



Violence in children and adolescents with an intellectual disability and the importance of safety.

Associate Professor David Dossetor

*The Children's Hospital at Westmead
Area Director for Mental Health*

Child Psychiatrist with a Special interest in Intellectual Disability

"It is easier to build strong children than to repair broken men."

— Frederick Douglass, 19th century American black social reformer.

Introduction

Family violence has benefitted from greater attention and has become not just a criminal but a public health issue with our Australian of the Year being recognised for her stand on domestic violence. In a civilized society, as our new prime minister says, we should have zero tolerance for violence whose roots come from a culture of failure to respect (women). Tackling this culture will no doubt help improve the mental health of many. Violence is defined as behaviour involving physical force intended to hurt, damage or kill someone. Aggression is a range of behaviours which can be physical, verbal, mental or emotional that can result in physical or psychological harm. Abuse is exploitative aggression in the context of an unequal relationship. Over half of adults and children with intellectual disability engage in aggression, although for only a minority is it frequent or severe (Benson *et al*, 2008; Matson *et al*, 2005).

Yet we live in the least violent time in history. As documented by Stephen Pinker (2011), this is due to the rise of democracy with the separation of law making, from legal process (courts) and law enforcement. It is also due to the rise of education and the greater empathy skills that arise from reading, leading to the decline in violent confrontation and the rise in collaboration and compromise where both parties benefit. These principals apply to the raising of children including those with intellectual disability.

Aggression is divided into impulsive or affective aggression, and instrumental or predatory aggression. The implication is that affective aggression is a failure of emotional or cognitive regulation whereas instrumental aggression has malice aforethought to cause hurt to another. The latter requires considerable mental development to have such awareness and insight of harm to another. In those with intellectual disability affective aggression is more common, and functional analysis subdivides affective aggression into the main subgroups of: attention demanding, task escape or avoidance, demand making, or for a sensory need. How-

ever for some this changes in different situations and in others no purpose can be identified. Aggression as a human attribute becomes as stable as intelligence by the age of 10. This is also confirmed in those with intellectual disability where longitudinal study shows that the presence of behaviour disturbance at 23years (mean age) is best predicted by the presence of behaviour disturbance at 12 (Einfeld *et al*, 2006), although it does decline a bit with time. But how can we understand aggression from the context of child development?

“affective aggression is a failure of emotional or cognitive regulation ”

Aggression and normal development

Did you know that toddlers are the most aggressive people on the planet (Pinker, 2011)? Of course they don't know it as initially they don't understand that their behaviour and feelings have impact on others. They are discovering their emotions, which progressively differentiate from an awareness of a level of arousal: too high to too low, where best human functioning is a calm alertness in the middle, to notions of internalising and externalising of affect: anxiety versus anger. These differences occur in the context of developing a theory of mind, whereby a child learns to match and compare emotions and thoughts with their primary attachment figure. Learning to compare and modulate feelings and thoughts in relation to others is at the heart of developing social skills. These social skills define us as a social animal and enable us to belong to families, communities and the human race. These skills are central to developing attachment, from which we learn the skills of making friends and contributing to creative reciprocity with others.

The normal pattern of behaviour development is that infants, as they grow older and develop motor skills, become increasingly active, exploratory, demanding and intrusive until the developmental age of 2-3years. At this age they develop their capacity of theory of mind, which has histori-



cally been described as the human spirit, involving the development of their internal world and awareness that others also have such consciousness. Their energy is then channeled internally into their imagination and their externalising activities moderated. A parent's role is to teach them mutual respect, collaborative social skills and the benefits of positive attachments (love) with themselves and with others before they are too big and strong that their natural aggressive capacities become dangerous to others.

Failure of this learning which Bruce Perry describes as types of parental empathy failure sometimes becomes engrained in the personality (Szalavitz & Perry, 2010). Psychopaths are amongst those who have miss-learned these skills and use violence to calm themselves or even for pleasure. Such clinical observations have contributed to the need for zero tolerance and the expanding of prisons to protect communities. Borderline Personality Disorders have problems in negotiating relationships with both problems of aggression and self-injury. They can benefit from long term specialised treatment approaches such as dialectical behaviour therapy. This evidenced-based treatment similarly involves negotiating safety and behaviour control, before focusing the therapeutic relationship on emotional wellbeing and relationships and problem solving.

