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THE ANTI – BULLYING RESEARCH PROJECT

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EXECUTIVE SUMMARY

This report outlines a research project undertaken at the National Institute of Intellectual Disability, Trinity College Dublin which aimed to document the nature and extent of bullying of people with intellectual disability, and to explore the experiences of those who are bullied.

The research comprised three core elements:
(1) A review of literature to document the nature and extent of bullying of people with intellectual disability.
(2) A series of three focus groups with people with intellectual disability and key stakeholders to explore the experiences of those who are bullied.
(3) The development of an easy to read guide on bullying for people with intellectual disability.
This report documents the first two elements of the research. The easy to read guide is a separate document which can be obtained from the National Institute for Intellectual Disability or the National Disability Authority.

The literature review was conducted via a search of peer-reviewed research databases available at Trinity College Dublin library. Of the 90 results which were returned, 20 were deemed relevant to the specific area of bullying and intellectual disability. These sources were then snowballed for additional references. The search is thus confined to peer-reviewed research and does not claim to be comprehensive of the broader literature. Findings from this search revealed a dearth of research examining the issue of bullying for people with intellectual disabilities. What literature does exist is fragmented but can be broadly classified as comprising large scale prevalence studies, typically undertaken in the UK; smaller scale inclusive projects, typically undertaken in Ireland; and a variety of educational studies conducted internationally which cover the experiences of children with a broad range of disabilities. The literature reveals that bullying for people with intellectual disabilities is a pervasive problem. Most people with intellectual disabilities report that they have experienced bullying, in a variety of locations, and with

regularity. Bullying is variously defined, either as a self-report by study participants or by more objective methods. Verbal bullying is most prevalent, but incidents of physical assault and more indirect forms of bullying, such as ostracism and exploitation are also common. Bullying of children with intellectual disability is highly prevalent in schools and extends to community-based locations for both children and adults. Bullying of adults with intellectual disability in public places is a significant issue.

The reasons for bullying are complex and under-researched, however, the notion of 'disablist' bullying is gaining momentum. Disablist bullying refers to the specific bullying of people because they have a disability and places the issue within a discriminatory framework. The impact of bullying on individuals with intellectual disabilities is cumulative and devastating. Victims become socially withdrawn and may be forced out of their own neighbourhoods. Despite this impact, the evidence base on prevention is extremely limited. What is apparent, however, is that the implementation of prevention policies is weak. This lack of implementation raises a deeper question as to the credibility those in authority give to individuals' accounts of being bullied.

To explore these issues, focus groups and interviews were conducted with a small sample of people with intellectual disabilities and other stakeholders nationwide. Mindful of the limitations in generalising from this small sample, six key issues were raised;

(1) Choice and Control: People with intellectual disabilities referred not only to traditional verbal and physical types of bullying, but also referred to imposed restrictions on their lifestyle which they perceived as a form of bullying. Activities that their age-related peers engaged in routinely were not so easily undertaken by those with a disability who may rely on the support or authorisation of others.

(2) Confrontation versus Avoidance: People with intellectual disabilities presented mixed views on how to tackle the issue of bullying. Some

advocated that individuals withdraw from the situation, while others recommended that people 'speak up for themselves' and confront a bully. Responses from participants who did not have an intellectual disability focused on the importance of victims having someone they can go to if they are being bullied.

(3) Defining Bullying: People with intellectual disabilities tended to identify a wider range of behaviours as comprising bullying when compared to participants who did not have intellectual disability. Physical bullying, feelings of being controlled, and of being disrespected, were higher on the agenda of those with intellectual disability.

(4) Prevention: Participants made few suggestions regarding prevention strategies. Accessible information was advocated to inform people with intellectual disabilities what they should, and could, do if they are being bullied. While those who did not have intellectual disability emphasised the need for victims to inform others if they are being bullied, participants with intellectual disability reported that where complaints are made, they are not always followed up appropriately.

(5) Perpetrators of Bullying: Participants with intellectual disabilities tended to describe attributes of perpetrators (e.g. nasty) rather than specific groups of perpetrators per se. Bullying among people with disabilities, teenagers, strangers and family members were various cited as perpetrators of bullying.

(6) Disablist Bullying: Participants' discussions of the types of bullying they had experienced made reference to being targeted because of their disability. Participants noted how a 'joking' atmosphere could, either intentionally or not, become a bullying issue. Disablist bullying was identified as being perpetrated by both those with and without intellectual disability.

A number of recommendations based on these findings are presented to address these issues:

- This study has found that bullying is an important priority for people with intellectual disabilities; albeit that this priority may not be shared by others.
- **RECOMMENDATION** – greater awareness is needed that bullying is an important priority for people with intellectual disability – it is a topic which needs to be aired among those who provide support.

Choice & Control

- This study has found that people with intellectual disability can live and work in more restrictive environments than their age-related peers; these environments, including day centres and residential settings, may promote a bullying culture.
- **RECOMMENDATION** – those who support people with intellectual disabilities should be made aware that restrictions placed on people with intellectual disabilities to exercise their right to choice and control are deemed a form of bullying.
- **RECOMMENDATION** – training for those who support people with intellectual disabilities should emphasise a rights based approach to exercising self-determination.

Confrontation and Avoidance/Prevention

- This study has found that people with intellectual disability would welcome strategies to deal with bullies. The study also found that people with intellectual disabilities are concerned that their complaints of being bullied are not acted upon.
- **RECOMMENDATION** – people with intellectual disabilities should have access to training sessions to improve confidence and self-esteem, and teach them strategies to tackle bullies. Role play should be used within these training sessions.
- **RECOMMENDATION** – anti-bullying policies must be provided in an accessible format to ensure people are supported to make a complaint.

- **RECOMMENDATION** - where an individual confides in someone that they are being bullied, their complaint must be listened to and given credibility.
- **RECOMMENDATION** – anti-bullying policies must be implemented in cases where a complaint is initiated.

Defining Bullying

- This study has found that bullying may be defined differently by different stakeholders; these different perspectives should not undermine the credibility of victims.
- **RECOMMENDATION** – greater awareness is needed that what constitutes bullying by people with intellectual disabilities may not be universally agreed; this does not diminish the impact of the bullying.

Perpetrators/Disablist Bullying

- This study has found that adults with intellectual disabilities experience bullying by strangers in their communities.
- **RECOMMENDATION** – public attitudes toward people with intellectual disabilities need to be regularly assessed.
- **RECOMMENDATION** – positive perceptions of the abilities and contribution of people with intellectual disabilities need to be promoted.
- **RECOMMENDATION** –bullying of people with intellectual disabilities needs to be classified as disablist and within a discriminatory framework.

1. INTRODUCTION

The National Disability Authority Research Promotion Scheme for 2011 focused on the theme of 'Promoting Safety and Freedom from Abuse for People with Disabilities'. The National Institute for Intellectual Disability (NIID) at Trinity College Dublin in conjunction with the National Anti-Bullying Advocacy Group (NAAG) were awarded a research grant under this scheme to explore the issue of bullying for people with intellectual disability. Bullying is a regular, long term occurrence for the vast majority of people with intellectual disabilities who are far more likely to be bullied than their non-disabled peers. Mencap, a leading advocacy organisation for people with intellectual disabilities in the UK, note that the occurrence of bullying is so pervasive as to be "institutionalised throughout society"[1]. This research sought to explore this issue by undertaking three key tasks:

(1) A review of literature to document the nature and extent of bullying of people with intellectual disability.

(2) A series of three focus groups with people with intellectual disability and key stakeholders to explore the experiences of those who are bullied.

(3) The development of an easy to read guide on bullying for people with intellectual disability.

This report documents the first two elements of the research. The easy to read guide is a separate document which can be obtained from the National Institute for Intellectual Disability or the National Disability Authority.

[1] Mencap (1999)

2. A Review of Literature examining the Nature and Extent of Bullying of People with Intellectual Disability

2.1 Classifying the Peer-Reviewed Literature

A review of literature was conducted using four library databases at Trinity College Dublin. Search terms included bully, bullying and bullied with the terms intellectual disability, intellectual disabilities, learning disability and mental retardation. A total of 90 results were returned, of which 20 were deemed relevant for the current search. These sources were reviewed, and allied references were sourced through snowballing. The search is therefore confined to peer-reviewed research and does not claim to be comprehensive of the broader literature.

