



# Is Inclusive Education Right for Every Child? An Account by the Parent of a Child with High and Complex Needs Due to Autism Spectrum Disorder

**Dr Stuart J. McLaren**

Senior Lecturer in Health Science, Massey University

## ABSTRACT

There is often intense and passionate debate about the inclusion of those students with the most complex social learning and behavioural needs. This paper, written from a parent's perspective, is based on a case study of a 15-year-old adolescent with severe and high functioning autism that was comparatively well-resourced through the new *Intensive Wraparound Service Initiative* and well-supported by the school, the Ministry of Education and his parents. His mainstream education ended after two terms of multi-level failure and he has been returned to a special residential school. This paper examines in detail the issues surrounding his inclusion and the resources provided to facilitate his education. It discusses the failure of the initiative in this instance, and whether it was due to any deficiencies in his inclusion, the intervention plan and implementation, the level of resources, or whether it was ever practicable or feasible to include a child with this level of need in the mainstream.

## Storied experience

**Keywords:** *Autism spectrum disorder, inclusive education, savant, sensory processing*

## INTRODUCTION

The inclusion of children with a high level of complex, social, learning and behavioural needs has often been the subject of passionate debate. In 2012, this debate intensified with a ministerial review of four state residential colleges. Children who attended these facilities were on a two-year maximum tenure where they received intensive support and therapy with the object of preparing them for integration back into their local communities and schools. Residential schools do not suit all children and being an environment with multiple carers, they are generally not suitable for those with serious attachment disorders. However there have been cases, including the child presented here, who have excelled in the residential school setting, only to experience a total collapse of their education once returning to a local school and community.

## POSITIVE BEHAVIOUR FOR LEARNING (PB4L) - INTENSIVE WRAPAROUND SERVICE (MINISTRY OF EDUCATION, 2012)

The support and management of children with severe behavioural difficulties or complex social, behavioural, emotional and learning needs with underlying intellectual impairment can present major challenges in their schools, homes and in facilities providing respite care.

The Intensive Wraparound Service (IWS) is a new initiative established by the Ministry of Education under the "Positive Behaviour for Learning" portfolio (Ministry of Education, 2012). The service was funded by ring-fencing funds that were previously set aside for the now defunct *Waimokoia Residential School* in Auckland. The Ministry of Education's focus (at the time our child was enrolled in the IWS) was to support children with high and complex needs due to an underlying impairment and/or those with severe behavioural issues, to live in their home community and attend their local school with support from the IWS. The Minister of Education planned to expand this service by reducing the four residential special schools catering for these children to two schools on the belief that these children would be better catered for in their home communities and schools with a high level of resourcing and funding. One of the two schools earmarked for closure ceased in 2012 while the other school remained open due to successful challenge to the Minister's decision in the High Court.

## CHILD PROFILE

Our child was diagnosed with autism spectrum disorder three months after his second birthday. He experiences the classical features of high functioning autism and savant syndrome. While his speech and communication remain severely delayed, he meets the hyperlexic criteria described by Larkey (2012; 2013) and is able to decode many words by/from sight. As an example, he decoded *Canterbury* the first time he read it as *San-ter-bury*. While his understanding or comprehension has never matched his reading skills, he was able to recite the alphabet at 18 months of age, could read words by age

two and soon after was able to read complete sentences. He has a fascination for letters and numbers but has major difficulty with questions containing *who*, *what*, *where* and *how*. The combination of hyperlexia and severe speech and communication is an unusual mix as the ability to read and comprehend is often closely linked to an individual's language abilities (Larkey, 2012).

