

Self-Injurious Behaviour: Challenging the cycle of distress! Multi-disciplinary, multi-modal models of examining behaviour.

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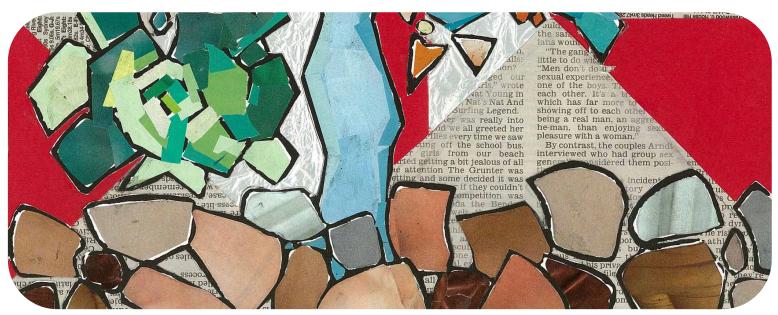
Self-injurious behaviour (SIB) is defined as a severe, recurrent and chronic form of aberrant behaviour that poses serious risks to people with intellectual disability and produces injuries to an individual's body (Matson et al, 2008). It is a different problem to self-harm or suicidal intent which is commonly seen in neurotypical teenagers and young adults. SIB is much more common in young people with autism (50%) compared with those with intellectual disability alone (12%).

The most common forms are head banging or face punching, self-biting or pinching, self-scratching, or pulling out hair. It can last for a few seconds, be episodic or go on for hours. It is problematic to family members, carers, teachers and professionals because of the psychosocial stress it causes (Oliver et al, 2017). Parents are most likely to be stressed as evidenced by them being more likely to rate the SIB as severe (19% versus 5% for other carers and professionals). When the level of behavioural disturbance is recognised to be so severe it can also impact on home/social/institutional placement. However, in the most serious cases, it can result in permanent tissue damage, bone fractures e.g. to the skull with brain damage, enucleation of the eye, dismemberment and

even death.

SIB is associated with severe and profound intellectual disability and communication deficits. Within this population it is also associated with overactivity, impulsivity, stereotypic and repetitive behaviour (Laverty et al, 2020). These symptoms of overactivity and impulsivity may be indicative of deficits in behavioural inhibition as a causal mechanism. They are also features of ADHD. These features are also predictive of self-restraint, such as restricting an individual's movement with clothing, objects or their own body.

The longest epidemiological study (Laverty et al, 2020) showed in a sample of 67 that 44% had persisting SIB 10 years later . This study showed that persistence was associated with overactivity and impulsivity but also stereotypic behaviour and repetitive behaviours and decline in the latter behaviours predict a decline in SIB. Severity of autism, co-morbid low moods, anxiety and behaviour disturbance are also associated with persistence. SIB is also associated with significant costs in care and intervention. SIB over the age of 20 is particularly prone to persistence and the authors suggest that early intervention and persistent intervention.



"It is also associated with overactivity, impulsivity, stereotypic and repetitive behaviour..."

tion in childhood and adolescence may be important to prevent problems persisting in adulthood. SIB is associated with some recognised genetic disorders, and also with medical problems particularly causing pain. There is a consistent finding of considerable paucity of access to services. It has been suggested that a lack of access to multidisciplinary multiagency services is a contributor to persistence. Overactivity and impulsivity are the biggest secondary risk factors and perhaps those with these risk factors should have intervention even before the onset of SIB.

Matson and colleagues' study (2008) showed that SIB in those with intellectual disability was associated with challenging behaviours of aggression, property destruction, sexually inappropriate behaviours, and stereotypies when compared with a control group without SIB. In fact, the level of behaviour disturbance on an Aberrant Behaviour Checklist predicted the SIB group in 73%!