The literature on bullying of people with intellectual disabilities sourced in this review can be broadly, but not exclusively, classified under three types; studies undertaken in the UK, studies undertaken in Ireland, and studies focusing on the issue of bullying within educational settings. The section below presents a brief summation of these studies prior to a more in-depth thematic analysis of their content.

UK studies

UK studies in this field are typically dominated by large scale studies which aim to estimate the prevalence of bullying of people with intellectual disabilities; more have been undertaken in the UK than in any other jurisdiction (Emerson, 2010; Mencap, 2007, 1999). UK research has also explored policy responses to bullying (Sharp, 2001) and the issue of bullying within a human rights framework (Mepham, 2010).

Mencap, a leading advocacy agency for people with intellectual disability in the UK, has played a pivotal role in determining the extent of bullying experienced by adults and children with intellectual disabilities. Mencap's pioneering study, conducted in 1999, examined the experiences of over 900 adults with intellectual disabilities resident in England, Scotland, Wales and

Northern Ireland (Mencap, 1999). The survey findings, that 88% of participants experienced bullying in the previous year, and almost 33% were bullied on a daily or weekly basis, were pioneering in highlighting the scale of the problem (Mencap, 1999). Mencap conducted a similar study in 2007, but on this occasion focused on the extent of bullying experienced by over 500 children with intellectual disability attending schools in England, Wales and Northern Ireland. Rates of bullying were similarly high to those reported for adults, with 82% of children self-reporting that they experienced being bullied (Mencap, 2007).

A number of UK studies have emanated from these Mencap studies. Sharp (2001), for example, completed a review of police policies towards people with intellectual disability on foot of Mencap's finding that only 17% of victims reported to the police bullying of a criminal nature. Sharp's qualitative study concluded that a lack of awareness and inappropriate assumptions about people with intellectual disabilities led to inadequate responses to reports of bullying (Sharp, 2001). The Mencap studies also provided the framework for an exploration of bullying within a human rights perspective. Mepham (2010) argued that, despite the high levels of bullying experienced by people with intellectual disabilities as revealed in these pioneering studies, legislative change and policy initiatives introduced in the UK to improve the well-being of children did not meet the needs of children with intellectual disabilities. Ratification of the United Nations Convention on the Rights of People with Disabilities is presented as a powerful tool to spearhead disability legislation and policy in this area.

More recent large scale UK research has explored the framing of bullying as a disablist issue, defined as 'discrimination on the basis of disability'. This issue was explored via secondary data analysis of the Adults with Learning Disabilities Survey 2003/2004 which comprised a sample of n=1,273 adults with intellectual disabilities (Emerson, 2010). Over 50% of the sample self-reported being bullied during their school years, and 34% reported disablism, operationalised in the survey as 'people being rude or nasty because of your

learning disability'. The study also reported an association between bullying and health status. In keeping with findings from studies of bullying within the general population, bullying was negatively associated with health status and well-being (Emerson, 2010).

This brief overview is intended to outline the scope of some of the key studies conducted in the UK. The focus may broadly be deemed to be one of large scale studies examining the extent of bullying of people with intellectual disabilities and the policy implications of these findings.

Irish studies

The literature search returned few, but very recent studies conducted in Ireland. All studies relate to adults with intellectual disabilities, although one includes an account of an individual's childhood experience of bullying (Roberts & Hamilton, 2010).

While modest, the literature suggests that bullying is as prevalent in the Republic of Ireland as elsewhere (McGrath, Jones & Hastings, 2010; Roscommon Advocacy Council, 2010). An inclusive research study conducted by the Roscommon Advocacy Group, for example, identified two-thirds of interviewees (n=6) and 85% of members of a focus group self-reporting that they had experienced being bullied. Prevalence estimates from Ireland are mixed, however, with lower estimates of 43% being reported from a qualitative study including sixty adults with intellectual disability (McGrath et al., 2010).

A notable Irish study is that authored by Roberts & Hamilton (2010) which documented a vivid account of the life story of one of the authors who has an intellectual disability. The article explores the lived experience and lifelong effects of bullying and abuse from the author's time living within an institutional setting in the Republic of Ireland.

In summary, Irish studies, while modest in number, can be characterised by being recent in date, having an inclusive research approach, and having a focus on adults in receipt of specialist disability services.

Educational studies

Educational settings are a common focus of research in this area internationally (Rose et al., 2011, Didden et al., 2009, Holzbauer, 2008). Similar to estimates of bullying cited above, educational studies reveal bullying as a major issue for children with intellectual disabilities. When surveyed, the vast majority of teachers (96.7%) reported that they have observed incidents of bullying, typically "slurs, mimicking, mockery and staring" (Holzbauer, 2008: 162). These traditional forms of bullying are now being expanded to include newer forms of bullying experienced by school children, most particularly cyberbullying via the internet and mobile phones (Didden et al., 2009). In whatever manner bullying in schools is manifest, the issue is now defined as a 'pervasive problem' in American schools (Rose et al., 2011). Of 32 studies reviewed on the issue of bullying among school children with all types of disabilities, definitional issues abound. In addition, research gaps are evident, most especially in the evaluation of effective intervention strategies. The authors propose, similarly to those in the UK, that greater implementation of anti-bullying policies is essential if this issue is to be fully and appropriately addressed (Rose et al., 2011).

This brief introductory overview has attempted to outline some of the key types of research studies undertaken in this field. In quantity, the number of studies sourced in the review was small, and can be classified broadly, but not exclusively, as studies undertaken in the UK, studies undertaken in Ireland, and studies with an educational focus. These, and other studies, will now be presented thematically.

2.2 The Extent of Bullying

Prevalence estimates of the numbers of people with intellectual disabilities who experience bullying vary depending on how bullying is defined and what

methodology is employed to estimate prevalence. In addition, studies differ in terms of the timeframe during which the bullying is reported, and the stakeholder group participating in the study. Table 1 presents some of the key prevalence figures, and an indication of the time duration over which the bullying occurred. As can be seen, prevalence estimates vary from 96.7% of 'observed' occurrences of bullying by teachers (Holzbauer, 2008) to estimates of 4% for those self-reporting cyber-bullying (Didden et al., 2009).

Despite this variation, there is general consensus that bullying is highly prevalent (Mepham, 2010; McGrath et al., 2010). Many studies show that the majority of people with intellectual disabilities have been bullied at some point in their lives. Large scale studies, most notably by Mencap (2007, 1999) and by Emerson (2010) may be considered robust given their sample sizes and consequently their estimates, ranging from 50% to 88%, are likely to accurately represent the true prevalence of bullying of people with intellectual disabilities.

Various commentators have argued that people with intellectual disabilities are more likely to be bullied than their non-disabled peers (McGrath et al., 2010; Frederickson, 2010; Holzbauer, 2008; Bramston et al., 1999; O'Moore & Hillery, 1989). Comparative studies conducted in the UK and the USA indicate that young people with intellectual disabilities are typically more likely than their age-related peers to be teased (Martlew & Hodson, 1991) and to self-report being threatened, physically assaulted, or having possessions taken from them (Sabornie, 1994). In addition, those with intellectual disability are significantly more likely to be assessed by their peers as being the victims of bullying (Nabuzoka 2003; Nabuzoka & Smith, 1993). Those with ill-health, disability or a visible medical condition are estimated to be twice as likely as their peers to experience bullying (Office of the Children's Commissioner, 2006; Mencap 2007).

Prevalence estimates of bullying have been found to vary by gender in the UK, especially among children. School aged boys in special schools are

more likely to report being bullied than those from mainstream schools, while the opposite pattern is observed among schools girls where bullying in mainstream exceeds that reported by those in special schools (Brahm & Kelly, 2004). Prevalence estimates also vary depending on the type of bullying being examined. Name calling and verbal abuse are typically the most prevalent types of bullying experienced by people with intellectual disability (Mencap, 1999).

Table 1 below provides prevalence estimates from some of the key studies examining bullying of people with intellectual disability. The type of bullying and duration over which it is examined are also cited.