Parenting skills especially for difficult children in difficult circumstances

Parenting skills are key to socialising aggression and learning to control and express anger in socially acceptable forms of thoughts and behaviour. The coercive pattern of parenting is a powerful explanatory model of the way in which parents allow their behaviour be determined by the intensity of affect from their child, when they give way to the distress or threat of aggression from their child and give them what they want (Patterson, 1982). This process reinforces the currency and power of aggression and intermittent reinforcement (by giving way sometimes), and teaches

the child that using emotional or physical threat is worth persisting with because it works. Parent training programs are dramatically helpful especially in preschoolers, before a child has a sense of permanence of self, as good or bad (Eldevik *et al*, 2009; Centre for Reviews, 2015). They both reward better, socially contributive behaviours, and inhibit aggressive or antagonistic behaviours accompanied with sufficient monitoring, for example knowing what the child is up to at all times. Structured activity and participation is another proven component to improving behaviour. After the age of 7 helping aggression takes a much more intensive and prolonged intervention as it involves changing established behavioural and emotional patterns, and changing self-concept and reputation (Mazzucchelli & Sanders, 2011; Scott *et al*, 2015). These processes for those with delayed development, are slower but the susceptibility to change also persists to an older age. Helping young people with delayed development requires greater understanding and skills such as Stepping Stones Triple P or the Incredible Years Program.

Where self-worth and family communication and relationships are vulnerable, there can be a recrudescence of aggression in adolescence which may be resolved by escape from troubled family relationships into independence. There is no doubt that hormones and brain immaturity contribute. This has been described as the maturation of the emotional circuitry in early teens before the higher functions of the frontal lobe control systems in the early 20s.

For those with an intellectual disability, rates of emotional and behavioural disturbance are related to their developmental age, much more than their chronological age. They remain in their developmental toddlerhood much longer, which influences both their capacity to learn emotional regulation and theory of mind, and are accordingly slower to improve. This applies to people with ASD where emotional understanding, theory of mind and social skills are specifi-

“the vast majority of people with serious psychiatric disorder are not violent”

cally delayed behind other developmental skills. However, in delayed development it is clearer that behavioural interventions to regulate behaviour and habits, and teach compliance, comes first before the development of an understanding of emotions and attachment.

Violence is not a psychiatric disorder

So often people link violence with psychiatric disorder. However the vast majority of people with serious psychiatric disorder are not violent. Depression and mania are associated with increased irritability and thoughts of harm to self or others. Occasionally someone with schizophrenia has delusional ideas that the world is against them, or that a hallucination tells them to do something awful. But as already stated, most violent people have an established pattern of this maladaptive behaviour. Is it maladaptive? Threats and violence are very powerful behaviours, which gets you what you want in many ways, but at someone else's expense and associated loss of quality of relationship (eg. fear and hate). In fact violent people often attract other violent people to 'sort them out'. Alternatively it is a route to a more restrictive environment, whether this is prison, or a community residence with restrictions on freedom to protect others. It is also a cause of premature death especially from accidents, and, despite tending to ameliorate with time, also leads to increased rates of depression and other mental health problems later in life. In childhood and early school attendance, peers recognise aggressive children very quickly and reject them from their social circle, leaving aggressive kids to associate with other socially excluded kids (Patterson, 1982).

I often explain that the neurotransmitter surges in rage are so great that if one attempted to block them in an attempt to prevent future recurrence, the client would be unconscious the rest of the time: like an anesthetic. The role of psychopharmacology in the management of aggression is dependent on finding an associated mental health disorder that can be modified with medication. For example treating ADHD can have a dramatic effect on a young person's lack of emotional and behavioural regulation, and in turn their relationships. What matters is whether the treatable psychiatric symptom is causally linked to the aggression. Sometimes traumatic, panic, obsessive or stereotypic driven anxiety can be treated and influence the frequency and severity of the anger and aggression. However, sometimes the anxiety is not related to the aggression. Indeed it is recognised that anxiety in a violent person is often a redeeming prognostic quality which may help them in moderating their aggression over time, possibly via engendering attachments, or encouraging people to persist in caring for them.

“He can't be naughty and be autistic”.

