

**“Self Injurious Behaviour & Intellectual  
Disability: A Family & Social Work  
Perspective”**

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## **Declaration**

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# **“Self- Injurious Behaviour in Children with an Intellectual Disability: A Family and Social Work Perspective”**

## **Abstract**

Little is known regarding many of the factors associated with Self-Injurious Behaviour (SIB) and intellectual/developmental disabilities. The limited research that does exist tends to focus on the prevalence, assessment and treatment of SIB, leaving many questions unanswered in relation to this complex and challenging behaviour. This study focuses on the implications of SIB for children with intellectual disability and for their families. From a family’s perspective, the emergence of SIB in a child can require adjustment not only for that person, but also for their parents and siblings. The research focuses on the role of the social worker in relation to working with and supporting this client group and their families. The study was conducted through identifying useful theoretical frameworks, exploring practice considerations and investigating the most relevant skills, knowledge and abilities. A qualitative methodology was adopted to fulfill the purpose of this study, as this approach provides the most appropriate medium to explore the views, opinions and emotions of family members of children with intellectual disability who engage in SIB. Non probability sampling was utilised to obtain data from six social workers and two psychologists via semi-structured interviews. The findings of the research study indicate that the implications of SIB on the whole family system can be significant and wide ranging. The findings also suggest the social workers should intervene at multiple levels to address the implications that emerge in this sensitive area to address the support needs of this client group and their families.

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For my husband Maurice Barry & my two boys  
Gregory & Michael

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# **Chapter One**

## **Introduction**

### **1.1 Introduction**

The aim of this study is to explore the area of self-injurious behaviour (SIB) in children with an intellectual disability, with particular focus on its effects on the whole family system. From a family's perspective, the emergence of SIB in a child can require adjustment, not only for that person, but also for their parents and siblings (Trepal, Wester & MacDonald, 2006; Jacques, 2003; Bell & Espie, 2002). This study will explore the physical, psycho-social, and emotional implications that SIB can have for both for the individual and the family. This study will examine the topic of self-injurious behaviour from a social work perspective providing an insight into the methods and interventions utilised by social workers when working with children and families affected by SIB. Allied professions, such as a psychology, will also be included to provide a comparative clinical perspective. The researcher will explore the topic and answer the research question by conducting semi-structured interviews with six social workers and two psychologists.

### **1.2 Background and Purpose**

According to Emerson (2001), self-injurious behaviour (SIB) is problematic and damaging behaviour with major implications for a person's quality of life. SIB is an external set of responses that have multiple sociological and psychological issues with multiple causes and effects (Schroeder, Reese, Hellings, Loupe & Tessel, 1999). SIBs are the types of behaviours which result in rapid damage to a person's own body by mechanical means (Emerson, 2001). They are displayed by hitting or banging some parts of the body with other parts or against objects, biting, tearing, pinching, gouging with



finger nails and hair pulling (Rojahn, 1994). In addition to the actual physical tissue damaged caused by SIB, it has negative consequences for an individual's ability to participate in social activities, community events, and to expand and maintain social networks. This can lead to isolation and social exclusion. Therefore, individuals with intellectual disabilities who display SIB can be viewed as an extremely vulnerable group. They have a poor quality of life and can also be on regular long-term medication (Emerson, 2001).

Considerable research has been conducted from a clinical psychological perspective with regard to SIB and challenging behaviour, for example, studies evaluating positive behaviour support (Carr *et al.*, 1999; Grey & McClean, 2004) and the impact of dealing with challenging behaviour for health services and the caring professions (O'Neill, 2004). However, much of the research appears to be relating to young people in mainstream care as opposed to the intellectual disability services (Keogh, 2001). In addition, there does not appear to be a specialised approach followed by the social work profession regarding service provision in this area. These gaps in research suggest that explorations of SIB within the intellectual disability field which incorporate a social work perspective are required.

From a social worker's perspective, various issues exist in relation to the management of services and support needs of persons who display self-injurious behaviour in the intellectual disability services, in addition to the support needs of their families. One of the main issues is the emotional impact of SIB on the child's family members and the implications this negative behaviour may have on the whole family system (Jacques, 2003). For social work practice, it appears that this factor has a bearing on the approaches used when working with these families (Trepal *et al.*, 2006). Thus, the study will examine the role of the social worker in terms of practice and support services provided to children and their families affected by SIB. Psychologists, who have experience of working with children with intellectual disability who self-injure will also be included to provide a comparative clinical perspective.

There seems to be relatively little research carried out and published which emphasises the perceptions of families and/or social workers with regard to SIB. It is for this reason that this MSW study will focus on ‘Self-Injurious Behaviour in Children with an Intellectual Disability: A Family and Social Work Perspective’.

### **1.3 Research Questions, Goals & Objectives**

The present research will aim to fulfill the following goals and objectives:

#### **Impact of SIB on the Family System**

- Explore the initial onset of SIB in the child and its impact on the whole family system.
- Examine the physical, psycho-social and emotional implications SIB has for the child and the family.
- Identify the coping mechanisms adopted by the family to help deal with the severity of SIB.

#### **Social Work Services and Practice Approaches**

- Explore what kind of social work services are available for children with intellectual disability and families who experienced SIB.
- Examine implications for social work practice and the role of a social worker
- Explore the social work interventions and approaches that are most applicable in practice when working with this particular client group and their families.
- Provide recommendations for social work practice

The researcher is particularly interested in the experiences of family members who live with and care for children who engage in SIB, their coping strategies and resilience. Most people in Ireland with intellectual disability live with their families and family members are usually the main carers of persons with an intellectual disability (Kelly, 2012). This

study will be relevant for social workers as it will offer an insight into the families' perspective and highlight the importance of having appropriate and effective social support services for parents and their children. The researcher is therefore proposes the following research question:

“What Implications does Self Injurious Behaviour in Children with an Intellectual Disability have for Families and Social Work Services?”

# **Chapter Two**

## **Literature Review**

### **2.1 Introduction**

In order to answer the research question, the literature review will provide a comprehensive overview of the topic of SIB and intellectual disability in terms of its prevalence and implications for both children who engage in SIB and their wider family systems and support networks. The area of SIB and intellectual disability will be examined in terms of its conceptualisation, theoretical perspectives on the behaviour, intervention and treatment approaches. The social work profession will be discussed with regard to its value base, roles and responsibilities, with a particular focus on children and families affected by SIB. Theoretical frameworks that guide practice and its application to this specific area of service provision will be considered. The literature review will provide background understanding for this research with the view to facilitating a comprehension of this specific subject matter.

### **2.2 Conceptualisation of SIB & Intellectual Disability**

Despite active research interest in the last few decades, a clear and meaningful definition for self-injurious behaviour remains elusive (Gates, 2000). It has been noted in the literature that SIB is a highly contested concept (Heslop & Macaulay, 2009). There is, however, a range of behaviours on the self-harm spectrum which are not socially acceptable in western culture and that cause direct injury to the body (Heslop & Macaulay, 2009). There appears to be a general consensus that a broad definition would include the following components:

“An intentional, self-directed act aimed to destroy, disfigure, or impair the appearance or function of some body part that whilst inflicting pain does not include suicidal ideation”.

(Jones, Davies & Jenkins, 2004: 487)

SIB is described as acts people direct towards themselves that result in deliberate tissue damage (Buono, Scannella, Palmigiano, Elia, Kerr, Di Nuovo, 2012; Gibson, 2005). SIB may take different forms and involve different parts of the body. Rojahn (1994) highlighted that the most common forms of SIB displayed by individuals with an intellectual disability include repeated self-biting, self-scratching and head hitting. Skin picking, self punching or slapping, head hitting against the floor, furniture or walls, and/or hitting other parts of the body have also been described as forms of SIB (Emerson & Einfeld, 2011; Khang, Iwata & Lewin, 2002). SIB appears to fall within the challenging behaviour spectrum (Buono *et al.*, 2012; Emerson & Einfeld 2011). In addition to above mentioned forms of SIB, approximately 50% of individuals who self-injure also display other forms of challenging behaviours including violently aggressive outbursts and property destruction (Emerson & Einfeld, 2011). Martin (2005) suggests the SIB should not be pathologised and almost reduced to the status of an item on a checklist of possible behaviours of a person who challenges. Emerson (1995:4) has defined challenging behaviour as:

“...culturally abnormal behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to limit seriously use of, or result in the person being denied access to ordinary community facilities”.

This definition suggests that challenging behaviour itself is a social construction (Emerson, 2001). It is also clearly apparent why SIB would be considered as falling within challenging behaviour spectrum. It appears that the safety of the individual who self-harms may be compromised and that they may be denied access to a range of facilities due to their behaviour (Jones, Davies & Jenkins, 2004). In the context of service

provision, this leaves individuals who self-injure in a very vulnerable position. Borthwick Duffy, Eyman & White (1987) point out that service users who self-injure are either over represented in large institutional settings or based in community residential placements which are poorly suited, and frequently threatened by their SIB (Emerson, 2001). There is often a lack of basic assessment and intervention services available to individuals with SIB and their families (Taggart & McConkey, 2001).

### **2.3 Prevalence of SIB**

Challenging behaviours such as SIB, although not unique to persons with developmental disabilities<sup>1</sup>, are at least two to three times more common in this group than amongst individuals without developmental disabilities (Sigafos, Arthur & O'Reilly, 2003). There are large numbers of families who are living with an intellectually disabled member who engage in SIB on a daily basis (Heslop & Macaulay, 2009). Studies relating to overall prevalence rates of SIB among individuals with developmental disabilities vary, depending on intellectual ability (Shearman, 1988), setting (Borthwick Duffy *et al.*, 1987) and causation (Myriantopoulos, 1981). The seminal study, carried out by Johnson & Day (1992) demonstrated increased prevalence rates for self injury and linked this behaviour with a range of personal and environmental factors including: age, severity of intellectual disability, autism, some specific syndromes, restrictiveness of environment, difficulties in mobility and/or sensory impairments and an individual's communication ability. One recent research, carried out by Heslop & Macaulay (2009) in the UK has also highlighted, among other factors, severity of intellectual disability to be one of the main factors to account for increased prevalence rates of SIB. Prevalence rates for self injury in people with intellectual disability have been reported to range between 1.7% to 24%, but in institutional settings rates of up to 41 % have been reported (Cooper, Smiley, Allan, Jackson, Finlayson, Mantry & Morrison, 2009b). Variations in prevalence rates may, however, be explained due to differences in study methodology (Heslop & Macauley, 2009).

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<sup>1</sup> Developmental disabilities is a slightly broader concept than intellectual disability which is typically used in the US

Constantly developing literature demonstrates some comorbidity between SIB and stereotyped and compulsive behaviours, such as Autistic Spectrum Disorders (Emerson & Einfeld, 2011; Baghdadli, Pascal, Grishi & Aussilloux, 2003), while connections have also been made with some genetically determined syndromes, e.g. Cornelia de Lange, Lesch-Nyhan, Rett and Fragile –X syndromes (Emerson & Einfeld, 2011). Although not syndrome specific, SIB appears to be related to brain damage or genetic brain abnormality (Deb, 1998).

Emerson & Einfeld (2011) outline that challenging behaviours, like severe SIB are likely to have their onset in childhood and may be persistent over time. As reported by Murphy *et al.* (1993), the mean age of onset of severe SIB was 7 years of age. Murphy, Hall, Oliver & Kissi-Debra (1999) in their 18 months study of children under 11 years of age in special schools with severe intellectual disability and/or autism reported that increases in SIB varied between individual participants, but noted that individual variation was associated with the level of concern expressed by teachers at the onset of the study, the only factor identified in the study as being associated with the trajectory of SIB in children over time.

Individuals who engage in self-injurious behaviour tend to have poor expressive communication and limited adaptive behaviours (Baghdadli *et al.*, 2003). Several studies report that the presence of SIB was highest in individuals with no speech (Baghdadli, *et al.*, 2008; McClintock, Hall & Oliver 2003; Deb, Thomas & Bright, 2001) although, Cooper *et al.*, (2009b) have not found this to be the case. From the professional social work perspective, this finding is important as it will determine the types of intervention implemented with individuals who engage in SIB. As a result of association between the greater severity of intellectual disability and SIB (Emerson & Einfeld, 2011; Cooper *et al.*, 2009a), interventions tend to focus more on what is appropriate for a person with a severe intellectual disability (Oliver & Petty, 2002).

## 2.4 Theoretical Explanations on the Causation of SIB

Historically, family members and professionals who provide care and services for individuals with intellectual disabilities have been frustrated in their attempts to understand the causes and to develop treatment approaches for this behavioural problem (Schroeder, Oster-Granite & Thompson, 2002). Emerson (2001) suggests that a range of cultural, social, biological, behavioural and psychiatric processes may account for the causation and development of SIB. Hence, this leads to the adoption of both social and medical perspectives in the analysis of SIB. Associating SIB purely with the existence of a specific impairment overly simplifies the complexities of the behaviour and, as a result risks further limitations in social workers' professional understanding of this behaviour (Jones *et al.*, 2004).

Mental health professionals may misunderstand SIB, interpreting them as forms of attention seeking and viewing clients as manipulative (Everett & Gallop, 2001). For social workers, it is therefore especially important that a thorough understanding exists in relation to the purpose of SIB from the perspective of the client and the family. This factor is essential if social workers wish to respond effectively in advocating on behalf of, and supporting this client group and their families.

Connors (1996) argues that SIB fulfills four primary functions: 1) as a re-enactment of trauma; 2) as an expression of feelings that are directed either against the self (such as guilt, shame, rage) or intended to serve a need for comfort and containment; 3) as a way to regain homeostasis, both emotional and physiological, when a sense of control or self-soothing functions are impaired; 4) for the management and maintenance of dissociative processes. Favazza (1996) supports this latter notion of dissociative theory and suggests SIB is a medium of separating the mind from the feelings that are causing emotional pain and frustration. This involves tricking the mind into believing the pain felt at the time of an emotional event is caused by self-injury instead of issues regarding the event. The physical pain may also act as a distraction from the emotional pain (Favazza, 1996).



Supporting Connors' (1996) argument of SIB being a re-enactment of trauma experienced, Halliday & Mackrell (1998) conclude that SIB may provide a clearer origin of pain for an individual to deal with as opposed to past emotional, sexual or physical abuse. SIB can also be considered as a way of coping with difficult environmental circumstances. James and Warner (2005), for example, reported that SIB was a coping strategy for women with learning disabilities in a secure unit.

Jones *et al.* (2004) argue that SIB can provide a self-directed outlet for anger. The researchers reported that the higher incidence of engaging in SIB by individuals with learning disabilities appears to be representative of the severity and nature of oppression they experience. Klonsky (2007) in his review of studies on functions of SIB found that in all eighteen studies the function of SIB was to reduce and stop feelings of anxiety and despair. Alexander (1997) found that SIB was significantly associated with attempts to communicate with or influence others, with the regulation of emotion, and with the creation of a sense of safety. Tantum and Huband (2009) also note that SIB can serve a function of communication and expression as well as control of others. Favazza (1996) contradicts this argument and states that SIB fulfills a purpose and primary motivation in itself and is not a means of communicating with or influencing others. Clarke & Whittaker (1998) believe that through the medium of SIB individuals with intellectual disabilities desire to gain control, which is often absent in their lives, especially in the context of service based life experiences.