Genetic conditions: often account for the most serious/dangerous cases. Huisman and colleagues (2017) specify 12 genetic conditions with different patterns of SIB. Amongst the more distressing images are people with Lesch Nyhan Syndrome who may chew their lips or cheeks severely (Oliver et al, 2017). Those with Smith Magenis may stick objects up orifices e.g. ear or anal. They also may pull whole nails off and head bang. Fragile X tend to head bang. Those with Prader Willi are prone to skin picking and have also been shown to have a special vulnerability of challenging behaviour due to rigidity to 'cognitive shift change', i.e. if asked to do something unexpected they can get angry or self-injurious. These differences in presentation indicate there are evidently complex genetic factors to even different types of self-injury.

Those with Cornelia de Lange's Syndrome are prone to SIB but systematic research has identified that many have self-injurious behaviour secondary to painful medical problems, specifically gastro-oesophageal reflux, sinus and ear problems, dental problems, not to mention constipation and gastric ulceration (Moss et al, 2017). Moss's team found that medical intervention, such as antacids for reflux, reduced the SIB. This illustrates that such medical causes of SIB behaviour,

particularly of non-observable causes of pain, need to be considered in all cases. Health services need to provide facilities for coordinating multidisciplinary assessment under anaesthetic for holistic care of the patient.

Whereas Applied Behaviour Analysis has more reports of intervention, they are mainly single case studies, and are therefore the recommended first-line intervention but often lack long term data of outcome. A functional analysis, over different conditions and locations is indicated to identify if there is a consistent meaning to the SIB, but frequently this is not the case. Further there has been a lack of widespread implementation, which, particularly in families, can have problems of translation. As one might expect from the above review there is an evident failure of benefit because any single approach is likely to fail across a case series, as multiple causes and mechanisms are likely to be at stake in different cases. It is recognised that family factors have only a minor causal contribution to the emotional and behavioural disturbance and parents should not feel blamed for these problems (Fitzgerald, 2020). However, I would suggest that high quality and persistent behavioural parenting skills can alter the behavioural trajectory of a case and this is best started in early life. For me, this is illustrated by the change in presentations of children with Smith Magenis Syndrome with earlier diagnosis and the support of the parents' organisation. 20 years ago, the cases of Smith Magenis Syndrome I met were amongst the most catastrophic and such cases don't seem to come my way anymore. The account by Yasmin Eris (2011) illustrates how the biological trajectory was altered by persistent, calm behavioural modification.

The association of SIB with such a range of factors indicates there is no single mechanism, but SIB needs to be seen within a holistic approach to understanding the presenting symptom, any possible functional role, associated emotional and behavioural disturbance and psychiatric disorder, as well medical or paincausing disorder. Some of the developmentally related issues include understanding in terms of the individual's sensory issues, such as overload or under stimulation, their capacity for moderating arousal levels, their communication capacity, their self-worth and selfesteem, (including hate of self or another), and the quality of their relationships. In autism, emotional and behavioural disturbance is specifically related to a lack of awareness of emotions in self or others, such they are expressed in extremes of explosive emotionality. Where feasible, specific intervention of building emotional recognition skills leads to better self-control (Personal communication, M Wong). However, for those who are severely delayed in intellect, communi-

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cation and autism, there are limited recognised interventions. The norm would be to expect a complex combination of these factors contributing to SIB.

Accordingly, it seems evident that any single approach to treating SIB or challenging behaviour in the context of Autism or intellectual disability is likely to be an excessive simplification of a complex human predicament. Each case needs to be considered as an individual in an environmental and social context with developmental, medical, temperamental, genetic, communicative, relationship, cultural, neuropsychological, neuropsychiatric models of examination and understanding. Further, causal mechanisms may not be the same as those available and helpful in treatment. Frequently, multidisciplinary and multimodal approaches are needed. Disability Services need a triaging structure bringing more multidisciplinary skills and resources, as many cases are resistant to treatment, as was provided by state disability services previously (Dossetor, 2011).