Why is there an epidemic of intensely violent autistic minors being brought to emergency departments? Emotional and behavioural regulation and wellbeing is one of the most important determinants for having a quality of life. Understanding and respecting the capacity every child has for autonomy and learning, despite their disabilities, is a crucial responsibility for every parent. All too often parents are permissive in their behavioural management, as they feel victims of their child's developmental disadvantage, and feel sorry for and infantilise the child's competencies. They often medicalise the explanation and therefore expect someone else to change the child they have failed to accept and respect. The increased recognition of this developmental disorder has rightly led to parents' increased demand for skills and treatments for promoting development, but has it also prevented parents for realising their primary responsibility for teaching emotional and behavioural regulation ie. learning to love?

Fetal Alcohol Spectrum Disorder (FASD)

Alcohol is a mutagen to the normal development of the brain in pregnancy. This is a critical piece of scientific knowledge for all binge drinking young women at risk of pregnancy. FASD children also often come from poor quality home environments, with abuse and neglect. Often by the time they are seen in child psychiatric services they are in better quality homes of foster care. They suffer a range of developmental disorders: ADHD, sensory processing disorders, coordination disorders, language and communication disorders, learning and memory difficulties, problems of executive function such as planning and sequencing skills, autistic spectrum disorders and particularly mood and behavioural regulation disorders. Part of their challenge is they often do not qualify as intellectually disabled (on IQ testing) and, despite the complexity and multiplicity of their disabilities, are not recognised for the level of support they need in a mainstream educational system. They often fail to develop emotionally, socially and educationally and don't survive in school. The rages of some of these young children seem to exceed most others I have been witness to. Helping them requires a combination of: understanding their domains of disability, providing the calm, persistence, warmth and encouragement of superlative parenting, support and intervention for them in the home, school and community, and determined pharmacological treatment of their ADHD, anxiety and mood lability. Providing all three requires loving families and a responsive health, mental health, welfare and disability system. I have seen caring families and their support services tested to the limit, but then witness the late development of a capacity in a young person for self-care, awareness of self and others and an interest in developing relationships that a year previously never seemed possible. This may be a lot to expect, but the costs of a dependent unemployed adult with a future of recurrent law breaking and substance abuse is likely to be considerably greater.

Challenging Behaviour versus Child Psychiatric Disorder

25 years ago the Training Resource Unit was set up by disability services to provide Applied Behaviour Analysis as the service solution to challenging behaviour, the then recog-

nised label of all severe emotional and behavioural disturbance in children and adolescents with intellectual disability. There is good evidence that behaviour intervention (ABA) including sensory intervention, relaxation skills, anxiety management skills, and emotional and cognitive behaviour therapy are effective interventions (Ali *et al*, 2015). Skill enhancement in self-help skills, communication, emotional understanding, monitoring and problem solving skills all contribute (See Dossetor *et al*, 2011). This requires a range of disability specific specialty professional skills. These interventions work to reduce the frequency and severity of aggression in a planned way but there is evidence that reactive management strategies also have a place in minimising the impact (Adams & Allen, 2001; Dossetor *et al*, 2011, Chapter 21). This also requires the monitoring of quality standards of practice to avoid excessive restraint and seclusion, which has been the blight of several public enquiries.

With the launching of the National Disability Insurance Scheme and closure of the State Disability Service we are at risk of losing the specialist therapeutic resource of skilled interdisciplinary positive behaviour support now provided by the Statewide Behaviour Intervention Service and Regional Behaviour Support Teams of the disability provision of NSW Family Services. They provide world class innovative treatment for the most complex cases in the state, such as play therapy, modified Trauma Focused CBT, Dialectical Behaviour Therapy, Systems Family Therapy and Parent Child Interaction Therapy for young people with intellectual disability, and then share their skills and train others around the needs of a challenging child. Is it possible that the NDIS will fund the non-government sector to provide this level of acute and multidisciplinary support?