Other theorists argue that the function of SIB is adopted by many individuals with intellectual disability primarily for stimulation purposes (Schroeder *et al.*, 2002). This suggests that individuals may engage in this behaviour for a variety of reasons, including boredom, under-stimulation etc. and that SIB can fulfill this requirement both physically and emotionally (Schroeder *et al.*, 2002).

It is unlikely that any of these possible perspectives on causations of SIB exist in isolation or provide a universal explanation as to why individuals with intellectual disabilities engage in SIB. It would appear that for most people a variety of functions are

served simultaneously by SIB, where as for some the meaning and purpose may not be determined (Heslop & Macaulay, 2009). Self-Injurious Behaviour in persons with intellectual disability can be viewed not only as communicative but also as functionally adaptive (Jones *et al.*, 2004).

## **2.5 Intervention & Treatment Approaches of SIB**

With regard to intervention and treatment approaches, Grey & McClean (2004) point out, that there is considerable variability in the treatment that persons with intellectual disabilities with SIB receive. This is due, at least to some extent, to a lack of coherent policy in the field and to a failure on the part of services and professionals to implement evidence-based interventions (Grey & McClean, 2004).

Khang *et al.*, (2002) emphasise that most of the research on effectiveness of treatment interventions in individuals who engage in SIB consist of case studies, anecdotal reports and studies with small number of participants. Historically, behavioural or pharmacological interventions formed the basis of treatment approaches of SIB (Oliver & Petty, 2002). In more recent times, newer interventions such as Positive Behaviour Support have been introduced (Grey & McClean, 2004).

The use of physical restraint techniques such as Crisis Prevention Intervention (CPI) and Therapeutic Crisis Intervention (TCI) are also typically used treatments in the management of SIB (Emerson, 2001). The rationale behind these approaches is to prevent individuals from inflicting serious life threatening injuries to themselves. The use of aversive approaches in the treatment of SIB has been widely debated (Duker & Seys, 2000). Traditionally, aversive approaches have constituted the withdrawal of pleasurable activities or restraint by mechanical or medical means (Emerson, 2001). In the past, mechanical restraints, causing immobility to individuals who self-injure, have been found to have detrimental effects on the physiology of the limbs, as well as cause negative psychological and social effects (Duker & Seys, 2000). Notwithstanding the amount of debate on the subject, Emerson (2001) suggests that the lack of empirical evidence on

effective reduction of SIB should not discourage outright condemnation of these approaches.

The use of mind/mood altering medication is often used with people who self-injure and has mixed results (McDonough, Hillery & Kennedy, 2000). According to Emerson (2001), between 40% and 50% of individuals who engage in SIB in intellectual disability services receive high levels of psychotropic medication over long periods of time. This finding has raised a number of questions in relation to the constant use of such powerful substances. For instance, there is a lack of methodologically sound evidence that such medication has a specific effect in actually reducing SIB (Emerson, 2001). Furthermore, prescription practices for people with intellectual disability have been judged to be inappropriate in between 42% and 55% of instances (Emerson, 2001). In addition, the various side effects of medication on people such as sedation, blurred vision, nausea, severe weight gain, all lead to the questioning of the validity/effectiveness of this widely used treatment approach (Emerson, 2001).

The latter half of the 1990's witnessed the emergence of Positive Behaviour Support, through the combination of work of several practitioner researchers, such as La Vigna, Carr, Horner, Dunlap and Koegal (Grey & McClean, 2004). Its main objective is to build appropriate behaviours that result in positive change and reduce problem behaviours such as SIB, promoting richer lifestyles for clients and their families (Carr *et al.*, 1999). In relation to functional analysis of SIB, Carr *et al.* (1999) identified the defining characteristics of Positive Behavioural Support. Positive Behaviour Support refers to those interventions that involve altering deficient environmental conditions, e.g. choice options, activity patterns, etc. With regards to deficiencies in behavioural repertoires, issues such as communication, self-management and social skills would have to be considered (Grey & McClean, 2004). Promoting and increasing positive behaviour, life style change and decreases in problem behaviours, including SIB define the core principles of Positive Behaviour Support (Carr *et al.*, 1999).

A number of other interventions are also used in the management of SIB in individuals with intellectual disability. Richman (2008) argues that children can benefit from intensive early intervention and prevention strategies. These may involve promoting appropriate use of play materials, reducing distracting external stimulation, as well as encouraging and reinforcing appropriate forms of communication. Picture Exchange Communication System (PECS) has been widely used with children with communication difficulties, including those on Autistic Spectrum Disorders in schools as well as by parents at home (Waterhouse, 2000). The importance of early intervention programmes in preventing SIB from becoming a serious problem is also highlighted by Murphy *et al.* (1993), Murphy *et al.* (1999), and Oliver (1995).

Jones *et al.* (2004) suggest that success with interventions and treatments to reduce the incidence of SIB need to be considered in an attempt to understand its causes. Diagnosis and treatment of the causes is considered by many to be the best approach. Khang *et al.* (2002: 220), in their review of behavioural treatments over a thirty six year period for people with severe or profound learning difficulties who engage in SIB state 'it is discouraging to find that self-injurious behaviour continues to be a disorder that is very difficult to treat'.

## **2.6 The implications of SIB on the Family System**

Caring for a family member with an intellectual disability can be both rewarding but also challenging experience (Kenny & McGilloway, 2007; Chadwick *et al.*, 2010). Individuals with intellectual disability and their parents and other family members are at risk of being stigmatized by contemporary society (Lindsey, 2003). Children with intellectual disability and their families often have to come to terms with this situation and adopt a different set of values, based on the inherent worth of every individual, which focuses on strengths rather than weaknesses (Lindsey, 2003).

As Emerson (2001) notes, individuals with intellectual disability who engage in SIB comprise an extremely vulnerable group, being socially excluded and on long-term

medication, resulting in a range of complex side effects. This in turn can have a negative impact on not only the health and well-being of the person themselves, but on the whole family system (Bell & Espie, 2002; Jacques, 2003).

People with intellectual disability who display SIB live in a social context that should be considered in order to understand and manage their behaviours (Bell & Espie, 2002). This social context will also influence and be influenced by the physical and emotional impact that SIB has on not only the individual themselves, but also on other family members (Bell & Espie, 2002). This factor is relevant to each family member's attitude towards this challenging and negative behaviour (Bell & Espie, 2002).

As such, the emergence of SIB in a child can require adjustment, not only for that person, but also for their parents and siblings (Trepal *et al.*, 2006; Jacques, 2003). Trepal *et al.* (2006) suggest that if a family member is unsure of the reason for self-injury or misunderstands the purpose of the behaviour, she or he may experience an increase in personal emotion, e.g. anger, frustration, isolation, blame, guilt and completely withdraw from or attempt to gain control over the individual who engages in SIB.

Similar findings are reported by White & Schultz (2000), in their study of a three year old boy who has an intellectual disability. His behaviour interfered significantly in family functioning, with his parents reporting considerable distress (White & Schultz, 2000).

Heslop & Macaulay (2009) found that most of the family members of people with intellectual disabilities who self-injure also reported considerable changes in their daily functioning, such as very little or no social life, and restrictiveness in their daily activities and outings. Furthermore, family carers had experienced change in friendships and sometimes had to distance themselves from friends and relatives due to embarrassment, possible discomfort and frustration (Heslop & Macaulay, 2009). The authors reported family members felt isolated, ashamed but often also unclear about the reasons of SIB and how best to help (Heslop & Macaulay, 2009).

According to family systems perspective, each family member may have a unique and valid perspective on the SIB of a family member. Thus, some family members may experience fear, and others may experience anger, while some may feel indifferently towards SIB (Trepal *et al.*, 2006).

Rojahn (1994) suggests that once a child who has an intellectual disability and engages in SIB reaches early adulthood (18-23 years old), SIB can become too difficult to control for family members and it is often at this stage that the individual who self-injure seeks residential/community supports. This transition, however, does not mean that the implications SIB has on the family system automatically cease. For this reason, as suggested by Lindsey (2003), professional, social and political systems need a greater depth of understanding and empathy for the needs of families that they have at present. Reports of families' experiences often contain examples of unhelpful and unsympathetic interventions from professionals, which potentially only further add to the family's stress levels (Heslop & Macaulay, 2009). The authors found, for example, that individuals who self-injured reported being 'talked to', rather than 'talked with' and being asked to stop SIB (Heslop & Macaulay, 2009). In addition, Trepal *et al.* (2006) note that while professionals working in this field have the benefit of professional supervision and debriefing following distressing encounters, these supports are not available to families (Trepal *et al.*, 2006).

## **2.7 Social Work in Intellectual Disability Services and SIB**

“The social work profession promotes social change, problem solving in human relationships and the empowerment and liberation of people to enhance well-being. Utilizing theories of human behaviour and social systems, social work intervenes at the points where people interact with their environments. Principles of human rights and social justice are fundamental.”

(International Federation of Social Workers, 2004)

The social context of people's lives and the right of individuals to make decisions for themselves are central to the definition of social work (IFSW, 2004). Principles of empowerment, advocacy, negotiation, partnership and participation are at the heart of social work practice, and central theme in the literature (SWRB, 2011; Fook, 2006; Payne, 2005; Mullaly, 2003; Thompson, 2003; Adams, Dominelli & Payne, 2002; Dalrymple & Burke 2002). These principles are particularly relevant to working with this vulnerable group of the population (Emerson, 2001). Given the specific needs of this group, social workers may be in a position to provide support, most especially given their unique role in supporting not only clients, but also their family members, to have their voice heard (Fook, 2006).

As highlighted by Trepal *et al.* (2006) family members often lack resources, which are available to mental health professionals, such as training and supervision. Thus, social workers can play a valuable role in improving the situation and lives of children and families affected by SIB by compensating for deficits in family resources (Jacques, 2003). Trepal *et al.* (2006) suggest that professional tasks when working with children who self-injure may involve the following: 1) to provide information and educate the wider family; 2) to assist in the assessment of reactions, feelings, communication patterns, family structure and dynamics, and coping mechanisms so that appropriate referrals and services can be provided. Finally, the social worker must also have the relevant skills, knowledge and abilities to offer an overall professional support service to clients and their families (Trevithick, 2005).

With regard to social workers working with families of persons who self-injure collaboratively, whether the individual is in a service based setting, i.e. day/residential services or living at home, this process and relationship between social worker and the individual and his/her family is of crucial importance to the welfare of the whole family system. It is for this reason that family systems theory in modern social work practice is widely recognised and adopted, particularly in the area of developmental disabilities (Kropf & Greene, 2002).

Exposure to incidents such as SIB can overwhelm the usual coping strategies used by individuals to help in overcoming the effects of this challenging behaviour (Lewis, 1993). Increased stress levels, intrusive thoughts, re-experiencing of traumatic incidents, numbing, avoidant behaviour and hyper alertness are common reactions to traumatic incidents such as challenging behaviours like SIB (Poster & Ryan, 1993).

The notion of stress as the tension between an event and the perceived ability to cope with or adapt to it has been developed to examine the effect on family functioning of an individual with developmental disabilities (Kropf & Greene, 2002). One model of stress that has been adapted to families, with its focus on response, rather than event itself is the 'Double ABCX' model (McCubbin and Patterson, 1983), which was built on Hill's earliest family stress model (Kropf & Greene, 2002). The more recent updated version, the Family Adjustment and Adaptation Response (FAAR) Model (Patterson, 1988; Patterson & Garwick, 1998), considers the process of family's adjustment and adaptation to stress, by exercising its resources and coping behaviours. Within FAAR model, central to the family's ability to cope and meet the challenges are meanings families attach to those challenges and demands (Kropf & Greene, 2002). Double ABCX and FAAR models could be used to understand the complex relationship between having a child with an intellectual disability who self-injures and family adaptation. These models focus on family events over time rather than single events (Kropf & Greene, 2002).

Research demonstrates that a family has to respond to a complex array of protective and stress variables to fulfill its care-giving responsibilities alongside its other family functions (Jacques, 2003). This would be particularly relevant to families experiencing SIB on a regular basis as this behaviour can be viewed only as a contributory stress factor (Poster & Ryan, 1993).

Antonovsky & Sourani (1988) outline that adaptation to crisis also includes family's regenerative power and highlight the importance of family coherence. From the strengths perspective, individuals possess inner resources to deal with life's adversities (Saleebey, 2009), which may be hidden under stressful situations and life events.



Therefore, formal social work support could be viewed as not only offering professional support but could also compensate for a lack of family resources (Jacques, 2003). Using an ecological perspective (Broffebrenner, 1979), social workers can intervene at multiple levels (Kropf & Greene, 2002). Social workers can provide practical, informational, educational and emotional levels of support. Kropf & Greene (2002) argue that interventions should involve assessment of ‘goodness-of-fit’ among the person with intellectual disability, their family, and their wider social and physical environments. The history of previous family functioning should be considered by a social worker, together with an understanding of the current problems experienced by the family; an opportunity should also be provided to build skills for the family’s future (Kropf & Greene, 2002).

The need for professional advice and support to families has been acknowledged in various research studies (Chadwick *et al.*, 2010; Heslop & Macaulay, 2009; Hogg & Lambe, 1999; Lambe & Hogg, 1995). Models of support and empowerment have been shown as particularly relevant for social work professionals in their engagement with this client group (Hogg & Lambe, 1999). Families of people with intellectual disability want professionals to work in a person centred way, listen, value, respect and include their family member in decisions concerning him/her and to respect the uniqueness and inherent worth of their family member (Chadwick *et al.*, 2010; Heslop & Macaulay, 2009). Professionals & family members emphasise the need for attitudes to change towards people with intellectual disability – both within services and by society (Heslop & Macaulay, 2009).

In relation to self-injury in Heslop & Macaulay’s (2009) research study, family members and professionals stress the importance of improved awareness of and attitudes towards self-injury and parent support groups. Both professionals and family members proposed improved training, particularly in relation to self-injury awareness, distraction techniques and the use of various communication tools. Improving staff communication and listening skills, in particular, were also emphasised (Heslop & Macaulay, 2009).

The concept of resilience has received growing interest within social work. Miller (1996: 255) uses this term in referring to 'individuals having some measure of success even though coming from situations where success is not predicted'. Jackson (2000: 296) proposes the following definition: 'an interaction between risk and protective factors within a person's background, which can interrupt and reverse what might otherwise be damaging processes'.

Jackson (2000) argues that social workers can play a crucial role in enhancing resilience by building on existing strengths and reducing risk factors. Walsh (1998), as cited in Greene (2002: 308) proposes family interventions from a resilience perspective, some of which may include: constructing meaning out of crisis situations; identifying and building family strengths by praising their past achievements; encouraging and complementing positive efforts and intentions; drawing out hidden resources and finding strengths in difficult circumstances; and finally, by adapting positive attitude and encouraging empathic connections among family members.

Heslop & Macaulay (2009) found that most of participants in their study of people with intellectual disability who self-injure were already using strategies of their own to try and delay or stop themselves from self-injuring. This factor can be considered as an individual's strength and can be built on, under conditions of trust, respect and encouragement on the part of a social work professional. Stalker (2003) notes, however, that more research is required in exploring the nature of protective factors as it is still at an early stage.