The child fits the description of savant syndrome (Howlin, Goode, Hutton & Rutter, 2009; Treffert, 2007) in having pockets of spectacular ability that stand in marked contrast to his overall limitations along with an exceptionally deep but narrow memory within the areas of his specialised skills. Advanced graphics and scientific calculators are his favourite toys which he takes everywhere in hand. He is able to perform advanced calculation which he has learnt from the handbooks that accompany the calculators and by trial and error. He has an extraordinary ability in music playing piano, electronic keyboard, violin and viola, and has performed in public as soloist with an orchestra. Much of his knowledge in music theory and reading has been learnt by intuition and observation rather than formal lessons. His music teacher, who was engaged on a private basis, described him in a television interview as being exceptionally talented and that they were only scratching the surface of what he was capable of. It can be a significant disadvantage for children in residential settings as parents facilitate private music lessons, sports activities, supervise practice, and enable participation in activities such as orchestral playing. Such support may not be possible from the staff in a residential facility, particularly if it involves taking a child off the premises.

Severe sensory processing difficulties are a key impediment for our child like many students with autism. Puberty has created many issues where these sensory processing issues have been elevated to extreme levels.

He has never shown any desire to socialise and has been described in his previous schools as a loner.

### **SENSORY PROCESSING DISORDER**

Larkey (2011) defines sensory processing disorder as a neurological disorder causing difficulties with taking in, processing and responding to sensory information from the environment and within one's own body. These can involve the visual, auditory, tactile, olfaction, gustatory, vestibular and proprioception senses. There can be hyposensitive or hypersensitive responses to sensory input. As an example, Larkey (2011) cites a hyposensitive tactile

response as a child showing no pain when injured or hurt, while a hypersensitive tactile response is the slightest touch causing pain.

Numerous articles identify sensory processing difficulties in individuals on the autistic spectrum including those by Ashburner, Ziviani & Rodger (2008), Baker, Lane, Angley & Young (2008), Bogodshina (2005), Iarocci & McDonald (2006) and Larkey (2007). Baker et al., (2008) reports that up to 95 percent of children experiencing autism, experience sensory processing disorder (also referred to as sensory integration dysfunction or sensory integration disorder). This condition results in aberrant (or atypical) behaviours in trying to make sense of and regulate sensory stimulation received from the environment. A range of specific sensory processing problems are experienced by our child. He has difficulties in auditory filtering (difficulty in distinguishing the spoken word from background noise) and hypersensitivity to certain sounds. Much of his behaviour is due to sensory processing difficulties and catastrophic responses to overwhelming sensory input. He also exhibited a series of behaviours such as smelling other person's hair or feet. These aberrant behaviours are described by Baker et al., (2008), Larkey (2011) and Miller et al., (2005) as sensory-seeking behaviours. Ashburner et al., (2008) and Eaves and Ho (1997) indicate the educational progress of such children can be affected by a limited capacity to self-regulate their emotions and behaviour, and as such, may underline maladaptive behaviour in response to classroom sensory environments (Anderson, 1998).

### **OBSESSIVE COMPULSIVE BEHAVIOURS**

The child exhibits some obsessive compulsive behaviours including the inspection of every BIC pen that he spots to examine the unique batch number on each item. This behaviour, described by his developmental paediatrician as particularly intense, has persisted right through his school years. Every effort to moderate or ameliorate the behaviour by professional input has not been successful. Professionals who have worked with him have even consulted an international expert on autism, who advised that while a replacement activity could be explored to lessen the intensity, it came with a caution that the behaviour could be replaced with a more destructive activity such as head banging. Considering the prolonged history and intensity around this behaviour, it would have been exceedingly difficult, if not impossible, to implement any successful strategy in the isolation of the school setting. While the intensity has varied over time, he still grabs pens out of other people's hands, pockets, from desks of other students and those displayed for sale. His fascination with

calculators resulted in him grabbing to inspect those that he sees being used by others and raiding the offices of staff at the school.

Obsessive compulsive disorder (OCD) is a co-morbid diagnosis defined by Larkey (2013) and Attwood (2007) as repetitive behaviours or mental acts compelling those affected to carry out due to an obsession, or according to rules that must be followed rigidly. Cashin (2005) describes obsessive compulsive disorder in those experiencing autism as being different to that of the aggressive contamination, religious, sexual or somatic content commonly associated with others experiencing this disorder. Rather, OCD in those experiencing autism is often related to a narrow and specific focus of interest (Cashin, 2005). His obsession around the unique batch numbers of BIC pens and calculators fits this category.