While it is regularly a sign of distress, such as due to discomfort or pain due to a medical problem, a large proportion have persisting and even chronic SIB, which indicates that they are basically resistant to treatment. While a functional analysis can be viewed as an initial investigation assessing the communicative intent of self-injury, often there is no evident communicative intent or interpretation, or a changing or multiple communication. Andrew Frakes (Personal Communication) from Giant Steps Autism School developed a questionnaire to provide a functional analysis, whereby their specialist skilled teachers could evaluate the communicative intent of SIB without protracted assessments taking weeks. Most common intents suggested are:

- to get attention,
- to avoid a task,
- to avoid social engagement/pressure
- environmental factors such as sensory or
- lack of control over their environment and its changes.

The emotional communication is often important to

understand, not just the cognitive function or intent, to attempt to modify this cycle of distress. An excess of parental/carer emergency emotions is likely to contribute to a sense of emotional insecurity for the young person hence parental/carer emotional response can be a source of maintaining dysfunctional behaviour.

Serious persisting cases need a full medical work up and a multidisciplinary psychiatric team are frequently required, without which family breakdown, in all its forms are at risk, which in turn often causes exacerbation of the SIB. Huisman and colleagues (2017) go so far to recommend that an interdisciplinary approach should be considered *mandatory*.

A few anonymised cases from my experience are presented in brief to illustrate some of the principals outlined above. Successful outcomes are a good evidence base on which to demonstrate causal processes and illustrate the wide diversity of causal mechanisms. Sequential clinical hypotheses can be tested, and the process is repeated until a solution is found.

Case 1. A 10-year-old non-verbal autistic, moderately intellectually disabled boy presented with recurrent head banging and pinching of thighs and arms so they were red and acutely bruised. He was referred by his paediatrician after he had failed to respond to SSRIs and Risperidone. He had been treated with fluoxetine as his parents felt he was unhappy and stereotypic,



suggestive of depression. He was treated with Risperidone as it is a third line treatment of ADHD, that also improves irritability in autism.

Family assessment revealed that at the time of onset of the SIB, that family had been faced with his mother's diagnosis with late stage carcinoma. This presentation was too late for a surgical treatment, and the first chemotherapeutic approach failed to work. However, 13 rounds of a second chemotherapy approach, with significant toxic side effects, halted the disease and gave the family some hope of her survival. However further family assessment revealed that both parents were severely depressed. Treatment of both parents with anti-depressants led to improvement, not just in their well-being and suffering but also improved their son's SIB by 80%.

Message: The importance of parental emergency emotional communication. Depression is a cause of SIB, but treating parental depression demonstrated that their emotional state and communication was sufficient to cause persistent SIB in their disabled son. This improvement occurred despite the family continuing to fight his mother's cancer, albeit with greater optimism. Young people often suffer from witnessing their parental distress. This scenario has been a not uncommon presentation in my practice.

Case 2 was a 12-year-old non-verbal autistic moderately intellectually disabled boy who presented with significant SIB. He had been seen 3 years previously when he was felt to be depressed and responded to SSRIs. He was re-referred by his paediatrician with a recurrence of his problem which had already been resistant to behavioural interventions for 4 months. He would stay in his bedroom self-injuring and groaning unhappily. This time he failed to respond to antidepressant treatment, although he still seemed depressed.

He was also agitated and had features of ADHD, for which he was treated with clonidine, and amitriptyline and then risperidone. He had had failed treatments with stimulants with unacceptable side effects in the past. Still, considering the presence of depression, the mood stabiliser, valproate was tried. During this time multidisciplinary multi-agency review was re-activated. He was attending a specialist autism school whose expertise in all manner of behavioural and sensory intervention had failed and he had been placed on short days attendance because of the severity of his behaviours. A re-examination of sensory processing profile did not help.

Both parents were very caring and committed, and the family lived in a small high-rise apartment. We at-

tempted to institute behaviour activation therapy, a recognised depression treatment for people with an intellectual disability, getting his parents to persist in getting him up and taking him out, but this was without benefit.