In summary, there is an element of both psychological trauma and family stress associated with SIB in people with intellectual disability. However, more research is required from a social work perspective in engaging this client group in the context of their whole family system. The social work profession may hold an important role on multiple levels: in providing practical, educational and informational support to families; in reducing distressing symptoms, enhancing and supporting emotional expression, and encouraging ventilation of feelings in the context of the professional family support

work. Using a resilience approach, social workers can play a crucial role in fostering family's strengths and resilience.

## **2.8 Conclusion**

The literature review has reviewed SIB and intellectual disability in terms of its prevalence and implications for both individuals and their wider family systems and support networks. The subject of SIB is examined in terms of its conceptualization, theory base and intervention and treatment approaches. In addition, the social work profession is discussed in terms of its value base, roles and responsibilities, and theoretical frameworks that guide practice and how in turn this is applicable to the disability field. The literature review provides a background understanding for the research study to facilitate a comprehension of this subject matter.

# **Chapter Three**

## **Methodology**

### **3.1 Introduction**

This chapter describes the research methods proposed in order to answer the research question: “What implications does Self Injurious Behaviour in children with an intellectual disability have for families and social work services?” The qualitative method used to address this issue is outlined, as are limitations to the methodology which may impact on the research findings.

### **3.2 Qualitative Research and its Advantages**

The choice of qualitative methodology for this research study is informed by interpretivist paradigm, which views reality as subjective, constructed, multiple and diverse (Crotty, 2003; Sarantakos, 2005). Researchers employ qualitative methods based on interpretation of subjective meanings which individuals place upon their behaviour to make sense of their world and the behaviour within it (Ezzy, 2002; Sarantakos, 2005). The researchers bring their own meaning and interpretation to the process and must be self-aware, recognizing and acknowledging the perspective from which they make their observations (Sarantakos, 2005).

The qualitative approach is inductive, rather than the deductive approach of quantitative research. For instance, classic grounded theory founded by Glazer and Strauss (1967) starts with no-pre-conceived ideas or theories of the researcher rather, core categories emerge directly from the participant.

The aims of qualitative research are to understand and interpret people and social life, not to measure them (Sarantakos, 2005). It allows us to hear voices of ‘others’, often

marginalized and oppressed people, like women, children, those with disabilities, mental illnesses, etc. (Ezzy, 2002). Thus, the value of this approach lies in its empathy and insightfulness. For these reasons, in order to get the richness of data and insight into the topic of self-injurious behaviour in children with intellectual disability, a qualitative methodology deemed most suitable.

### **3.3 Disadvantages of Qualitative Approach**

The qualitative approach also has some weaknesses which were highlighted by Sarantakos, (2005) and Ezzy (2002) as follows: qualitative research is unable to study cause-effect relationships between variables with a high degree of accuracy. This type of research is usually small-scale and does not produce representative details. Therefore, findings are difficult to generalise. Due to the nature of this research it does not ensure objectivity, like the quantitative approach. Ethical problems including the researcher's bias are often possible. Therefore, it might be difficult to ensure that the researcher correctly and comprehensively captures and interprets the true meanings of the participants. Due to the subjective, individualistic nature of this research model, replicability can be problematic. It is acknowledged that these, and other limitations of the qualitative method, may have impinged on the present study.

### **3.4 Sampling**

In total, eight interviews were conducted during this research, six with social workers and two with psychologists. The researcher applied in writing to the Principal Social Worker of two large service providers for people with intellectual disability located in the eastern region in order to gain consent to carry out the interviews with their social workers. A total of five social workers were recruited using this method. Ethical consent from one service provider had to be obtained from an ethical committee of this organisation. The researcher undertook non-probability sampling as the choice of people involved in the study could not be random, thus the sample for this study was a purposive sample (Denscombe, 2003). There was no criteria for age or gender. The researcher also

interviewed two psychologists who have experience of working with children with intellectual disability who self-injure. One of the psychologists and one social worker had been personally known to the researcher and expressed an interest in the study. Therefore, the researcher contacted these two participants directly in writing explaining the study and extending an invitation to participate in the research. In order to gain consent to interview the other psychologist, the researcher gained consent from the Principal Social Worker of one of the two organisations.

The reason for the selection of a purposive sample is consistent with the rationale of the study, to avail of the specific knowledge on the topic of self-injurious behaviour from a professional point of view based on social workers' and psychologists' experience of working with children with intellectual disabilities who self-injure and their families. The advantage of selecting a purposive sample is that despite difficulty in generalising, it can provide the researcher with in-depth information and understanding of specific issues which might not be possible to obtain from more randomised participants.

### **3.5 Method of Data Collection**

In order to conduct this research, a qualitative method for data collection was adopted in the form of semi-structured interviews with six social workers working in the field of intellectual disability and two professional psychologists who have experience with this client group. The rationale behind qualitative method is to get an insight into this sensitive topic by exploring the meanings people attach to their subjective experiences from the perspective of an 'insider', a person who works with this client group and has experience of interacting with children with intellectual disability who self-injure in the context of their family system on a regular basis.

### **3.6 Advantages and Disadvantages of Interviews**

Denscombe (2003) emphasised that semi-structured interviews allow the interviewee to develop ideas and reflect as the interview progresses, providing an opportunity to gather

data in a moderately structured but also in a relatively free flowing way. This approach was considered to be most suitable for providing facilitating conditions for interviewees to have control over what topics and issues they could develop and discuss in detail and in turn make them feel comfortable with the researcher.

Interviews are adaptable and can be adjusted to many different situations. Interviews can provide rich, in-depth and detailed data. Bell (1999) suggests that a person's response in an interview such as their tone of voice and facial expression can provide additional valuable information. During the interview, the researcher made efforts to probe, investigate and follow up on responses. The interviewer helped the participants to clarify the questions and supported the interviewee by using non-verbal communication, prompts such as facial expressions, tone of voice, smiling, and nodding. This technique may help the researcher to discover openings for further exploration; new insights which questionnaires could not provide (Bell, 1999). Interaction and cooperation between the researcher and interviewer are at the heart of this research method. The identity of the respondent is known and s/he is viewed as an expert who provides valuable information.

The role of the interviewer is crucial (Sarantakos, 2005). The interviewer was aware that the quality of responses and the flow of information are embedded in the personal qualities and expertise of the researcher; whether the researcher will come across as genuine and trustworthy; how well he/she will be able to engage the respondent. This can also be a major limitation of this method and affect its validity and reliability (May, 2001; Ezzy, 2002; Sarantakos, 2005). Therefore, the researcher tried to be self-aware, paying attention to language, body language, facial expressions, as well as tone of voice. Among other limitations of interviews as a research method is that they could be time consuming.

### **3.7 Ethical Issues & Procedure**

Any research regardless of the topic and purposes of the study has to adhere to ethical principles which involve responsibility to the participants, such as anonymity,

confidentiality, non-transferability, respect for respondent's privacy and courtesy (Sarantakos, 2005; May, 2001, Ezzy, 2002).

A full ethical application was submitted to the TCD School of Social Work and Social Policy's Research Ethics Committee and was successfully approved. The researcher was particularly aware of the ethical issues inherent in this sensitive topic and thus, adhered to all ethical principles in line with TCD Ethics Guidelines. In addition, the researcher was committed to the values of honesty, authenticity, personal integrity and professional conduct (Walliman, 2001).

The written consent of five social workers and one psychologist was sought through the Principal Social Worker of the two disability services (see the Appendix A). The written consent from the second psychologist and the remaining social worker who were known to the researcher were sought in advance of the interview after the information sheet and interview schedule were provided to the participant. An ethical approval from one of the two organisations which provides disability services was also required. In order to obtain this approval, the researcher applied to the ethical committee of this service in writing and attached the ethical approval previously obtained from TCD's ethical committee. This application also included research protocol, which included the information sheet for the participants (see Appendix B1 for the social workers and Appendix B2 for the psychologists) and the interview schedule (Appendix C). Letters to the relevant professionals stated the aim and purpose of the research and the researcher's contact details. The letter stressed that all data collected throughout the study would be anonymous. Confidentiality was guaranteed to all the participants and it was emphasised that the information gathered would be used for the purpose of this study alone. Participants' names were coded and all recorded data (tapes, transcripts) were locked securely in cabinets at the college to be destroyed in compliance with the regulations for student data as required by the School of Social Work and Social Policy.

On arranging each interview the researcher outlined that the interview should take approximately 40-45 minutes. Time allocation and the location of the interview was



based around the choice and availability of the participants. Bell (1999) stresses the fact that interviews can create obstacles when it comes to making hard 'rules of conduct', but at the same time, the interviewer should be clear and precise in relation to the purposes of the research and aims of collecting information and also the time it takes for its completion.

The researcher stressed to the participants that they could withdraw from the study at any time, before or during the interview. Before the interview the participants were given a list of scheduled questions that would be covered during the interview. The researcher sought written consent from the participants, including an option to use their direct quotes from the interview (Appendix D). The participants were offered an option of debriefing after their interview and also at any stage during and after the study by directly contacting the researcher. This research was carried out in compliance with Data Protection and Freedom of Information Acts.

### **3.8 Data Analysis**

In qualitative research data analysis is an ongoing, dynamic process which starts usually during data collection (Sarantakos, 2005; Ezzy, 2002). The objective of data analysis is to organise, provide structure to and to extract meaning from research data so that it can be synthesized, interpreted and communicated (Sarantakos, 2005). For the present study, data analysis included thematic analysis, which allowed themes and categories to emerge from interview data (Ezzy, 2002). This approach is an inductive analysis as categories are not decided prior to coding of the data. Coding involved underlining key words or phrases in order to identify categories (Bryman, 1988). The researcher listened to the recorded data and manually transcribed each interview, making notes on the transcripts. Unfortunately, data from two of the eight interviews did not record properly; the sound was poor. For these two interviews, the researcher had made comprehensive handwritten notes on the day the interviews had taken place. Transcripts of the interviews were re-read several times in order to get ideas for further analysis. This process was followed by editing in order to sort and organise the data. The researcher tried first to think at a more

abstract level, then reducing the text, looking for similarities and differences. The researcher then sought review from the academic supervisor in order to address reliability and validity of qualitative analysis.

### **3.9 Limitations of the Research Design**

All research studies have limitations of some kind. With regard to confirmability (how objective the data is) and transferability (generalisation of data) of the study, it is important to mention some limitations. The small size of the sample is a limitation. Therefore the proposed design and the outcome of the study may not allow the data to be easily generalized to larger samples. The findings of this study will require further validation by undertaking a larger study employing a bigger sample of social workers and other professionals working with children with intellectual disabilities who self-injure and their families.

The researcher originally planned to interview parents and other family members of children with intellectual disability who display self-injurious behaviour in order to get an insight into this topic from the perspective of those who witness and cope with self-injurious behaviour from their loved ones on a regular basis. Unfortunately, the researcher met with reluctance on behalf of service agencies with regard to obtaining ethical approval on the grounds that families of this client group were under 'research fatigue'. The researcher thus explored the topic of SIB in children with intellectual disabilities from the professionals who work with such families.

With regard to interviewing, the subjectivity of the researcher's analysis of data and coding of categories would, to a certain extent, have influenced the results. Independent coding and re-coding by two peers would have been beneficial and helped improve the consistency of coding. This would have required additional time and resources but would be beneficial for the research outcome. The responses of the interviewees might have been influenced by the questions in the interview schedule. Finally, the researcher's efforts to probe, prompt, remain self-aware and explicit about her role in the interview process hopefully helped minimise any effects of researcher's bias.

### **3.10 Conclusion**

This chapter outlined the research design and methods used to address the research question: “What implications does Self Injurious Behaviour in children with an intellectual disability have for families and social work services?” The qualitative method of interviewing professionals who work in this field was outlined, as were limitations to this approach which may impinge on the interpretation of data.

# **Chapter Four**

## **Results, Findings and Discussion**

### **4.1 Introduction**

In this chapter the researcher presents the results and findings of the research study. The results and findings are linked to the objectives of the research study and are represented as key themes throughout this chapter. Each key theme revealed by the primary research, by the interviews with six social workers and two psychologists is presented and discussed in detail in the context of the research study. Their responses are explored, contrasted and examined, with common themes identified, enabling the researcher to get an insight into the reality of living and working with families of children with Self-Injurious Behaviour and Intellectual Disability. This chapter also aims to highlight common and contrasting themes that emerged from the research results and findings in the context of the existing literature presented in chapter two. This coincides with an inductive thematic analysis of data, allowing categories and themes to emerge from interview data (Bryman, 1988). Through adequate discussion, analysis and recommendations, the research also offers a means of testing the relevant theories applicable to this research study. Although this research study was carried out with two respondent groups - social workers and psychologists, the discussion, analysis and recommendations relating to the collected data will examine key themes from both groups simultaneously throughout this chapter.

### **Key Themes**

- Demographic profile of the respondents
- Self-injurious behaviour in children with intellectual disability and its function
- Physical, psycho-social, emotional implications of SIB on the family system
- Coping mechanisms utilised by families

- Main implications for social work practice
- Professional supports available to families of children with intellectual disability and SIB
- Interventions/Approaches
- Challenges in working with children with intellectual disabilities and SIB and their families

## **4.2 Profile of Respondents**

All social workers interviewed for the research study have professional qualification in social work. The two psychologists interviewed are professionally qualified psychologists. All six social workers interviewed had a variety of professional experience. Five of the six social workers are currently employed by disability services located in the eastern region of Ireland. One social worker is currently employed by the HSE, but in the past worked as social worker in disability services. In terms of professional grade, one social worker was employed as Principal, one as Team Leader grade and four as social work practitioners. The respondents were two males and four females.

Principal Social Worker – interviewee # 1, over 30 years of practice experience, female

Social Work Team Leader – interviewee # 2, over 20 years of practice experience, male

Social Worker – interviewee # 3, 7 years of practice experience, male

Social Worker – interviewee # 4, over 20 years of practice experience, female

Social Worker – interviewee # 5, over 20 years of practice experience, female

Social Worker – interviewee # 6, 30 years of practice experience

The two psychologists who participated in this research study were both female, one currently working as a psychologist in a disability service with several years of practice experience. She will be referred in this research study as interviewee # 7. The other psychologist is currently employed by the HSE in a non-disability setting but had

extensive experience in the 90s and early 2000s in a disability setting. She will be referred in this study as interviewee # 8.

### **4.3 Self-Injurious Behaviour and its Function**

All the participant social workers and psychologists reported self-injurious behaviour in children with intellectual disability to be highly negative and distressing not only for the individuals themselves, but also for their family members, including parents and siblings. From the current study it emerged that it can also be distressing for the professionals witnessing and working with families of the children with ID who self-injure.