#### **FULL INCLUSION UNDER THE INTENSIVE WRAPAROUND SERVICE (IWS)**

After the February 2010 earthquake in Christchurch, our child was evacuated along with other boys enrolled at Halswell Residential College to his home community and placed in the local special (day) school. After a year in school, his education ended abruptly. Concerns had been raised with the new school by us, his parents, over his education, but these were not resolved. When his mother visited the school, she found him locked in a classroom alone, screaming with blood-shot eyes. Two days later he returned home in a highly-distressed state and cried continuously for three hours, asking to not go back to this school and to return to Halswell Residential College. This was the first time to experience this level of distress in his school years. His mother believed he would have to be taken by force, if he was going to continue at that school. As he could not explain what was happening at school, we were left with no option but to assure him he would never go back to calm him down. Concerns were later raised with the school's Board of Trustees and Ministry of Education over the standard and quality of education he received. As a result, an IWS package was offered for him to attend a regular state-integrated school close to his home. He met the criteria for IWS with highly complex and challenging behaviour along with social and education needs associated with an intellectual impairment (of classical autism). This made him one of the highest-funded students in mainstream education. Due to his level of need, a consultative decision was made to start him at two years behind his chronological age and place him in the intermediate school rather than the high school. A classroom was chosen where the form teacher and her children were well-known to be welcoming and accommodating.

The general expected outcomes of IWS included:

- increased participation, engagement and achievement
- decrease of antisocial behaviour, and
- positive engagement in school and community.

The IWS objectives aim to:

- support children learn new skills and ways of behaving
- to stay or return to their local school
- behave in a positive way, and
- enjoy a successful school life.

At the first individual education plan (IEP) meeting soon after beginning his education at the school, the need for occupational therapy to manage the high level of sensory input expected in a busy, vibrant and dynamic classroom was highlighted by the learning and behavioural support staff from Halswell Residential College. Speech language therapy was also proposed as a key therapy he would need, due to his severe delay in language. In addition, crisis intervention and management would be needed to appropriately respond to episodes of challenging behaviour. Even though these resources were clearly identified as being necessary, especially in the transition phase, the meeting was told that these were not available until the following year, so his transition into full inclusion proceeded without this support. Otherwise, the general support provided by the Group Special Education case worker was thorough.

He began schooling at the start of the third school term attending school for two hours per day which was gradually increased to four hours per day. During this time there were ongoing issues with medication prescribed to moderate his behaviour. The side-effects of the medication sometimes made him drowsy, sleepy and created difficulty in attending to learning tasks during the time at school. At other times he wandered at will either inside the classroom or finding his way into staff offices and other rooms looking for items of interest such as pens and calculators. As time progressed, the medication became less effective at moderating his behaviour. As a result, episodes of challenging behaviour began increasing in intensity and frequency leading us to seek help from his developmental paediatrician who proposed a new medical regime. When a new anti-psychotic medication (Aripiprazole) was prescribed, the effects of the transition from one medical regime to another resulted in elevated levels of extreme behaviour at home and at school which included screaming, hitting and biting himself and those

around him. After a physical attack on his education support worker, who resigned over the incident, his hours were reduced at school while a new staff member was recruited. At a crisis meeting involving all parties in an attempt to find a way forward, we, the parents, declared that we were struggling to provide the care necessary and if like before, the new medical regime was not successful, we could not provide the care needed.

### PERSONALISED WRAPAROUND PLAN

The regional team leader of IWS became actively involved in an effort to resurrect the deteriorating situation. The personalised wraparound intervention plan provided for all children enrolled in the Intensive Wraparound Service was in progress at the time so considerable efforts were made to finalise an Interim Wraparound Intervention Plan. This involved extensive consultation with the school, staff and parents. This comprehensive document covered widespread aspects of his education and life at school by proposing the following:

1. Principal goals
  - function positively at school
  - gain the necessary skills and strategies to experience success at the college, home and community
  - maintain a calm and engaged state at school
  - develop independence in preparation for life after college.
2. Goals of intervention
  - attend school full time by the end of Term 1 of the following year
  - reduction of biting and hurting others (and himself) will reduce ideally to zero or a manageable level
  - self-management skills, a reduction in behavioural outbursts and to progress academically
  - targeted behaviours including aggression to others, non-compliance, wandering, screaming and inappropriate touching of himself or others.

