receiving advice back from them on the best management for some of my patients. I came into the field of rehabilitation medicine and meeting victims of the Troubles in 1980. So, I did have 30 years or so of meeting victims of the Troubles directly and being responsible for certain aspects of their care. The 70's were particularly bad for a lot of atrocities when I was training in surgery. I would have met people injured with gunshot wounds during the course of the 70s when I was in surgery working directly with them. It was after 1980 when I got my post as consultant that I met with people with major limb loss. There were many injured who would have had shrapnel and qunshot wounds to other parts of their body, not requiring an amputation and I would not have met them particularly. I met those with severe injuries where limb loss was caused."

Dr Parke has encountered a number of the injured people interviewed for this study. As later discussion shows, he can confirm many of their assertions about the unmet need in pain management, and unsatisfactory treatment of compensation claimants.

He looked back on the development of the rehabilitation service and the deficiencies has had met over his time in Musgrave Park Hospital.

"Looking back...certain aspects of a comprehensive rehabilitation service were not necessarily in place – particularly psychological counselling and the assistance of a psychologist to get people through both the early stages following their trauma and later stages as well. That is much better looked after now than it was during the 70's. Certainly that came out when I talked to my patients subsequently for studies that I would have done, that they were aware that they should have had counselling that wasn't available during the 70's or indeed 80's. Even into the 90's it was a bit variable. It is only comparatively recently that my service has had a permanent clinical psychologist on the staff."

Dr Parke has extensive experience of treating people with a wide range of gunshot, bomb and other injuries, and those needing long-term hospitalisation.

"For people with limb loss who are using prostheses, they do require regular review and follow-up. ... Many of their requirements would simply be for repair or maintenance of their prosthesis but if the prosthesis had begun to cause pain or discomfort or some problem with their gait or caused pain in some other part of their body perhaps ... It would be not at all rare for skin problems to occur on the stump. When we say ulcerate that sounds bad but a minor form of ulceration would simply be a blister. Wearing a prosthesis requires great care — meticulous care in donning it correctly — putting it on with the correct number of socks ... for that person to wear. The stump sock is an interface between the skin and the materials of the prosthesis itself. ... One of the great advances has been so many superior methods of fitting the prosthesis since the 70's. So yes, abrasions and minor ulcerations, and in one or two cases more severe ulceration, could certainly occur and would be a reason for the doctor to be involved to assess the extent of the problem. ... That's one of the reasons why people would need to re-attend from time to time."

Dr Parke has seen people of all ages in need of rehabilitation.

"Age is a significant factor, but not the most significant factor by any means, in determining how someone rehabilitates. Psychological factors are terribly important as well as physical factors. I would often have had a situation where a younger person doesn't do as well as expected and an older person does much better than expected."

Referring to the WAVE book "Injured ... on that day" he notes:

"It brings out the psychological distress that these people suffer many years later. I didn't find that all my patients by any means had this intense psychological trauma as is indicated in the book, but of course many do, and it's very variable and depends on the individual.... Some come through relatively unscathed. ... It is so variable."

Dr Parke spoke of the variability of coping and adapting to disability and limitation. Some adapt well, despite worse prognoses, where others are more limited simply by dint of their restricted employment opportunities and education or qualifications.

"I would think it is very interesting the variability with which injured persons adapt – or otherwise – to the injury or disability. I've had a patient who over thirty years wore 2 prostheses' having lost both legs through the thigh. The patient worked as a farmer and had long-since accepted that fully and certainly had no psychological distress and had been able to get by employment-wise into his eighties – not that he needed to ... but he played an active part until he was quite old driving machinery and even walking behind, herding, cows. He was an extreme example perhaps of someone who adapted so excellently, despite all the odds, in a manual profession. Another point would be the type of work a person was involved in. ... The less educated would be more likely to be in manual work and they would potentially have the most difficulty getting back to their previous or any manual job if they suffered either upper or lower limb injury, whereas a professional person or a person working in an office might well be able to continue working very adequately."

Another, and increasingly important factor for those needing prostheses, is the complexity and expense of modern false limbs.

"There can be the assumption that you need the most sophisticated and up-to-date, advanced and hi-tech, hugely expensive prosthesis to succeed and to gain the mobility you want – not necessarily so. The personality is more important. Great mobility can be achieved with low-tech prostheses. ... I've met people who have achieved great mobility with low-tech, old-fashioned prostheses, disparagingly referred to as 'tin legs' by some or 'wooden legs' by others. I had cause 2 years ago to hear a fascinating and fantastic talk by a guy called Norman Croucher, in his 60's who had lost both legs when he was about 20 below the knee. ... He is a most amazing chap. He is a mountaineer and he has climbed many mountains. He nearly succeeded in climbing Mount Everest, in which case he would probably have been the first and last bilateral amputee to have climbed Mount Everest. ... He has climbed a number of very challenging mountains, including climbing ice cliffs and sheer faces with these old leather and wood and metal prostheses – which he still wears. I've talked to him... The technology has increased almost exponentially since about 1990. There are even computerised limbs now for those with above the knee amputations where the resistance to movement in the knee is controlled by a computer, measuring what is required at any instant or at any step – but it is very challenging now to supply these prostheses and this is leading to inequalities."

Access to the latest technological advances in prostheses is limited. They are often issued to injured service men in the UK, but Dr Parke spoke of a young service man from Northern Ireland injured in Afghanistan who was given these advanced prosthesis inappropriately, as it was too early a stage in his rehabilitation.

"He will benefit from them shortly, but, for the last 2 or 3 years since he was injured, he has needed only lower-tech prostheses. ... The MOD want to be seen to be providing the highest-tech prostheses, but sometimes it's inappropriate to do that."

Dr Parke commented that, whether to have prosthesis is a choice entirely for the individual. At some levels of amputation, prosthesis may not be so beneficial; such as an amputation through the hip. New developments such as osteointegration [where the prosthesis is fixed internally, for example to the stump of an arm] open up huge possibilities but also huge costs.

Dr Parke has been content with the resourcing of the Limb Centre, thanks to the activities of the User Group in the past, but is anxious about future funding:

"We have been very well funded to provide the appropriate prostheses here; I think because of the historic situation here in Northern Ireland this has made the Health Trusts and Boards very aware of this particular and very specialised service within the overall health service. Now, in these economic times, it is proving more difficult and one doesn't know what the future will bring. Funding has been adequate thanks partly to the user group and people like Mark [Kelly] creating an awareness of the need."

He recognises the need to keep the issue of resources on the political agenda:

"Overall there is the Parliamentary Limb Loss Group in Westminster ... who have an interest in maintaining a good service for people with limb loss. So we must be very supportive of these groups that are outside of the main statutory health service which are flagging up the need. In the future, it is exciting, but also worrying that there are going to be greater disparities of provision, but there has to be. One of these prostheses I'm talking about in the private market place is costing £30,000. How many of those can a statutory organisation fund now? - very few. And this is not a just UK problem. There are different levels of provision in different countries."

Dr Parke also pointed to the importance of user involvement.

"User involvement is obviously terribly important. At each attendance, the views of the user would be taken into account... There was very close user input to decisions that would have been made about their prosthesis and their on-going management and treatment. In a more general sense, to make sure that all patients attending my unit in Musgrave Park Hospital, which is named Regional Disablement Services, are gaining excellent attention and that the service is not short of resources. There is a user group at Musgrave Park Hospital who would be cognisant of resources available to the service — of shortfalls there might be — and whose role it is to make a fuss about it. Such a group, I felt, was always very important to patients but also to us the staff ... because the resources needed in prosthetic rehabilitation are considerable, especially with advances in technology."

Asked about ambitions for the service for the future, Dr Parke spoke of wanting to see a 'seamless service'.

"From the point of acute admission for emergency treatment and surgery what I'd like is a seamless service right through until rehabilitation is complete... particularly in terms of the victim being able to remain in hospital, if necessary under the care of the different services involved, rather than having to be discharged at too early a stage... a seamless service is something we don't necessarily achieve these days... So there would have been times when victims of the Troubles would have been discharged back home too early perhaps, when they could have been availing of more physiotherapy and occupational therapy... It does happen but not as universally as would be desirable. We hear of the incredible physiotherapy services there are for the American veterans coming home from Afghanistan at the moment – such as the centre in Texas, "The Centre for the Intrepid" it's called... The fantastic facilities there, I think, are superior to ours. However one of the great advantages of our NHS here is that it doesn't depend on who you are – perhaps where you are – it doesn't depend on who you are in terms of your own personal [financial] resources."

Other key providers in the NHS are general practitioners (GPs). Both Dr Hill, interviewed about pain management, and Dr Parke, pointed out that much of the day-to-day care in terms of treatment of pain and stump ulceration is part of the normal GP service.

# **Pain management**

Significant numbers of injured people raised the issue of chronic pain for which there are specialist services to help address these issues. We interviewed Dr Hill from the Ulster Hospital, whose specialist field is pain management. Dr David Hill is a consultant in Chronic Pain management, and head of Research & Governance for the South Eastern Health and Social Care Trust. Asked if he encountered people with injury due to the conflict, he said, "I do from time to time but it's not a majority group that I would see in my pain clinic." Dr Hill also said that chronic pain is quite common in the general population and that about 25% of the population suffer chronic pain, that is, pain lasting longer than 3 months. Dr Hill also pointed out, as did other professionals we interviewed: "I may see patients with chronic pain but not realise that there's a connection with the Troubles – as they don't necessarily verbalise that."

The pain clinic approaches patient pain management by explaining what pain is, and how a person's beliefs about pain can be made more positive.

"We discuss the goals, what we can achieve. Sometimes it's just giving an explanation of why they have something that doesn't go away; for example, that pain can be a disease in itself. The injury has healed long ago yet you've still got pain. So, pain can be a disease in itself and just because you have it doesn't mean your body is being harmed and just because you do activities that are painful doesn't mean that you are harming yourself either. Maybe we get people's beliefs about pain into a more positive way. We always optimise medication. Occasionally there are interventions we can do but that's very rare because usually they are un-resolvable."

Dr Hill does not distinguish those experiencing this generic pain be it from:

"a car or motorcycle accident or a kitchen knife. In some ways those suffering trauma from the Troubles cope better because their injury is legitimised and acknowledged – whereas others ... if it was just a kitchen knife and then they are severely affected then people doubt the connection between the cause and the impact."