Among all the participants in this research study, some common forms of self-injurious behaviour have been identified. These included severe head hitting and banging, biting, scratching and skin picking. This is consistent with data in research literature, which describes some most common forms of SIB displayed by individuals with an intellectual disability including repeated self-biting, self-scratching and head hitting (Rojahn, 1994). In addition, skin picking, self punching or slapping, head hitting against the floor, furniture or walls, hitting other parts of the body have also been described as forms of SIB (Emerson & Einfeld, 2011; Khang *et al.*, 2002). Several respondents also reported eye-poking as another form of SIB. Several social workers (# 1, 2, 3, 6) and both psychologists (# 7, 8) used the term '*challenging behaviour*, or '*behaviour that challenges*' and described SIB as being under the umbrella of challenging behaviours. This is consistent with research literature, whereby SIB appears to fall within the challenging behaviours spectrum (Emerson, 2001; Buono *et al.*, 2012).

All the respondents in this research study reported that Self-Injurious Behaviour in children with ID was associated with various factors and often served multiple functions. Respondents highlighted that SIB, from their experience was evident among children with intellectual disability combined with certain syndromes, such as those on Autistic Spectrum Disorders, but not exclusively so. This association of SIB with autism and other syndromes, such as Cornelia de Lange, Prada Willi syndrome, and with repetitive,

stereotyped and compulsive behaviours is outlined throughout the literature (Oliver & Petty, 2002; Baghdadli *et al.*, 2003). However, not all the studies report that the higher degree of autism is likely to show higher level of SIB. Murphy *et al.* (1999), for example, found that degree of autism does not vary between children with and without SIB. What appeared to emerge from the current research findings is the correlation between severity of intellectual disability and self-injurious behaviour, which was also reported in other research (Johnson & Day, 1992; Heslop & Macaulay, 2009). In addition, sensory impairments have been reported by several respondents in the current study as present in children with intellectual disability who engage in SIB (# 1, 2, 5, 6, 7, 8). In addition, restrictiveness of the environment, for example, lack of large open spaces or sensory equipment, was reported to be associated with SIB (# 1, 5, 6, 8). This finding is consistent with previous research (Johnson and Day, 1992).

All the participants in this research study emphasised that Self- Injurious Behaviour and its severity was closely related to children's communication ability, including expressive language ability. This supports research studies, reviewed in the literature that SIBs were more severe in children with a lower level of speech and adaptive skills (Baghdadli *et al.*, 2003) and that the presence of SIB was highest in individuals with no speech (Baghdadli *et al.*, 2008; McClintock *et al.*, 2003; Deb *et al.*, 2001). In addition, in relation to children's expressive language ability, one of the two psychologists (# 7) interviewed in the current study made a valuable observation:

*"... We would see some children not able to express their emotional distress well, even if they are able to communicate certain needs verbally".*

Despite a common theme in the literature of an association between SIB in children and their communication ability, the present research findings are not supported by Cooper, *et al.* (2009b) study, who did not report significant relationship between language ability and SIB. The reason for the discrepancy in findings are multiple but may include sampling differences and the fact that participants in the current study highlighted their views being based on their experience and 'anecdotal' evidence.

Several participants reported an association between SIB and ageing, which has also been noted in other studies (Schroeder, Mulick & Rojahn, 1980; Baghdadli *et al.*, 2003). Participants' views in this regard, however, differed. Participants # 1, 2, 3, 8 highlighted that self-injurious behaviour is often a life-long condition and in many cases does not remit. However, in certain cases SIB can be reduced and in one example given by the participant social worker (# 3), an individual who is now an adult in his late twenties was SIB free for the last two years, after he engaged in SIB during childhood and adolescence.

As Baghdadli *et al.* (2003) argue adaptive skills may increase over the age span resulting in a decrease of self-injurious behaviour. It is important to note, however, that decreases in SIB can be related to a number of other factors, such as positive changes in person's environment, and early intensive interventions and supports, including family and professional supports. The importance of early intervention is highlighted in previous research (Richman, 2008; Murphy *et al.*, 1993; Murphy *et al.*, 1999; Oliver 1995). This research study tried to explore these factors including family resilience and effective professional approaches with critical discussion to follow later in this chapter.

With regard to self-injurious behaviour in children with intellectual disability and its functions, all the respondents stressed that it varied from individual to individual but noted that SIB could have multiple functions. As Jones *et al.* (2004) highlight, attributing self-injurious behaviour to the existence of a specific impairment only succeeds in oversimplifying the complexities of SIB and, consequently, risks further limitations in professional understanding of this behaviour.

The following functions of SIB have been identified in the present research study: *communication function*, including the expression of person's desires, wishes and sensory needs (participants # 1, 2, 4, 5, 6, 7, 8), also a *dual function* (participant # 8), as an expression of frustration, anger, and pain (#1, 2, 3, 5, 8), and a need to gain some control over one's environment (# 8). In addition, SIB can serve an *escape function*, as suggested



by respondent # 7, meaning: *“I don’t like it here. I don’t like this. I am overwhelmed”*. One psychologist (# 7) stated that SIB can be *tangible*, whereby the child engages in SIB to get attention and to get what they want. *Self-stimulation* (respondent # 2) and *sense of relief* (# 2, # 3) were also reported by the participants as SIB functions. One social worker (respondent # 6) noted that some children with autism self-injure without even realizing they hurt themselves. One psychologist (# 7) stressed that SIB is usually *symptomatic*:

*“The behaviour is symptomatic. The behaviour the child is trying to communicate has a meaning. You need to deal with an underlying issue, not the behaviour itself”*.

Both psychologists in the research study commented that understanding and determining the function of self-injurious behaviour thorough functional analysis was an important part of their role.

The findings of the present study are consistent with the common theme in the literature that a variety of functions are served simultaneously by SIB, albeit that for some the meaning and purpose may not be determined (Heslop & Macaulay, 2009).

#### **4.4 Physical, Psycho-Social and Emotional Implications of Self-Injurious Behaviour on the Family System**

Exploring the physical/psycho-social/emotional effects of self-injurious behaviour on the family system, from the professional perspectives of social workers and psychologists, offers a crucial insight into the multiple implications that SIB can have on the family unit.

The six social workers and two psychologists offered comprehensive accounts of what they felt were the most pertinent effects of SIB on the family system from their experience. One of the central themes that emerged from the interviews was that there is a great deal of adjustment required on the part of all family members, including parents, siblings and other caregivers. As one of the psychologists (respondent # 7) highlighted:

*“Families structures, routines, all have to be adjusted to fit in with individual who self-injures”.*

This is consistent with the literature, which emphasises that having a child with a disability can be viewed as a major stressor for a family, whereby the established patterns of family functioning are challenged (Lewis, 1993). Therefore, it is viewed as a process which requires re-adjustment and adaptation (Jacques, 2003; Trepal *et al.*, 2006) by re-consideration and change in family roles and routines (Kropf & Greene, 2002).

Several respondents shared their experiences of working with families who were negatively affected by the self-injurious behaviour of their child/sibling and found it very difficult to watch and witness. One of the social workers (respondent # 3) gave a detailed account of the effects of SIB from his experience:

*“...In terms of the family, ...while they are not the victim of an injury or the behaviour, in many ways they are. Because they have to watch their loved one, their child that they brought into the world, whether it's a child or an adult. They have to watch physically injuring themselves, which is incredibly difficult for a mother, or a father or sibling to look at on a daily basis. Many struggle with this to a great extent...And emotionally, I think, the emotional impact is worse on the family in my experience, because the family again are left to cope and carry all the complexities that comes with this, you know, quite serious and negative behaviour. And it can be especially emotionally terrible on the mothers, from my experience, to watch their sons and daughters engage in repeated SIB and constantly ask questions as to why their child is doing this on a daily basis. So, emotional implications are huge on the family”.*

Mothers were also mentioned by another two social workers (# 2, 6) who emphasised that the main caring responsibilities for the child with intellectual disability who engaged in SIB lay with the mother. The respondent # 2 commented:

*“...Families get physically tired, emotionally tired. Some families look for support, guidance, cope brilliantly. Some families can break up. Relationships get strained, parents blame each other. Primarily, men leave”.*

Another social worker (participant # 5) spoke about physical and social implications of Self-Injurious Behaviour on families:

*“Families feel very isolated...Many families don't have a social life, they can't plan for a wedding or a social occasion...Families never get a full night sleep...Knock on effect is on parents' ability to parent, relationships are affected, tempers are strained, nerves are strained. This becomes a pattern, and it does not change for the families”.*

The theme of social isolation was highlighted by several other social workers, (#1, 3, 4) impacting on individuals who engage with SIB and their families alike. Participant # 1 described it as follows:

*“Parents can't attend the same facilities, e.g. swimming pool, due to uncertainty how a child would behave, what would be the reaction of others”.*

Participant social worker # 3 summarised his view as follows:

*“In terms of social impact on individual, it would be the main aspect of their life. I mean, I've seen the SIB determine where an individual can go, what time they can go there at. Can this individual go to the swimming pool as everybody else? Generally, they don't, because they don't want 30 people staring at them, which is very isolating. So, the individual often books when there is nobody in the pool, which is further isolating. So, it throws up huge social issues for people, and has a big social impact on the individual themselves”.*

The theme of social isolation and exclusion has been highlighted in the literature by Emerson (2001), who argued that people who engage in SIBs are often denied access to

public facilities because of their Self-Injurious Behaviour. In addition, Emerson (2001) argued that many individuals with SIB also display other forms of challenging behaviour, such as property destruction and aggression against others. This was also evident from the responses of several social workers who emphasised that many children have a range of other behavioural issues, among which aggression and destruction of property were mentioned (# 1, 2).

Several social workers spoke about siblings '*missing out on many things*' (# 1, 4, 5). Among them were not getting enough parental attention and time, problems having friends over in the house because of embarrassment, fear and an uncertainty of the reaction from others. Assisting with care responsibilities for the sibling who engaged in self-injurious behaviour and sometimes fulfilling caregiving roles were also mentioned as realities for some siblings. This, in turn, can affect siblings' own accomplishment of developmental needs which may include forming friendships, engaging in afterschool activities, team sports, music, whatever is necessary and beneficial for their age and stage of development. In addition, a few social workers spoke about siblings being afraid when watching their brothers/sisters hurting themselves (# 2, 3, 5, 6). Social worker # 5 described their fear of sustaining an injury.

*"Some would lock themselves in the room. They never come out because they are physically afraid"*.

A fuller listing of these categories is presented in the Appendix E.

The range of emotions and reactions experienced by different family members, as described by participants in this study supports Trepal's *et al.* (2006) claim that each family member may have different reaction and perception of SIB, and some may experience feelings of fear and completely withdraw from a situation, whereas others may feel anger, guilt or feel indifferent.

The respondent social workers used the terms ‘helplessness’ and ‘hopelessness’ to describe the implications of self-injurious behaviour on family members. These feeling states support Bell & Espie’s (2002) argument of SIB and social context. This context includes family members and requires consideration of their levels of satisfaction, stress and emotional involvement with the culture and environment in which they live and how they contribute and respond to the needs of the person who engages in SIB. This social context will also affect and be affected by the physical and emotional impact that SIB has on, not only the individual themselves, but also on other family members (Bell & Espie, 2002). This factor is relevant to each family member’s attitude towards this challenging and negative behaviour (Bell & Espie, 2002). Therefore, how SIB impacts on family members can have a direct link on how families view the behaviour. Self-Injurious Behaviour which has such significant physical, psycho-social and emotional implications can lead to some family members resenting the individual, which is demonstrated by the response above (participant # 5) in relation to reaction of siblings.

#### **4.5 Coping Mechanisms Utilised by Families**

When exploring coping mechanisms utilised by families of children with intellectual disabilities who engage in self-injurious behaviour, the general consensus among respondents was that families do cope the best they can, but how well they cope varies from family to family and depends on the severity of SIB, family dynamics and commitment, and the supports that are available. It would appear that the reality of looking after a child with ID who self-injures is, in many cases, a life long commitment and a process which requires adaptation and adjustment from everybody involved. The responses of some social workers illustrate this point:

Social worker # 1: *“Families find it difficult to cope and adjust at the start, but they do adapt. Positive mindset is very important: this is my son or daughter, Self- Injurious Behaviour and their disability is secondary”*. She also added: *“parental commitment is hugely important, for example speech & language therapy would not work if not reinforced and encouraged at home”*.

The concepts of family stress and resilience are particularly relevant to this discussion (Kropf & Greene, 2002). The Family Adjustment and Adaptation Response (FAAR), Model (Patterson, 1988; Patterson & Garwick, 1998) considers the process of family's adjustment and adaptation to stress, by exercising its resources and coping behaviours. Central to the family's ability to cope and meet the challenges are the meanings they attach to those challenges and demands (Kropf & Greene, 2002). Therefore, '*positive mindset*' highlighted by the interviewee #1 and '*accepting the child for who they are*' emphasised by respondent # 6 is crucially important in changing perception of their situation, for example by separating their child from their SIB, and developing new coping strategies.

Social worker # 5 provided an insight into parental coping with children who have moderate/severe/profound intellectual disability and emphasised the importance of professional supports:

*"...Families would really be struggling with day to day care with children who would be on the Autistic Spectrum with moderate/severe ID. Their self-injurious behaviour is usually very difficult for parents to cope with. Parents, as I said earlier know their children best, and yet they are the people, who when they are at home, they don't have the structure that there would be in school. Parents are on their own at home. So, they manage self-injurious behaviour as best they can. I suppose, if they have the advantage of having link with psychology and Behavioural Support that is a huge part of managing Self-Injurious Behaviour. And if they have those supports, the families that I have feel that they acquired skills to work with SIB. Where families don't have that link in, they really use their own wisdom in terms of how to do it".*

One of the psychologists interviewed (# 7) spoke of families naturally coping prior to receiving professional supports:

*“By the time referral is made to psychology, families would have used a number of strategies already.”*

Among the strategies used by families, the following were reported by interviewees: using some form of restraint (# 7), changing the child’s environment, like taking a child for a walk, putting on the music which the child liked (#1, 2, 6), using protective gloves (# 1), helmet (# 6), using distraction (# 7) but also introducing barriers to minimise the injury, such as cushions (# 6, 8).

Social worker # 3 spoke of families being resilient because they had no other choice:

*“Families are resilient because they have to be”.*

This is consistent with Antonovsky & Sourani (1988) argument, that adaptation to crisis also includes the family’s regenerative power. From the strengths perspective, individuals possess inner resources to deal with life’s adversities (Saleebey, 2009), which may be hidden under stressful situations and life events.

These comments raise concerns with regard to timing and waiting lists, the barriers which make it more difficult for families to manage their children with intellectual disability, who often present with a range of behavioural problems (as highlighted by all the respondents) especially those with self-injurious behaviour. This means that many families could miss on an opportunity for early intervention, the importance of which in terms of preventing escalation of SIB has been emphasised by a number of studies (Murphy *et al.*, 1993; Murphy *et al.*, 1999, Oliver, 1995). In addition, parents and carers of a child with intellectual disability who self-injures may use certain strategies which would not necessarily be appropriate. They may stop one form of self-injurious behaviour, for example scratching, but reinforce some other form of SIB, like head banging, for example. This point was highlighted by psychologist # 7, who stressed the importance of addressing the underlying issue and teaching parents appropriate skills to manage SIB.

This social worker (# 5) also made an observation with regard to how some siblings cope:

*“...Siblings distance themselves, really, ‘cos that is their means of coping”.*

This provides some level of insight into the individual self preservation mechanisms that are adopted in some families in order to cope with negative implications of SIB.