To increase the child's time in education, a range of programmes were proposed for education outside the classroom including swimming, riding for the disabled and music. The classroom environment was substantially modified with set areas in the room that were predictable and comfortable. While a quiet space was proposed, it wasn't physically able to be separated from the classroom so there was no physical attenuation of noise levels from other activities in the room. Break times were to be carefully managed in which set routines were to be established. Social

stories about such events would be devised and read aloud to him. Visuals such as timetables and scheduling were an integral part of his inclusion into learning routines. Tasks would be carefully planned and broken down into manageable chunks. The plan proposed that the child would experience success and rewards before tasks were increased in difficulty. Opportunities for over-learning, introductions to upcoming topics, and changes in programme would be provided by the specialist teacher through one-to-one sessions with the child with work that was to be reinforced through drill and rote learning. Strategies were devised to manage transitions between activities and support for parents who agreed to participate in the *Triple P Stepping Stones Parenting Programme* for parents of children with autism spectrum disorders. Respite care to a high level was provided through Needs Assessment and Support Coordination (NASC) of the District Health Board. This included three nights per week and a buddy programme. The plan suggested that this programme could actively promote the goals of the IWS.

The plan also covered in detail short- and long-term strategies for communication needs, sensory needs, socialisation needs and self-management needs. The plan outlined 'Non Violent Crisis Intervention' for the staff at the school to learn strategies to cope with sudden explosive behavioural incidents but due to the lack of resource, this could not be provided until the following year.

### IMPLEMENTATION OF PLAN

No objectives of the IWS or those proposed in the plan were achieved and his education under IWS ended in multi-level failure. After the first serious incident a new education support worker was engaged by the school. This experienced and highly-committed worker made considerable efforts to integrate and include the child in the classroom environment. As previously, the new medication had significant side-effects which greatly affected his ability to concentrate at school and participate in activities. The efficacy in moderating his behaviour appeared to likewise decrease as time progressed. He never attended school any longer than four hours a day and for most of the school term it was just two hours daily.

It became apparent that there was no solution for much of the behaviour observed in the child. He often wandered at will around the class, sniffing the other children's hair, smelling their feet, pulling back their clothing to check the tabs, and raiding their pencil cases looking for BIC pens to inspect the unique batch numbers on each item.

After the first serious incident, staff at the school became very concerned and asked for advice at a meeting as to what they would do if, and when, a repeat occurred. The Ministry of Education has a Behavioural Crisis Policy to put an immediate plan in place to link to an effective and sustained crisis intervention plan (Ministry of Education, 2013). At the time we, the parents, and apparently the school staff, were not made aware of this policy which we now believe would have justified an immediate crisis intervention procedure to respond to sudden meltdowns or catastrophic reactions. A further serious incident occurred towards the end of the school term in which the intensity was such that the police were called to assist but the meltdown had subsided by the time the officers arrived. The child was immediately suspended for two days. The school staff were unable to provide any reason or possible trigger saying that this happened suddenly and without warning. Further inquiries revealed that at the time of the incident there had been a sudden downpour of rain with a clap of thunder, a known trigger. This was confirmed as the most likely cause when a few days later the child was in a large retail warehouse with a non-insulated iron roof. The sound of rain striking on the roof led to a similar meltdown with the child rushing through the store screaming and lashing out. The school principal made it clear that there would be consequences for any further incidents as the police had been called as a last resort. As further incidents of this nature could not be avoided we believed that exclusion was inevitable should he remain at the school. We cannot stop the rain from falling or the dogs in the vicinity from barking!