Table 1: Sample of prevalence estimates of bullying experienced by people with intellectual disability			
Study	**Author, Year**	**Prevalence**	**Time period where available**
Outcomes of anti-bullying intervention for adults with intellectual disabilities.	McGrath, Jones and Hastings, 2010	43%	Three months
Self-reported exposure to disablism is associated with poorer self-reported health and well-being among adults with intellectual disabilities In England.	Emerson, 2010	50%	In the last year
I'd like to choose who I dance with.	Roscommon Advocacy Council, 2010	75% of interviewees 85% of focus group attendees	Lifetime prevalence
Cyberbullying among students with intellectual disabilities in special education settings.	Didden et al., 2009	4-29% 4-9%	In preceding month Once a week
Disability harassment observed by teachers in special education.	Holzbauer, 2008	96.7% (of teachers witnessed bullying)	
Bullying wrecks lives: the experiences of children and young people with a learning disability.	Mencap, 2007	82% 77% (verbally hurt) 60% (physically hurt)	Lifetime prevalence

Pupils' Views on Inclusion.	Norwich & Kelly, 2004	83%	
Bullying and people with severe intellectual disability.	Sheard, Clegg Standen & Cromby, 2001	19% have bullied 11% were 'picked on'	At time of study
Living in Fear.	Mencap, 1999	88% 66% 32%	In preceding year More than monthly Daily or weekly basis
The nature of stressors reported by people with an intellectual disability.	Bramston, Fogerty & Cummins, 1999	37% were bullied 47% (verbal abuse)	
Sociometric status and social behaviour of children with and without learning difficulties.	Nabuzoka & Smith, 1993	66.7% women with ID 'rejected'	
Bullying and children with special education needs.	Whitney, Smith & Thompson, 1994	55% victimised	

2.3 The Nature of Bullying

Currently there is no one universally accepted definition of bullying (Carter & Spencer, 2006). While there is some agreement in the literature that a salient feature of bullying involves an imbalance of power (Ross, 2003), there is little consensus as to whether a single incident can be regarded as bullying or whether it must be refer to a series of actions over time (Olweus, 2001; Byrne, 1994). There is also debate as to whether 'the odd fight or quarrel between two individuals of equal strength' can be deemed as bullying (Smith & Sharp, 1994).

Studies examining bullying as an issue for people with intellectual disability use both subjective and objective definitions of bullying. Subjective definitions emanate from the study participants themselves. The Living in Fear study conducted by Mencap (1999), for example, asked respondents to describe the types of bullying or harassment they faced. Respondents reported a range of behaviours including being pushed, kicked, and for many, being robbed of their possessions during an assault. Name calling and verbal abuse were reported most commonly (47%), followed by physical assault (23%). The Roscommon Advocacy Group's inclusive research project on bullying (Roscommon Advocacy Council, 2010) similarly asked respondents to define the concept. Bullying was described as being 'told to shut up', 'being called nasty names... pushing', 'people imitating you', 'being called names on the street', 'being ignored', and 'damaging your property'. Similarly, Emerson's (2010) survey of over 1,000 adults with intellectual disability did not provide a definition of bullying for respondents, but rather asked questions such as 'did anyone ever bully you at school?' Participants' responses thus reflect their own interpretation of bullying.

Other studies have provided an objective definition of bullying. McGrath et al., (2010), for example, presented the following definition of bullying to people with intellectual disabilities in order to measure self-reported bullying amongst the group: "Bullying can take many forms. It can be by one person only or several persons, it happens more than once and can be any of the following:

kicking, biting, name-calling, stealing, pushing, threatening, making rude gestures, texting upsetting messages, not being let join in, spreading rumours. Bullying often makes us feel sad and frightened and upset" (Olweus & Limber, 1999). Similarly Holzbauer (2008) employed an objective definition of bullying when exploring bullying among school children with disabilities, including those with intellectual disabilities. A variety of sources were employed to develop a working definition of bullying, including the adaptation of an existing workplace harassment survey and a dictionary definition. From these sources, a total of fifteen types of harassment were identified including 'slurs', 'mockery', 'intimidation', 'ostracism' and 'exploitation'.

More recently, social media has been identified as a new vehicle for bullying (Didden et al., 2009). Bullying via mobile phone is defined by the following actions; sending anonymous text messages, bullying via text messages, sending photos, films, and 'bombs' of text messages, ignoring calls and making frequent calls. Behaviours on the internet which may comprise bullying include 'hurting, harassing, insulting, name calling, making fun of or ignoring'. Of these behaviours among students with intellectual disabilities, ignoring or making overly frequent calls and sending anonymous text messages were the most frequent forms of mobile phone bullying. Cyberbullying, which occurred less often than mobile phone bullying, took the form of posting malicious information about others, and sending anonymous emails.

Of the many behaviours that may be considered bullying, it is important to note that these acts do not necessarily occur in isolation (Mencap, 1999). Some acts may lead on or escalate to other types of bullying, abuse and assault (Mepham, 2010; Mencap, 1999). Studies investigating acts of bullying have revealed criminal acts against the person including severe physical abuse, torture and theft (Roberts and Hamilton, 2010; Mencap, 1999). Despite the severity and criminal nature of these acts, however, bullying is often unreported (Sharp, 2001).

This under-reporting may reflect disagreements as to what constitutes bullying. There is evidence of a disparity between what people with and without intellectual disability comprise as bullying (Sheard et al., 2001). Individual accounts illustrate how reports of bullying are sometimes ignored or not perceived as a bullying issue by staff. “Others are picking on me all the time and staff won’t do anything about it” (Mencap, 1999: 9). “I was told to ignore the bullying. That’s easier said than done” (Mencap, 1999: 11). This trivialisation of bullying can result in figures of authority failing to provide appropriate support (Sharp, 2001).

The following table shows the various forms of bullying, classified as physical, verbal and indirect, which are cited in the literature.

Table 2: Types of Bullying as Defined in Research Studies		
Physical	**Verbal**	**Indirect**
Punching	Slurs	Staring
Spitting	Mimicking	Ostracism
Slapping	Mockery	Exploitation
Being knocked over	Ridicule	Spreading rumours
Assault	Tormenting	Not being let join in
Kicking	Intimidation	Name calling on internet
Biting	Retaliatory threats	Insulting on internet
Stealing	Name calling	Ignoring phone calls
Throwing objects	Teasing	Frequent phone calling
Hitting	Asked to leave a building	Ignoring on the internet
Hair pulling	Shouting	Receiving anonymous texts/ texting upsetting messages
Throwing stones	Swearing	Putting information on the internet
Spitting	Demanding money	Sending anonymous emails

Poking	Threatening	Hacking someone's computer
Being beaten up		Making rude gestures
Having ones' head banged against a wall		Being made fun of on the internet
Pushing		Media denigration (criticism)
		Making someone feel uncomfortable
		Shunning
		Isolating
		Making somebody do something they should not

2.4 Where does Bullying Occur?

Bullying in schools can be an extremely common experience for children with disabilities (Fredrickson, 2010; Rose et al., 2011; Didden et al., 2009; Department for Children, Schools and Families, 2008; Holzbaurer, 2008; Brahm & Kelly, 2004: Kuhne & Weiner, 2000; Whitney et al., 1994; Nabuzoka & Smith, 1993). Many school children with intellectual disability report being rejected and victimised (55% Whitney et al., 1994; 67%: Nabuzoka and Smith, 1993). For the vast majority (80%), this bullying occurs within the school setting (Mencap, 2007). In comparison with their age-related peers, school children with intellectual disabilities are 3.5 times more likely to be bullied (Saborine, 1994). Communal non-teaching areas such as school corridors, lunch queues, toilets and playgrounds tend to be locations where bullying is most reported (Department for Children, Schools and Families, 2008). Despite the extent of the problem within the school environment, the implementation of school anti-bullying policies is poor (Holzbauer, 2008). Bullying of school children, however, extends beyond the confines of the

school location. One third of children who have been bullied report that this has occurred on the street, in parks and on public transport (Mencap, 2007).