Although no one felt he was sick or in pain, he was admitted after a few months of failed treatment for an extensive medical review with an examination under anaesthetic including brain scan, sinus x-rays, gastroscopy, dental review, general examination and wideranging blood tests. This revealed no indication of an underlying medical problem that might be causing pain.

Early in the course of a year-long clinical contact, with reviews each month, recommendations were regularly made to suggest that the parents should trial protective head gear, but this recommendation was not heeded. Over the year of treatment and in the absence of progress, there was increasing frustration from different stakeholders raising the pressure to find a solution. This led the clinician to become more and more insistent on trialling various forms of helmets, with discussions ranging from a rugby scrum helmet, to bicycle helmet to cricket helmet, with or without plastic visor to prevent head and facial injury from the SIB. In the meantime, there was a small degree of improvement with high doses of olanzapine, as a treatment for agitation, low mood, anxiety ADHD and stereotypies.

Following the Christmas break the family returned with C2 wearing a bike helmet, reporting that he was so much better that they were ready to reduce all his major tranquillisers. He would sleep without a helmet, but start hitting himself each morning, until his bicycle helmet was fitted. He did not strive or struggle to take it off.

Why the SIB had returned in this last year and more severely than previously? In retrospect his parents felt this was due to C2 entering puberty and the associated intensification of his predispositions due to adolescent hormones.

Message: Always consider the role of protection as a treatment. Treatment of SIB requires multimodal approaches, and efforts to prevent injury are one such empirical and sometimes the critical treatment. There is undue philosophical blindness to this important modality of treatment, which should regularly be examined and tested empirically.

Case 3. A 14-year-old with autism level 3, severe intellectual disability and low adaptive functioning was so aggressive and violent to himself that he could not be

brought out of his home to see any doctor or hospital. Both siblings also had ASD and mother suffered anxiety disorder. They had moved because of domestic violence but the moves made C3 worse. A generous member of the treating team agreed to do a home visit. C3 was initially treated for depressive disorder and increased anxiety due to change in routines leading to increased self-injurious behaviour. He was started on Mirtazapine, and had his major tranquillisers transferred from Risperidone to Quetiapine with the introduction of Aripiprazole, partly because of weight concerns on his Risperidone. His mother remained worried about constipation that needed an enema but was also worried about him not breathing through his nose. Accordingly, as he was more settled, a day admission was arranged for examination under anaesthetic, including a CT head scan, dental examination, ophthalmology examination, blood tests and general examination. The ENT registrar questioned the need for a routine ENT examination, but this revealed a mycetoma, i.e. a large submucous membrane infected swelling, that needed surgical removal. He subsequently settled down and was able to resume school.

Message: The importance of specialist multidisciplinary medical examination under general anaesthetic. Any SIB that fails to respond to first approaches needs a full multidisciplinary medical examination and investigation which requires a general anaesthetic. GPs so often do an amazing job scanning for intermittent medical problems without specialist medical back up, but they need active support of specialist hospital services.

Another case with a similar presentation after a complaint to the minister was admitted. He was also on omeprazole, a proton pump inhibitor (PPI) for helicobacter pylori. His mother was still concerned he had gastric pain, but the gastroenterologist didn't think a further endoscopy was indicated. Fortunately, a second opinion from another gastroenterologist showed that the ulcers were resistant to omeprazole and did much better when changed to a different PPI, esomeprazole.