Seff and Gecas (1992) have pointed to the correlation between injury, pain and depression, which is consistent with the findings of this study, given that many of the injured people interviewed reported varying degrees of depression as well as pain:

"The strongest relationship in the path analysis is between pain and work limitation. Individuals in pain frequently restrict their activities in an effort to avoid pain. Part of the effect of pain on depression is mediated by work limitation. This result confirms conclusions reached in pain treatment programs. When such programs are successful in returning patients with chronic pain to normal activities, success is related to reduction in functional limitations, often without any change in overall pain intensity (Swanson et al. 1979). Individuals who have learned ways to increase their ability to work in the face of pain are less depressed." (Seff & Gecas, 1992, pp. 584-5)

Pain consultant Dr David Hill has a similar opinion, stating:

"it's not so much the severity, it's the impact on their life. That's what varies and what varies also is the person's ability to cope and manage... Lay people might think that some people can have very severe pain and some people have less severe pain. That isn't quite so prominent because pain has an emotional component to it as well and that varies hugely – and that can make the impact of it severe for them, but the pain may not be in the physiological sense that severe."

Respondents in this study reported a variety of ways in which they coped with pain, and this was particularly evident in those with injuries from the 1970s and 1980s. Services in the pain clinic service have expanded over time, but not sufficiently to meet the needs of all those who might ideally be referred. Dr Hill described how injured people might be referred to the pain clinic:

"They can be referred by their GP, ... secondary care – by orthopaedics, by plastic surgery – by anyone actually, but it tends to be surgical specialties that refer to the pain clinic. ... Rarely medical specialties but they can. By far the majority are GPs. ... And all orthopaedics are triaged by GPs and physios and they're a very large referral. ... The capacity of the service has changed ... to try and meet need. The problem is the need is endless ... There is an unmet need but we exceed all our commissioned work. ... I do chronic pain 1 ½ days a week but I could do it full time if ... someone funded it."

Asked specifically about treatment for those who lost limbs and who suffer chronic pain, Dr Hill said:

"My observation of people with stump pains is that they function quite well. The ones who don't manage so well are those who have post-traumatic stress disorder, because that appears to affect their whole ability to function now – globally. Even a minor pain to them is a big deal because of their ability cope with anything is poor. So I would see them as ... run of the mill with wear and tear ... but it's a big deal because they don't cope well with anything. ... We are aware of that. Usually they would bring their partner with them and that helps ... we explain and their partner helps out. ... Repeat visits you get to know them and the relationship changes. It's always the first time is hardest because no-one knows what to expect."

In retrospect, with 30 years consultant experience, although Dr Parke can see some improvements in the service, there is stillroom for service development:

"I think pain control is one area that hasn't been adequately serviced. There's a better realisation now of the need for specialist input to pain control. Most people, most victims, don't require specialist pain clinics, because all doctors are trained in management of pain ... pain is variable as to its extent, its severity, its psychological impact, the ability of the individual to control it, and the length of time for which it persists. For that minority of persons in whom it's difficult to control the pain, then certainly the specialised pain clinics are very necessary. We have an enhanced level of expertise available and they are generally run by anaesthetists interested in the subject. That resource has been lacking. The response times have been poor for patients referred – as, if you have too many people referred, some are going to have to wait, if the resource isn't there to see them all quickly. That has been a severe deficiency and still is, I'm quite sure. Also the follow-up time; once seen and assessed on the first attendance at a pain control clinic, it is important to see that patient quite soon afterwards – at a time determined to be optimal for that patient, to determine the effect of the treatment which has been advised. Often the intervals between reviews will be far, far too long. ... It is important to know when you are going to be seen."

This expert knowledge is an important resource, which is central to the planning and provision of future services for injured people. The involvement of the patient in planning and monitoring the service is essential in empowering patients to take greater control of what are usually long-term conditions where total recovery is not always possible.

Both Dr Parke and Dr Hill see user involvement in planning, managing and evaluating services as very valuable. In relation to the pain clinic, Dr Hill said:

"We have user involvement in evaluating the service and that's conducted by people independent of us ... at least yearly. At the moment we don't have user involvement in planning the service but that's an ambition we have, because we have a Patient Participation Partnership Initiative."

That initiative is a wider development in the NHS, and at a remove from individual patients' empowerment of involvement. Indeed the plan is to move much of the delivery of the service into community settings.

"A lot of it is medicines management and you don't need to be in a big acute hospital with high expense resources to discuss medicines management. Also psychological therapies are very important and you don't need to be in an acute hospital. In fact we are just starting a pain management programme here ... and whilst we will start it here ... our ambition is to take it out of the hospital. We're looking to see if we can have it in the Ards Leisure Centre, because we are going to try to de-medicalise it."

When asked about the goals for the future, Dr Hill said:

"Our ultimate goal for our clients is self-management. We are trying all the strategies we can to promote that — which is reducing dependency on secondary care and primary care. ... I think people taking control of their own circumstances definitely is more beneficial to them."

So it would appear that the involvement of the injured person in planning and monitoring services - what is referred to elsewhere in this report as 'agency'- together with good mental health, are important factors in the ability of the injured person to engage with rehabilitation and manage pain.

### Psychological trauma and mental health

Dr Oscar Daly is a Consultant psychiatrist in general adult psychiatry in the Lagan Valley Hospital in Lisburn, servicing an adult population between the ages of 18 and 65:

"Because of the area in which I serve I have come across many people who have been traumatised by involvement in Troubles-related incidents over the last twenty years or so... ... the two main therapies would be cognitive behavioural therapy and Eye Movement Desensitisation and Reprocessing called EMDR for short... The natural course of something like PTSD is that two thirds of people make a full recovery... one third unfortunately don't. Now with treatment they can expect to see some improvement and mainly in the sense of being able to adapt to the problems they have, the problems don't go away, they learn to cope better with the problems."

Dr Daly addressed the issue of the balance between attending to physical and psychological problems:

"... we probably don't see as many people with physical injury as we should because I would imagine that a lot of those individuals also have psychological problems... if it is left to long without attention to the psychological – psychiatric problems that can lead to long term consequences... I think it is quite right that that the physician or the surgeon is involved in the first instance, I don't think that the psychiatrist or the mental health worker should be near the individual when they are going through the surgery or whatever treatment they require. However, as part of the rehabilitation process there certainly is a role for psychological interventions at that time because I don't think you can separate out the physical from the psychological.

Certainly in the seventies and eighties and part of the nineties [psychological needs not being met as part of the rehabilitative process] that would have been the case. I think now things are much improved, there are health psychologists who are involved in the major hospitals in Belfast."

Dr Oscar Daly explained the relationship between mental health and physical recovery:

"People who have psychological problems such as depression, one of the core features of depression is the lack of motivation. So if somebody is not motivated to help themselves or to seek the help that is available, obviously that is going to adversely affect the outcome at the end of the day."

Failure to provide timely treatment for people with symptoms of trauma has long term consequences according to Dr Daly:

"The longer someone endures psychological symptoms, the less likely is full recovery. Nonetheless, with treatment... helping the individual to adapt to their physical loss and their psychological problems that could bring about, certainly, some improvement anyway."

Apart from the availability of services, Dr Daly points to other factors that impinge on whether or not individuals get treated for trauma:

"Stigma [associated with seeking help for mental illness] is huge. It permeates all of our society, I think, particularly in professions such as the police and the military where the stiff upper lip is still very much to be expected. The culture there is very much that if you do seek help with psychological problems, your career is over. That is certainly the perception that individuals have and there may well be some truth to that."

David Bolton has worked with the aftermath of violence both within the statutory services and more recently with the Northern Ireland Centre for Trauma and Transformation. He thinks that mental health services directed at the effect of the Troubles have not developed in the same way as other medical services:

"In terms of the mental health problems linked to the Troubles, we did not develop the same very, very creative and imaginative response that the surgeons in the Royal and the Belfast City Hospital did. In relation to the very serious injuries from gunshots and bomb explosions and they became world leaders in that and we should have been doing the same in terms of mental health and we didn't."

David pointed to some of the barriers to developing services in a situation of ongoing violence.

"It is not all to be laid at the door of health and social services... I think there were problems that people in communities had in knowing whom to trust and where to seek help. There was a very clear lack of an evidence base upon which to develop commissioning and to develop services and training."

With the advent of the peace agreement and research on the level and characteristics of need, some of these problems were alleviated to some limited extent. However, the way that government and funding bodies thought about these issues in the past has had an impact on the way services have developed, according to David.

"there was another effect that came into play through funding that was put in place to support community development, community relations and other similar initiatives... The view was in some quarters that the mental health problems linked to violence were not a classic or typical mental health problem and that they could be addressed if other wider social issues or community relations issues were addressed. So if we sort out these problems, then the mental health and trauma will sort themselves out. That has been plainly shown to be not the case."

He argued that there has been a lack of strategic direction in the way services were developed in the past:

Voluntary sector programmes were funded on the basis of applications being made... but the funding and commissioning bodies did not have the wherewithal to make judgements about what the needs were or how best those needs might be addressed. So for example, claims were made in applications that trauma was present and trauma could be addressed by these measures ... but there was no evidence base to enquire into how effective that might be or if there was a better way of spending those resources."

According to David Bolton, the problems of making proper provision for the mental health needs of people affected by the Troubles persists and there is a need at government level to make certain changes:

... and it [the problem] is largely still there because we still don't have the commissioning structures in place either in the statutory or the voluntary sectors... to attend to the very distinctive mental health needs that have arisen as a consequence of the Troubles. .. that's not to say that there aren't individuals and services and teams that are doing their best to attend to the very clear need that presents itself at their doorstep day in day out, there are many clinicians who have given a lot of personal time to try to understand and address the consequences of the violence. What we are talking about are structural, formal processes that, in my view need to improve radically in order to address what is now a major public health problem for this community."

He points to the existence of services for former members of the security forces and the lack of parallel provision for civilians:

"... We need to see similar provision for the civilian population as there have been for members of the services, for example. We all accept that those services are important...but we do need to see the same attention and imagination being given to the development of services for the civilian population because the needs are very significant. In this centre through our treatment programme we can see the range of the depth of need that people face when they have, for example, chronic post-traumatic stress disorder with depression and a whole range of other problems."

For him, statutory funding for the sector is essential, is not yet in place, but is a key component of the peace process itself:

"Given the need that is now becoming clear because of research on the impact of the Troubles, it is totally unrealistic that the voluntary sector would rely on largely voluntary sources of funding. The need is of public health dimensions and will for some years to come require public funding to be applied to it in both the voluntary and the statutory sector. It requires interdepartmental cooperation between the Department of Health and the OFMDM and also requires the building of capacity on the part of delivery organisations both in the statutory and voluntary sectors. It is a necessary piece of the response to the years of violence, it is as important as the reform of the police, it is as important as all of those other changes that were put in place on the foot of the Good Friday Agreement..."