At the end of the interview, the same social worker (# 5) reflected on families’ resilience and the importance of continuity of professional supports:

*“You know, parents are great. People that I work with, they cope with extremely difficult situations every day of the week. And they are really copers, workers, I mean. And they love their children dearly, and most of them provide a very secure family for their children...The ideal would be where the need arises, if they feel they can link in with the supports, to keep them ticking over”.*

#### **4.6 Implications for Social Work Practice**

A number of important themes emerged while discussing the considerations for social work practice. The respondents offered crucial insights into this topic. Most participants shared the following points:

- The importance of understanding what families are actually looking for, where they are at.

One Social Worker (# 1) emphasised that for social workers interacting with families of children who have intellectual disability and self-injure, it was essential to *‘know where families are coming from, what’s important for them, understand what it must be like to be in their shoes’*. She also added that social work was very much *‘to support the whole*



*family system, by encouraging, guiding and helping parents to help their child, as they are the experts, they know their child best*'.

These views are consistent with humanistic values of empathy, unconditional positive regard and respect for the individual and, in this context the whole family. The humanistic perspective sees clients as agents in their lives and the social worker's professional task in this context is to promote individual clients' and families' agency (Thompson, 1992).

Social worker # 2 mentioned the importance of understanding '*where the family is at*'. Social work # 3 highlighted that social workers should be '*in tune with families needs*'. Social worker # 5 saw her role '*to understand where people are at every step of the way and to feed that back*'.

This is an important consideration, given that from a family systems perspective, things are never the same, they change in terms of family's life cycle, as the needs of family change.

- The importance of the relationships social workers build with families of children with ID who engage in SIB.

This is central to effective social work practice with any client group, but most especially with this group in particular, given the sensitive nature of the topic and the vulnerability of families of children with an intellectual disability who engage in SIB. All the respondents, without exception, emphasised that the relationships social workers build with families were central to successful interventions. In this regard, both psychologists viewed social workers as the main source of support and advocacy to families, with the quality of their relationships being paramount for effective work with this client group and their families.

- Communication skills and qualities such as honesty, being genuine, and being empathic were considered crucial for professionals working with this client group, especially social workers, as they worked with families on a long-term, continuous basis.

These qualities were highlighted by all the respondents as essential qualities that social workers should have. Honesty, empathy, being genuine are values of social work and have been outlined throughout the literature (Thompson, 1993; SWRB, 2011). Communication skills, in particular, are identified as being central for effective practice (Trevethick, 2005).

- Providing and sourcing financial support, guidance, information, education, and emotional support was seen as being an important part of the social worker's role with families.

All the respondents mentioned the above categories as essential parts of social work role. Education in terms of appropriate skills, teaching, help and advice with communication tools, and coping strategies, were all mentioned by respondents # 1, 2, 4, 5, 6.

In the context of working with families to follow their Behaviour Support Plans, social worker # 5 referred to her role as to *'help families through this process'*.

Social worker # 4 viewed the social worker's role as *'mainly supporting families to cope, adjust and educate'*.

Social worker # 2 expressed how he viewed educational role of social work: *"We teach families new coping strategies"*.

Two of the social workers interviewed (# 3, 6) described part of their role as providing opportunities for families to ventilate their feelings and offer emotional support and reassurance. Respondent # 3 commented:

*“I can think of particular families now, who would ring us and ask us to come out and we would go and it might be just going and sitting for a couple of hours and listening to a mother or father express their anxieties. Or maybe they would not be clear about certain elements of their Behavioural Support Plans...So, I suppose, offering clarity, reassurance, professional reassurance to the family is very much a social worker’s role in that”.*

- The advocacy role of social workers on behalf of families was considered by all the respondents as central to social work practice.

Social workers used terms such as *‘the link person’*, *‘the first point of contact for the family’*, *‘the mediator between the family and other professionals’*.

In the context of multidisciplinary work, respondent # 3 described the advocacy role as follows:

*“You are the one at that meeting who is representing family’s views and that very much is taken on board by all other members of that team...Very much you are advocating the family’s desires and beliefs and also at the point of disagreement, whereby a family might not want to follow a certain path, or they don’t want to go with a care plan conditions, like medication...Behavioural Support Plan or certain programme that is put in place”.*

Social worker # 2 shared his views with regard to the effects of medication on children and social workers’ responses:

*“Drugging children is not the solution. I don’t believe in it...not allowing children to be children. They blunt their imagination, their creativity. They see children as problem”.*

This social worker spoke of diagnoses often as being *‘subjective’*:

*“Families are tired and often take doctor’s advice as true...As social workers, we don’t educate ourselves enough, we take diagnoses as a given, we have to question more: ‘What’s your evidence?’”*

The above statements reflect Emerson’s (2001) argument that in many instances prescription practices for people with intellectual disability can be inappropriate and many of drugs undesirable side effects.

In terms of promoting best practice, Fook (2006) highlights the importance of advocating for individuals and their families, that it enables them to have their voices heard, and it facilitates the development of trust and meaningful relationships between families and social workers. In addition, it is beneficial in terms of fostering families’ strengths and resilience.

- Encouraging and promoting families’ strengths and resilience was essential for effective social work practice.

Social worker # 1 stated:

*“Families are already very resilient. Social workers often reassure and encourage them, drawing on their strengths and abilities”.*

Social worker # 5 reflected as follows:

*“Help families find their skills to cope with what they have...help people find ways of coping...find the space for them to recognise that they have skills and for them to maybe have some respite so they can have a bit of rest themselves so they can actually step back...and look more objectively where to go from here. My job is to help people do that and look at the positives...help them refocus to where their strengths are”.*

From a resilience perspective, these findings reflect Walsh's (1998), as cited in Greene 2002: 308) suggestions of family interventions by a practitioner which include identifying and building family strengths by praising their past achievements, encouraging and complementing positive efforts and intentions, drawing out hidden resources and finding strengths in the face of adversity.

- Clarity of role and context in which social workers work in combination with knowing one's limitations was considered central to effective practice.

Social worker # 2 emphasised the importance of *'knowing your limitations, what you can and cannot do, being confident and competent, being clear in your role'*.

Social worker # 3 stressed the importance of *'knowing your defined function and role'* and added:

*"So, a good knowledge of what the family is looking for, the system you are working within, whether you are able to help, that's crucially important"*.

- Self-care and the use of supervision and peer discussions were considered essential in working with children and families with such negative behavior as SIB.

Professional responses in this area varied. It emerged that formal regular supervision was not part of the practice for all the respondents. For instance, social worker #5 spoke about her reliance on peer discussions, *'peer supervision'* as opposed to formal supervision with her manager, which she said she did not have. She commented:

*"Our peer support is what keeps us in"*.

Social worker # 3 spoke about supervision with his manager in order to sustain ‘*controlled emotional involvement*’ because witnessing self-injurious behaviour and talking to families who experienced it on a regular basis was emotionally difficult:

*“And, I suppose, you have to take the bad days with the good days. And I would certainly use my professional supervision with my line manager as my coping mechanism to sustain controlled emotional involvement with the case and the family”.*

#### **4.7 Professional Supports Available to Families**

When exploring the area of professional supports available to families of this client group including social work support, all the respondents mentioned the importance of multidisciplinary team work and for families to avail of respite. Social workers # 2, 4, 5, 6 also provided weekly support to special schools for children with intellectual disability.

Social worker # 1 emphasised the importance of a holistic approach to working with children with intellectual disability and SIB:

*“Multidisciplinary work is great, holistic approach is hugely important. I am in this area for many years and I am still learning from others, psychologists, occupational therapists, speech and language therapists”.*

All the respondents, without exception emphasised that early intervention when working with children with intellectual disability who engage in SIB, was the key to successful management and reduction of self-injurious behaviour. This is consistent with the arguments in the literature (Murphy *et al.*, 1993; Murphy *et al.*, 1999; Oliver 1995) that early intervention programmes can prevent self-injurious behaviour from escalating and becoming a serious problem.

In the present study, a common theme emerged between the respondents relating to entitlements to certain services, such as behaviour support team, which would serve as a

barrier to early intervention. This was not an ‘*automatic right*’ for a family (interviewee # 5) and ‘*behavioural issue had to be identified first with referral following to psychology department*’ (respondent # 7). In this context, several respondents commented that the system of referral was ‘*crises driven*’ and that challenging behaviours, including self-injurious behaviour had to be quite severe to get an allocation of behaviour support service.

As respondent # 8 commented:

*“The system is slow to respond to those who don’t fit the model of service”.*

In relation to early identification of self-injurious behaviour in young children with intellectual disability, Murphy *et al.* (1999) found that it was the social responses of others, teachers in their study, which were best predicted increases in SIB in young children, most likely because they saw them on a daily basis for six hours. This is consistent with some responses in this study, which emphasised the importance for social workers to obtain more feedback from teachers (respondents # 1, 4, 5). As social worker # 5 commented:

*“Teachers are brilliant. They know children more than we do. We don’t know those children. We only know them in the context of their families”.*

Respondent # 4 spoke about facilitating family groups in her area on a weekly basis for parents/carers of children on autistic spectrum and their specific needs. SIB was one of the areas of concern for the families. These groups were run as part of multidisciplinary work by two facilitators, by the social worker and speech and language therapist, and sometimes psychologist or occupational therapist. The interviewee emphasised the importance of providing families with an opportunity to meet, validate their feelings, share their common concerns and learn parenting tips and coping strategies from each other. In addition, it was identified as an excellent forum for providing families with

reassurance of their strengths and abilities in coping and managing challenging behaviours, such as self-injurious behaviour.

Among participants interviewed in this study, even within one organisation this kind of support was available in one area only. It would be beneficial for families to have access to such a service in all the areas where disability services are located. The parenting programmes would provide an excellent opportunity for social workers to receive feedback from parents and also help build positive relationships between families and professionals which would foster families' resilience in the face of adversities that families encounter. The importance of having parent support groups was highlighted by family members of persons who engaged in SIB and professionals in Heslop & Macaulay's (2009) study.

When asked to discuss the level of professional support available to families, all the respondents stated that they were satisfied with the services which were provided in the area they worked. Respondent # 7 added: *"yes, I am happy, but there is always room for improvement"*. In general, the common comment was that in many other parts of the country services were not as well developed as in the eastern region. In order to address specific needs of children with intellectual disability and challenging behaviours, such as SIB service provision should be more universal and be accessible to families in all parts of Ireland.

#### **4.8 Interventions/Approaches**

On exploring the different approaches/interventions adopted by social work professionals the researcher aimed to gain an understanding of the most beneficial methods of working with families who look after a child with intellectual disability and self-injurious behaviour. A variety of responses were given by the participants in this study. In addition to a resilience/strengths based approach highlighted by all the respondents and a range of skills and qualities essential for effective practitioner, discussed earlier in the chapter, the following interventions/approaches of working with this client group were listed:



All respondents noted that all interventions had to be person centred and needs based, meaning keeping the child and their individual needs in focus of any intervention and planning. Methods based on Positive Behavioural Support were mentioned by respondents # 3, 7, 8. Specific behavioural strategies were also cited as being of benefit in managing behaviour in children engaging in SIB and other challenging behaviours. These included breaking tasks into smaller, more manageable chunks, creating environment to suit the child's sensory needs and using Picture Exchange Communication System (PECS) to facilitate appropriate forms of communication.

These methods reflect developments in the last decade or two with regard to the emergence of Positive Behaviour Support (Grey & McClean, 2004) with its focus on mediating environmental conditions to promote better life choices for individuals in order to increase positive behaviours and decrease challenging behaviours, including SIB (Carr *et al.*, 1999).

An ecological perspective and system theory were considered central in working with families (respondents # 4, # 2, # 3). As interviewee # 3 described:

*“An ecological perspective, when you are taking the whole system, the whole family unit more into perspective. In working with this complex phenomena, self-injurious behaviour is not a cause and affect...From an advocacy point of view, you definitely come over using ecological perspective and also systems theory to know systems, to know family systems, to know the professional systems...to know how those systems work and to know how you work as a social worker within that system certainly benefits.”*

Sw # 2:

*“...Families within their ecological framework, taking into account complex multilayered relationships that families have”.*

Using an ecological perspective, social workers can structure various levels of intervention (Kropf & Greene, 2002), using informational, educational and emotional levels of support (Trepal *et al.*, 2006). In the context of intellectual disability and self-injurious behaviour, social workers can assess family functioning and dynamics over time, focusing on the child and family's past and present functioning, coping and future expectations.

#### **4.9 Challenges**

The aim of this line of inquiry was to attain information about the specific challenges and difficulties that can arise with this particular client group and their families. For example, exploring the areas which social workers feel were most challenging in terms of the provision of professional support.

The issue of consistency among family members was considered important in terms of adhering to behaviour plans, and was also considered a challenge for social workers.

As social worker # 4 commented:

*“Having everyone on board can be a problem”*

Social worker # 1 expressed her view as follows:

*“Balancing wishes and interests of all family members is often what a social worker does. Getting everyone on board to follow up the plan like Behaviour Plan can be a challenge for social workers”.*

The participant psychologist # 7 commented:

*“Social workers can be well placed to do work with families around consistency”.*

Consistency was also highlighted as an important factor among professionals in multidisciplinary teams, in terms of achieving a common ground when it comes to working with families on Behaviour Plans.

As social worker respondent # 2 commented:

*“What’s important is when all professionals speak the same language, that parent gets consistent information, not that occupational therapist says one thing and social worker the other”.*

Improving staff communication and listening skills is highlighted by Heslop & Macaulay (2009) as one of the areas for professional development, alongside training specific to SIB. Findings in this study are similar in terms of a need for greater consistency among the professionals, including communication skills, professional training and development.

The issue of scarce resources was identified among all the professional respondents as a major challenge to working with families of children with ID who engage in SIB. Social worker # 5 commented on the need to ‘*prioritise*’ the families who are in most need of social work support.

*“I look where I see that I can be most effective at that moment of my time and I look at how I can best support people within that and I do that”.*

Residential placements were mentioned among the participants as becoming very scarcely resourced. It was highlighted that they are considered as ‘*the last resort*’ (respondent #1). However, most respondents, when asked about correlation of SIB in childhood and residential care in adulthood suggested that in severe cases of self-injurious behaviour people had to be placed in residential care because families could not cope at home.

One of the social workers (# 6) spoke of cuts in funding for home extensions from County Councils for families of children with intellectual disability as having direct impact on families' managing challenging behaviours, like self-injurious behaviour. This social worker emphasised that lack of extra space in a family home may contribute to increase of challenging behaviour, including SIB and therefore, make it more difficult on families' already stressful lives.

In the context of constrained resources, it would be especially important for social workers to be resourceful, to use their creativity, communication and negotiation skills in order to obtain resources for families, whether it is respite, financial help or time with families. In addition, advocating to their organisations on behalf of families in order to increase resources would be an important way to advocate for positive changes at organisational level. The need for social workers to be more assertive and more involved in policy development is crucial not only for the profession itself but for service users and their families (SWRB, 2011). Hence, professional development and self care would appear as particularly important for social workers to avoid burnout.