Yet another case was diagnosed with bipolar disorder because she could go 10 days without sleep in state of continued agitation. Having tried a number of medications, she improved on lithium carbonate, with olanzapine. However, following a delay of access to a gastroenterologist she was also found to have a gastric ulcer caused by helicobacter pylori and may well have been suffering pain especially at night. Patients with pica, or recurrently putting their (dirty) hands in their mouth, are at high risk of helicobacter pylori, and if a gastro-enterology opinion is not forth coming but

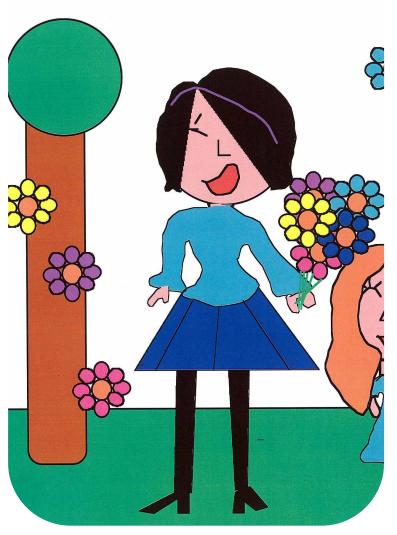
gastric symptoms may be causing pain, it is sometimes necessary to treat on presumption of helicobacter infection with the triple therapy antibiotic treatment and PPIs.

Case 4. A 14-year-old girl with Cornelia de Lange Syndrome had had distressingly severe, persistent and repetitive self-injurious behaviour for 10 years. She had the difficult temperamental features of Cornelia de Lange Syndrome, including being non-verbal, autistic, hyperactive, impulsive, and repetitive in her behaviours. Her behaviour had led to breakdown of family and substitute family care and she was institutionalised. Numerous and persistent efforts by all disciplines had failed to achieve improvements over a number of years. She was assessed for her sensory needs and found to enjoy tactile experience. Regular massage sessions were instigated 2-3 times a day for 30 minutes as a treatment. The use of massage oil and talcum powder became a source of engagement with the nurse and developed into a playful to and fro game. Over a few months the intensity of her self-injury declined and she became happier (Dossetor et al, 1991).

Message: Sensory experience is important; look for creative ideas in treatment. There is a professional consensus on the importance of sensory processing in those with autism and or severe intellectual disability and consideration as for potential therapeutic intervention. Although there is a lack of empirical evidence of the therapeutic benefits of sensory intervention, it is frequently found to contribute to wellbeing and improved behaviour in case reports such as this.

Case 5 was a girl with profound intellectual disability with a rare genetic disorder (Pyruvate Dehydrogenase Deficiency), micro-cephaly, a seizure disorder with blood curdling screaming of a stereotypic and repetitive nature. The severity of this screaming is difficult to comprehend unless you live with it. All siblings had left home and, although her parents were skilled articulate and committed after years of trialling treatments, including multiple psychotropics, they were at the end of their tether. As this screaming was so painful to others, I postulated that it may constitute a form of SIB, and therefore trialled her on Naltrexone (50mg 8am and 2pm). This medication made a dramatic difference to the screeching for the next 5 years, until she was transitioned to adult services.

Message: The Endorphin theory of SIB: There is an interesting literature on the value of Naltrexone, on the theory that SIB gives an endorphin high, which is compulsive, which is blocked by Naltrexone (Bansal, 2020). In my experience, it is significantly helpful in 30-50% of cases in which I trial it, as a third line pharmacological



treatment for SIB.

Case 6 was 9 at presentation with severe intellectual disability, autism, hyperactivity, and later was thought to have significant anxiety and depression. His presenting problems were aggression, destructiveness and head banging. He presented to the consultation 'howling with agitation and needed to be sedated with clonidine to continue the interview. He lacked all concentration and would climb the fence and run away. He also had breath holding attacks and on occasion this led to fits. He also had a twin with the identical developmental problems who was more anxious than his hyperactive brother (who didn't cope without 0.5mg of risperidone a day). They had a dedicated and proficient mother but were estranged from their father who subsequent to separation developed mental health problems. C6 was treated with a range of medications and behavioural approaches. The medications focused on ADHD, anxiety, depression and SIB and included: clonidine, stimulants, amitriptyline, risperidone, quetiapine, propranolol, fluoxetine. With a focus on treating a mood disorder in the context of a possi-

"Often SIB is part of a wider picture of severe disturbance, especially in ASD...."

ble family history of bipolar disorder he was trialled on valproate to supplement the fluoxetine. We subsequently established that the valproate was the critical medication to alleviate both aggression and SIB. He continues to do well on risperidone and valproate 300mg bd. His breath holding has also ceased but he has now had a few epileptic fits independent of breath holding being reviewed by a neurologist.