For David Bolton, and for the interviewed families we whose children had suffered and continue to suffer because of the injuries of their parents, this is not simply about addressing the consequences of what happened in the past.

"There is a strong case for addressing the mental health problems not just as dealing with the past, but an investment in the future, particularly when you think about

young people living in families where the parents have serious mental health problems linked to their experience of the Troubles."

Michael Patterson, who lost both lower arms and hands when serving as a police officer in Northern Ireland is now a clinical psychologist who specialises in working with issues of trauma:

"My treatment of choice [for trauma related symptoms] would be Eye Movement Desensitisation and Reprocessing, it is one of two therapies recommended by the National Institute of Health and Clinical Excellence the other is trauma focussed cognitive therapy. EMDR is a very psychological effective treatment for single incident trauma, it is recommended that there are 3-6 sessions that it would take to resolve the post-traumatic stress symptoms. For multiple traumatised people such as ex-military, police, you would be looking at 12 plus sessions of EMDR to resolve the post-traumatic symptoms... it involves linking in to the memory that is stored... whenever psychological trauma occurs, the experience becomes locked in the brain, stored in the way it was experienced at the time."

Michael explained the brain mechanisms by which traumatic memories are stored:

"...what is stored are sights, sounds, smells and tastes.. thoughts that the person might have had at the time... emotions ... and beliefs about themselves that are generated by that experience or a whole cluster of experiences that have the same themes... beliefs hinge around responsibility or defectiveness.."

He also pointed out how these might impact on the present:

"...there are other areas that can be tapped into by these beliefs, one to do with present safety... so the traumatic experience happens maybe a year ago... maybe fifty years ago...if that is locked in the central nervous system, when a reminder occurs it activates that memory and then that feeds up into the present to cause disturbance."

So those traumatised in the past, for example former police officers, to name but one cohort of people affected by the Troubles, who live with untreated traumatic conditions may continue to feel strongly that their safety is in jeopardy. This will have consequences for their quality of life and ability to mix with other people, for example. Yet Michael reports a high level of success for his methods and services, which he provides from a private facility in South Belfast:

"What we do with EMDR is to help the client process this [memory]. There is a 50% chance that within 6 months they will no longer be symptomatic."

However, those with long-standing problems may not be motivated to seek treatment for symptoms of psychological trauma, and we interviewed several people who were unwilling to pursue this course, some saying that it was 'too late' although stigma may also be a factor, as would be the ability to access services privately due to cost considerations.

Resources and accessibility of services is an issue raised by several of the service providers and experts, but the issue of the financial circumstances of the individual injured person and his or her family has also proved to be a challenge.

### **Financial support for victims**

One of the services most lauded by the injured people we interviewed was that provided by the Northern Ireland Memorial Fund, which provides direct financial support to victims. Carolyn Madda who managed the Memorial Fund was interviewed:

"The Memorial Fund is an independent charity set up by government in 1998 to address the needs of the victims of the Troubles in Northern Ireland. We help people who are bereaved, those who have lost a close family member — people who were injured, whether it is physical, psychological or both or the carers of someone who was injured. We have a budget at the moment of about £3.5 million per year. We have currently 5,000 clients who are actively on our books — so we have helped 11,500 to date. We... re-opened for the month of October [2011] and received another 500 applications. This will probably be our last year in operation because we are going to be replaced by the Victims and Survivors' Service from April 2012-13 onwards"

#### Caroline said:

"We have 303 people who have physical injury, 405 who have psychological and 294 who have both physical and psychological injuries."

On the definition of physical injury, and how people are assessed for financial assistance, she said:

"There are two things that have to be confirmed – the incident and the injury. So the incident is confirmed later by PSNI compensation agency or solicitors' records. So that's your first hurdle to get over. The second is the person's GP who has to confirm that. Our classification is 'injured as a result of the Troubles that has a long term and lasting effect on your well-being and mobility – so anyone who got hit with a bottle in a riot and has recovered doesn't have access to any of the help from the Fund."

There are, however, borderline cases that cannot be offered help:

"... there are cases ... where a person has been shot but when you write to the GP the GP says 'no on-going injury'. ... There are other cases too where with ex-service people who were maybe injured – especially psychological injury – years ago and it wasn't the manly thing to do to go and seek medical help. So they went home and opened the bottle or opened the tablets and self-medicated and because there's no medical record of these people we can't help them."

In other cases past records are inadequate:

"Sometimes it's the GP who confirms it – sometimes it's the psychiatrist or the psychologist – or the likes of Combat Stress for ex-army personnel. So we try our best to exhaust every avenue before we rule anybody out. ... Sometimes, with ex-service people the police can't confirm what the GP states as a mental condition that they were at the incident so you're caught in the middle of it. The Fund asks about past compensation [which some applicants don't answer as they think it will rule them out] because it is easier to get information than from the PSNI. PSNI have a bottleneck – so the Fund asks people to get evidence from solicitors' records or old newspaper coverage. If records have not been kept solicitors can provide an affidavit."

The Fund operated on the basis of inclusion, for approximately 600 with physical injuries the fund has not turned down many:

"Out of 5000 applications we have only declined 52 people, because we can't get proof of on-going injury. We are inclusive. We include combatants and victims of paramilitary assault as well. There can be difficulty with those ... because they [in some cases] won't or don't co-operate with the police."

However, some applicants are not comfortable with some of the requirements of the scheme and are unwilling to comply with them. In order to receive support, applicants:

"have to work with the Police Service of Northern Ireland (PSNI), and have to know about the Fund — which used to exclude these people. Then there is the chill factor — knowing that the Fund will ask the PSNI."

Carolyn summarised the kinds of support that the Fund provided:

"They can get financial help of £20 per week to help with day-to-day living expenses – I can give you the forms. If they are seriously injured – if they are in receipt of high level DLA they get £1,000 a year for additional need – for household maintenance, replacement electrical goods. If they're just injured, they get £500. They're means tested schemes... They can get educational and training assistance to do courses. They get the chronic pain management grant, which is up to £2,000 a year – that's to help with private medical consultations, conventional treatments, and complementary therapies. There's £1,000 a year if someone needs adaptations to their home or handrails put in. ... They get 'short break' as well, which is equivalent to £200 per adult and £150 per child. ... Financial help with school uniform. Over 60s payment of £250 a year. ... The most severely injured will qualify for pretty much all of these schemes."

However, the Fund closed, then reopened and has now closed again. Carolyn explained:

"In 2009-2010 OFMDFM told us we wouldn't get funding again unless we moved towards a needs-based approach in this year, thinking that the Service would be up and running. We spent summer of 2010 changing to the needs-based approach — which changed all of the application forms into one single application for the year — so you can access help at any time through the year — which is brilliant. We'd a database set up and everything was going well until they decided it was too expensive and the demand was too high — and instructed us to close for applications on the 18<sup>th</sup> April. We told them we had unallocated funding and were asked to re-open in October for the month.

So, it's not by choice ... we would rather stay open and get a steady stream of applications through. ... There's a bigger problem now in that some of our most needy and most injured are coming out for November this year. There's no funding to give them continuous support."

Carolyn spoke of the challenges of managing the consequences of closing the scheme in order to move to the new integrated service:

"I've put a paper to government. Because we make an award for 12 months and not everybody uses everything there's what we call a release back. I've suggested that rather than leave these people with nothing at all — the two priority schemes would be the regular allowance of £20 a week for people in real bad hardship and the chronic pain management scheme. There's a very genuine need there that's not being met. And ministers and politicians always made the point that there would be a seamless transition between the Memorial Fund closing and the new Service being set up."

Historically the Fund was allocated £1m a year, which rose to £3.5m – sometimes with extra funding from departmental under-spend allocated to NIMF late in the financial year.

Almost all of the injured and carers interviewed has received support from the Memorial Fund, albeit some of them belatedly. Some did not know about the Fund until very recently and there were also some complaints about the claims procedure which some felt overly intrusive, and others felt the criteria to be too rigid — i.e. being granted money for complementary therapies that they did not want, but not granted sufficient funds to visit a relative in Canada. Overall, however, the help of the fund was much appreciated as a supplement that would tide people over at times of need, or for things that they could not normally afford, such as holidays, heating or home adaptations. This is probably related to the fact that financial problems rank highest amongst the concerns and problems reported by injured people.

# **Welfare benefits**

The main source of financial support for those injured in the Troubles is derived from pensions in some cases and in others disability and welfare benefits. Annette Creelman, WAVE welfare worker in Armagh, is experienced in giving advice and support to injured people and their families across Northern Ireland and as a result of assisting injured people with their financial worries and difficulties with the benefit system is very familiar with the key issues. Her writing on the subject is also reviewed in the literature review of this study. She believes that benefit reform is a major concern for many injured people and changes to the benefit system may negatively impact on them:

"The changes on the way and the welfare reform are going to have drastic effects on our membership. There are a number of changes, which began last year and will continue in the next 3-4 years. The main one which is a big cause of concern, is the transfer of clients from Incapacity Benefits over to Employment Support Allowance [ESA]. The migration began in February [2012]... It will affect all our clients apart from those who are three years from the state pension age. The test for ESA is very different

from Incapacity Allowance. The changes initially were not too bad but then at end of March this year the government changed the ESA descriptors radically. I think they went too far. As a result I do expect now that a lot of people will fail the test. For instance, the walking indicator has now been replaced by a "mobilising" indicator, which implies the use of an aid. This means that not all the wheelchair users will automatically get the maximum score (15) but will be scrutinised whether they can manually propel themselves through a manual wheelchair for 50 yards: if they can they would not score 15 points so they would be reassessed for a further distance. Another example is the Sight indicator now been replaced with "navigation". Now if you can use an aid (like a stick or a guide dog) in an unfamiliar place without any help from anybody, they would not get the points. Now you have to weigh this up with the possibility for these people to be able to get a job, realistically in the real world. I think that the government went too far."

Annette, too, has concerns about the mental health dimensions of benefit provision, both in terms of qualifying and in terms of the impact of the changes in benefit on mental health:

"I am also concerned about the indicators for mental health. The symptoms for PSTD are not really reflected or included. I think it's going to be hard for a lot of our members to pass this new test...I see big problems in the long term: loss of income, people falling into debt and poverty, impact on mental health and relationships and possibly house repossession."