The incidence of community bullying is not restricted to children. In fact, with regard to adults Mencap note that bullying in public places is the most significant problem facing people with an intellectual disability (Mencap, 1999). The vast majority of adults with intellectual disabilities who have experienced bullying (73%) report that it has occurred in a public place. Respondents reported being targeted by groups of individuals, and by people they did not know within their communities. One quarter of adults reported being bullied on the bus, a substantially higher proportion than for any other form of transport. This finding is likely to reflect the fact that the bus is a main form of transport for people with intellectual disability. Bullying was also reported in local leisure areas such as shops (12%) and pubs (10%). Public parks are identified as an unsafe area due to the presence of 'gangs' (Hartas & Lindsay, 2011). Day centres were also identified as a key location of bullying (McGrath et al., 2010; Roscommon Advocacy Council; 2010, Mencap, 1999). In fact, people with intellectual disability are more likely to report being bullied in day centres than in any other day-time location such as work, college or home (Mencap, 1999). The hierarchical structure of day centres is thought to contribute to an environment where bullying is likely to occur (Sheard et al., 2001).

2.5 Why is bullying of people with intellectual disabilities so prevalent?

Bullying typically occurs where there is an imbalance of power, whether social, emotional or physical, between the bully and the victim (Didden et al., 2009). People with intellectual disabilities are often referred to as a vulnerable group, and may be perceived as 'weaker victims' (Sheard, et al., 2001; Mencap, 1999). They are more likely to experience difficulty in resisting bullies; to be perceived as having lower social status; to experience isolation due to having a disability; to exhibit a lack of awareness of what may or may not comprise bullying; and to experience difficulty in reporting bullying

(Department for Children, Schools and Families, 2008; Brahm & Kelly, 2004; Sheard et al., 2001; Kuhne & Wiener, 2000).

The specific bullying of people because they have a disability is termed 'disablist' bullying and is deemed comparable to other discriminatory forms of bullying such as homophobic bullying (Emerson, 2010; Mepham, 2010). The higher prevalence of verbal bullying (Mencap, 1999), most especially using derogatory terms about people with disabilities, attests to the discriminatory nature of much of the bullying experienced by this population.

Some commentators argue that the pervasive lack of choice and autonomy extended to people with intellectual disability promotes a culture that may be disrespectful, controlling, and one which may foster bullying (Roberts & Hamilton, 2010). Within such cultures peer to peer bullying may thrive. Peer to peer bullying refers to bullying of people with intellectual disabilities by people with intellectual disabilities. Prevalence estimates are few, but figures of approximately 25% have been reported for bullying by people with intellectual disability (Didden et al., 2009; McGrath et al., 2010). These incidents have been found to occur more often within restrictive settings such as special schools (O'Moore & Hillery, 1989) and segregated living environments (Sheard et al., 2001). The complexities of whether this interaction represents characteristics of the individuals or of the settings have yet to be explored (Rose et al., 2011). The literature does suggest, however, that those who report that they have engaged in bullying of peers were often the victims of bullying themselves (Whitney et al., 1994).

Societal factors may also contribute to the higher rates of bullying experienced by people with intellectual disabilities. Negative attitudes towards people with disabilities go unchallenged as efforts to promote equality through policy are deemed to be insufficiently implemented (Mepham, 2010). More specifically, the failure to develop and implement anti-bullying policies has been identified as a contributing factor to the high prevalence rates (Sharp, 2001; Sheard et al., 2001). Finally, societal attitudes of the capacity

of individuals with an intellectual disability to understand and experience bullying may, albeit unwittingly, trivialise the impact of this issue. As Bill Roberts, whose life story is documented in one of the papers, and his co-author state: "[There is still a] prevalent belief that people with intellectual disabilities are not affected by bullying and they do not understand what is happening to them" (Roberts & Hamilton, 2010: 132). Mencap acknowledge that 'being called a name may appear trivial in itself' but also note that it assumes a considerably greater significance 'when it happens all the time to the same person' (Mencap, 1999).

2.6 The Impact of Bullying

Bullying can have cumulative and devastating effects. Those who are the victims of bullying may feel embarrassed and humiliated. For people with intellectual disabilities who may already experience social isolation, bullying can severely undermine their self-confidence (Mencap, 1999). Victims of bullying may experience significantly high level of stress, live in fear of their perpetrator and can be driven out of their own communities (Mencap, 2007, 1999; Bramston, Fogarty & Cummins, 1998).

The impact of bullying on children is pervasive. Victims of bullying experience emotional distress and engage in restrictive behaviours to avoid their perpetrator. For children with intellectual disabilities, strategies to cope with bullying include retreating to their bedroom, avoiding the places where the bullying occurred, and being too scared to leave their homes (Mencap, 2007). As a consequence children's social and recreational activities are markedly restricted. This impacts not only on their own quality of life, but extends to other family members. In particular, parents may become fearful of letting their child with an intellectual disability play outside with other neighbourhood children (Mepham, 2010; Lee et al., 2008). Educationally, all children who are bullied are at risk of experiencing academic problems, discipline problems, truancy, dropping out, delinquency and mental health difficulties. These risks are magnified for children with special educational needs (Frederickson,

2010) and indeed are apparent both for those who bully and those who are the victims of bullying (Reiter & Lapidot-Lefler, 2007).

For adults with intellectual disability, the impact of bullying is similarly pervasive. Early studies on independent living and community based arrangements for people with intellectual disabilities indicated that quality of life is significantly impaired for victims (Halpern et al., 1986; Flynn, 1989). People with intellectual disability themselves rate bullying as a leading stressor (Bramston, Fogarty & Cummins, 1999). But it is perhaps individual accounts of victims that illustrate best the impact of bullying on people with intellectual disabilities:

"Ben, now 19, is receiving counselling to help him deal with the ongoing distress that bullying has caused. He is much happier. Nonetheless, he is still very upset about what happened and refuses to go anywhere near his old home" (Mencap, 2007: 8).

2.7 Prevention

There is very little literature on preventative strategies to combat bullying of people with intellectual disabilities. A recent review of outcomes of bullying interventions returned no published research in the intellectual disability area (McGrath et al., 2010). The study itself did, however, examine the effectiveness of two psycho-educational programmes in the UK and found that those who participated in the programmes reported a decrease in being bullied following their participation (McGrath et al., 2010).

The research also indicates a failure to implement existing anti-bullying policies (Hartas & Lindsay, 2011; Holzbauer, 2008; Sharp, 2001; Sheard et al., 2001) and a failure to follow up on disclosures of bullying (Mencap, 2007; National Autistic Society, 2006). This lack of implementation does little to encourage victims to disclose their situation. This is regrettable, as when asked, people with intellectual disability recommend 'talking about it' to a confident as a key strategy in combating bullying. They also recommend that

‘maybe by doing a role play of somebody getting bullied would help us understand better’ (Roscommon Advocacy Council, 2010: 9).

The failure by figures of authority to respond appropriately to bullying incidents reinforces a proposed prejudice that people with intellectual disabilities are simply not taken seriously when they report an incidence of bullying (Mencap, 1999). Bill Roberts, whose life story has been cited previously, illustrates the empty rhetoric of those charged with supporting him:

‘It went on for about five years. I tried to say at one stage. It was a question of whether they’d believe you or not. It was more or less your word against theirs. Most of the nurses would say it’s none of their business. It’s part of the school. You have to put up with it’ (Roberts & Hamilton, 2010: 129)

2.8 Research Gaps

There are significant gaps in knowledge of the nature and extent of bullying for people with intellectual disabilities. In fact, the field is only emerging in recent years. This dearth of literature is noted;

“Given the potential negative outcomes of bullying and the relatively high prevalence of victimization and bullying behaviour among people with intellectual disabilities, the lack of research on bullying is a serious omission in the field” (McGrath et al., 2010; 337).

The gaps in research are mirrored by gaps in anti-bullying policies and their implementation for people with intellectual disabilities. The evidence, albeit limited, suggests that educators, the police and service providers are ill prepared to support those who experience bullying (Mepham, 2010, Flynt & Morton, 2004: Sharp, 2001). Preventative strategies may be plentiful, but only one paper was sourced which evaluated the efficacy of such interventions. The study provides evidence of the effectiveness of the programmes, but the authors acknowledge that the reasons as to why the programmes are successful remain unknown (McGrath et al., 2010).

2.9 Conclusion

This literature review has found that bullying is a significant problem for the vast majority of people with intellectual disabilities. It varies in nature and includes physical, verbal and indirect manifestations. It occurs across a range of settings and occurs on a regular basis. People with intellectual disabilities may be specifically targeted as the victims of bullying on the basis of their disability. Disablist bullying places the issue within a discriminatory framework and illustrates how people with intellectual disability must be listened to seriously when they report an incident of bullying. The impact of bullying is pervasive, not only on the individual victim, but also on those who support the individual. Preventative measures are few and require greater implementation and evaluation. The evidence base is, regrettably, poor and considerably more research and implementation of good practice is required.