Message: Always consider a differential diagnosis of co-morbid psychiatric disorder and persist with treatment trials for them. C6 illustrates how often SIB is part of a wider picture of severe disturbance, especially in ASD. It illustrates the need for successive treatment testing for different components of the presenting picture. Perseverance in treatment (he was rereferred after a 2-year break) was one key and resulted after 5 years in a good outcome. Was this a forme fruste Bipolar Disorder, or did the mood stabilising qualities of valproate have a special effect on him?

Case 7. 7-year-old with autism level 3, moderate to severe intellectual disability, presented with hyperactivity, excitability, tantrums, defiance, lashing out, risk taking, running away and self-injury. His motor and independence skills were 3-4 years developmental age, whereas his language and social development were 18-24 months developmental age equivalent. His parents had shown unusual resolve in exploring wide range of alternative treatments including extensive ABA, and other behavioural interventions, oxytocin, treatment for immunological problems and stem cell treatment overseas. His mental health co-morbid diagnoses included Anxiety Disorder, ADHD, Tourettes, and Motor Dyspraxia. Trials of many psychotropics over a number of years were not felt to be consistently helpful but side effects were commonly reported. Yet he had a number of presentations to the emergency department and even a long supportive admission under neurology. He was taking a mixture of clobazam, fluvoxamine, clonidine, cannabinoids and quetiapine with mild improvement. In the context of a failure of progress, his SIB was reformulated as a reflection of attachment behaviours: his head banging left his parents feeling helpless and depressed and brought out



feelings of blame with conflict over differing parenting approaches, shame at not having helped him more, and guilt e.g. from post-natal depression, and this was associated with an attachment which was insecure in style. Mother was interested to learn more about childhood attachment and difficulties with the aid of the Circle of Security Framework of counselling. This led his behaviour to be understood as a communication to be reflected on rather than respond with more parenting behaviour. This led mother to feel calmer and better able to set limits. She was able to emphasise moments of closeness and slowly was able to help him to move from a sense of danger to one of greater security. He was able to tolerate wearing a helmet, and his parents were better able to tolerate their inability to stop his headbanging but calmly give him chillout time until he settled. His behaviour improved and he was able to be positively settled in school.

Message: Attachment and Relationships still matter in Autism. Although the literature on attachment styles in autism is not clear; it is clear that autistic behaviour is significantly traumatising to family relationships and parenting skills (Mukhejee et al, 2019; Fitzgerald, 2020). The deficits of emotional recognition and reciprocity skills makes attachment more difficult for a child with autism and also with intellectual disability. These autistic qualities mean that attachment behaviour is developmentally related, and like that of a much younger child, rather than chronologically aged related. Successful treatment of the severe problems of autism often also includes repair of the family attachment and relationships, as it is this 'belonging' that is critical to the emotional survival of the young person with autism and their family. Awareness of attachment is important and sometimes can be therapeutic, but not used as a basis of blame for the behaviours.

Another case of a 4-year-old presented with autism. severe intellectual disability, ADHD, severe tantrums and self-injury. He had also suffered multiple additional adversities: prematurity, a difficult temperament, gastro-oesophageal reflux, feeding problems, hydrocephaly of unknown origin that needed surgery, and recurrent otitis media with deafness and needing recurrent grommets. His ADHD was treated with clonidine, amitriptyline and a small dose of risperidone. The key intervention was providing his mother with insight as to why he had become so vulnerable, sensitive, attention seeking and reactive in his temperament, secondary to these adversities and supporting her calm engagement and limit setting. This skilled and now confident parenting cured his SIB and steadily improved his emotion and behavioural disturbance and development over a 9 month period. This illustrates the competition between adversity and biology versus confident skilled parenting.