Annette points out the specific difficulties that Northern Ireland faces in relation to benefit dependency levels:

"Northern Ireland depends on benefits a lot more than the mainland so these changes are going to have a huge effect here... It is not just the benefit changes."

She sees attitudes to benefit dependency in the wider community as a further challenge:

"Sometimes you don't realise that outside the [victims'] sector there is a different perception. They are not only fighting the benefit changes, they are fighting the perception that's out there as well."

Injured people showed an awareness of this perception, commenting that the changes in the benefit system created the impression that they were 'on the make' or 'milking' the system.

## **Compensation**

Service providers were also aware of other aspects of financial support for injured people. As a consultant, Dr Parke had also been asked to report on or support compensation claims during his years in the field:

"... I would have provided medical reports on very many, if not the majority of people, who came to me. ... In doing so for each individual patient, I had reason to delve into the effects of their injury on their lifestyle and on their family. I am aware of the variability there is in that. Of course, with compensation claims, there is the natural tendency sometimes to exaggerate the impact and it can be difficult just to decide what is the true level of loss, but that wasn't for me to do. I simply reported on the facts. I gave an opinion too, to assist in the process. I would have been advising on mobility matters ... and following on from that, what is the potential for employment in different fields. Everything is interdependent really."

Dr Parke's confirmed the reports of some interviewees that, without prior information or notice, when at the High Court they had been required to strip off clothes and show their injuries and scars:

"I can verify that that did happen. For many years the case was heard in front of a jury and it was the jury's job — advised by the judge — to decide on the matter of compensation, which was not a good system. And that was changed I think some time in the 90's. I've been present when the litigant has been so asked ... to show the injured leg — to take off the prosthesis on occasions in the court in front of the jury — and I would absolutely agree that that was not a good idea. After I had experienced that 2 or 3 times, I personally would have advised when previously seeing my patient that, if the case did come to Court, there might be this requirement by the judge. So at least I was able to prior warn the patient. If that was not acceptable to the patient, I think that could have been made known to the court via the solicitor... More recently we would have retired to the judge's quarters to do that."

Dr Oscar Daly also had experience of the compensation system, and his role was to verify the veracity of claims:

"Individuals come along and they rightly seek compensation if they have been affected by the troubles whether physically or psychologically. If they are affected physically, it is relatively easy to tell that and to quantify it. If they are affected psychologically it is much more difficult and there is an attitude amongst some people that many people who attend seeking compensation are perhaps malingering. Now, there is no doubt that in a small number of cases that is true. But the majority of people in my experience who come along seeking compensation are genuine in their complaints and tend not to exaggerate."

He also confirms that there can be a contradiction between the role as assessor for compensation and the provider of care and treatment for the injured person:

"There could be [a contradiction between the caring role and the role whereby the psychiatrist reports to the court deciding compensation about the persons mental health] and that's why psychiatrists now would tend not to give – some people still do – but most tend not to give reports about their own patients because the therapeutic

relationship is quite different to the assessment relationship in the medical-legal context..."

Some injured people were aware of and frustrated by these contradictions and were also disappointed by the way in which their interests were represented by their legal advisors. However, we did not interview legal advisors for this study.

#### **Statutory services to victims**

In response to recommendations made by the Bloomfield Report (1998) 'We Will Remember Them' and the Social Services' Inspectorate Report (1998) 'Living with the Trauma of the Troubles' Trauma Advisory Panels were established in 1999 in each of all of the then four Health and Social Service Board areas in Northern Ireland. The roles of these panels were further articulated in the victims' strategy 'Reshape, Rebuild, Achieve' launched in April 2002. The purpose of these panels was to enhance the quality of life for victims/survivors of the conflict in the particular Health and Social Services Board's area, by recognising, acknowledging and respecting their various needs and promoting the provision of appropriate support services.

The Trauma Advisory Panel in the Southern Board area sets out its role as:

- To provide a forum where the impact of the Troubles on the whole community is acknowledged;
- To represent the needs and views of groups and individuals affected by the Troubles;
- To make statutory bodies more aware of and responsive to these needs through the participation of their representatives on the Panel;
- To improve service delivery to people affected by the Troubles in a sustained and focused way;
- To make the views of those who have no other voice known to agencies and policy makers;
- To develop an effective communications strategy;
- To provide networking and training opportunities for Panel members (Available at: <a href="http://www.shssb.org/partnerships/trauma-advisory-panel/">http://www.shssb.org/partnerships/trauma-advisory-panel/</a>)

Martina Mullin O'Hare is Trauma Advisory Panel (TAP) Coordinator for the Eastern Health Trust, which covers the Belfast and the South East areas. It has been operating for 10 years. Martina describes her role, which is to ensure the work is cross sector, cross-community and based on a partnership approach to improve quality and quantity of services for victims and survivors of the Troubles. The work falls into three broad areas, according to her:

- 1. **Policy formulation and change** involving providers and victims and survivors at government and health board/trust levels;
- 2. **Research** mainstreaming the social, economic and psychological effects of the conflict;
- 3. **Practical** signposting services and identifying needs of people who come to her

Focusing on the severely physically injured, Martina reported that in her area, TAP has examined their needs and is aware of their financial need, the need for a voice in policy making and their longer-term needs and those of other victims and survivors. She pointed to

their awareness that the needs of people who were severely physically injured increase over time, in terms of hospital treatment, adaptations in their homes, and for recognition of their situation. She also outlined the needs and pressure on their carers as both the injured person and their carer ages. Although, she pointed out that the need for resources to support this work are greater in Northern Ireland than in the rest of the UK, she was positive about what had been achieved to date:

"There are good foundations to build on – good organisations across the voluntary and community sector in particular. And also in the statutory sector what we have built on is the foundation of partnership. The Panel is made up of 40 voluntary and community and statutory agencies ... working in partnership ... and relationship building."

The work of the panel has filled a gap, although, according to her, there is a need for continuing policy and practice development and political commitment. However, commitment, for her, is central:

"Finance is important but if there's a commitment sometimes resources will follow."

The TAP advocates a step-care model of service provision for victims in general:

"a one-door – not a one-step – where they can get the help that they need – the respite care, the financial support, the social support, the campaigning support, knowing that their needs – as carers as well as the injured – is being recognised by society, is supported by society and that society is not turning away from them..."

The step-care model used by the TAP requires trust and partnership working between the public and third sectors. She is hopeful that any gaps will be met by "the imminent Victims and Survivors Service" which, she believes, should "be needs-led rather than funding-led". With the advent of the new Victims and Survivors Service, she noted that this is a very uncertain time.

Whilst noting that it is often the carers who campaign for the injured, Martina noted the change in service provision that had taken place over the ten years of TAP operation and the:

"personal and professional development of those working is this area ... There has been a move away from the medicalisation of this issue – from the medical model – ... but there is still a need in the statutory sector to make it more trauma-sensitive, to be aware when someone comes to them that this may be a result of the Troubles. It might not just be alcohol, or prescription drugs or a physical condition that doesn't seem to be getting better."

Some of the HSC trusts have taken initiatives in relation to justice issues facing people injured in the Troubles. Martina reported that the Eastern TAP has recently set up a 'dealing with the past' working group including broad community and cultural traditions and statutory and voluntary sectors to examine justice issues. She also indicated that the Eastern

TAP was concerned with the need to deal with secondary stress in those who are working with trauma and has plans to do some further work on this issue.

According to Martina Mullin O'Hare, the key issues for people injured in the Troubles are:

- 1. Changes in entitlements [e.g. DLA] creates uncertainty and is stressful on survivors and carers and there is a need for more information and support;
- 2. Increasing need for pain management and the support for that in terms of wider policy and service level; and,
- 3. The ripple effect with carers and families of those with severe injury is much larger than is presently recognised and impacts on the wider community.

According to Martina, specialist psychological therapies are available through the Trusts, although in order to deliver CBT and EMDR practitioners must be appropriately supervised and a recent report highlighted a shortage of such supervision. The use of trauma specialists is essential in dealing with traumatic experience — especially in those who present with complex PTSD and the Trauma Services Directory produced by the TAP shows services that are available, although this can change each year:

"It is increasingly recognised that you do need trauma therapy. The DSM-IV, shortly to become the DSM-V diagnosis is important in an integrated approach...and how to get a different level of help and support quickly ... That needs more prominence. ... People need more help and support."

The Trust uses the 'One Point of Referral' system, which deals with all first referrals for mental health assessment for people between 18 and 65 years old in the Belfast area. It offers 'one golden number' for all emergency and urgent referrals and an electronic or written referral for all routine referrals. All referrals are triaged and directed to the most appropriate service so that care and treatment can commence immediately. Clinics are at a number of locations across Belfast. Referrals go to a case meeting to ensure that the person is referred to the appropriate specialist therapy – whether statutory or voluntary since some voluntary organisations have service agreements with the Trust.

Within the Belfast area, the Family Trauma Centre, located in South Belfast offers a family therapy service and covers all of Northern Ireland through its outreach centres. This provides specialist treatment services for children, young people and their families following severe trauma of all kinds. They also provide consultation and training to a wide range or organisations.

The Belfast Helath and Social Care Trust also provides a Trauma Resource Centre, located in North Belfast's Everton Centre, and covering whole of Belfast area. The Director of the Trauma Resource Centre, Mary Corry, described the work of the Centre, which provides multi-disciplinary treatment for those adults who have been affected by the Troubles. The services they offer include counselling, usually consisting of hourly sessions normally held on a weekly basis, occupational therapy focussed on the person's quality of life and the impact of trauma on their daily ability to cope. The occupational therapist provides a programme aimed at moving the individual towards an improved state of health and well-being.

Alongside this, the Resource Centre provides physiotherapy. This assists individuals to explore the physical impact of trauma on the body, offer them insight into their condition, and provide practical ways of coping with their symptoms.

The Trauma Resource Centre is located in North Belfast, which is the area of Northern Ireland that has been worst affected by the Troubles in terms of death rates. Furthermore, it is an area of high deprivation, suffering the worst of both poverty and political violence. It also continues to be the site of violent political division, even after the Good Friday Agreement. Mary Corry described the history of the service:

"We started in 2005 the North and West Belfast Trust, the people who were insightful enough to recognise that in the victims' sector that there wasn't a statutory provision up until 2004. John McGeown had the insight to then develop a service ... and to recognise that within the community sector and voluntary sector, fantastic work was going on."