#### **EXTENDED CARE FOR CHILDREN WITH SERIOUS LEVELS OF NEED**

The Children, Young Persons and Their Families Act, 1989 (Section 141) makes provision for children who are so severely mentally or physically disabled that suitable care can only be provided in the care of an approved organisation. We finally declared that the needs of our child were such that we could no longer provide the care necessary for him at home and wished for the procedures in the above provision of professional residential care to be initiated. In these cases, it is government policy that our child had to be placed within his local community as a priority. The needs-assessment coordinator of the district health board sought a placement with the two local residential providers and advised us that both could not provide care for him due to his level of need. The only option available was a specialist residential school 300 kilometres from our home. As required by the Act, a Family Group Conference was held with all the interested parties. The school principal and

senior school staff attended and explained that they had warmly welcomed our child and family into the school community and had tried their best to facilitate his inclusion without success. We praised the form teacher, the specialist teacher, and teacher assistants who had provided a high level of compassionate and professional support. The Family Group Conference participants collectively acknowledged that our child's need was such that he qualified for the extended care provisions as provided by the Act.

IWS ceased and Ministry of Education approval under the Education Act, 1989 (Section 9) was given for the child to be placed into a residential special school. Due to the diverse levels of need, the Ongoing Resourcing Scheme (ORS)-funded category was raised to 'Very High Needs' on application. The child began his schooling and residence at the start of the 2013 school year.

#### **INCLUSIVE CLASSROOM**

MacArthur (2009) in her report, *Learning Better Together - Working towards Inclusive Education in New Zealand Schools*, states that "research suggests that all students do better in inclusive classrooms. Everyone benefits from the changes in teaching and learning needed for teachers to work successfully with a mixed group of student" (p. 6). The experience of our child does not support this claim and therefore strongly questions such absolute statements which give no leeway for any exceptions. On examination of the above MacArthur report, there was only minimal coverage of issues confronting the high and complex issues characteristic of children on the autistic spectrum with no in-depth analysis of the issues that many in this cohort face. The sensory processing difficulties and effects of sensory inputs such as noise were not addressed. In addition, it was critical to address the management of serious behavioural episodes because these are the issues most pressing in the ultimate success of inclusion.

This experience has demonstrated that there are exceptional cases of children with highly complex and challenging behaviour, social or education needs associated with an intellectual impairment whose needs may not be met by IWS in inclusive education. Prochnow and Johansen (2013) have stated that learners with difficult behaviour can be fully included in the classroom by functionally understanding the behaviour in context. An initial functional behavioural assessment (FBA) was carried out in this case by the IWS team and outlined in the Individualised Intensive Wraparound Plan. On further examination, the work by Prochnow and Johansen (2013) was based around a case study of a new entrant supported by the Resource Teacher: Learning and

Behaviour (RTLB) service. This service is provided for those children assessed as having moderate needs. Unlike the child profiled by Prochnow and Johansen, the child in this case was successfully mainstreamed in the early years of education under the Ongoing Resourcing Scheme in the high needs category. As time progressed, an increasing number of challenging issues in his inclusion and home life led to his two-year placement in Halswell Residential College (for boys with complex social, behavioural and learning needs) when he turned 11 years of age. Clearly this case was very different to the child profiled by Prochnow and Johansen in terms of need, age and characteristics.

Behaviour has a very wide meaning, but Prochnow and Johansen (2013) identify behaviours such as levels of distraction, defiance, non-compliance, obstinance, aversion and aggression as proving to be the most difficult to facilitate inclusion. They did not specifically identify explosive behaviour, catastrophic reaction or specifically identify obsessive compulsive behaviours characterised by our child and exhibited by some individuals on the autistic spectrum. The success of any FBA primarily depends on the ability to be able to moderate or remove any triggers or stimulus which give rise to difficult behaviour. Behavioural management cannot be negated or ignored because success in an inclusive education environment is often determined by being able to moderate and manage difficult behaviours.