Case 8 presented at 6 years with severe intellectual disability, autism, ADHD, anxiety, aggression and SIB since the age of 5years when 'he became an aggressive monster'. I saw him over a 6-year period whereby he needed several psychotropics including major tranquillisers, his mother recovered from anxiety and depression and became determined and effective in behavioural management. He required a specialised helmet, including a visor (which needed regular replacement from damage), particularly after he had severely smashed his face on a concrete corner at school. He had a specifically built sensory room, supported by an OT, in which he could self sooth and provide safety from his violence. He required specialist behavioural support to be maintained in school. One challenge was supporting his mother's challenges to maintain adequate funding from the NDIS for the therapeutic services, as well as for in home support/respite and his sensory room and protective equipment. When all these components were in place, the level of his SIB was reduced by 50% and containable in his home and his school.

Message: Interdisciplinary multiagency multimodal intervention support may be all that can be done. One couldn't say this long hard road was a success story, but his mother is so committed to him and, with this level of support, he maintains family and school placement and such high-level support is still so appreciated by such special families.

These cases illustrate some similarities of developmental context but differences in the cause of SIB as indicated by successful management. SIB is a key and frequent problem in autism and related neurodevelopmental difficulties. Fundamentally, a developmental understanding of autism means the young person with autism is not able to understand our thinking, feelings and motives, but as adults, armed with this framework and knowing the individual with autism we are able to have some inkling of what it is like to be that autistic child. They are not different from us but delayed in their emotional and social development. Behavioural intervention is a sophisticated form of non-verbal communication, not a specific treatment. Although it is in many ways intuitive, it can be enhanced by expertise.

However, we also need to take account of other models of understanding, which can include motor and sensory processes, alternative and augmented communication, emotional understanding and theory of mind, temperamental and neuropsychiatric qualities, as well as their interactions with the environment and relationships.

History and learning are also impactful. Yet multidisciplinary, multimodal child psychiatry intervention can make a large difference to the level of disability that arises from the emotional and behavioural difficulties. Early intervention remains important, as well as psychosocial context. These case scenarios are a shorthand of how much concern and effort goes into helping such complex cases that are so resistant to treatment. However, they also testify that the whole range of modern child neurodevelopmental psychiatry skills can make a difference. We are necessarily talking about a small, minority population with huge problems of developmental and emotional and behavioural impairments, where much scientific funding and exami-

"These case scenarios are a shorthand of how much concern and effort goes into helping such complex cases ..."

nation is still in its infancy, but those with clinical experience share important skills and expertise (Dossetor et al, 2011). Successful treatment therefore requires different disciplines and skills from different agencies to have mutual respect and collaborate and work together from the same framework, supported by funding, and infrastructure to enable such tertiary services

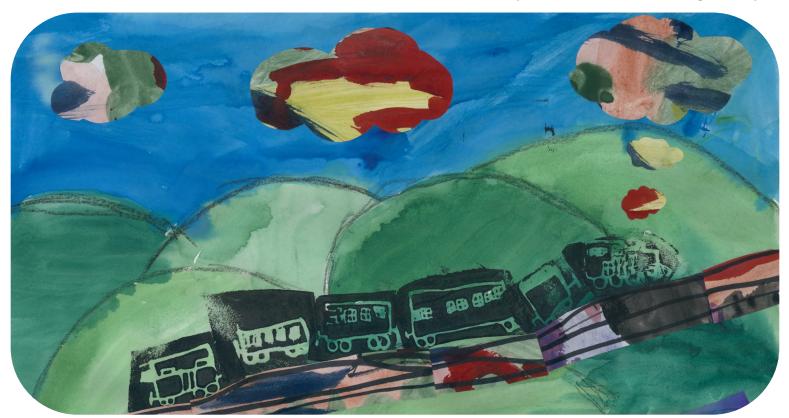
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