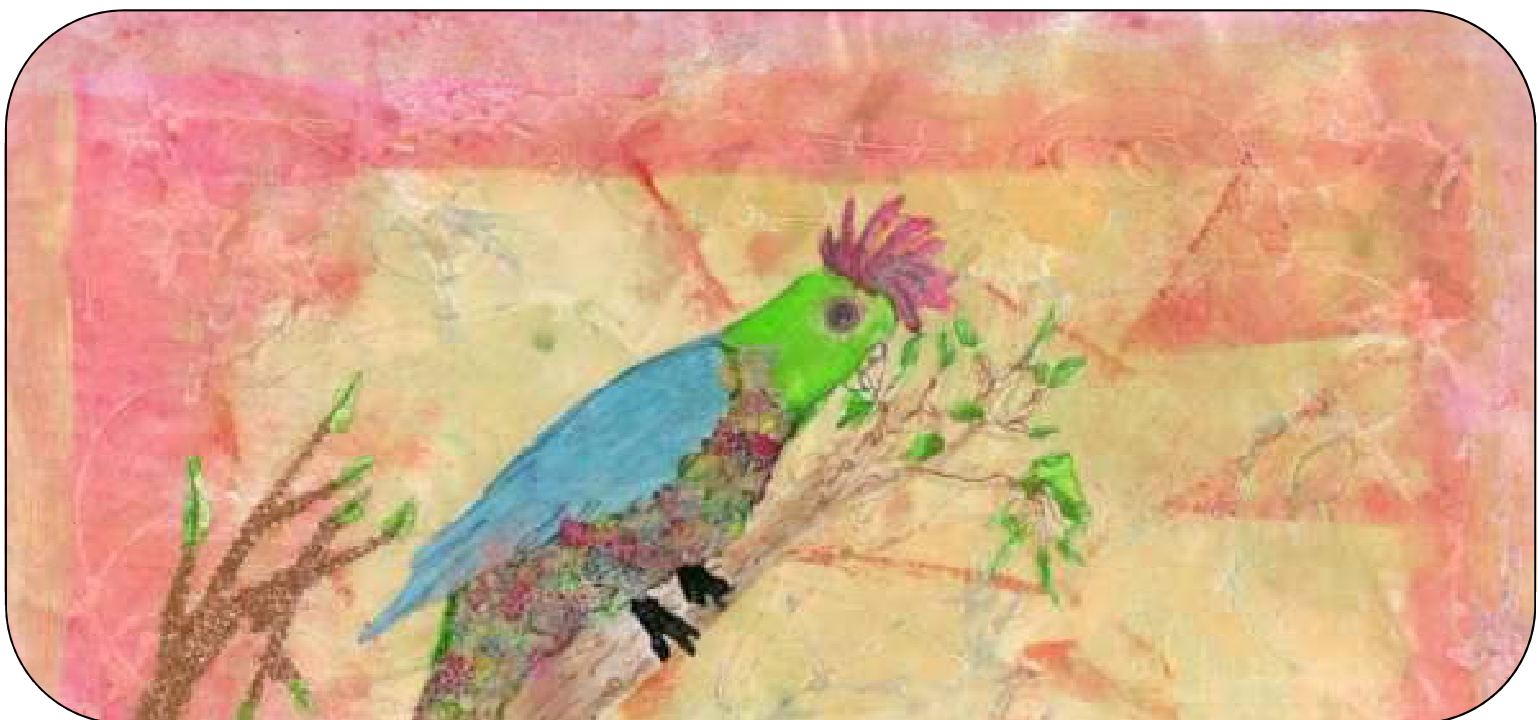
I was recently confronted with the referral of a severely abused and neglected out of home care 12 year old, who started assaulting his case manager and carer as soon as I asked them to tell me what his problems were, (there being no one else to look after him). He had already seen 6 highly

regarded child psychiatrists and had so many established diagnoses: moderate intellectual disability, ASD, ADHD, attachment disorder, language problems, coordination disorder, oppositional defiant disorder, anxiety disorder, depression, possible bipolar disorder. Many treatments and psychotropic medications had been tried without significant benefit. If your development is so badly impaired and your aggressive behaviour traumatises both you and your carers, it is not clear that recognising these multiple psychiatric disorders in isolation to a specialist service system of care and welfare can possible achieve much for someone who is a danger to others.

The Developmental Psychiatry Partnership (DPP) with Statewide Behaviour Intervention Disability Service

I have been privileged to be part of a tertiary interdisciplinary partnership between a small developmental psychiatry team, a small tertiary disability team and representatives from the Department of Education. Central to this partnership is conjoint work over cases of emotional and behavioural disturbance in young people with intellectual disability that have challenged their local multiagency health, disability and education services. Evaluation of some of these cases indicate that families valued the quality and sustained support that enabled them to keep on caring for a high needs and troubling disabled child. Other cases have relinquished care into long term respite. The traditional view of respite care is that respite is only part of a pathway to relinquishing care. What a simplistic view of families! We have had a number of children who have been relinquished for several months, but have then resumed family-based care (sometimes with a shared care arrangement), with ongoing support from developmental paediatrics and psychiatry, disability services, respite services and special education. All these cases involve high levels of aggression and violence in the context of a minor with intellectual disability.