I believe that the provision surrounding the inclusion of those children experiencing severe autism, who can have highly complex needs linked to this impairment, cannot be generalised across other cohorts and must be person (child) centred. This is supported by Breakey (2005) who explains the 'person centred' concept where the school match their provision to the needs of the individual. Authoritative references by Lipsky and Richards (2009) and Lipsky (2011) provide in-depth analysis of the types of behaviours experienced in autistic individuals and identify two specific categories, tantrums and meltdowns or catastrophic reactions. These references have been selected as they best describe the behaviours exhibited by our child and given in-depth insight to the causative triggers and environment.

### MELTDOWNS AND TANTRUMS

Lipsky and Richards (2009) describe a meltdown as an uncontrollable, extreme emotional or behavioural response to overwhelming stress or over-stimulation. It causes a sudden release of adrenaline into the system creating heightened anxiety and a switch to a primitive survival mode.

This is often referred to as 'sensory defensive reaction' due to sensory overload. It can involve a 'fight' or 'flight' response. On the other hand, a tantrum is a voluntary behaviour to manipulate someone else to do something. This involves pre-meditation and planning (Lipsky & Richards, 2009).

Lipsky and Richards (2009) describe conditions such as noise, sensory stimulation and overload, novel situations, sudden unexpected changes, and transitions (class, topic or subject changes) where the stage is set for frequent meltdowns. These are conditions typically found in the vibrant, active and dynamic classroom (Baker et al., 2008). Compare this is to the delivery model of a special education classroom with far fewer students in the classroom and careful control of the environment and delivery to reduce the number of triggers. It therefore follows that in the case of autistic individuals, the inclusive classroom environment is considerably more prone to produce the triggers that create meltdowns. In this case, the school staff were not skilled nor had the necessary planning and strategies in place to deal with the inevitable consequences. The IWS interim plan established a goal to reduce the child's biting or hurting others ideally to zero. This type of behavioural response can be referred to as sensory overload where the individual has a hypersensitivity (hyper-reactivity) to certain sounds. The plan did not identify these behaviours as the 'fight' response in a meltdown and therefore conditions triggering meltdowns had to be reduced to likewise reduce or moderate these behaviours. Lipsky and Richards (2009) challenge any explicit or implied claims that with careful planning and scripting, all such behaviours can be prevented. They emphasise that in the case of meltdowns there will always be events well-beyond control and one can never be totally prepared even with the best intentions and comprehensive planning. In other words, this supports the argument that where there are children with a known history of behavioural issues due to underlying impairments, well-defined behavioural management and crisis intervention strategies and responses must be implemented, no matter the type of school, to respond to out-of-control behaviour or a catastrophic reaction due to unavoidable events.

### EFFECTIVE BEHAVIOURAL MANAGEMENT AND CRISIS INTERVENTION

There are a number of established procedures for crisis management and intervention. The Ministry of Education has adopted *Nonviolent Crisis Intervention*. Halswell Residential College uses *Safe Crisis Management* and Lipsky and Richards (2009) developed the S.C.A.R.E.D. calming

technique for children and adults with autism especially for use in US emergency rooms.

Lipsky and Richards (2009) warn of a high risk of injury, even fatalities, using physical restraints on individuals experiencing a meltdown and strongly advise against the use of any kind of restraint. Besides that, it is likely to increase the intensity of self-harm and aggression towards those applying the restraint. However as Lipsky (2011) points out, the safety of all involved has to be the number one priority. Once the 'fight' or 'flight' response has been established, they are no longer processing the world around them and are totally unaware of their surroundings. They are acting solely on instinct and can have greatly increased stamina and strength. This makes them and those around them vulnerable to injury. It may be necessary to remove the child away from other children and contain them in a safe area. While it may be possible to de-escalate a meltdown in the early stages, once a full-blown meltdown occurs, Lipsky (2011) reports that nothing can be done other than to do as much as possible to keep the child and those around him/her safe, and let the meltdown take its course.

## SUMMARY

While the benefits of inclusive education cannot be questioned, as children can learn as much from each other as they do from formal instruction by the teacher, the success in inclusive education firstly depends on a child being able to comfortably be in, and learn in, an environment typical of a regular classroom. We, his parents, recognise that his placement back in a special education facility was a necessity and compromise for which we hold much regret. If he was able to be placed in an inclusive learning environment close to home he would have numerous opportunities to progress his extraordinary (savant) abilities in music and mathematics where he has shown to well-exceed his typical peer group. He could join a school orchestra and participate in advanced mathematics learning.