#### **4.10 Conclusion**

This chapter has offered an insight into the results and findings of this research study. Findings represented in the study were based on data which emerged from the methodological approach used for this study. The results and findings are directly linked to the primary objectives of the research study and are represented as key themes throughout this chapter and discussed in the context of the literature reviewed in chapter two. This research study has highlighted the outlook of six social workers and two psychologists through exploring, contrasting and examining the experience of working with children with intellectual disability who self-injure and their families.

# **Chapter Five**

## **Conclusions and Recommendations**

### **5.1 Introduction**

This chapter encapsulates the overall key findings, conclusions and recommendations that can be drawn from the research study. The research questions sought to provide an insight into the implications of SIB in children with an intellectual disability for their family system and the subsequent practice implications this has for professional social workers. A qualitative methodology was adopted to examine the subject topic and answer the research question: “What Implications Does Self-Injurious Behaviour in Children with an Intellectual Disability have for Families and Social Work Services?” In total, eight interviews were carried out, six with social workers and two with psychologists. The results and findings of this study were identified, discussed, and examined with relevant implications for social work practice. A formal summary of the conclusions and recommendations drawn from this study are presented below.

### **5.2 Key Findings and Recommendations for Social Work Practice**

- SIB can serve multiple functions

Communication and expressive language difficulties and frustration as a consequence of these difficulties, were found to be commonly reported in children with intellectual disability who self-injure. Improved means of communication may serve to reduce SIB.

- Self-injurious behaviour has a number of negative implications for the whole family system and can be a major stress for a family.

Children, family members and their networks can be negatively affected on various levels by SIB as these behaviours challenge usual functioning and coping strategies. Adjustment

and adaptation are required on the part of all family members to cope with these behaviours.

- Families can be very resilient in managing self-injurious behaviour in their children with intellectual disability.

Families often manage SIB long before it comes to the attention of professional support services. Families try their best and have inner resources to adapt and manage SIB. Parents and carers live with SIB and they are the ‘experts’ when it comes to knowing their child best.

- Professional social workers may experience burnout. Supervision and peer support were important strategies for self-care.

Professionals may receive more support in dealing with cases that are distressing when compared with families. This finding emphasises the complexity of SIB and the multiple effects of this challenging behaviour, especially emotional effect that it can have not only on families but on professionals working with this client group as well. It also highlights the need for professional supports to these families.

- Proper supports and early intervention are crucial for the families for preventing SIB from escalating and managing this self-injurious behaviour appropriately.

By the time families get professional supports, SIB can become very severe. Feedback from teachers in identifying SIB early can be invaluable. Families cope with SIB the best they can, but sometimes their strategies might not be appropriate and can reinforce SIB.

- In the Irish context, lack of resources may result in a failure to intervene at the appropriate time.

This finding relates to the fact that some specialized supports are unavailable, such as behavioural support service. Initiatives which may not be resource intensive such as parent support groups can alleviate some of the challenges faced by parents. Hence, facilitating parental groups as a more universal service for the families can provide excellent opportunities for families.

- Social workers can be invaluable in providing support to the children and families on multiple levels, including informational, educational and emotional supports, using ecological systems perspective, crisis intervention, theories of family stress and resilience, and a strengths perspective among many others.

This study emphasised that professional interventions should be person centred and needs based and tailored towards family's needs at particular point in time as family systems and structures change over time and require timely supports. Thus, for social workers it is important to stay in tune with families' needs and wishes and utilize wide range of interventions and approaches.

- An advocacy role is especially important with this group, given the extent of vulnerability of children with ID and the sensitive nature of SIB.

Advocating on behalf of children and families is especially important in terms of early intervention, most especially lobbying for resources and supports as early as possible as well as having family voices heard.

- The manner in which social workers conduct their professional work with children with intellectual disability who self-injure and their families is no different to any other client group.

Values of empathy, respect for the client's dignity and self-determination, authenticity and honesty are social work values and are crucial for working with all service users.

Children with intellectual disability who self-injure and their families want to be heard, respected and understood. Relationships social workers build with families are at the heart of effective practice.

### **5.3 Conclusion**

Overall, the research objectives pertaining to this study were met and explored appropriately in a professionally sound manner. This research study has examined the area of self-injurious behaviour in the intellectual disability services specifically from a social work perspective giving an insight into implications of self-injurious behaviour on the family system and the methods and interventions that are/should be utilised by social workers when working with this client group and their families.



## **Reflection on the Research Process**

This short reflection section highlights some observations with regard to conducting this research, its benefits and challenges, and learning which occurred as a result of it.

On a personal level, the researcher has been interested in the topic of self-injurious behaviour in children with intellectual disability for some time. The researcher has had experience of working with children with challenging behaviour, including SIB (with Autistic Spectrum Disorders and Mild General Learning Difficulties) in the Special Needs Unit in a school setting. It has also inspired many thoughts about the whole area of self-injurious behaviour, especially in relation to the family's and social work perspectives.

The researcher originally wanted to conduct case studies with families of this client group as well interviews with social workers in order to get an insight from the 'lived' experience of the families of children who are affected by this negative behaviour. Unfortunately, the researcher could not get ethical consent from the disability service provider. The methodology was therefore changed to find an alternative sample while retaining the richness of data from those with experiences of this sensitive topic. The researcher learned that one has to be flexible and consider various options. In consultation with her supervisor, the researcher decided to interview a sample of social workers and psychologists, the latter group providing a contrasting clinical perspective.

Accessing the sample was more difficult than was originally expected. The researcher applied to two large disability service providers to obtain the sample. An ethical approval from one organisation was required. There were difficulties associated with finding the last participant to fulfill the required minimum of eight participants. In the end, the last interview was arranged at the very last stage of completing this research, practically, when all other findings have been almost analysed. The researcher was consequently required to conduct additional analysis at a late stage in the research in order to ensure these findings were appropriately incorporated into those previously analysed. However,

the researcher was glad she had the complete sample, given that the research is a small scale qualitative study and any findings can be limited by this constraint.

Once the researcher started collecting the data, everything started making sense and research became 'alive', it definitely inspired even more interest in the topic than at the start. Conducting interviews turned out to be a great learning experience. The researcher learned that the researcher is very much involved in the interview process and can either facilitate the discussion or can inadvertently elicit irrelevant material. The ability to probe, reflect, clarify questions is very important as well as the tone of voice, facial expressions and body language. There researcher aimed to be self-aware, ask open ended questions and create facilitating conditions to promote good flow of information. However, when the researcher listened to the recordings of her own questions and the manner in which they were asked, some were clearly more effective than others.

The researcher learned to pay more attention to have proper recording devices and making sure they work. From her experience, when two interviews recorded so poorly that were not suitable for transcription, attention to small detail like quality of sound and practice prior to interview is essential.

Overall, the researcher got an opportunity to practice her communication skills, writing skills and analytical skills and learned how to work under pressure. In addition, the researcher learned how to combine undertaking research in a tight timeframe with her private life, including a busy family and home.

Thanks to everybody who helped me through this research process.

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## **Appendix A**

### **Letter to the Principal Social Worker**

Date

Dear Sir/Madam,

As part of fulfillment of my Masters in Social Work at the Trinity College, Dublin, I propose to conduct a small-scale study to explore the subject topic of self –injurious behaviour in the area of intellectual disability.

I am writing to ask if you would approve to my contacting social workers in your organisation who have experience of working with children with intellectual disability who self-injure to participate in this research. Participation will entail each social worker taking part in a semi-structured interview which will last approximately 40 minutes. I will arrange to meet each interviewee at a time and place convenient to them and at all times aim to cause minimum disruption to their working day. The interview will aim to answer the research question:

“What implications does self-injurious behaviour in children with an intellectual Disability have for families and for social work services?”

I enclose a copy of the information sheet for the potential participants and hope you will consider the benefits of the study. I also enclose a copy of the interview guide which will be used in this research. I would be grateful to have an opportunity to discuss further with you the most convenient method to you and your organisation of distributing this material to your colleagues in order that they may make an informed decision regarding their participation in this research. I would then ask that, with the interviewees consent, you would forward me the names of social workers who would like to take part so that I can arrange for written consent to be completed and for interviews to be scheduled.

I would like to assure you that the responses of all the participants of the study will be treated in a confidential manner. Identities of all the participants and interview data will

be anonymised by the use of numeric codes thus ensuring confidentiality. While all information will be treated with the greatest confidentiality, should a situation arise where information is disclosed that raises concerns regarding the welfare of a child, this information will be reported to Dr. Linehan, who is the TCD supervisor of this study, and to the Principal Social Worker of the participating agency. Ethical principles in line with TCD Ethics Guidelines will be adhered to. All the information provided by your staff will be used for this research study only.

I would greatly appreciate if you would consider giving me your consent to carry out this research with the social workers in your organisation who have worked with families of children with intellectual disabilities who display SIB.

I will be happy to address any concerns or questions you may have with regard to this proposed research study. You can contact me by e-mail \_\_\_\_\_ or phone \_\_\_\_\_ My supervisor, Christine Linehan, PhD can be contacted by e-mail \_\_\_\_\_ or \_\_\_\_\_.

I look forward to hearing from you.

Yours faithfully,

Signature

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Daria Rodgers

MSc in Social Work Candidate

# **Appendix B1**

## **Information Sheet for Social Workers**

Dear Participant,

As part of fulfillment of my Masters in Social Work degree at the Trinity College, Dublin, I propose to conduct a small-scale study to explore the subject topic of Self – Injurious Behaviour in the area of intellectual disability. There is a dearth of research in this field, insufficient to address all the implications of SIB that emerge. SIB influences not only individuals with intellectual disabilities who self-injure, but the whole family system. This study will explore the role of the social worker in terms of practice and support services in relation to children and their families affected by SIB. Allied professions, such as a psychology, will also be included to provide a comparative perspective.

Participation will entail taking part in a semi-structured interview which will last approximately 40 minutes. I will arrange to meet you at a time and place convenient to you and at all times aim to cause minimum disruption to your working day. The interview will aim to answer the research question:

“What implications does Self-Injurious Behaviour in Children with an Intellectual Disability have for Families and for Social Work Services?”

I would greatly appreciate if you would consider giving me your consent to participate in this research. Your professional expertise and knowledge in the area of disability and with children who engage in SIB and their families is very valuable to me. I enclose a copy of the consent form for your attention. I also enclose a copy of the interview guide which will be used in this research.

Your decision to participate is voluntary and you may withdraw from the study at any point, before and during the research. I would like to assure you that all your answers will

be treated in a confidential manner. Your identity and interview data will be anonymised using numeric codes thus ensuring confidentiality. While all information will be treated with the greatest confidentiality, should a situation arise where information is disclosed that raises concerns regarding the welfare of a child, this information will be reported to Dr. Linehan, who is the supervisor of this study, and to the Principal Social Worker of the participating agency. Ethical principles in line with TCD Ethics Guidelines will be adhered to. All the information provided by you will be used for this research study only. All interviews will be audio recorded. All the tapes and transcripts will be anonymised, stored securely and destroyed after this research in keeping with the ethical practices of the School of Social Work and Social Policy, Trinity College, Dublin.

Anonymised quotes from interviews will be used in publications and presentations of this research. You will be requested to consider permitting the use of anonymised quotes from your interview being used in this manner (see the Consent Form attached). Please be assured that you are not obliged to consent to the use of such anonymised quotes and your interview will be valued irrespective of your consent on this issue. The research will be carried out in compliance with Data Protection and Freedom of Information legislation.

I will be happy to address any concerns or questions you may have with regard to this proposed research study including your participation in this research. You can contact me by e-mail \_\_\_\_\_ or phone \_\_\_\_\_. My supervisor, Christine Linehan, PhD can be contacted by e-mail \_\_\_\_\_ or phone \_\_\_\_\_.

I look forward to hearing from you.

Yours faithfully,

Signature

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Daria Rodgers

MSc in Social Work Candidate



## **Appendix B2**

### **Information Sheet for Psychologists**

Dear Participant,

As part of fulfillment of my Masters in Social Work degree at the Trinity College, Dublin, I propose to conduct a small-scale study to explore the subject topic of Self – Injurious Behaviour in the area of intellectual disability. There is a dearth of research in this field, insufficient to address all the implications of SIB that emerge. SIB influences not only individuals with intellectual disabilities who self-injure, but the whole family system. This study will explore the role of the social worker in terms of practice and support services in relation to children and their families affected by SIB. Allied professions, such as a psychology, will also be included to provide a comparative perspective.

Participation will entail taking part in a semi-structured interview which will last approximately 40 minutes. I will arrange to meet you at a time and place convenient to you and at all times aim to cause minimum disruption to your working day. The interview will aim to answer the research question:

“What implications does Self-Injurious Behaviour in Children with an Intellectual Disability have for Families and for Social Work Services?”

I would greatly appreciate if you would consider giving me your consent to participate in this research. Your professional expertise and knowledge in the area of disability and with children who engage in SIB and their families is very valuable to me. I enclose a copy of the consent form for your attention. I also enclose a copy of the interview guide which will be used in this research.

Your decision to participate is voluntary and you may withdraw from the study at any point, before and during the research. I would like to assure you that all your answers will

be treated in a confidential manner. Your identity and interview data will be anonymised using numeric codes thus ensuring confidentiality. While all information will be treated with the greatest confidentiality, should a situation arise where information is disclosed that raises concerns regarding the welfare of a child, this information will be reported to Dr. Linehan, who is the supervisor of this study, and to the Principal Social Worker of the participating agency. Ethical principles in line with TCD Ethics Guidelines will be adhered to. All the information provided by you will be used for this research study only. All interviews will be audio recorded. All the tapes and transcripts will be anonymised, stored securely and destroyed after this research in keeping with the ethical practices of the School of Social Work and Social Policy, Trinity College, Dublin.

Anonymised quotes from interviews will be used in publications and presentations of this research. You will be requested to consider permitting the use of anonymised quotes from your interview being used in this manner (see the Consent Form attached). Please be assured that you are not obliged to consent to the use of such anonymised quotes and your interview will be valued irrespective of your consent on this issue. The research will be carried out in compliance with Data Protection and Freedom of Information legislation.

I will be happy to address any concerns or questions you may have with regard to this proposed research study including your participation in this research. You can contact me by e-mail \_\_\_\_\_ or phone \_\_\_\_\_. My supervisor, Christine Linehan, PhD can be contacted by e-mail \_\_\_\_\_ or phone \_\_\_\_\_.

I look forward to hearing from you.

Yours faithfully,

Signature

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Daria Rodgers

MSc in Social Work Candidate

## Appendix C

### Consent Declaration

#### **“Self-Injurious Behaviour in Children with an Intellectual Disability: A Family & Social Work Perspective.”**

I \_\_\_\_\_ give my consent to be interviewed as part of a study to examine Self-Injurious Behaviour in children with an intellectual disability from a family and social work perspective. I have been informed that this research will be carried out by Daria Rodgers as part of her fulfillment of the Masters in Social Work Degree at Trinity College, Dublin and supervised by Dr. Christine Linehan, School of Social Work and Social Policy, Trinity College Dublin. I understand that I can contact Ms. Rodgers if I have questions about my participation in this research.