Mary Corry, who was born and reared in North Belfast, knows the community intimately and has had her own experience of the Troubles. However, shortly after her appointment she recognised the scale of the challenge in North Belfast:

"But the levels of violence that happened in schools... I worked for 18 years in Turf Lodge, West Belfast, I worked with a lot of very socially deprived people...Typical urban big estate with all the problems... I managed a family centre there, I thought I had heard everything till I came into this job [in North Belfast]. I used to say to myself, did I live in the same country?"

The Centre has a high percentage of people attending who have sustained gunshot wounds, raising issues of pain management, circulation problems, 'feeling the cold' and restricted mobility. The overwhelming majority have broken family relationships, are divorced, or separated. Amongst their clients; 75-80% male, many have been targets of paramilitary shootings, or were shot in feuds, or by the security forces. Many have symptoms of PTSD. Asked about the continuing fears of people who were attacked in these ways in the past, Mary explained:

"It's all about safety. This is where the relationship difficulties come in, because families are saying why are you sitting in a room, why are you afraid to go out, sure them people have moved on, there's no guns any more. But the individual still doesn't feel safe, paranoia is a huge part of it. Fear of going out, fear of seeing those people, anger, the injustice of it, why me those \*\*\*\*ing people who are now the great and the good and working in communities, you have to really work with challenging the paranoia, how real is it... but for them at that particular time it is very, very real. You try to help them rationalise it, how rational is it that someone is going to kick your door in and go up your stairs and shoot you, for them on a scale, that can be 10 but for us and for families, it is very unlikely...but unless the person begins to understand that it is not rational fear..."

Mary reflected on the reasons for some of her clients' difficulties in recovery from traumatic experiences, since some people manage to stop or avoid living in fear after such events. So what is different?

"In my experience, what I am finding is that the trauma occurred ... much earlier in their lifetime. I think if something happens when you are younger you lose your ability to be resilient. If trauma happens when you are younger you are more likely not be able to deal with traumatic experiences in later life... Trauma in younger life undermines resilience. Most clients also come from backgrounds of deprivation, where there is family violence, social problems...layers and layers of trauma, particularly male clients, maybe badly beaten, a lot of neglect, living on the streets, absent father maybe, interned, jailed, on the run, marriage breakdown, mother not coping, being traumatised themselves by what is going on in their environment, so how can traumatised parents be proper parents? And that's where the whole transgenerational stuff comes in. So you get a lot of anger, a lot of sense of injustice, some of the poverty is frightening, some of the experiences that people had in childhood ... some awful things."

Mary reports that although people come to the Centre identifying one traumatic event, that most have experienced multiple traumas. She also believes that it is only now being recognised the impact that multiple traumas have had and she welcomes the inclusion of complex PTSD in the new DSM-V. The Centre operates a comprehensive needs assessment that encompasses mental and physical health, and the centre can offer support with drug and alcohol addiction, occupational and physical health as well as mental health and traumatisation, all on one site, so clients do not have to juggle appointments and treatment plans are discussed and coordinated by the multidisciplinary team. The ethos is based on a recovery model, aimed at fostering change, which can be a challenge when some clients have been using mental health services for some considerable time.

The model and approach of the Trauma Resource Centre is one, which merits closer examination, particularly the operation of comprehensive needs assessment, the use of a multi-disciplinary approach and the emphasis on recovery.

### The archive and film

The final part of the work on this project comprises the assembling of an archive of filmed interviews with those injured in the Troubles, their carers, service providers and various experts and advocates on topics related to the issues that face injured people and their families. By the mid April 2012, the second round of filming will be complete, comprising approximately 35 hours of film footage.

# Editing will take three forms:

- a. Editing for the purposes of archiving. This will leave the interview intact, as conducted, but will remove interruptions, breaks and distractions;
- b. Editing for the purposes of a short campaign film for use during talks and briefings;
- c. Editing to produce a full-length feature documentary, comprised of a wide range of interviews and covering the key topics raised in this research.

The processes involved in incorporating film into the research process will provide the focus for another report and will not be elaborated here. Filming of this nature raises a range of ethical, methodological, psychological, political and aesthetic considerations which are to be taken up in ongoing work on other projects with colleagues in Surrey, Palestine and Serbia.

### Conclusions and further research

The key findings of this research are drawn together in Section 2, the Executive Summary of this report. Recommendations arising out the research are set out in Section 3.

In this concluding section, comments will focus on the implications for the development of future knowledge about injured people and their carers and families and for the development of service provision for injured people.

### **Future research**

As has already been pointed out, it is not possible to conduct a scientifically definitive study of people injured in the Troubles without arriving at a definition of injury. An attempt to do this would constitute a useful exercise in itself. This will involve an exploration of the relationship between injury on the one hand and disability on the other. This is a complex relationship, since although injuries can be described to some extent in terms of specific physical or mental damages to the individual, the concept of disability relies on the extent to which the environment supports or inhibits the injured person to lead a full life. This distinction is not always clarified or explored in policy terms, yet it offers a useful insight into the focus of policy development, since surely policy and intervention should be aimed at minimising disability for injured people.

A further area of enquiry would be to scrutinise the variety of definitions of disability that are already utilised by various agencies for various purposes. Such an exercise is beyond the capacity of a study of this size, although drawing together and evaluating the various definitions used for the purposes of compensation, police disability pensions, state disability benefits including mobility allowances and for policy purposes would be a worthwhile exercise and could also serve to clarify new policy directions. The incorporation of some of the international perspectives on disability in the conduct of this exercise will also be important.

Better estimations of the size of the population of people injured during the Troubles could be arrived at utilising a two-stage research strategy. First, a generally useful definition of what is meant by 'injured in the Troubles' could be crystallised by a discussion between key policy maker and practitioners. This would involve arriving at a set of criteria designed to identify who is included within the definition. Second, a research instrument could be designed and piloted which would identify those who met the criteria and eliminated those who did not. Third, this instrument could be applied to a true random sample of the population of Northern Ireland with a view to establishing a more definitive picture of the prevalence and incidence of injury in the general population. This process would facilitate a more robust total figure and a more reliable picture of the demographics and features of the population of injured people.

Although such an exercise might be desirable in order to ensure scientific standards in the study and understanding of the needs of people injured in the Troubles, the results will be limited by the quality and utility of the definition used.

For this reason, it is suggested that this current study's findings are likely to be reliably indicative of general levels of need, priorities and concerns of injured people and their carers and provide enough basis on which to proceed with policy development. This can be concluded because of the convergence of findings between the various parts of the study. The literature review pointed to issues that were confirmed, particularly in the interviews with service providers but also with injured people themselves. The interviews with injured people and their carers threw up issues that were confirmed by the survey findings, and further reinforced by evidence from service providers.

# **Policy directions**

As several people have pointed out in the course of this study; future policy, services, and interventions that will result, depend on political will and on the ability of policy makers to forge policies that are needs driven and inclusive. Policies that also demonstrate a political will to recognise and address the issues and difficulties faced by injured people and their families. In the past, and even since the advent of the Agreement, many have felt that the political will has not always been present, and some have reported feelings of being sidelined or ignored. Yet service providers report continuing need, injured people coming forward for the first time many years after they were injured, and increased concern about the implications of ageing and a changing financial climate.

The challenge facing politicians and policy makers is significant. It is to ensure that public policy and the public purse is managed in such a way as to ensure that we collectively meet our moral obligation to those who live in close proximity on a daily basis to some of the worst consequences of our communal disputes. Those are our moral obligations to injured people, their families and carers.

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# **Appendices**

# **Advisory committee**

### **Chair of the Advisory Committee:**

Mark Kelly MBE Treasurer of WAVE Management Board

**Committee members:** 

Damien McNally Chair of WAVE Management Board

Isobel Reilly School of Sociology, Social Policy and Social Work

Queen's University Belfast

Marianne Moutray School of Nursing and Midwifery,

Queen's University Belfast

Dr Oscar Daly Dept. of Psychiatry, Lagan Valley Hospital

Dr Margaret Cupples General Practice, Queen's University Belfast

Marie Therese O'Hagan Dept. of Trauma Studies, WAVE

Jennifer McNern WAVE Injured Support Group

Pauline Donnan Research Unit, OFMDFM

Philip Gault Chair of WAVE Injured Support Group

Alec Bunting WAVE Injured Support Group

Peter Heathwood WAVE Injured Support Group

Paul Gallagher Victim's and Survivors Trust/ WAVE Injured Support Group

Adrian McNamee Commission for Victims and Survivors NI

Neil Foster Commission for Victims and Survivors NI

Hazel McCready Wounded Police Officers and their families

Eugene Morrissey WAVE Injured Support Group

Sean Coll Community Relations Council Victims' Committee

representative

Sandra Peake CEO, WAVE

# **Ethical approvals**



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HSC REC 1

27 September 2011

Professor Marie Breen-Smyth
Director of Research School of Politics
University of Surrey
School of Politics, AC Building
Guildford
Surrey
GU2 7XH

Dear Professor Breen-Smyth

Study title:

Research on the Needs of the Injured and their families

REC reference:

11/NI/0128

Protocol number:

n/a

Thank you for your letter of 14 September 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC at a meeting held on 27 September 2011. A list of the sub-committee members is attached.

### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a <u>favourable ethical opinion</u> for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

### Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Providing Support to Health and Social Care



21st December 2011

Prof Marie Breen-Smyth Director of Research School Politics University of Surry School of Politics, AC Building Guildford Surrey GU2 7XH

Dear Prof Breen-Smyth

Study Title: Research on the Needs of the injured and their families

HSC Trust Ref: 11047MBS-SP(Please quote this in all future correspondence)

REC Ref: 11/NI/0128

I am pleased to advise that Belfast HSC Trust has given final Research Governance Permission for the above project to commence. Permission is granted for the duration of the project to 1<sup>st</sup> April 2012

The following documents have been approved for use in the project:

Document	Version	Date
Protocol	V1	12/08/11
Interview Schedules/Topic Guides: Injured Interview	V1	12/08/11
Interview Schedules/Topic Guides: Carers Interview	V1	12/08/11
Interview Schedules/Topic Guides: Service Provider Interview	V1	12/08/11
Participant Consent Form: Film Consent	V2	
Participant Consent Form: Interview Consent	V2	
Participant Information Sheet: Film Participant	V2	
Participant Information Sheet: Interview Participant	2	
Participant Information Sheet: Survey	2	
Summary/Synopsis	V1	12/08/11

Research Office, 2<sup>nd</sup> Floor King Edward Building, Royal Hospitals, Grosvenor Road, Belfast, BT12 6BA

V1.0 Date: 08/02/2010



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HSC REC 1

09 December 2011

Professor Marie Breen-Smyth Director of Research School of Politics University of Surrey School of Politics, AC Building Guildford Surrey GU2 7XH

Dear Professor Breen-Smyth

Study title:

Research on the Needs of the Injured and their families

REC reference:

11/NI/0128

Protocol number:

n/a

Amendment number:

Substantial Amendment 1

Amendment date:

28 November 2011

The above amendment was reviewed at the meeting of the Sub-Committee held on 08 December 2011.