Is it ever reasonable to expect a child with serious sensory processing difficulties to be able to manage in a noisy, unpredictable and over-stimulating environment? Breakley (2005) promotes the concept of being person-centred in the provision of education are matched to the needs of the person. She uses the analogy of forcing a square peg into a round hole if it means slotting a person into a ready-made provision. Being person-centred in this case, would be to turn the education delivery typical of a regular school classroom on its head, drastically reduce the class size and implement strict controls necessary to regulate the sensory input of this child? If this is what is required, it

is forcing a square peg into a round hole to do anything else. One has to ask if ever it is possible to provide what was needed here in a regular school? While the concept of inclusive education is constantly being researched and developed, it is still a 'ready-made' provision in which this child was being slotted into.

There is now an urgent need for dedicated and targeted research into facilitating the inclusion of children with high and complex needs due to autism within the current models of class sizes and delivery of education. It is unlikely, in the foreseeable future, to be able to reduce class sizes to less than ten students in regular classrooms or drastically modify the education delivery model to meet the needs of this exceptional group of children. Even if this was possible, the parents of the other children may perceive that the needs of one child were being met at the expense of their children.

Could his education have been saved if all the required resources had been provided when they were critically needed? As his parents we have given this much thought and consideration but feel sure it would not have been possible, as the regular school environment cannot be locked down to match that of a special school classroom. In addition, so many other important factors were at play well outside the control of the school such as medication and the stress on our child in having to cope in school, at home and at the IHC respite care facility. One has to ask that if our child's needs are such that he cannot be supported at home, then how can regular schools manage, even with an extraordinary level of resource?

Our situation has been followed by other parents of autistic children in our support networks, as they consider solutions for their children. The IWS is a positive initiative for those parents who decide that residential placement is not an option (even if their child would qualify), and decide to live with the consequences of serious behavioural outbursts involving meltdowns, aggression, screaming and damage to their property. It will mean that these children can now be resourced and supported to an increased level. However, it doesn't mean that the local schools will necessarily be so accommodating, no matter the level of resource and support. Where the environment of a regular school is in serious conflict with any child's needs, and the management of behaviour is well-outside the capacity of the school, exclusion is inevitably the final outcome if the child is not voluntarily withdrawn.

As the name suggests, autism is a spectrum or continuum across the disorder where there are a

wide range of diverse needs within this cohort. As a pervasive developmental disorder, degrees of characteristics, severity and need can vary through development. What may have applied in the early years of education, may not apply later (as clearly happened in our child's case). As demonstrated, our child's characteristics are well-defined and documented in the literature. While there are children I know experiencing autism who have been successfully included in regular education, we are also aware from personal contacts and advice from organisations working with and advocating for autistic children and their families (i.e. Autism New Zealand) of a significant number of children who are struggling in regular school classrooms.

It would be considered inhumane treatment if a child with physical disabilities was expected to negotiate their way up a flight of stairs. However, children presenting with major sensory processing difficulties are expected to negotiate their way through the noisy and over-stimulating environment of a regular classroom. It can also be argued that if this environment causes them considerable pain and distress, it is likewise an inhumane form of treatment.

The Ministry of Education has indicated, in written correspondence, that the IWS service delivery model for children with high and complex needs has changed from February 2013 to a 'mixed model' which will allow a residential placement for any student enrolled in their IWS programme. This appears to be in recognition of the outcomes and experience gained (Ministry of Education, 2013).

It is the right of every child to an inclusive education at their regular or local school, but I now have to question if inclusion, in its current form, is right for every child?

The views expressed in this paper are not those of any school this child has attended nor any agency involved in the education or welfare of this child.