3.0 Research Aims and Questions

The aims of this research project were to:

(a) Investigate the nature and extent of bullying of people with intellectual disabilities via a review of literature.

(b) Explore the experience of bullying and bullying prevention among people with intellectual disabilities and other relevant stakeholders via a series of three focus groups.

(c) Employ an inclusive research methodology whereby trained co-researchers with intellectual disabilities participate in the development of research materials and in the facilitation of focus groups.

(d) Develop an Anti-Bullying Guide for people with intellectual disabilities based on the findings from the literature review and the focus groups.

(e) Ensure that the Anti-Bullying Guide presents the issues regarding bullying in an accessible and relevant format for people with intellectual disabilities.

(f) Supplement the evidence-base of research where currently a research gap is present.

The key research questions were:

(1) What is the evidence base regarding the nature and extent of bullying of people with intellectual disabilities emanating from the literature?

(2) What is the perception of people with intellectual disabilities and other relevant stakeholders concerning their experiences of bullying of people with intellectual disabilities?

(3) What strategies do people with intellectual disabilities and stakeholders consider useful in preventing bullying?

4.0 ETHICS

Ethical approval was obtained from the Research Ethics Committee of the School of Social Work and Social Policy, Trinity College, Dublin. Ethical considerations identified at the outset of the project included:

- Communicating the purpose of the research to people with intellectual disabilities.
- Obtaining informed consent from people with intellectual disabilities.
- Acknowledging the importance of not naming individual perpetrators of bullying during the focus groups.
- Acknowledging the sensitive nature of the topic.

These issues were addressed in the information sheets, flyers and consent forms developed for this study. Ethical approval was awarded by the Research Ethics Committee on 19th August 2011.

5.0 Research Methodology

5.1 Methodology

A qualitative research approach was adopted as the most appropriate methodology for this research on the basis that it would elicit an in-depth understanding of the perspectives and experiences of stakeholders. In addition, the literature review indicated that an exploratory approach was warranted.

Three focus groups were proposed to gather data for this research, each targeted at the following groups:
(a) people with intellectual disabilities,
(b) family members and direct care staff,
(c) 'community workers', defined loosely as people working in a mainstream community setting who provide support to people with intellectual disabilities.

5.2 Sampling

Convenience sampling was used to select gatekeeper organizations and individuals who were providing services to people with intellectual disabilities. In total, one hundred and fourteen organizations and individuals were contacted by email. Each communication included an invitation to participate in the focus groups and accompanying documentation:

- A Study Information Sheet (Appendix A)
- A Consent Form (Appendix B)

In order to ensure that there was national representation among participants, three locations nationwide were selected to host focus groups: Galway, Cork and Dublin. Each location targeted a different group: people with intellectual disabilities in Galway, family members and direct care staff in Cork, and community workers in Dublin.

5.3 Procedure

Participants of focus groups and interviews were all sent information prior to the focus group/interview (see appendices). On arrival at the venue, participants were asked to provide written consent. Specific support was provided by the research team to participants with intellectual disability to ensure that they were appropriately informed about the research study. Participants were then invited to discuss the issue of bullying. No definition of bullying was provided rather, in keeping with previous research, participants themselves reflected on their own interpretation of the term. Participants were asked to discuss their views on:

- what behaviours comprise bullying?
- who are the perpetrators of bullying?
- where does bullying occur?
- what can people do to prevent bullying?

While the original research methodology proposed three focus groups, each located within a city nationwide, a poor attendance at some focus groups resulted in a modification to this methodology. These modifications are outlined below:

(a) The focus group for people with intellectual disabilities hosted in Galway was well attended.

(b) The focus group for family members and direct care staff hosted in Cork attracted only two attendees, both of whom worked in the disability field. No parents presented at this focus group. Due to restricted numbers a qualitative group interview was conducted with the two attendees. In response to the poor attendance at this focus group, a second focus group for family and direct care staff was organised in Dublin. In an effort to increase attendance the following steps were taken:

- Two nationwide parent and family member associations agreed to disseminate information about the study via their mailing lists.

- Two advocacy organizations were approached.
- Parents attending a workshop at the NIID were invited to participate.
- Support staff in three organisations providing services to adults with disabilities were invited to disseminate information about the focus group to family members of adults using the service.

Despite these efforts no individuals attended this focus group. Consequently, there is no contribution within the research findings from family members.

(c) The final focus group, for community workers, was scheduled to take place in Dublin. Contact was made with a number of community workers to participate in this focus group. It became obvious at an early stage in these communications, however, that these potential participants were experiencing difficulties taking time from their working day to attend a focus group. With the agreement of the community workers, one-to-one qualitative telephone interviews were organized as a viable alternative. This alternative methodology ensured the views of community workers were represented in the study.

While the responses to some focus groups were poor, the researchers were mindful of the considerable interest expressed by people with intellectual disabilities in this issue. Consequently, an additional focus group was hosted specifically for people with intellectual disability in Dublin. As per the focus group for people with intellectual disability hosted in Galway, this focus group was also well attended.

In summary, a total of two focus groups were hosted, each of which were attended by people with intellectual disabilities. These were supplemented by qualitative (individual and group) interviews with those working in the disability field and with those who worked within community settings who may be involved in cases of bullying. No family members were represented in this study.

5.4 Participants

In total, twenty adults with intellectual disabilities participated in the two focus groups. Eight of these participants were women and twelve men.

Two individuals attended the focus group for those working directly in disability services, an advocacy worker and a direct care staff worker, both of whom participated in a group interview.

Finally, the 'community worker' sector was represented by four individuals; an educational instructor, an employment support worker, an access officer for a transport company, and a Community Garda. Each of these individuals participated in individual qualitative telephone interviews. All of the interviewees were women.

6.0 ANALYSIS

Each focus group and interview was openly recorded and transcribed verbatim upon completion. The researcher read through the focus group transcripts and identified statements relating to the research questions, as well as frequently occurring themes outside of these. The transcripts were uploaded into the software program NVivo version 8 and thematic content analysis (Braun & Clarke, 2006) was conducted. The definition of theme used by Braun and Clarke (2006) was used, that is, a word or phrase that 'captures something important about the data in relation to the question, and represents some level of patterned response or meaning within the data set'(p. 82). From these analyses, a total of six core codes/themes were identified[2]. These findings were then triangulated with the telephone and group interviews which were manually coded.

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[2] A fuller account of the codes/themes, including the sub codes/themes, number of references attributable to each code/theme and number of sources in which it occurs is available on request from the NIID.

7.0 Research Findings

A total of six themes were identified.

These included:

1. Choice and Control
2. Confrontation versus Avoidance
3. Defining Bullying
4. Prevention
5. Perpetrators of Bullying
6. Disablist Bullying

Each theme is presented in turn, commencing with commentary provided by participants with intellectual disabilities. These comments are then supplemented with the comments of other relevant stakeholders as appropriate.

7.1 Choice and Control

As well as the standard types of bullying described in literature on bullying, such as verbal, physical and exclusionary behaviours, participants with intellectual disabilities in this research mentioned that being controlled and denied opportunities to live autonomously are deemed forms of 'bullying'. When asked what bullying was, and at other points in the focus groups, participants made reference to being controlled and restricted in where they go or what they do. One participant with an intellectual disability described bullying as being held back from participating in activities:

> You know you go around -do your own thing and somebody says, 'You're not going to that place, not going to the pub. You're not allowed to do your own thing. (…) They're grown men and their family know about it, when they're going off (inaudible 1:20:52) if you want to go places it's up to you. You're allowed to do your own thing and don't let anybody walk all over you. Because they will walk over you and not let you do your own thing. That's bullying.
>
> (Participant 5, male, focus group 2)

Another participant talked about being over controlled by a staff member and standing up to them:

> One day I was making a sandwich. I was in the house and I was making a sort of a sandwich and she said 'Oh you can't make that, you have to make a different one'…I said 'I won't', she said 'You will', I said 'I WONT!
>
> (Participant 10, male, focus group 1)

Terms such as being 'shouted at' or 'bossed around' were used to describe the phenomenon of control. Participants related these experiences as happening in the service and the workplace:

> I don't like my job because they control people's minds…control people's minds Like let me say me something about ..Richard's[3] not a boss but he's working a lot. Richard's not my key worker anymore, you see. He bosses me all the time around. He bosses people all the time.
>
> (Participant 8, male, focus group 2)

Other stakeholders in this research, those who did not have intellectual disability, expressed mixed views on the issue of control. Some observed that family members can restrict the choices and activities of people with intellectual disability by exerting too much control over the person's finances.