# Ethical opinion

The Sub-Committee had no ethical issues with the survey instrument submitted for review.

The members of the Committee taking part in the review gave a <u>favourable ethical</u> <u>opinion</u> of the amendment on the basis described in the notice of amendment form and supporting documentation.

# Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Draft Data File		
Questionnaire: Survey Instrument with PDS	1	22 November 2011
Participant Information Sheet: Survey		
Notice of Substantial Amendment (non-CTIMPs)	Substantial Amendment 1	28 November 2011

Providing Support to Health and Social Care

# Interview Schedule - injured people

# Research on the needs of the injured and their families

5 Chichester Park South, Belfast, BT15 5DW tel: (028) 9077 9922 fax: (028) 9078 1165

Principal Investigator: Professor Marie Breen-Smyth; m.breen-smyth@surrey.ac.uk

Research Officers: Dr Roz Goldie: rozgoldie@btinternet.com; Maria Deiana; m.deiana01@qub.ac.uk

RESEARCHING THE NEEDS OF THOSE SERIOUSLY INJURED IN THE TROUBLES AND THOSE WHO CARE FOR THEM

# Thank you for agreeing to this interview about your experience

We are interested to learn about the experience of people injured in the Troubles, and want to ask you about how this has affected you.

#### Injury

I understand that you were injured in DATE, PLACE and BY [named perpetrator/s]. Am I correct in this?

#### **Impact**

What did it change immediately after this? [Pointers – residence, job, family circumstances]

# **Medical Services**

What was your experience of hospitalisation/ medical services: in the immediate aftermath What was your experience of hospitalisation/ medical services: in the time since?

What was your experience of hospitalisation/ medical services: at the present time?

How would you rate the medical attention you have had?

What was good about it?

What was not so good about it?

Could it/How could it be made better?

Do you feel your health and needs changed since then – over the past (explicit number of years)?

#### Compensation and financial assistance

Can I ask you if you received any kind of compensation for the injuries they sustained?

Was it difficult to get? How did it happen?

Can I also ask if you get other financial support?

Do you feel that this support is adequate for your needs?

# Emotional, social and personal support

Who helped you in the aftermath?

How did your family cope?

How did your friends, social circle, and neighbours respond to your injury?

Did you get or want counselling help?

What kind of help would be best for you now?

Who helps you now?

How does your family cope? Do they need respite?

How are your relationships with your friends, social circle and neighbours now?

Was there a time when you coped less well, because of a particular event [that triggered traumatic stress]?

#### **Justice**

Can you describe what was your experience of the justice system regarding those who injured you? Could you tell me if there was a criminal case taken?

If so, Can you describe how do you feel about the outcome in your case? How do you feel the outcome has affected you?

Do you feel that the changes since the Good Friday Agreement have included and given appropriate recognition to the injured, their families and carers?

### **Support from Victims' groups**

Are you aware of victims groups in your area? Are you a member? Are these groups helpful or not?

#### The Future

Having come through such extraordinary circumstances, could you tell me any kind of concerns/worries that you might have about the future?

As you look forward what are your hopes and plans for the future ahead?

As we discussed at the beginning of our conversation this research is dedicated to learn about your experience and identify your personal/individual needs, as well as those of your family. Can you tell me what would you hope might happen or change once this research is published?

Thank you for your time and giving me very sensitive but important information

# Research on the needs of the injured and their families

5 Chichester Park South, Belfast, BT15 5DW tel: (028) 9077 9922 fax: (028) 9078 1165

Principal Investigator: Professor Marie Breen-Smyth; m.breen-smyth@surrey.ac.uk

Research Officers: Dr Roz Goldie: <a href="mailto:rozgoldie@btinternet.com">rozgoldie@btinternet.com</a>; Maria Deiana; m.deiana01@qub.ac.uk

# Thank you for giving your time and expertise

# Service provider interview

We are interested in the services you provide for those injured in the Troubles.

Your role?
Aim of the service?
Range of service?
Is the service adequate to meet the need?
Plans for service development?
How has the service changed over the years?
Catchment area? Has this changed?
Who can use the service?
How do they access it?
How is it funded? How have funding levels changed?
What kind of user involvement is there in planning, evaluating or managing the service(s)
How does your service interface with other services for injured people and their families?
How do you evaluate services to injured people generally?
Are there areas of unmet need?
Challenges/ frustrations?
If you were in charge of services to injured people, what sorts of things would you do/change?

# Research on the needs of the injured and their families

5 Chichester Park South, Belfast, BT15 5DW tel: (028) 9077 9922 fax: (028) 9078 1165

Principal Investigator: Professor Marie Breen-Smyth; m.breen-smyth@surrey.ac.uk

Research Officers: Dr Roz Goldie: rozgoldie@btinternet.com; Maria Deiana; m.deiana01@qub.ac.uk

#### **Carers interview**

I am interested in the experience of people who care for those injured in the Troubles. I would like to ask about your experiences both before and after your relative's injury.

# Pre injury

Would you begin by talking about what your life was like before your relative was injured? Where did you live, occupation, family circumstances Ambitions/ plans?

#### Injury

When they were injured, can you tell me how it happened? How badly were they hurt/ How were you affected?

# **Impact**

What did it change immediately?

Health
Relationships
Finances
Aspirations/ plans for future

How have their health and needs changed since then? How has this affected you?

# Compensation and financial assistance

Did your relative get compensation?
Was it hard to get? Do you get other financial support?
Are your financial needs met?

#### **Justice**

What was your experience of justice in relation to those who injured your relative? Do you think that justice was served?

How do you feel about the outcome in your case?

How has the outcome affected you?

#### **Services**

What services were provided for your family in the aftermath?
How did you and your family cope?
How did your social circle, neighbours respond to your changed circumstances?
What was your experience of medical services, hospitals / medical services: in the immediate aftermath, over the time since? Now? How would you rate the medical attention

your relative has had? What was good about it? What was bad about it? How could it be made better?

Did they or you get or want counselling help?
What kind of help do you need now? What support do you get/ need?
How do your family cope? Do you need respite?
How do your social circle, neighbours relate to you and our relative now?

Are you aware of victims groups in your area? Are you a member? Are these groups helpful or not?

# **Participant information sheets**

# Interview participant information sheet

### INTERVIEW PARTICIPANT INFORMATION SHEET

This is a research study to find out about the needs of individuals and their families injured as a result of the Troubles. It has been commissioned by WAVE, a voluntary group made up of those injured and bereaved in the Troubles from both communities and the research is being carried out by a team from the University of Surrey, helped by trained volunteers from local victims groups.

The purpose of the study is to investigate the circumstances of people injured in the Troubles, so that their needs can be highlighted and improvements in services suggested. The study sets out to:

- 1. Find out about the numbers of people and the levels of injury sustained as a result of the Troubles in Northern Ireland from 1969-1998.
- 2. To record and archive personal experiences of a cross section of those injured through the Troubles, identifying both their short and long term needs.
- 3. To examine the physical, emotional and psychological effects of injury through the Troubles.
- 4. To find out how injured people and their families coped with their situation
- 5. To find out what services and sources of support were available for injured people and their families.

Due to the limited amount of money available for the study we have narrowed the focus to concentrate on people who have suffered life threatening, disfiguring or other severe injury in the Troubles, their families and carers. We will carry out the study through a series of individual interviews with a small number of injured people and their families, and the professional, statutory and voluntary organizations that support and serve them. Should you decide that you want to take part, the information you give us will be anonymised - that means that your name and identifying characteristics will be removed from the record of the interview, unless you wish to be identified. Any and all information stored will be archived in compliance with the Data Protection Act (1998).

Interviews will take place in your own home, unless you prefer to be interviewed elsewhere and if this is so, we can organize another venue. Interviews will last between forty five minutes and two hours, depending on how much information you wish to give us. At any stage during the interview you can stop it, if you wish. Should you require follow up support,

the person who interviews you can advise you of a suitable supporting organization — a list of which these organisations is provided on page 3.

We will send you a written excerpt of the parts of your interview that we wish to use in this study. We would wish to keep all the information that you give for use in future studies, if you agree for us to do so. If you agree, your interview transcript and the sound recording of the entire interview will be stored, depending on your agreement, protecting your identity if you wish us to do so.

The study will also review all the previous research on injury due to the Troubles and this analysis will be included in the final report. If you are asked to participate, you will be asked to sign a consent form to record that you are willing to participate. You are free, however, to refuse at any stage or to withdraw from the study even after the interview is conducted, up to the point when the final report is prepared in December 2011. You will be told about the final findings of the study, using the contact details you provide.

If you have any questions about the study, please contact one of the people <u>listed below</u>. We will be happy to talk to you about the study.

Many thanks,

Marie Breen-Smyth Principal Investigator Project Office 91 Clady Road Portglenone BT44 8LB Tel 02825822916

Email: m.breen-smyth@surrey.ac.uk

Principal Investigator: Professor Marie Breen-Smyth Tel: 07710438183

Research Officer: Maria Deiana Tel: 07902 527 439

Survey Research Officer: Dr Roz Goldie Tel: 0759 1136 820

WAVE Project Manager: Marie-Therese O'Hagan Tel: 02890 779922

# Survey participant information sheet

### SURVEY PARTICIPANT INFORMATION SHEET

This is a research study to find out about the needs of individuals and their families injured as a result of the Troubles. It has been commissioned by WAVE, a voluntary group made up of those injured and bereaved in the Troubles from both communities and the research is being carried out by a team from the University of Surrey, helped by trained volunteers from local victims groups.

The purpose of the study is to investigate the circumstances of people injured in the Troubles, so that their needs can be highlighted and improvements in services suggested. The study sets out to:

- 6. Find out about the numbers of people and the levels of injury sustained as a result of the Troubles in Northern Ireland from 1969-1998.
- 7. To record and archive personal experiences of a cross section of those injured through the Troubles, identifying both their short and long term needs.
- 8. To examine the physical, emotional and psychological effects of injury through the Troubles.
- 9. To find out how injured people and their families coped with their situation
- 10. To find out what services and sources of support were available for injured people and their families.

