

Injured in the Troubles: the needs of individuals and their families

Executive Summary - May 2012



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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.”

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, hopefully encouraging cross party political will to address need.

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

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 Minister 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

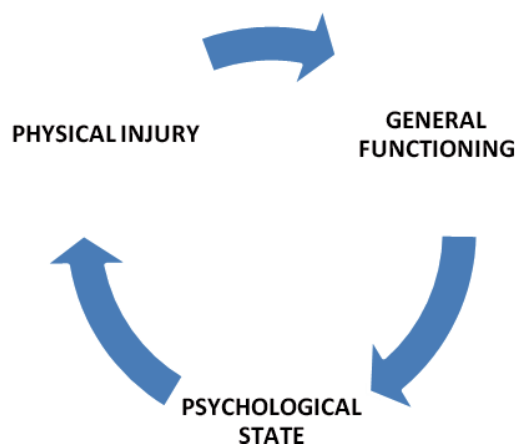
Ethical Approval

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 (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 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 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 for alleviating psychological trauma symptoms (trauma focused 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 on 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.

Justice

- 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 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.

APPENDIX 1: 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

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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

Dr Neil Foster Commission for Victims and Survivors NI

Hazel McCreedy Wounded Police Officers and their families

Eugene Morrissey WAVE Injured Support Group

Sean Coll Community Relations Council Victims' Committee representative

Marilyn Hyndman Northern Visions

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