## REFERENCES

- Anderson, K. A. (1998). *Sensory motor issues in autism*. Texas: Therapy Skill Builders.
- Attwood, T. (2007). *The complete guide to asperger's syndrome*. London: Jessica Kingsley Publishers.
- Ashburner, J., Ziviani, J., & Rodger, S. (2008). Sensory processing and classroom emotional, behavioural and educational outcomes in children with autism spectrum disorder. *American Journal of Occupational Therapy*, 62(5), 564-573.
- Baker, E., Lane, A., Angley, M., & Young, R. (2008). The relationship between sensory processing patterns and behavioural responses in autistic disorder. *Journal of Autism and Developmental Disorders*, 38, 867-875.
- Bogodshina, D. (2005). *Sensory issues in autism are recognised but...*. Paper presented at the Awares Online Conference, <http://www.awares.org/conferences>.
- Breakey, C. (2006). *Inclusion, being person centred and further education*. Paper presented at the Awares Online Conference (October). Retrieved from the Awares Conference Centre, <http://www.awares.org/conferences>
- Cashin, A. J. (2005). Autism: Understanding conceptual processing deficits. *Journal of Psychosocial Nursing*, 43(4), 22-29.
- Eaves, L., & Ho, H. (1997). School placement and academic achievement in children with autistic spectrum disorder. *Journal of Developmental and Physical Disorders*, 9, 277-291.
- Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2009). Savant skills in autism: Psychometric approaches and parental reports. *Philosophical Transactions of the Royal Society B*, 364, 1359-1367.
- Iarocci, G., & McDonald, J. (2006). Sensory integration and perceptual experience of persons with autism. *Journal of Autism and Developmental Disorders*, 36(1).
- Larkey, S. (2007). *Practical sensory programmes for students with autism spectrum disorders*. London: Jessica Kingsley Publishers
- Larkey, S. (2011). Newsletter – *Making it a Success with Sue Larkey* (Issue 23, February).
- Larkey, S. (2012). Newsletter – *Making it a Success with Sue Larkey* (Issue 29, July).
- Larkey S, (2013). Newsletter – *Making it a Success with Sue Larkey* (Issue 33, August).
- (Larkey newsletters available on <http://www.suelarkey.co.nz>)
- Lipsky, D., & Richards, W. (2009). *Managing meltdowns: Using the S.C.A.R.E.D. calming technique with children and adults with autism*. London: Jessica Kingsley Publishers.
- Lipsky, D. (2011). *From anxiety to meltdowns*. London: Jessica Kingsley Publishers.
- MacArthur, J. (2009). *Learning better together: Working towards inclusive education in New Zealand schools*. Wellington: IHC Inc.
- Ministry of Education. (2012). *Positive behaviour for learning (PB4L) - Intensive wraparound service*. Retrieved from <http://www.minedu.govt.nz/theMinistry/EducationInitiatives/PositiveBehaviourForLearning.aspx>



Ministry of Education. (2013). *Behaviour crisis response service*. Retrieved from <http://www.minedu.govt.nz/NZEducation/EducationPolicies/SpecialEducation>

Prochnow, J., & Johansen, A. (2013). Learners with difficult behaviour can be fully included in the classroom: A case of functional assessment. In Centre of Excellence for Research in Inclusive Education, Massey University, *Inclusive Education - Perspectives on Professional Practice*. Auckland: Dunmore Publishing.

Treffert, D. (2007). *Prodigious savants: How do they know things they have never learned?*

### ACKNOWLEDGEMENT

The author would like to thank Drs Alison Kearney, Tracy Riley and Valerie Margrain for their assistance in the preparation of this paper.

### AUTHOR PROFILE

**Dr Stuart J. McLaren**



**Dr Stuart McLaren** is a Senior Lecturer in Health Science in the College of Health, Massey University. As a specialist in noise and acoustics, he recently co-authored a chapter on noise issue in inclusive learning environments for a textbook on inclusive education. He is also the parent of a 15-year-old adolescent with high and complex needs due to autistic spectrum disorder. This is a storied account of his son and family in response to the implications of government policy and expectations around full inclusion.

#### Email

S.J.McLaren@massey.ac.nz