Due to the limited amount of money available for the study we have narrowed the focus to concentrate on people who have suffered life threatening, disfiguring or other severe injury in the Troubles, their families and carers. We will carry out the study through an earlier series of individual interviews and a survey of injured people and their families, and the professional, statutory and voluntary organizations that support and serve them. Should you decide that you want to take part, the information you give us will be anonymised - that means that your name and identifying characteristics will be removed from the record of the interview, unless you wish to be identified.

If you are willing to take part in the survey, please complete the questionnaire and return it to us preferably through the person or organization that provided you with it. If you prefer, you can post it to us directly to: **Research on the needs of the injured and their families, 5 Chichester Park South, Belfast, BT15 5DW.** Should you require follow up support, WAVE can advise you of a suitable supporting organization. You can contact WAVE on 02890779922.

Completing the questionnaire should only take between twenty to thirty minutes. If there are questions you don't want to answer, please leave them blank and move to the next question.

\_We would wish to keep all the information that you give for use in future studies, if you agree for us to do so. Depending on your written consent at the bottom of the questionnaire, your completed questionnaire will be stored, and may be used in future studies.

The study will also review all the previous research on injury due to the Troubles and this analysis will be included in the final report. You will cab find out about the final findings of the study on the WAVE website at http://www.wavetraumacentre.org.uk.

If you have any questions about the study, please contact one of the people listed below. We will be happy to talk to you about the study.

Many thanks,

Marie Breen-Smyth Principal Investigator Project Office 91 Clady Road Portglenone BT44 8LB Tel 02825822916

Email: m.breen-smyth@surrey.ac.uk

Principal Investigator: Professor Marie Breen-Smyth Tel: 07710438183

Research Officer: Maria Deiana Tel: 07902 527 439

Survey Research Officer: Dr Roz Goldie Tel: 07591136820

**WAVE Project Manager: Marie-Therese O'Hagan Tel: 02890 779922** 

# Film participant information sheet

### FILM PARTICIPANT INFORMATION SHEET

This is a research study to find out about the needs of individuals and their families injured as a result of the Troubles. It has been commissioned by WAVE, a voluntary group made up of those injured and bereaved in the Troubles from both communities and the research is being carried out by a team from the University of Surrey, helped by trained volunteers from local victims groups.

The purpose of the study is to investigate the circumstances of people injured in the Troubles, so that their needs can be highlighted and improvements in services suggested. The study sets out to:

- 1. Find out about the numbers of people and the levels of injury sustained as a result of the Troubles in Northern Ireland from 1969-1998.
- 2. To record and archive personal experiences of a cross section of those injured through the Troubles, identifying both their short and long term needs.
- 3. To examine the physical, emotional and psychological effects of injury through the Troubles.
- 4. To find out how injured people and their families coped with their situation
- 5. To find out what services and sources of support were available for injured people and their families.

Due to the limited amount of money available for the study we have narrowed the focus to concentrate on people who have suffered life threatening, disfiguring or other severe injury in the Troubles, their families and carers. We will carry out the study through a series of individual interviews with a small number of injured people and their families, and the professional, statutory and voluntary organizations that support and serve them. A small number of those people we interview will be asked to have their interviews filmed as part of making a film about people injured in the Troubles. Should you be asked to take part in the film and decide that you want to, you will be asked to sign a consent form.

Filmed interviews will take place in your own home, unless you prefer to be interviewed elsewhere and if this is so, we can organize another venue. Interviews will last between forty five minutes and two hours, depending on how much information you wish to give us. At any stage during the filming of the interview you can stop it, if you wish. Should you require follow up support, the person who interviews you can advise you of a suitable supporting organization. Should you become uncomfortable about taking part, you can also withdraw from the film up until the final edit has been made. This is likely to be in December 2011.

Northern Visions will invite you to a viewing of the edited film showing the parts of your interview that we plan to use. At that stage, you can request that alterations be made to your part of the film. We would wish to keep all the filmed material of you for use in future studies, if you agree for us to do so. If you agree, your entire filmed interview will be stored, depending on your written agreement. The film makers will discuss with you how this material will be stored, before you decide to sign the consent form.

You can find out about the final findings of the study, on the WAVE website at <a href="http://www.wavetraumacentre.org.uk">http://www.wavetraumacentre.org.uk</a>.

If you have any questions about the study, please contact one of the people listed below. We will be happy to talk to you about the study.

Many thanks,

Marie Breen-Smyth Principal Investigator Project Office 91 Clady Road Portglenone BT44 8LB Tel 02825822916

Email: m.breen-smyth@surrey.ac.uk

Principal Investigator: Professor Marie Breen-Smyth Tel: 07710438183

Northern Visions Film maker Marilyn Hyndman Tel: 02890 245495 Ext 207

**Survey Research Officer: Dr Roz Goldie Tel: 07591136820** 

Research Officer: Maria Deiana Tel: 07902 527 439

WAVE Project Manager: Marie-Therese O'Hagan Tel: 02890 779922

# **Consent Protocols**

# **Interview consent**

BRAILLE, AUDIO VERSIONS AND TRANSLATIONS OF THIS FORM CAN BE MADE AVAILABLE, PLEASE ASK IF REQUIRED.

# Interview Consent Form WAVE study on research on the needs of the injured and their families:

and their families:	
	Please circle as necessary
I, the undersigned, voluntarily agree to take part in the study on injury due to the Troubles	YES/NO
I have read and understood the Information Sheet provided. I have been given a full explanation by the investigators of the nature, purpose, location, and likely duration of the study, and of what I will be expected to do	YES/NO
I have been given the opportunity to ask questions on all aspects of the study and have understood the advice and information given as a result	YES/NO
I understand that all personal data relating to me is held and processed in the strictest confidence, and in accordance with the Data Protection Act (1998)	YES/NO
I understand that if I require follow up support, the person who interviews me has advised me of suitable supporting organizations.	YES/NO
EITHER	
I wish to have my identity protected and my anonymity ensured in all data relating to me in this project	YES/NO
OR	
I wish to have my name and identity credited in relation to any data relating to me in this project. The implications of having my name used have been discussed with me, and I am aware that material relating to me may make its way into the public domain as a result, and I am agreeable to this	YES/NO

I understand that I am free to withdraw from the study at any time up to the point when final reports are published, without needing to justify my decision and without prejudice	YES/NO
I understand that if my circumstances change and I am no longer able to consent to participation in the study that:	YES/NO
EITHER	
Any interviews I have contributed up to that date may continue to be used, but no further information about me will be sought or used	YES/NO
OR	
All my contributions to the study will be withdrawn and all data relating to me destroyed	YES/NO
I understand that a transcript of the excerpts of my interview that will be used in the study will be sent to me and I will have an opportunity to amend the transcript within an agreed period prior to the data being used in the project	YES/NO
I understand that data relating to me will be kept in an archive established by WAVE and the University of Surrey and that the data for the entire study will be registered at the University and the anonymised data may be available to other researchers with the consent of WAVE may be used for historical purposes	YES/NO
I understand that if personal interview data in the form of quotes or information associated with me is going to be used for further publications or studies, I will be informed of this in advance by WAVE, and will have the opportunity to withdraw my consent for this further use	YES/NO
I consent to my interview transcript being archived (Sign)	
(DATE)	

I understand that in the event of my suffering a significant and enduring injury (including illness or disease) as a direct result of my participation in the study, compensation will be paid to me by the University subject to certain provisos and limitations. The amount of compensation will be appropriate to the nature, severity and persistence of the injury and will, in general terms, will be consistent with the amount of damages commonly awarded for similar injury by an English court in cases where the liability has been admitted

I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation and agree to comply with the instructions and restrictions of the study

Name of Participant (BLOCK CAPITALS)	
SignedDa	te
Contact details	
Address:	
Telephone:	
In the presence of:	
Name of Witness (BLOCK CAPITALS)	
Signed	
Date	
Name of person taking consent (BLOCK CA	APITALS):
Signed	
Date	

### Film consent

BRAILLE, AUDIO VERSIONS AND TRANSLATIONS OF THIS FORM CAN BE MADE AVAILABLE, PLEASE ASK IF REQUIRED.

### Film Consent Form WAVE study on research on the needs of the injured and their families:

In consideration of Northern Visions, acting on behalf of the University of Surrey for the Research on the needs of the Injured and their families, granting to the undersigned ("Undersigned") the opportunity to participate in certain interview(s) (alone or with others) as designated, the Undersigned agrees with Northern Visions, its licencees and assignees as follows:

- (1) Northern Visions undertakes to make every reasonable effort to ensure that the Undersigned is shown a final rough cut of the film and his/her interview therein. The Undersigned will be given the opportunity to comment on their interview as portrayed in the film and Northern Visions will make all reasonable efforts to ensure that the undersigned is satisfied with the final version. This provision relates only to the interview given by the Undersigned and the Undersigned accepts that no provision exists to change the interviews of other contributors to the film.
- (2) Northern Visions may photograph Undersigned and record Undersigned's voice conversation and sounds during and in connection with the film.
- (3) Northern Visions shall be exclusive owner of the results and proceeds of such photography and recording with the rights throughout the world and in perpetuity to use and to reproduce all or any portion thereof and Undersigned's name voice likeness biography and editorial comments in cinematograph films of all types and kinds, including the Internet, and in books and publications based upon or adapted and in connection with the unlimited use and sale thereof in all media now known or hereafter invented and in the advertising sale publicising and exploitation thereof.
- (4) On completion of the film, Northern Visions will assign the above rights to the University of Surrey, Department of Politics, Guildford, Surrey, GU2 7XH, UK.
- (5) Undersigned recognises that the interview(s) may be cut or edited and/or used alone or with other material and/or accompanied by editorial comment and releases and discharges Northern Visions, its assignees and licensees of and from any and all claims demands or causes of action that may hereafter arise whether for libel violation of rights of privacy or publicity or any other matter arising out of or in connection with the use and exercise of any of the rights granted hereunder in whatever manner and whether arising out of the cutting editing or editorial comments or otherwise howsoever.
- (6) I understand that if I require follow up support, the person who interviews me can advise me of a suitable supporting organization.