The interview process has been explained to me, and I fully understand what it entails, including audio recording. I understand that all the tapes and transcripts will be anonymised, stored securely and destroyed after this research in keeping with the ethical practices of the School of Social Work and Social Policy Trinity College Dublin. I have been told that, should a situation arise where information is disclosed that raises concerns regarding the welfare of a child, this information will be reported to Dr. Linehan and to the Principal Social Worker of the participating agency. I also understand that anonymised quotes from interviews will be used in publications and presentations of this research. I understand that I am requested to consider permitting the use of anonymised quotes from my interview being used in this manner. I am aware that I am not obliged to consent to the use of such anonymised quotes and that my interview will be valued irrespective of my consent on this issue.

I agree to the use of anonymised quotes from my interview in publications \_\_\_\_\_

or

I do not agree to the use of anonymised quotes from my interview in publications\_\_\_\_\_

My right to withdraw from the study at any time has been explained and I understand that ethical principles will be adhered to at all times.

Signed\_\_\_\_\_

Date\_\_\_\_\_

Daria Rodgers contact details: e-mail:\_\_\_\_\_, phone: \_\_\_\_\_

## **Appendix D**

### **Interview Schedule**

Interview schedule to be adopted when conducting semi-structured interviews with health care professionals, who have had experience of working with children with an intellectual disability who engage in Self-Injurious Behaviour.

General Demographic Information:

Health Care Professional (social worker, psychologist): Numeric code

Gender:

Years of Practice Experience:

#### **Questions:**

Please note that in the context of this research, the working definition of Self-Injurious Behaviour is as follows:

“An intentional, self-directed act aimed to destroy, disfigure, or impair the appearance or function of some body part that whilst inflicting pain does not include suicidal ideation”.

(Jones, Davies & Jenkins, 2004)

**Q.1** Can you describe your role as a social worker (psychologist) in a disability setting, in particular, working with children with intellectual disabilities who engage in Self-Injurious Behaviour?

**Q.2** What are the main practice considerations for social workers (psychologists) when working with families with an intellectually disabled member who engages in Self-Injurious Behaviour?

**Q.3** From your professional perspective, what do you think are the main physical/social/emotional effects of Self-Injurious behaviour (SIB) on the individual and the whole family system?

**Q.4** From your experience of working with families of children who display SIB, how do families cope with this behaviour (SIB) at the time of its initial onset and as time goes by?

**Q.5** What professional supports (if any) were available to the families of individuals who engage in SIB you worked with?

**Q.6** In your opinion, do children who self-injure are more likely to receive special educational supports than children who do not engage in SIB, e.g. distinct from mainstream classes?

**Q.7** From your experience, is SIB in childhood associated with residential care in adulthood, in other words, are these children more likely to enter residential care in adulthood because of their SIB?

**Q.8** If the child lives at home, do families receive in house support or any respite care?

**Q.9** In your view, what are the most effective social work (psychological) interventions when working with this client group and their families? What interventions would you consider unhelpful, albeit well meaning ones?

**Q.10** As a professional, what do you feel are the main challenges when working with individuals who engage in SIB and their families?

**Q.11** What do you think children with intellectual disabilities who engage in SIB and their families expect from health care professionals (social workers, psychologists)?

**Q.12** In general, how satisfied are you with the level of professional support that is offered to families (by your service provider) of a child with an intellectual disability who engages in SIB?

## Appendix E

Implications of SIB on the Family System	Child	Parents/Caregivers	Siblings
<b>Physical</b>	<p>Infliction of pain, damage to body parts (respondents # 1, 3, 8) Lack of structure &amp; equipment at home as opposed to school (e.g sensory equipment, gym) (respondents # 1, 5, 8)</p>	<p>Difficult to witness, lack of or poor sleeping pattern, tired, exhausted (reported by all the participants); trying to protect their child by reducing impact of SIB by inserting cushions, creating physical barriers, weight blankets (respondent # 6, 8)</p> <p>Dependence on driving, taxi or a lift/ can't use public transport with their child</p>	<p>Trying to get away from seeing SIB; lock themselves in their rooms; tired; fulfilling care giving role; assisting with caregiving of sibling, who engages in SIB</p>
<b>Social</b>	<p>Restriction/ Isolation from social activities/Exclusion; outings made difficult (# 1, 3, 4, 6)</p>	<p>Family structures, routines adjusted to fit in with the child who self-injures (# 1, 4, 6, 7); social isolation - families cut out from community participation, outings (# 1, 3, 4, 5, 6, 7, 8); Friendships &amp; relationships are affected</p>	<p>Can't invite friends home &amp; enjoy ordinary activities at home (TV, games)</p>



		(reduced/strained/disrupted/broken) (# 1, 2, 4, 5, 6, 7); Families unable to plan any activities, holidays, etc. (# 1, 5) Contact with other parents often limited (# 7)	(resp. # 1, 4, 5, 7); Restriction in community participation, isolation (# 1, 3, 4, 5, 6, 7, 8)
<b>Emotional</b>	Frustration, anger, lack of stimulation, boredom (# 1, 2, 3, 6, 7, 8)	Distressing, families feel under constant pressure and stress (all the respondents). Feelings experienced: frustration, uncertainty, blame, (# 1, 2, 4, 5); fear, guilt, embarrassment (# 1, 3, 4, 5, 6); helplessness (1, 3, 4); upset (all participants). Many families become more resilient (# 1, 2, 3, 5, 8)	Not enough attention from parents/caregivers; feeling afraid, embarrassed, uncertain (all the respondents)

## **Interview Transcript**

### **Interviewer:**

- Hi, \_\_\_\_ Thank you for participating in my interview. I suppose, today we are trying to explore the topic of self-injurious behaviour in children and adults with intellectual disability and explore its impact on individuals and the whole family system and also, examine most effective approaches from social work perspective and, as well, to talk about challenges. How social workers can be useful and effective to families in working with this problem behaviour. The working definition of self-injurious behaviour would be that SIB is deliberate infliction of body damage to himself or herself, but without suicidal ideation. So, and also about your experience as a professional working in this area, what do you think service users expect from us as social workers. Thanks very much. I suppose, we can look at the first question. If you can tell me about your role as a social worker in this particular setting?

### **Participant:**

- Thank you, \_\_\_\_ Thank you for including me in your research. My name is \_\_\_\_ I am professional qualified social worker with seven years experience in this area. My gender is male and I have, as I said, seven years experience, most of which is specifically in this area and specifically in the area of self-injurious behaviour with both children and adults. I hope my experience will help you in your research.

### **Interviewer:**

- Thank you very much \_\_\_\_ I suppose, we can start with the first question. Your particular role in this setting and maybe your main responsibilities and duties.

### **Participant:**

- I suppose my role within a disability organisation as a social worker. You are part of a multi-interdisciplinary team and, therefore, you have responsibilities to that

team. But first, and foremost, as a social worker, you are very much the point of contact for not only the individual, but very much the individual's family. And you are often used as a mediational point by the family with the organisation and with the team or direct social care work, and maybe... You see high support teams or challenging behaviour teams. So, you are, generally, the person for family's first point of contact in relation to that, whereby a family require support or the individual requires support. And they utilise you as a social worker for that... I suppose, may other things involved in the role of a social worker. Organisation of the general support issues and maybe financial problems maybe in the house and they require support. Linking and liason with different services and ensuring that family have access to the services they require and ...service users themselves is the focus in relation to person-centred family planning.. You are really a 'jack of all trades' in a disability service as a social worker, because, as I said, you are primary focus of all that. Part of being in a multidisciplinary team is that there is a lot expected of you, probably too much of what we can do.

**Interviewer:**

- Thank you, \_\_\_\_\_, and from your professional perspective, what do you think are the main physical, social and emotional effects of this behaviour on the individual and their families?

**Participant:**

- The main physical, social and emotional... I suppose, if we take the individual first. Obviously, when you are working with self-injurious behaviour, the physical impact will be quite stark for the individuals with self-injurious behaviour. The first think that strikes them, because you are working with children and adults who repeatedly hammering their bodies on a daily basis. So, this can be quite difficult on the outset of looking on, but it must be incredibly difficult for individuals themselves who cannot stop, or cannot manage their emotions or their behaviours and this manifest itself in quite extreme self-injurious behaviours. So, this would be the main physical impact. In terms of the social impact on

individual, it would be the main aspect of their life. I mean, I've seen the self-injurious behaviour determine where an individual can go, what time they can go there at. Can this individual go to the swimming pool as everybody else. Generally, they don't, because they don't want thirty people staring at them, which is very isolating. So, it throws up huge social issues for people, and has a big social impact on the individual themselves. In terms of an emotional impact on individual themselves, it would, you know, obviously, most people with intellectual disability have psychiatric needs. So, emotionally, obviously, they can be very turbulent and they are using self-injurious behaviour as a coping mechanism often. I know that would be the results of many psychiatric studies. In terms of the family in the same question, the impact physically can be, while they are not the victim of an injury or the behaviour, in many ways they are. Because they have to watch their loved one, their child that they brought into the world, whether it's a child or an adult. They have to watch physically injuring themselves, which is incredibly difficult for a mother or a father or sibling to look at on a daily basis. Many struggle with this to a great extent. Again, socially, the impact on the family, while they are not experiencing first hand as an individual is the social impact of the behaviour. In many ways they are even more, because the other family don't have an intellectual disability themselves. They are left to pick up the pieces, when the rest of the town or the place are fearing that they are their child which...it is very very difficult and socially isolating. And emotionally, obviously, I think the emotional impact on the family is worse on the family in my experience, because the family, again, are left to cope and carry all the complexities that comes with this, you know, quite serious, you know, negative behaviour. And it can be especially emotionally terrible on the mothers, from my experience, to watch their sons and daughters engage in repeated self-injurious behaviour and constantly question as to why their child is doing this on a daily basis. So, emotional implications are huge on the family.

**Interviewer:**

I gathered, it is a complex phenomena which is emotionally and socially, as well as physically impacting on everyone, really, around that individual and very frustrating. What kind of self-injurious behaviours would you be talking about, would you see most common?

**Participant:**

- In terms of my work I would be working with many different types of self-injurious behaviour: severe head banging, whereby individual would bang their head with a fist, with a closed fist, open hand against the wall, against the floor. Again, very hard repeated trauma to the head. The individual I worked with...so deformed by the amount of self-injurious behaviour, he would have engaged in, again on a regular basis. That would be light SIB for him, whereby he wanted to see blood to get a sense of release from, he would get down on all fours and repeatedly cut their face...hard floor, wooden floor, concrete floor; open up his nose, breaking his nose repetitively. Again, very difficult to manage from the professional point of view, you are obviously, where you are trying to make sure adequately, an individual is OK. From social work, psychology, psychiatric point of view and, then working as part of multidisciplinary team you have to ensure that the right interventions are put in place. In terms of my experience, I would have experienced very mild self-injurious behaviour, from how it starts and manifestations of children scratching their hands, repetitively scratching the same area, until they deform that area, to severe head banging, to severe biting, to severe tooth grinding. Many different, hair pulling...many different manifestations I would have worked with.

**Interviewer:**

- And, I suppose, how would you find the staff actually manages that behaviour? Would it be, a kind of just to ask a person to stop, or would there be more emphasis on, sort of, doing it safely, reducing harm?

**Participant:**

- I suppose, when you mentioned staff, you immediately work from the assumption that the individual has a service, but unfortunately, many people who out there engage in self-injurious behaviour are at home with elderly parents who are trying to manage it and don't have a service, because of huge amount of reduction of service provision and the social work database and everything else attached to disability services now. So, but individuals we are looking at now who are attached to disability organization would have key workers working with them, and would have behaviour support teams who focus on positive behaviour support which is really pushed by Dr. XXXX<sup>2</sup>, Dr. XXXX who wrote much about it. I think, on a day to day basis, that (managing)<sup>3</sup> has to be clinically informed and has to be working from a professional basis as it is not something that ...It is such a specific complex area, it is not something that there is an ad hoc response to a team, something that has to work from the same team sheet, if you like. And that can vary from Positive Behaviour Support, which is ultimately rewarding good behaviour as opposed to putting consequences to negative behaviour. That does not work...from my experience. Medication, therapy and a combination of both as a plethora of different service responses.

**Interviewer:**

- And, I suppose, for a family, perhaps, it is even more difficult, because they would lack the resources which are available to professionals, such as professional training and supervision and debriefing with colleagues.

**Participant:**

- Yes, without a doubt, we would talk about all these buzz words, \_\_\_\_\_in a professional setting. And as professionals, we need those things as supervision, we work regularly with such a negative self-injurious behaviour. As a professional it can start affecting you as individual. It is very hard to watch. But we talk about all the professional supports that are available in a professional world, but as you rightly say, there are parents at home who have to deal with this

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<sup>2</sup> Names were coded for confidentiality reasons

<sup>3</sup> Please note, that the words in brackets might not be accurate. Due to low sound or noise the word was not heard properly.

day and day and it has huge implications for not only their general wellbeing, but for their mental health as well, for families who cope with this daily.

**Interviewer:**

- How, from your experience, do you find families cope with this negative behaviour?

**Participant:**

- I find in many scenarios families do what they have to do. And, again, you've talked about resilience earlier. I think, families have become, particularly families I've worked with, have become very resilient because they had to. They had to work with this and they love their child, despite their behaviour. And the behaviour is behaviour, it is not their child. And, I suppose, what I've seen, is families very much separate things, that, perhaps those on the outside could not. They are not part of the family, I suppose, they would not see the individual if they bang their head a lot, if they self-injure, you know 90% of the day. It is easy to see the individual for what they do, you would see nothing else. But those families can see Billy or John or Mary and they see their child, or adult for who they are and, they see their little idiosyncrasies, what they like, what programmes they like to watch and their triggers. And they get to know all that precedents, what makes the behaviour happen. So, families can become an invaluable part of a clinical assessment process because they would be able to identify those triggers and they know their child so well, be that a child or an adult. So, I believe, the system which is adopted now – to bring the family more frequently on board and have them as part of step by step interventions with SIB, has proven to be effective.

**Interviewer:**

- It is really the families who are the experts rather than the professionals.

**Participant:**

- I would certainly think so. I think there is a huge clinical law in terms of SIB and yet a lot more people are put on advanced medication. Families have to be part of intervention. They have to be because of self-injury...they simply have to be part of an intervention, in my experience.

**Interviewer:**

- And what professional supports, if any were available to families of those individuals from your experience?

**Participant:**

- The families would have had confident social work professional support. I am thinking now...I can think of particular families now, who would ring us and ask us to come out and we would go out. It might be just going and sitting for a couple of hours and listening to a mother, or father, express their anxieties. Or, maybe, they would not be clear about certain elements of their Behavioural Support Plan; or they would be worried and anxious as a lot of people are when medication is mentioned. And they don't want their son or daughter to be medicated because they would feel that it is just sedating them or it is just slowing them down or neutralizing their child. While, I suppose, social work is not a medical profession, I think, sometimes we are the first port of call, really. Whereby the doctor or psychiatrist does not have the time, or does not go to great lengths explaining what a medication does. So, certainly, the family would be asking what would it do, how would it help, how would it help in the greatest context of Behavioural Plan. So, I suppose, offering clarity, reassurance, professional reassurance to the family is very much a social worker's role in that.

**Interviewer:**

- And in terms of advocacy, would you be fulfilling that role as well?