> Sometimes within their families you know particularly the whole financial area is a really tricky, really peculiar. But sometimes I don't think that people with disabilities realise themselves that….well it might constitute as bullying but they might not have the money to do activities that they want to do or whatever. They don't have control over their own finances sometimes.
>
> (RT manager, individual interview)

[3] Fictitious name

> It could be a family member not allowing the person to make their own life decisions with regard to how they spend their money or how they spend their time or you know taking away their freedom of choice - saying you are not allowed to do this or you are not allowed to do that…rather than you are an adult you are capable of deciding you know…that is quite small, strong form of bullying that I recognise that people who use our service would encounter you know.
>
> (Educational Support Worker, individual interview)

Other stakeholders expressed varying perspectives on this, with some articulating the opinion that the term 'bullying' can be overused. One participant, for example, expressed the view that sometimes people with intellectual disabilities perceive themselves to be bullied when a person without disabilities' intention is to give them guidance on what to do:

> I suppose I find it hard to say what isn't bullying...I suppose if someone is trying to help you and guide you then but if the person with the intellectual disability feels it is bullying…like perceives it as that even though it could be that they were trying to help them.
>
> (Community Garda, individual interview)

This view was shared by another participant, who reasoned that sometimes being 'cajoled' by staff to try out new activities once could be perceived as 'bullying' whereas the staff were

> 'saying, well in order to make an informed decision sometimes we have to try something [a new group activity]'.
>
> (RT manager, individual interview)

To conclude, the identification of 'choice and control' for people with intellectual disabilities as a key theme in their discussions regarding bullying raises some interesting issues regarding the expectations people have to live a life comparable to their age-related peers. Being afforded an opportunity to

manage one's one money, make a sandwich or go where one wants are everyday behaviours. The impact of others in a person's ability to engage in these behaviours may not be cited by those who do not have intellectual disability as bullying on the basis that most adults engage in these behaviours without restriction. For those with intellectual disabilities who aspire to leading a life comparable to their age-related peers, such restrictions are perceived as a form of bullying, comparable to more traditional forms of verbal and physical bullying.

7.2 Confrontation versus Avoidance

There were directly oppositional views aired by people with intellectual disabilities when asked what they could do to 'keep safe from bullying'. Some participants spoke of 'going to their room' or 'walking away' while others talked about reporting the bully or 'tell someone'. In terms of walking away, these are some of the comments made by participants in the focus groups:

> I'd say walk away from it.
>
> (Participant 4, female, focus group 2)
>
> *I'm going to ask this question -what things can <u>you</u> do to keep safe from bullying?*
>
> Participant 2, male: Walk away
>
> *Walk away*
>
> Participant 2, male: Ignore people, if you're being bullied
>
> Participant 3, female: That's right
>
> Participant 4, male: Mind your own business
>
> Participant 5, female: Keep a distance and not to get involved. Walk away.
>
> (Focus group 1)

Below are some comments made by those advocating telling someone or standing up for themselves:

> Tell someone to stop and <u>keep doing it.</u>
>
> (Participant 6, male, focus group 1)

> You could talk to the bullier and tell them to stop or you'd report them.
>
> (Participant 7, male, focus group 2)

Within one focus group there was lively debate on the correct course of action – avoidance or tackling bullying head on.

> Participant 9, female: How do you stay away from the bullies?
>
> Participant 2, female: It's easy
>
> Participant 9, female: How?
>
> Participant 3, female: You can walk away…
>
> Participant 2, female: Don't do anything
>
> Participant 9, female: I stood up for myself. I wouldn't let anyone bully me…what's wrong with you, like?
>
> (Focus group 2)

The views of other stakeholders without intellectual disability corresponded with the latter point, with many stating that it was important that the person with intellectual disabilities could tell someone or talk to them about bullying:

> Well like there is key workers for each person…so I'd like to think that they are comfortable enough with a key worker that you would like discuss things, like issues, you know?
>
> (Care staff, group interview)

> (…) you know it's very important that they [people with intellectual disabilities] feel if they have a worry or concern that they have you know somebody they can go to that they can feel comfortable and confident in being with…
>
> (RT manager, individual interview)

In summary, people with intellectual disabilities were mixed in terms of their response to being bullied. Many stated that they would withdraw from a situation of bullying. Others commented that they would confront the bully and ask that the bullying stop. Responses on this issue from those who do

not have intellectual disability were more likely to refer to the importance of a victim having someone to talk to, rather than about withdrawing or confronting. This disparity may reflect different experiences of stakeholders of being bullying.

7.3 Defining Bullying

In general, the list of behaviours and interactions labelled as 'bullying' by people with intellectual disabilities encompassed a wider range of behaviours compared to those generated by other stakeholders. As previously cited, feelings of being controlled by family or staff members was characterized by participants with intellectual disability as bullying. In addition, participants with intellectual disability included in their descriptions of bullying occasions whether they felt they were not respected or listened to:

> [struggling to speak] They pretend, not listening to you. You say something to them and they don't want to know about it.
>
> (Participant 5, female, focus group 1)

> Not listening to other people - what people are saying.
>
> (Participant 1, male, focus group 2)

> You might be out with your friends and you're going out for dinner and the friend with you. And they ask what they want before you and you might be first in line.
>
> (Participant 10, male, focus group 1)

A pattern emerged in the data whereby different forms of bullying were emphasized by the various stakeholder groups. Verbal, physical and cyber bullying were mentioned by most participants in this research. The types of physical bullying were described in more detail by the participants with intellectual disabilities and emphasized more by this group. Examples included hitting, slapping, pinching, hair pulling. Also, participants with intellectual disabilities emphasized more being 'bossed around' and a lack of

control as bullying. Extortion of money was referred to by both people with intellectual disabilities and one other stakeholder – the Community Garda:

> (…) like one girl now she had a severe disability and she said that she used to get harassed at bus stops for money.
>
> (Community Garda, individual interview)

> You know like when we're getting the 41C [bus]…like strangers coming up asking us for money and like taxis coming up asking us to get in the taxi or calling us.
>
> (Participant 3, female, focus group 2)

To conclude, the findings emerging from participants' discussions regarding what comprises bullying revealed different perspectives from different stakeholders. People with intellectual disabilities expressed a wider range of behaviours as comprising bullying. This may reflect the experiences of different stakeholders in being the victims of bullying. People with intellectual disability were more likely to mention physical bullying and, as discussed previously, restrictions on their activities. In addition, they cited bullying from strangers as a specific problem, whether being harassed at bus stops, or strangers enticing them into cars. While these behaviours may be experienced by all members of society, people with intellectual disabilities are particularly vulnerable in these situations.

7.4 Prevention

There was little dialogue in the focus groups and interviews about the practical steps people with intellectual disabilities could do to prevent themselves from being bullied or 'keep safe from bullying'. The Community Garda was the exception to this trend, advising that people with intellectual disabilities don't go out alone but in pairs, to avoid becoming a target.

Other interviewees in this research commented on the importance of having accessible information about bullying for people with intellectual disabilities,

including general printed information and anti–bullying policies. Two interviewees described accessible anti–bullying policies/programmes that had been implemented. Anti-bullying policies were not identified per se as a preventative measure by people with intellectual disabilities rather they spoke of complaints procedures that were not always perceived as being effective:

> A lot of the reasons why some people don't report bullying who are bullied don't report it because not taken seriously, followed up.
>
> (Participant 6, male, focus group 2)

Another participant's account of being bullied suggested that they were not informed sufficiently to access the complaints mechanism itself:

> Participant 7, female: People with no disability bully us 'cause they think its [pause] fun and I was bullied by em my brothers friends and they don't like understand like - they got, like they know how to do things that I don't know how to do and they make fun of me...and it kind of hurts your feelings…it hurts your feelings and you don't know what to do and we usually go and to tell people but they don't listen to us because we have a disability (…)
>
> Participant 6, male: Actually you should do Sarah[4], tell your key worker or your social worker. That's the way.
>
> Participant 7, female: [interrupting] I don't know who my social worker is!
>
> (Focus group 1)

Finally, all stakeholder groups identified the strategy of going to a trusted person such as a Garda, key worker, anti-bullying group or family member if they were being bullied. The general consensus was that bullying prevention hinged on people with intellectual disabilities feeling that they could approach a trusted person if they were being bullied. As stated earlier, those without intellectual disability were more likely to prioritise this strategy.