- (7) I understand that I am free to withdraw from the film at any time, or to ask for filming to stop, up to the point when final film is released, without needing to justify my decision and without prejudice
- (8) I understand that if my circumstances change and I am no longer able to consent to participation in the film that:

### **EITHER**

Any interviews I have contributed up to that date may continue to be used, but no further information about me will be sought or used

YES/NO

### OR

All my contributions to the film will be withdrawn and all data relating to me destroyed YES/NO

NORTHERN VISIONS
23 Donegall Street
Belfast BT1 2FF

Phone: 028 9024 5495 Fax: 028 9032 6608

Email: feedback@nvtv.co.uk
Web: www.northernvisions.org

Web: www.northernvisions.org
Signature on behalf of Northern Visions
Name (printed in capital letters)
Address: 23 Donegall Street, Belfast, BT1 2FF
Signature on behalf of Undersigned
Name of Undersigned (printed in capital letters)
Address
Phone
Email
Date of Interview

All filmed material will be deposited with WAVE on completion of the film, including all unedited

Material and will be kept in their archives.

# **QUESTIONNAIRE**

We wish to learn about the experience of people **seriously physically injured in the Troubles**. If you have been **seriously physically injured**, please complete this questionnaire and return it to us, either through the person or organization that provided you with it, or you can post it to us directly at the address above. The information you give us in **anonymous**, and you can signal your consent at the end by making a mark without signing your name.

Completing the questionnaire should only take between twenty to thirty minutes. If there are questions you don't want to answer, please leave them blank and move to the next question.

quesi	tions you don't want to	aliswei, piease iea	ve them blank and move to the ne	At question.
<u>Abou</u>	t you			
1. Ho	ow old are you?			
	e you male or female?			
	hat is your home town			
			d, single, cohabiting, divorced	
5. In	Northern Ireland, are	you perceived to be	a Catholic [1], protestant [2] or ne	either [3]?
<u>Physi</u>	cal injury			
	hat year were you inju			
	hat age were you then			
8. W	here did this happen?	(which city, town or	rvillage?)	
9. W	ho was responsible for	causing the injury?	· <del></del>	
			mb, beating etc)?	
			lems have you experienced?	
Pleas	e circle all that apply t	o you		
loss c	of one legs	Yes/No	loss of both eyes	Yes/No
loss c	of both legs	Yes/No	Partial loss of sight	Yes/No
loss c	of one arm	Yes/No	total loss of sight	Yes/No
loss c	of both arms	Yes/No	partial loss of hearing	Yes/No
loss c	of one hand	Yes/No	total loss of hearing	Yes/No
loss c	of both hands	Yes/No	facial disfigurement	Yes/No
loss c	of one eye	Yes/No		
	npaired physical function lease explain)	on like ability to wal	k, bowel function, breathlessness,	sexual function etc
 13.01	ther physical problems	 . please explain		
			you were injured? Yes totally/ Ye	s partially/ No
		•	h is now	•
<u>Impa</u>	ct of the injury			
	hat changed immediat fect your work? Did thi		y? (For example, did you have to m ly circumstances?)	ove home? Did this

**Medical Services** 17. In the immediate aftermath what was your experience of the hospital and medical services? (Please circle one option and comment if you wish.) Good [2] Not great but they did their best [3] Excellent [1] Not good [4] Bad [5] Comment 18. How many years ago did your medical treatment happen? 40 years [1] 30 years [2] 20 years [3] 10 years [4] less than 10 years ago [5] 19. Do you **still attend** hospital as a result of this injury? Yes/No If yes, how often do you go? 20. Monthly [1] 3-4 times a year [2] each year [3] every 2-3 years [4] less than that [5] If yes, why do you attend? Regular check-ups [1] Degeneration of injury/ies [2] Complications due to injury/ies [3] Rehabilitation [4] Other (please explain) \_\_\_\_\_\_[5] 21. Do you feel your health needs have changed since the time when you were injured? Yes/No 22. How do you rate your medical attention from your GP or District Nurse today? Excellent [1] Good [2] Not great but the are doing their best [3] Not good [4] Bad [5]. 23. How do you rate your medical attention from your hospital or clinic today? Excellent [1] Good [2] Not great but the are doing their best [3] Not good [4] Bad [5]. 24. Do you suffer from constant pain from the injury now? Yes/No 25. If yes, do you attend a pain clinic?Yes/No 26. If you suffer constant pain and do not attend a pain clinic, how do you manage your pain Alcohol [1] Non-prescription drugs [2] Prescription drugs [3] Meditation or Complementary therapies [4] Religion or faith [5] Accept my pain [6] **Emotional, social and personal support** 27. Who helped you in the aftermath? Family [1] Friend/s [2] Church [3] Work [4] Other (please explain) [5] 28. Would you have benefited from counselling or emotional support help at that time? Yes/No 29. Did you get counselling or emotional support help at that time? Yes/No 30. If yes, was this helpful to you? Yes/No 31. Did you get counselling or emotional support help later? Yes/No Approximate date 32. If yes, was this helpful to you? Yes/No

33.	Where did any help yo	ou received come from? S	tatutory sector/Voluntar	y sector
34.	How did your injury affect your family and those around you?			
	(such as friends, social	l circle, and neighbours)		
	No effect [1] Some ef	ffect [2] Quite a lot of eff	ect [3] Strong effect [4]	It changed everything [5]
35.	My main carer is my :			
	wife/husband/partner	r [1] brother/sister [2] so	n/daughter [3] parent	[4]
	Other (please explain)		[	5]
36.	Does your carer get Ca	arer's Allowance? Yes/No.		
37.	Does your carer get th	e option of a respite brea	k that that they take up?	Yes/No.
38.	Does your carer get th	ne option of emotional sup	oport? Yes/No.	
39.	. Does your carer need any other kind of support? Yes/No			
40.	If so, what do they nee	ed (please explain)		
prol		e carefully and circle the a in the past month. Rate of the moment.		
0	)=	1=	2=	3=
	lot at all or only one	Once a week or less that		
τ	ime	once a week	the time	week/almost all the time
41.	Having upsetting thou	ghts or images about the	traumatic event that car	ne into your head when
	you didn't want them	to <b>0 1 2 3</b>		
42.	Having bad dreams or	nightmares about the tra	umatic event <b>0 1 2</b>	3
43.	Reliving the traumatic	event, acting or feeling a	s if it was happening aga	in. <b>0 1 2 3</b>
44.	Feeling emotionally up	oset when you were remi	nded of the traumatic ev	ent (for example, feeling
	scared, angry, sad, gui	Ilty etc.) <b>0 1 2 3</b>		
45.	Experiencing physical	reactions when you were	reminded of the trauma	tic event (for example,
	break into a sweat, he	art beating fast). 0 1	2 3	
46.	Trying not to think abo	out, talk about, or having	feelings about the traum	atic event. 0 1 2 3
47.	Trying to avoid activiti	es that remind you of the	traumatic event. 0 1	2 3

49. Having much less interest or participating much less often in former interest or pastimes
0 1 2 3

48. Not being able to remember an important part of the traumatic event [even though you were

50. Feeling distant or cut off from people around you 0 1 2 3

conscious at the time] 0 1 2 3

51.	Feeling emotionally numb (e.g., being unable to cry or unable to have loving feelings)			
	0 1 2 3			
52.	Feeling as if your future plans or hopes will not come true (for example, you will not have a			
	career, marriage, children, or a long life) 0 1 2 3			
53.	Having trouble staying or falling asleep 0 1 2 3			
54.	Feeling irritable or having fits of anger 0 1 2 3			
55.	Having trouble concentrating (for example, drifting in an out of conversations, losing track of a			
	story on television, forgetting what you read) 0 1 2 3			
56.	Being overly alert (for example, checking to see who is around you, being uncomfortable with			
	your back to a door) 0 1 2 3			
57.	Being jumpy or easily startled (for example, when someone walks up behind you) <b>0 1 2 3</b>			
<u>You</u>	r ability to work since your injury			
	If you were working at the time of your injury, what was your job or occupation?			
	Were you able to return to your job or occupation after the injury? Yes/No			
	Did you want to return to your job or occupation after the injury? Yes/No			
	If you wanted to return to work but could not do so, what were the barriers? (tick all that apply)			
	th, Physical disability or access [1] Fear/intimidation [2]			
	ety, depression or loss of confidence [3] Lack of job opportunities [4]			
	ers (Please explain) [5]			
62.	About your ability to work since your injury please circle the option that best describes your			
	experience			
	Never been able to work since [1] Only able to work part-time or reduced hours [2]			
	Can work sometimes but not others [3] Had to leave my job but have got other employment [4]			
	Other (Please state details)[5]			
63.	About your inability to work since your injury please circle the option that best describes your			
	experience			
	Due to the results of my physical injury I cannot work, even though I want to [1]			
	Due to the results of my physical injury and also the stress and trauma I cannot work [2]			
	Due to the stress and trauma after my injury I cannot work [3]			

# Compensation and financial assistance

64. Did you receive any kind of compensation for the injuries you sustained? Yes/No

65.	In relation to my compensation experience, my legal advice was:				
	Excellent [1] Good [2] Not great but they did their best [3] Not good [4]	Bad [5].			
66.	6. How many years did it take to settle your case (in or out of court)?				
67.	7. Do you feel that the compensation was adequate to your needs? Yes/No				
68.	8. Do you receive Disability Living Allowance? Yes/No				
69.	9. Do you receive Incapacity Benefit? Yes/No				
70.	0. Do you receive any other benefits or pensions? Yes/No (If yes, describe these)				
71.	How well are your financial needs met?				
	Very well [1] Well enough [2] Just adequate [3] I struggle to get by [4]				
	I cannot survive on my current income [5]				
72.	2. What kind of additional financial assistance, if any, would you find helpful?				
73.	3. Are you aware of victims groups in your area? Yes/No				
74.	4. If yes, are you a member? Yes/No				
75.	. If you are aware of victims groups in your area and have not become a member, could you say why?				
76.	5. Are there any other comments you wish us to have?				
	<del></del>				
Thank you for taking the time to help us in this study. Finally, please fill in the consent below.  I give my written consent to having this information stored, and agree to its use in this study and future studies.					
Sign	gnature <u>or</u> mark of consent Date:				
The study will also review all the previous research on injury due to the Troubles and this analysis will be included in the final report. You can see the results of the study on the WAVE website http://www.wavetraumacentre.org.uk					
	Please return this questionnaire to us <b>either by post or through the person or organisation that provided you with it.</b> You can also post it FREE OF CHARGE in the envelope provided or to:				

WAVE Trauma Centre, 5 Chichester Park South, BELFAST, BT15 5DW

Should you require follow-up support, WAVE can advise you of a suitable supporting organisation. You can contact WAVE on 028 9077 9922. WAVE have offices in Belfast, Ballymoney, Armagh and Derry/Londonderry.