**Participant:**

- Oh, without a doubt, without a doubt. You certainly are. We would have fortnightly or monthly interdisciplinary meetings. And a social worker, because of the intensive involvement with the family. You are the one at that meeting who is representing family's views and that very much is taken on board. All other members of that team, the psychiatrist, the psychologist: "What does Mr. Smith say?" And they would look at social worker...Very much you are advocating for the family's desires and beliefs and also at the point of disagreement, whereby a



family might not want to follow a certain path, or they don't want to go with a care plan or they don't agree with certain conditions, like medication, behavioural support plan or certain programme that is put in place. So, as a social worker you would have to go back and advocate for organisation as a team in relation to and for the individual themselves because it may be in their best interests. As maybe the family is so protective that they don't want them to take the next step. One particular individual I've been working really well in terms of reducing SIB through a number of different interventions and it was working. Staff working with this particular individual felt that she was ready to start going in to public places more, which family had stopped a long time ago because of all the social implications and the embarrassment and that people watching. So they were reluctant to start that again. But it was started through the perseverance from the social worker. It was recommended that that particular girl would go to restaurant for lunch, staff like that which is a huge, huge step forward, socially.

**Interviewer:**

- Absolutely. And how did you find multidisciplinary working with other professionals?

**Participant:**

- It can be difficult and challenging at times because sometimes, and I said it at the start of the interview, you can be 'the jack of all trades'. It is the bad way to (exploit) the social worker. And if you go in with that mentality, you can end up with a number of an awful lot of work which is not really defined. So, I suppose, knowing your defined function and role, I suppose as a professional, support and advocate for the family. There is a huge amount of, I suppose, as a social worker, you often become a case manager, you become an individual who manages the whole lot, because there is a clinical piece, the psychiatric medication piece, there maybe a behavioural supporting piece, social care plan piece. I suppose, as a social worker working with the family, often you are the case manager who pulls all that together. That is part of a job, you know.

**Interviewer:**

- And, in your opinion, children who self-injure are more likely to receive special educational support, than children who don't engage in SIB, distinct from mainstream?

**Participant:**

- Without a doubt, without a doubt. To be fair, self-injurious behaviour in intellectual disability services, because it is often very extreme and complex, in my experience, and I have to say, while a lot of experience is not extensive, a huge amount of my experience fell over a Celtic Era, where there was a lot of funding. I suppose, in my experience, and it is only in my experience, there would have been services and service responses there. But now, with the challenging times ahead, who knows whether that would be there, because at the end of the day, an awful lot of those supports and services got boiled down which is unfortunate, but this is the reality which is facing services now.

**Interviewer:**

- I suppose, it could further, kind of exclude this group of children?

**Participant:**

- It could and most probably will. Many of the most vulnerable...(noise) because of lack of funding that is made available.

**Interviewer:**

- In your experience, is SIB in childhood associated with residential care in adulthood, in other words, are those children more likely to enter in residential care in adulthood because of their self-injurious behaviour?

**Participant:**

- Again, I would say, 'yes', but this would be anecdotal, based on my own experience. I would say that children I worked with who displayed self-injurious behaviour at a young age, they may have just started displaying it. As they get older, it gets harder for parents to manage. So, generally, they start to get a bit respite with service, maybe on Sat. or Sunday (*phone rings*). They maybe able to get....In terms of correlation between childhood experience of SIB and then

increasing, maybe manifesting into residential, or these individuals coming into residential. I would have certainly seen anecdotal evidence of that happening. I would have worked with many children whose behaviours got to the point where parents struggled and started off with respite and then...depending on the family, of course. Some families would go the end of the earth to accommodate their home and then re-do their home to ensure to keep their child. And other families are maybe less equipped or don't have the resources to do that, or not have the strengths themselves to do it. The parent becomes frail or elderly or passes away. I've worked with all those experiences. No alternatives due to the high level of behaviours that individual came into residential. I think, I think it is very hard. If I take the most extreme examples, I've worked with I would see it as very difficult for a family to manage at home without a huge amount of support, because this behaviour can be so negative, you know, without the support of the behavioural support team and staff on-site. I wondered, how many families got on, I have to say, when the behaviours really manifested. But at the same time, some families, early intervention can be the key, like with many things. And I had experiences whereby a certain balance between medication and therapy was reached at a younger age and behaviours did not escalate. However, I would have to admit that the majority would have, yes. In my experience, there would be direct correlation of childhood experience of SIB and turn into residential, because of add up to it.

**Interviewer:**

- And would you find those children or young people themselves tried to use strategies to stop or reduce their behaviour? I suppose, from the strengths based perspective looking at it.

**Participant:**

- Yes, I've worked...Again, depending on an individual, it is quite subjective. I've worked with children and adults, who, you know, huge amounts of interventions have been tried. Some have been very successful and some have not. I've worked with one particular individual and I worked with him as an adult. He was probably approximately 22 or 23 years of age when I worked with him. And he engaged in very, very severe self-injurious behaviour: beating his face and head

banging. But I remember looking back on all social work files when he was two and the behaviours he engaged in, they were identical to the behaviours he engaged in when he was 23 – the head banging with closed fist and where he hit, areas he targeted on his face. And the behaviour was quite stark. To find that and see that he still engaged in all these behaviours despite every effort...He had about 10 psychiatrists over his life and enormous number of clinicians, probably about 100 and still he engaged in SIB. And this individual now, I know, has been incident free for the last two years, I believe. He is older now, he must be about 30 now and I don't work with him anymore.

**Interviewer:**

- It is a great improvement. It would be interesting to do a case study on that. An I wonder, in this particular case, was SIB associated with any particular syndrome or autistic spectrum?

**Participant:**

- Oh, yes he was on autistic spectrum, he had autism. The diagnosis is there. Obviously, there is a huge correlation between autism and self-injurious behaviour and intellectual disability. Most of the individuals I've worked with, if not all would have been on autistic spectrum on some level.

**Interviewer:**

- And, if a child lives at home, do families receive in-house support or any respite care. Of course, maybe the situation now might be different.

**Participant:**

- And again, I suppose, there would have been. And now, I suppose, there are developments. There are autism support teams set up in many areas and families qualify, obviously and entitled, under the Disability Act to an assessment of need and that is a welcome support which came in past '05 and prior to that...(if I can remember). Unfortunately, geographically, if you look at the national perspective it depends on the area. While there are many disability service providers in XXXX, in XXXX, we are lucky. Certain parts of the country aren't as lucky. I've worked in XXXX and XXXX, and further south, XXXX and the disability services aren't as plentiful as they would be in this part of the country. So, I

suppose that's unfortunate because it boils down to amount of services that are made available to you on where you live, you can argue the same with hospitals and everything else. I think around XXXX,<sup>4</sup> XXXX area where I did most of my work. There are many organisations. You have XXXX, you have XXXX, XXXX, XXXX formed by XXXX, also private providers as well. There would be voluntary organisations set up by groups of parents, obviously, religious orders. So, depending where you live has been a factor for people. But, I think, generally speaking, is there support available to families at home? Yes, there is. How much of it will continue, that would depend on the ministers of the house and the upcoming budget.

**Interviewer:**

- In your view, \_\_\_\_\_ what are the most effective social work interventions when working with this client group and their families. And what interventions would you consider unhelpful, albeit well meaning ones?

**Participant:**

- I would say at the start interventions that would be helpful. I think, an ecological perspective, when you are taking the whole system, the whole family unit more into perspective. In working with what is a complex phenomena, self-injurious behaviour is not a cause and affect. It can't be treated with the simple interventions that are going to improve things, the likes of Brief Solution Focused Therapy. It would not work, where it is a long-term, in many cases behaviour. So, to go in and think that this is going to be cause and effect and a simple thing to work from a certain platform or theoretical framework would be a bad idea, because an ecological perspective, whereby you take a family as a whole, whereby you are working as part of a multidisciplinary team from organisational and professional point of view, but you are working very much as part of a family in terms of the family's not only perspective, but from the experience of the behaviour. And, I think that is the best way to come from, that you have to look at and, as a social worker that is where you fall into. You are, as I said earlier on, as a social worker, you are the mediator between the family, organisation,

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<sup>4</sup> XXXX – Names of areas and organisations were coded for confidentiality reasons

individual. From an advocacy point of view, you definitely come over using ecological perspective and also systems theory to know systems, to know family systems, to know the professional systems and, obviously, the health systems, to know how these systems work and to know how you work as a social worker within that system certainly benefits; because it can be very difficult. Families may be seeking supports...It is important that a good knowledge of systems theory...and a family may be seeking concrete supports and you, as a social worker, may be giving informational support which is not what a family is looking for. So, a good knowledge of what the family is looking for, the system you are working within, whether you are able to help, that's crucially important. In terms of theories that don't work, I've probably touched on that, Brief Solution Therapy. Task-centred analysis would work quite well with these individuals themselves with autism, because individuals, generally, with self-injurious behaviour who are on autistic spectrum...as I said, because it is working in quite methodological way, and it is often helping, no matter what family, because it is working in methodological way...But I have to say, the one (approach) certainly does not work with self-injurious behaviour, far too complex, it is generalized. It is so subjective, depending on a family. You can have a family very willing to work with services and hugely on board and very open and try to balance, want to learn more and put themselves out there; and, you have families who are very weary and cautious of services which is understandable, given the day care and a state. They are very cautious of clinicians and people, social workers and there is a fear attached to that. So, I think, again, tapping back to person-centred approach, humanistic approach would be very helpful to that, in terms of interventions one can rely on.

**Interviewer:**

- Thanks you. And, I suppose, it is being eclectic in a way and trying all different ...

**Participant:**

- Without a doubt, without a doubt. I think, you have to be open and depending on the family, you have to chop and change your perspective. And, sometimes, you can get shouted at, and you have to take that on a chin as well. You must get an

estimated anger towards you and, again, going back to emotional and social hurt and pain that is attached from a family point of view. You know, sometimes, I think you can be a target of that, but this is part and parcel of it. You just have to go through that as a professional social worker.

**Interviewer:**

- I suppose, it leads to my next question which you've already started answering with regards to what are the main challenges to working with those families as a social worker, I suppose.

**Participant:**

- I think, the main challenges in many ways is the behaviour itself, because having worked with this behaviour for such a considerable period of time, you begin not to see the behaviour and you begin to see things like family, you begin to see the individual. And, I suppose, that could be challenging, challenging to see that individual struggle with what is horrendous negative behaviour that is holding them back in many aspects of their lives. And that can be difficult to see and watch and witness as a professional. And, also, you have a huge sense of empathy to the family who you could see crying and dealing with this. You know, we sat with mothers and fathers who just want their child to be OK, who just want this horrible thing to stop. Because many families with intellectual disability, they grieve, they grieve the child they thought they thought they were going to have, and the fact that you have a child with a disability. And, I suppose, having a child with a disability is one thing. Having a child with a disability who engages in extremely difficult self-injurious behaviour and who punishes themselves daily, who self-harm...and mutilation. It is pretty much the hardest thing a parent can watch; and, as a professional working with those parents and watching them going through that is incredibly challenging. So, it is important that you look after yourself as a worker as well in that, because it's quite emotive working with families who struggle with that.

**Interviewer:**

- I suppose, what feelings would you have experienced yourself, being in the middle of all that. And, especially when families cry.

**Participant:**

- I think, your professional supervision kicks in; and you have to remember your role and your function and you have to have controlled emotional involvement; and you have to realise that you are part of the process. And you are the professional, that person to be there who is to be there to listen, to hear, to assist and to support. And you are that person the family, sometimes, cry to. And that is part of your job as a professional social worker. And it can be difficult at times and it can be rewarding at times. And, I suppose, you have to take the bad days with the good days. And I would certainly use my professional supervision with my line manager as my coping mechanism to sustain controlled emotional involvement with the case and the family.

**Interviewer:**

- And, I suppose, what do you think families and individuals themselves expect from healthcare professionals and professional social workers? What expectations are in terms of the way we deal with them, what qualities are they looking for?

**Participant:**

- I think families, it depends on a family. I think there has certainly been a generational shift in families and families with older parents, maybe of adults with intellectual disability who engage in self-injurious behaviour are very grateful. Where as other generation, whereby there was no support, the support they get they are very grateful for, and maybe a little bit weary and anxious but very grateful with any support they can get in relation to their son or daughter. I think, there has been a shift in generation. I think it is a good thing. I think modern families expect the supports to be there and they expect the health service to offer the supports and to ensure their son and daughter is safe and happy people and have the supports; and that they are not waiting for 6 and 12 months and a year and two years for an assessment of need and/or psychological support. I think, I can certainly see a gap, or a difference between the old and the new, if you like, in the expectation there. And, again, depending on resources being there, there is worry about that, particularly now, in the times facing us. In years gone



by, the assessments were flowing. It was easier to get support...It was never easy, but it was certainly easier, than it is now.

**Interviewer:**

- And, on a personal level, do you think the relationship you build with the family plays a part as well?

**Participant:**

- Yeah, I think so.

**Interviewer:**

- And the way you work.

**Participant:**

- I think, social work is largely, if you take by the definition, it is social work and you can't do social work unless you have social personality and an ability to communicate with people and an ability to read people and, so, trying to support people is the very backbone of social work. So, if you don't have that, you keep (developing) that skill. It can be very difficult to be going to a family and speak about most intimate details of their relationships with their child, their son or their daughter. I mean, you won't be taken seriously and you won't be allowed in. So, you have to have that. Every social worker should develop year on year. It is something that you can never say: 'yes' at the end of your degree or your masters that I have that, that box ticked. I mean, seven-eight years on from qualifying, I am still very much learning as I go and, depending on the family, you know you certainly have to have a (comfort) and a toolbox to master those skills and to make sure you stay sharp and you stay in tune to the family's needs. That's why you are there for.

**Interviewer:**

- I suppose, they still value genuine-ness and openness

**Participant:**

- Without a doubt. I think, honesty goes a long way. I think, the last thing these families want when they go through all those things, because some of those families had many clinicians coming and going in their lives, many social workers, many psychologists, many psychiatrists throughout their life, depending

on the age of their son or daughter. So, I would always try not to be just another face and try and offer, as you say, I think being genuine and being honest and, you know, empathizing and offering the sense that: “Listen, I am not here with all the answers, I am here to help and support you and to help you and help your family, your son and daughter”. And, I think, families recognise that in you, they recognise genuine-ness, as you say, that is basically founded on dignity and respect that you give while you work with the family.

**Interviewer:**

- And, I suppose, to conclude, how satisfied would you be with the level of professional support that is offered to families by your service provider of a child, or an adult with an intellectual disability who self-injures.

**Participant:**

- I think I suppose, my experience would be based on a couple of organisations that most certainly be...I would be very happy with the service that I witnessed. As I said, I would have been working with the ones who received the service, I suppose. I think that would always have happened. But I think, disability service in Ireland is well put together. I know, it differs, as I said earlier, on where you live, but I would be very satisfied with the service I've seen delivered to people I've worked with.

**Interviewer:**

- Thank you very much,\_\_\_\_\_It was very helpful. You gave me a lot of useful information and insight and into the topic.

**Participant:**

- No problem,\_\_\_\_\_Good luck with your research.

**Interviewer:**

- Thanks, bye bye.