---

[4] Fictitious name

To conclude, practical measures of ‘staying safe’ were rarely mentioned by participants in this research as a preventative strategy, other than by a Community Garda. Rather, participants without disabilities commented on anti-bullying policies and on the need for victims to confide in someone about their experiences as preventative strategies. In contrast, participants with intellectual disability were more likely to comment about the challenges of making a complaint, and of being listened to. It may be that while victims of bullying are being encouraged to inform others of their experiences, the responses of those who they approach are sometimes deemed to fall short of the support being sought.

7.5 Perpetrators of Bullying

The perpetrators of bullying identified by the various stakeholders participating in this research differed.

Within the discussions among participants with intellectual disabilities, for example, it was difficult to discern from many of the accounts who was being identified as a bully. There were several instances of identifying specific groups such as direct family, strangers and staff. However, generally, when asked ‘Who bullies who?’ focus group participants described the personal characteristics of the people, such as ‘mean’ and ‘nasty’.

In contrast, most of the other stakeholders identified specific groups such as teenagers, strangers and family members:

> I don’t know why teenagers are the first that come up in my mind there would be others that would be adults.
>
> (Transport worker, individual interview)

Overall, peer to peer bullying was cited by the interviewees as the most frequent type of bullying:

> Em I suppose what I've mentioned before is around the more dominant person in any sort of a group setting, you know maybe bullying or teasing or you know picking on somebody that they perceive to be weaker and not as the same ability as themselves like or it could be something as…like well you can't do this and I'm much better than you kind of thing you know that kind of thing?
>
> (Education support worker, individual interview)

> I suppose it's hard to em to be very hard to look out all the time...because they [her clients] can be very sneaking in the their ways of picking on one individual person and I suppose the people they pick on then are afraid to say it…
>
> (Care staff, group interview)

In combination, findings from all stakeholders identified a range of perpetrators, among them family members, staff and strangers. Of interest was the commentary by people with intellectual disabilities themselves which tended to focus on the characteristics of those who bully, rather than their social group. Where bullies were identified, peer to peer bullying was dominant.

7.6 Disablist Bullying

People in the focus groups talked about disablist bullying – bullying people because they had a disability. Some focus group participants characterized making fun of people with disabilities as bullying:

> Well I'm just getting my thinking cap on [laughs]. There's all kinds of things going into my mind now. And another subject that we didn't hear, or I didn't hear was people with stigmas. Things wrong with them – speech problems, physical problems of that nature and people make fun of them, which is not a very nice thing at all. That's another form of bullying.
>
> (Participant 6, male, focus group 2)

> I know another thing – copying other people that can't walk properly or anything like that now…mocking them, do you know the way. And we should be lucky now the way we can walk straight now.
>
> (Participant 4, male, focus group 1)

> Imitating what you say.
>
> (Participant 5, female, focus group 1)

However, there was not universal agreement that making fun of people's disability was bullying:

> (Participant 1, male, focus group 1): This comedian like he makes jokes about people with Down Syndrome which is very hurtful like, you know, yeah, yeah.
> […]
> *And is that bullying?*
> (Participant 1, male, focus group 1): I don't know if you could say it is or not.

Other stakeholders flagged the issue of disablist bullying, describing it as people without disabilities 'making fun of' a person's disability:

> *When you think of what happened there [bullying of person without a disability] can you think of any examples of people being bullied with intellectual disabilities?*
> Not off hand but like I suppose they would call people 'slow' or they wouldn't know how to address people with disabilities in general or people with intellectual disabilities so…they'd be called names then as well…
>
> (Advocacy worker, group interview)

In one case, a participant asserted that people with intellectual disabilities were also perpetrators of disablist bullying:

> I'm thinking of the day service that we run. And emm I suppose the instance of bullying that I would have been most familiar with would come from within that setting, you know, where perhaps somebody with higher abilities is bullying or teasing or taunting someone with a lower ability. You know, maybe in a joking way to begin with. But then, you know, that it has escalated to, like well actually this – this is a form of bullying.
>
> (RT manager, individual interview)

The findings reveal that participants with and without disabilities identified some bullying incidents as disablist in nature. These incidents may start from a joking atmosphere but can escalate to bullying. Participants were unclear on where an offence joke becomes an act of bullying.

8. Discussion

The findings presented above are elicited from two focus groups with individuals with intellectual disability and a series of qualitative interviews with those who work in the disability field, or those who work in mainstream community settings that provide supports to people with intellectual disability. The sample is undoubtedly small and as such cannot be deemed representative. Also, despite considerable effort, the voice of family members is not included in this study. The findings should therefore be interpreted with caution.

Prior to reviewing the findings, a reflection on the process of undertaking this research provides a useful insight. Of the three focus groups proposed within the research design, only one was completed as originally planned. This focus group was hosted for participants with intellectual disability. The two focus groups for other stakeholders were cancelled and defaulted to qualitative interviews due to a poor response rate. These focus groups were planned for family members and those who work in disability or mainstream services. The poor response rate was attributed to difficulties in taking time off work for the latter group, but did not explain the low attendance by family

members. A follow up with family members invited to the focus group revealed that some parents did not perceive the issue of bullying as 'current' and that service agencies were perceived to be dealing appropriately with this issue. This view contrasts with that of the participants with intellectual disability who expressed considerable interest in the topic, so much so that an additional focus group was organised and successfully attended. These observations from the process of the research suggest that the issue of bullying is prioritised differently by those with and without intellectual disability. This disparity may reflect the previous findings whereby people with intellectual disabilities comment that their complaints of bullying go unheeded (Roberts & Hamilton, 2010).

- This study has found that bullying is an important priority for people with intellectual disabilities; albeit that this priority may not be shared by others.
- **RECOMMENDATION** – greater awareness is needed that bullying is an important priority for people with intellectual disability.

Six core themes related to bullying and intellectual disability emerged from the focus groups and qualitative interviews undertaken in this research. They comprised issues relating to 'choice and control', 'confrontation and avoidance', 'defining bullying', 'prevention', 'perpetrators' and 'disablist bullying'. The findings reflect those previously reported in the small body of literature that exists on this issue. These categories are collapsed below for the formulation of recommendations.

Choice and Control

Issues emerged in the current study around restrictions placed on people with intellectual disability when engaging in everyday activities. Participants perceive these restrictions as a form of bullying. Those who do not have disabilities may not have experienced these limitations in adulthood. As a consequence, they may not perceive them as a form of bullying. These findings are in keeping with the existing literature which references the

potential of restrictive environments where people with disabilities live and work to promote a bullying culture (Roberts and Hamilton, 2010; Sheard et al., 2001; O'Moore & Hillery, 1989).

- This study has found that people with intellectual disability can live and work in more restrictive environments than their age-related peers; these environments, including day centres and residential settings, may promote a bullying culture.
- **RECOMMENDATION** – those who support people with intellectual disabilities should be made aware that restrictions placed on people with intellectual disabilities to exercise their right to choice and control is deemed a form of bullying.
- **RECOMMENDATION** – training for those who support people with intellectual disabilities should emphasise a rights based approach to exercising self-determination.

Confrontation and Avoidance/Prevention

Participants in the current study cited a variety of interventions to prevent bullying. Participants with intellectual disability had mixed views. Some advocated that the victim withdraw from the situation, others that the victim should confront the bully. These participants called for support in how best to deal with a bully using role play. Participants who did not have intellectual disability, in contrast, emphasised the importance of victims being able to confide in someone. The literature to date suggests that the latter strategy can be problematic. There is evidence that those who complain are not taken seriously (Roberts and Hamilton, 2010) and that follow up is seldom (Mencap 2007; National Autistic Society, 2006).