One study in adults with intellectual disability showed treating 'challenging behaviour' with a major tranquilliser is not



effective (Tyrer *et al*, 2008). However to suggest all people with challenging behaviour and intellectual disability need the same treatment is facile. There is limited research available for drugs studies in children with intellectual disability and complex, often multiple, psychiatric disorders. Our clinical experience has demonstrated the importance of medications that treat ADHD, anxiety, depression, lability of mood, occasionally explosiveness, and excessively sexualised behaviour. These are the common psychiatric disorders associated with aggression. Often, adequate treatment of the comorbid psychiatric condition is necessary before other modalities or treatment can work.

Children that abuse their parents

Children are protected from abuse before the law, but parents are not protected from violence by their children. Human sensibility to the welfare of these parents still makes this a serious concern for others including professionals involved. It is distressing hearing the stories of a young person, often over 100kgm, hitting, kicking, throwing objects, leaving bruises and breaking bones of a parent. Police will intervene and take such a young person to hospital for review but most rages settle in a reasonable length of time and this is not the access route to an in depth assessment for what is usually an acute predicament in a chronic problem. Medical assessment will consider whether this is naughty/angry behaviour or a significant acute psychiatric disorder. Admission to hospital is reserved for high risk psychiatric disorders. It is a welfare issue when families feel they can no longer tolerate their child's violence, with the breakdown of the family's capacity for care, custody and control. There are concerns about Restrictive Practice Guidelines that sometimes lead to confusion over how to manage violence. These Guidelines are provided so that where restrictive practices are in the best interests of a minor, there are sufficient professional standards and monitoring to protect all involved.

These situations are complex: Parents have responsibility for the safety of their child with a disability and indeed the other siblings in the house. I regularly point out that parents have greater authority than police, doctors, courts or other support professionals for the care, custody and control of their children, at least till they are 16, and arguably until they have a capacity for informed decision making capacity (which may be even older). They can do anything in their powers to support and control their child, so long as they do not inflict hurt or harm. They are therefore seen as having all the power, but often it is the young person who may be as young as 7 who has the control over a parent by virtue of their strength and use of violence. In effect they have been

“Parents have responsibility for the safety of their child with a disability and indeed the other siblings in the house”



allowed to get away with terrorist-like tactics and to have an exaggerated control over their family.

Psychologically for a child, part of feeling safe is to know that your attachment figure (parent) is in charge. Feeling that your rage and loss of control is not under the control of a loving parent is an existential anxiety and threat. Swaddling an infant who is angry and thereby reassuring that such distress will pass is part of such security. Accordingly, those children, who have unsafe and unresponsive aggression, often respond to holding therapy. Holding therapy has been found helpful in ASD, as it teaches the parent that it is the child that lacks the skills of social engagement, and helping them involves going into the child's social space and teaching them human closeness which their autism makes them naturally avoid. I feel it is psychologically harmful for a child to be able to inflict harm to a parent. That a child is allowed to inflict distress, pain or injury is allowing them to establish an abusive pattern of behaviour. Sometimes this is fuelled by self-sacrificial attitude and behaviour from a parent. Conversely parental retaliation with hurtful punishment is not just harmful to the child, but sets an example of aggressive parental behaviour. Calm containment is needed for safety.

The key skill in parenting is not to allow aggression to influence a parent, and to contain and modify this behaviour without a show of anger oneself. It involves teaching alter-

native prosocial behaviours, with distraction or rewards (eg. differential reinforcement of incompatible behaviour). It involves teaching self-regulation skills (sometimes referred to as extinction of behaviour). Time sitting on the bottom stair, or time out in another room teaches the young person that only they are ultimately the only one in charge of their emotions and behaviours, and once they have re-established control, they are welcome to re-engage with others in the family for which they can be rewarded. Ultimately it teaches that aggression begets boredom, loss of influence and attention. (Where a child has regular predatory aggression, I feel that, with due family judicial process, a punishment of brief isolation is justifiable as parents can teach how the rules of our community work for crimes such as grievous bodily harm).

These approaches really do work with younger children, but older and larger minors may have well established patterns of behaviour. Frequently they are fuelled by an autistic misunderstanding of the world and sense of threat via any primary sensory modality, such as distress from seeing an obsessive fear, eg myna birds, or hearing a noise, or a temperature change, or some other stereotypic obsession. Often these provocations only make sense to someone with ASD. Nonetheless allowing a minor to inflict significant injury is harmful and can be dangerous. If such behaviour is not controlled in the home it tends to become generalised to other settings such as school.