- This study has found that people with intellectual disability would welcome strategies to deal with bullies. The study also found that people with intellectual disabilities are concerned that their complaints of being bullied are not acted upon.

- **RECOMMENDATION** – people with intellectual disabilities should have access to training sessions to improve confidence and self-esteem, and teach them strategies to tackle bullies. Role play should be used within these training sessions.
- **RECOMMENDATION** – anti-bullying policies must be provided in an accessible format to ensure people are supported to make a complaint.
- **RECOMMENDATION** - where an individual confides in someone that they are being bullied, their complaint must be listened to and given credibility.
- **RECOMMENDATION** – anti-bullying policies must be implemented in cases where a complaint is initiated.

Defining Bullying

While bullying was regarded by participants in the current study as an important issue for people with intellectual disability, respondents with and without disabilities struggled to come to a consensus on defining bullying. Behaviours which were deemed as a joke or a cajoling by some participants were deemed bullying by others. People with disabilities also identified bullying as occasions where they were not listened to, and where their opinion was not respected. Bullying for these participants was defined subjectively and differently to those identified by participants who did not have disabilities. The disparity perhaps reflects the general lack of an agreed definition of what constitutes bullying (Carter & Spenser, 2006; Sheard et al., 2001).

- This study has found that bullying may be defined differently by different stakeholders; these different perspectives should not undermine the credibility of victims.
- **RECOMMENDATION** – greater awareness is needed that what constitutes bullying by people with intellectual disabilities may not be universally agreed; this does not diminish the impact of the bullying.

Perpetrators/Disablist Bullying

Among the perpetrators of bullying cited by participants in this study, peer to peer bullying was identified as the most frequent type of bullying. This finding reflects other studies which have identified bullying among people with intellectual disabilities as problematic (McGrath et al., 2010; Roscommon Advocacy Council; 2010, Sheard et al., 2001; Mencap, 1999). Participants in this study also cited bullying from strangers in public places as a specific problem; examples included being harassed at bus stops. Previous research has reported similar findings (Mencap, 1999). The high incidence of bullying in public places may be framed within a disablist bullying context whereby people with intellectual disabilities become targets of bullying within their own communities largely on the grounds that they have a disability (Emerson, 2010).

- This study has found that adults with intellectual disabilities experience bullying by strangers in their communities.
- **RECOMMENDATION** – public attitudes toward people with intellectual disabilities need to be regularly assessed.
- **RECOMMENDATION** – positive perceptions of the abilities and contribution of people with intellectual disabilities need to be promoted.
- **RECOMMENDATION** –bullying of people with intellectual disabilities needs to be classified as disablist and within a discriminatory framework.

In conclusion, this study has gathered the views of people with and without intellectual disability on the issue of bullying. The sample is small and cannot be deemed representative. Mindful of these limitations, the findings from this study mirror those from previous literature. This study continues the trend of Irish research in this field promoting an inclusive research methodology. The planning, implementing and interpretation of study findings have undoubtedly benefitted from the input of researchers with intellectual disability on this project.

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APPENDICES

Appendix A: Study Information Sheet

Bullying Study

Participant Information Sheet

Hi, we are

Ciara Brennan

Julie Byrne

Christine Linehan

Siobháin O' Doherty

Emer O' Malley

Conn O' Rathaille

William (Bill) Roberts

Fiona Weldon

Marie Wolfe

We are the research team.

We work at the National Institute for Intellectual Disability.

This is in Trinity College, Dublin.

NATIONAL INSTITUTE FOR INTELLECTUAL DISABILITY

TRINITY COLLEGE DUBLIN

We wrote this form to tell you about our study.

This form has 5 parts.

1. **Information about our study**

2. **What we ask you to do**

3. **What happens at the Focus Group**

4. **What happens after the Focus Group**

5. **What you need to think about before taking part**

1. Information about our study

We are doing research about bullying.

We want to answer these questions:

1. What does bullying look like?
2. What do people think about bullying?
3. How can we stop people being bullied?

We are asking you to take part because your ideas are important to us.

Trinity College said it is OK to do this research.

2. What we ask you to do

We would like you to come to a focus group.

There will be 3 focus groups:

Group 1:

- People with intellectual disabilities

Group 2:

- Family members of people with disabilities
- People who provide direct support to people with intellectual disabilities (e.g. care staff, advocacy workers)

Group 3:

- People who work in the community (e.g., bus drivers, gardai)
- People who provide specialised services to people with intellectual disabilities (e.g., social worker, psychologist)

Where?

Group 1:

National Federation of Voluntary Bodies, Oranmore Business Park, Co. Galway.

Group 2:

Maldron Hotel, John Redmond Street, Shandon, Cork.

Group 3:

National Institute for Intellectual Disability, College Green, Trinity College, Dublin 2.

What day / time?

Group 1:

Wednesday, 14th September, 2011, 11am – 1pm.

Group 2:

Thursday, 15th September, 2011 2pm – 4pm

Group 3:

Friday, 16th September, 2011 2pm – 4pm

3. What happens at the Focus Group.

In a focus group people come together to talk and answer questions.

Our questions are:

- Who bullies people with intellectual disabilities?
- What does bullying look like?
- What does bullying feel like?
- What things can we do to prevent bullying happening?

Talking about bullying can be difficult for some people.

If you become upset, we will ask you if you want to stop taking part in the focus group.

Emer O' Malley will be happy to talk to you about it too.

We will record the focus group using an audio recorder.

We will make a CD so we can listen to the focus group again.

Anything you say in the group will be kept private.

We will ask everyone in the focus group:

- to keep what people say inside the room
- not talk about it afterwards.

4. What happens after the Focus Group

We listen to the CD of the focus group.

We type out what everyone says.

- We call this a transcript.

I was bullied by ~~John~~ Mark.

I live in ~~Dublin~~ a big city.

We will ask people not to say the names of people who have bullied them.

We change everybody's name in the transcript.

We change names of places you talk about.

This means:

- Everybody will know what the group said.
- They will not know who was in the group.

We will write a report about what the group said.

We will put this on the internet.

We promise to do these things:

- Keep the CD and audio recorder in a safe place
- Keep the transcripts in a safe place.

This means only the research team can

- Read the transcript
- Listen to the CD of the focus group.

Destroy the CD on 31st December 2021.

Destroy the transcripts on 31st December 2021.

Tell you what you said in the focus group if you ask us after.

5. What you need to think about before taking part

This research will not help you if you are being bullied.

It will help us know more about:

- Bullying of people with intellectual disabilities
- What needs to be done to stop this happening.

If we hear some things that make us think that people are unsafe, then we would ask you to meet with another person:

- To talk to them about what has happened
- To support you to decide what to do next.

If you become upset after the focus group, you can contact Fiona Weldon at (01) 896 3885.

She will try to get help for you.

Please think if you want to take part in the research.

Ask us any questions you have about it.

It is OK if you do not want to take part.

If you decide to take part, it is OK to stop taking part whenever you want.

If you decide to take part, we will ask you to sign the consent form.

If you have any questions, please contact Siobháin O' Doherty at (01) 896 2179 or siodoher@tcd.ie
Ciara Brennan at (01) 896 3489. or . brennc10@tcd.ie.
Thank you!

Appendix B: Consent Form

BULLYING STUDY

CONSENT FORM FOR RESEARCH PARTICIPANTS

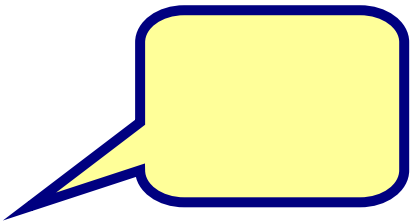
Please tick if you agree

❑ The researcher has talked about the research to me.

❑ I have been able to ask questions about the research.

❑ I understand that I will join a group of people and I will talk about bullying with them.

❑ I agree to have what I say recorded.



❑ I can stop being involved at any time on this project.

❑ Nobody will know that I took part in the focus group.

❑ My name will not be in the report about the study.

❑ I would be happy to talk to another person if I am unhappy about anything in this focus group.

❑ I agree to take part in this project.

Print name_____

Signature_____

Date_____

Name of witness_____

Signature of witness_____