The architecture of safety

In such situations, I feel parents have a responsibility to protect themselves by putting a strong door between themselves and an attacking child. It often helps to have a quiet room, sensory or chill out room. Often these extremely aggressive young people have major sensory sensitivities and the room needs to be adapted with personalised sensory experiences, such as a darkened atmosphere, cushions and mattresses for touch, pressure and proprioceptive experience, chewies, soothers, music, favourite visual entertainment etc. All of these sorts of contributions can be aided by a skilled occupational therapist and behaviour support therapist. Similar approaches have been shown to be effective with aggressive teenagers of normal intellect in mental health wards (Champayne *et al*, 2010). The principals include: creating a sense of safety, soothing through senses, distraction, stabilising through senses, creating positive associations, creating a sense of control, supporting appropriate expression and release, facilitating self-management (Sutton, 2011).

In extreme situations the room may need to be adapted so the young person is protected from self-harm, such as unbreakable windows, soft furnishings, mattresses round the walls, and even rubber walls. It is remarkable how having such a chill out room can start by providing a capacity to protect caring parents, but becomes a favourite place for the young person to go and play and seek sensory stimulation. Sometimes metre-square cushions or portable gym mats can be used to present a soft façade to an aggressive teen, while preventing access to hurting an adult, and can be used to corral the teen to their chill out space. Case examples demonstrate that such a capacity to set limits and

protect from harm can bring about changes in violence and behaviour when every other psychological or pharmacological approach had failed. Critically, the parents need to make these architectural modifications themselves. We need to build a repertoire of architectural modifications and sensory supports from different people's experience; I regularly recommend a split or stable door, for young people with profound intellectual disability, to restrict access but maintain visual and verbal contact. It can be viewed as creating a specialised play pen for a 100kgm 15year old developmental toddler! Parents and carers may also need to learn aggression minimisation skills that include self-protective skills, which are now mandatory training for all mental health professionals, and for many disability, care and teaching staff with government policies of zero tolerance. It is just as important to protect parents as it is staff of the caring professions.

What is the alternative?

Parents often fail to appreciate what capacity they have for making a difference, possibly like other trauma victims they feel frozen from taking such initiatives. Yet they have the authority, responsibility, and the long term relationship and often the love and commitment. The only alternative is to give up and relinquish care which is not an easy thing to do. Many care providers will not take on difficult-to-care young people as it requires high levels of staffing and staff skills (and high levels of funding). Once dangerous violent behaviour is established, it can take years for skilled management and developmental maturity to improve it.

The legal context

Actual violence is an offence, but if the offender is intellectually disabled, and lacks capacity to understand the offence and legal process, then they are dismissed under a section 32 of the NSW Mental Health Act (2009), as it is inappropriate to punish such innocence. However the responsibility falls to the family and the community to provide for, protect and intervene to help such violent individuals. So often there is no service willing to help, and a lack of guidelines on what families can do, especially when they feel they are the victims of the situation. I hope this article provides some guidance for such families, with further support from the involved professionals.

Conclusion

Dealing with violence in young people with intellectual disability is a common but complex problem. Frederick Douglass' quote reminds us that early intervention is the best way to avoid these problems, but valuing all children including those with disability and acting to prevent emotional and behavioural problems is not a strong enough part of our culture. Part of that culture is the acceptance and inclusion of disabled children by the wider family and community, to share the additional burden of care and need for attention. Accordingly we need to consider what best practice for this serious problem is. In tackling violence, clients and parents/carers are regularly injured and occasionally die.

Safety intervention can have a role whether the extreme violence is predatory, affective, insightful or dissociative,

although differences in the type of violence may alter the way it is managed. When one considers ‘state of the art’ of intervention to help young people with intellectual disability and recurrent violence, such approaches to safety intervention is an under-researched and little documented area. These issues have been considered mostly in institutions or group homes for adults with intellectual disability. Very little has been written from the perspective of a family faced with this challenge. Every case needs to be tackled individually with a practice-based-evidence approach. Clinical experience shows that safety interventions, if implemented in these extreme cases, works quickly in preventing further injuries and is an important contribution to changing the pattern of behaviour for the young person with intellectual disability. This in turn can have long lasting effects to improving their quality of life, independence and freedoms.

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