



**Submission into the Inquiry into the identification and support for students with the significant challenges of dyslexia, dyspraxia, and autism spectrum disorders in primary and secondary schools**

**2 October 2015**

**Trish Grant**

**Director of Advocacy**

**IHC Wellington**

## **TABLE OF CONTENTS**

1. INTRODUCTION
2. RELEVANT BACKGROUND
3. PREVALENCE
4. BEST PRACTICE
5. SCREENING
6. SUPPORT, TRANSITIONS AND ADAPTATION
7. TEACHER EDUCATION AND CAPACITY
8. ASD GUIDELINES IMPLEMENTATION
9. CONCLUSION
10. BIBLIOGRAPHY

## 1. INTRODUCTION

- 1.1. IHC welcomes the Inquiry by the Education and Science Select Committee into the identification and support for students with the significant challenges of dyslexia, dyspraxia, and autism spectrum disorders in primary and secondary schools. We hope that the Select Committee Inquiry will result in increased cross party understanding of the difficulties and barriers that disabled children and young people, including this specific cohort of children, face in having equitable access to, within and through education.
- 1.2. In addition IHC hopes that given the repetitive discussions and raising of serious concern about special education policy implementation over several decades that the Education and Science Select Committee Inquiry process will result in the outcomes for disabled children promised within domestic legislation and through New Zealand's obligations as a signatory of international human rights Conventions.
- 1.3. IHC's submission is largely focused on the issues relating to autism spectrum disorder as there are high levels of co-morbidity between autism spectrum disorder and intellectual disability. IHC's submission is less focused on dyslexia and dyspraxia given our limited knowledge and experience although we acknowledge that many disabled and children and young people have complex and interrelated needs in the education system. IHC notes also that what needs to change for students with dyslexia, dyspraxia and autism spectrum disorders holds true for all students with disabilities.
- 1.4. IHC is now the largest disability advocacy and service provider organisation in New Zealand and a leader in the disability sector. It has a long history in education advocacy, from its inception in 1949 onwards. IHC played an integral role in the lobby to ensure that children with disabilities have a legal right to enrol in their local school (s.8, Education Act 1989).
- 1.5. IHC's education advocacy work is targeted at the systemic, community and individual level. The Advocacy team responds to a large number of communications from families who require intervention assistance, advice and information about special education and how to resolve the difficulties they experience with securing access to education for their disabled children at their local school. It forges links and networks across the education and disability sectors so as to better advocate for best outcomes in education.
- 1.6. IHC has lodged a complaint under Part 1 A of the Human Rights Act arguing that disabled children and young people experience discrimination at their local school in

that they are treated differently from their non disabled peers in matters to do with enrolment, access to the curriculum and participation in school life.

- 1.7. Hundreds of families and education professionals have provided evidence and support to IHC's complaint action. The evidence collected identifies the significant difficulties related to teacher capacity, school leadership, and the special education resourcing and policy framework which adversely impact on schools and families as they together attempt to ensure that disabled children's human rights to, within and through education are recognised and responded to.
- 1.8. An IHC survey completed by families and educational professionals identifies strong agreement between those groups that the priority issues of concern are teacher capacity and access to specialist supports.
- 1.9. Children with autism spectrum disorders are at very serious risk of poor outcomes in adult life. For those who have ASD plus intellectual disability, the picture is even bleaker. According to Howlin & Moss (2012), less than 20% of adults with ASD achieved good outcome overall, with less than 50% having any type of employment and only 14% having any kind of meaningful long term relationship. They are also at significant risk of additional comorbid mental health problems. Esbensen et al (2008) found 88% of adults with ASD taking at least one psychoactive medication and 40% taking three or more medications. There are also significant impacts for families. A number of studies have shown that the mental health of the parents of children with ASD is significantly worse than that of other parents (Totsika, Kerr and Hastings 2010), which in turn leads to further risk of family breakup, abuse and neglect. There is now a large body of research indicating that early intervention is the best method for improving outcomes for children with ASD (NZ ASD Guideline, MoH, 2008).
- 1.10. In order to address these issues IDEA Services (IHC's service arm) provides three services to families with ASD, all of which are aimed at improving families' knowledge, skill and resilience with the intention of improving outcomes for their children.
- 1.11. Parent training has been shown to be an effective approach for improving parenting skills and outcomes for children. For the families of very young children, ASD Plus provides an individualised parent training programme for 225-240 families per year. The programme has achieved significant outcomes for children with ASD and their families, with families having a 25.6 % improvement in their overall, skills, knowledge and coping ability and particularly in improvement in communication and management of behavioural difficulties. Unfortunately, the available funding for this service is well below actual need, with funding for 225-240 families, but 435 families being referred in the last 12 months.

- 1.12. The ASD Communication & Behaviour Service is a more intensive therapeutic service which provides individualised intervention directly with children with ASD and their families to improve overall functioning, increase communication and reduce the likelihood of severe behaviour problems occurring. This service has achieved excellent outcomes for families, but again, referral numbers hugely outstrip the contracted volume of service funded by the Ministry of Health. As at October 2015, there are over 600 children and families on the waiting list for this service, but the service has had a reduction in funding of \$850,000 from May 2015, meaning it will only be available for a maximum of 305 children a year.
- 1.13. The third service, Growing Up With Autism, an evidence based 20 week parent training programme for families of 11-16 year olds with ASD. In addition to giving families the skills to improve outcomes for their children, it has a strong focus on improving parental mental health. The programme has been shown to improve the overall well being of families and significantly improve mental health and reduce the level of stress experienced by the parents of children with ASD (Brereton, Tonge & Kiomall, 2006).
- 1.14. Overall, there is a significant shortfall in the availability of early intervention services for this group of children, with over 800 children and families unable to access services due to funding restrictions. Bearing in mind the known poor outcomes for this group, the major impact having a child with ASD has on parental mental health and the known strong evidence for the effectiveness of early intervention, this situation is simply not good enough for children with autism and their families.
- 1.15. For a number of years IDEA Services has provided CYF contracted foster care for children with intellectual disability. Through this partnership, CYF identified a number of young people with mild intellectual disability and complex behavioural needs resulting from trauma, neglect and abuse. These young people were identified as requiring a specialist residential service, with ongoing clinical support. These children have already experienced multiple failed placements and were often inappropriately placed in CYF secure facilities in the absence of a viable alternative. Despite disabled children being over represented in the overall numbers of children and young people coming to the attention of Child, Youth and Family the current review has no particular focus on this vulnerable group of vulnerable children.

## **2. RELEVANT BACKGROUND**

- 2.1. In the past 18 years the government has provided education for children with disabilities via 'mainstreaming'. In the late 1990's it closed down many special schools and units and replaced them with a system whereby children with disabilities would learn alongside their non disabled peers in mainstream classes at

local schools. IHC was an enthusiastic supporter of mainstreaming, believing that inclusive education for disabled children in their local school is the vital building block for inclusive communities.

2.2. The government has continued to fund and support a dual special education system where parents are able to “choose” between the mainstream ‘regular’ neighbourhood school and a special school. Many parents say that because of the lack of welcome, support and teacher capacity at their local school that the decision to enrol their child at a special school was not a real choice.

2.3. However for mainstreaming to work a child or young person with disabilities must be provided with the particular accommodations they need to access an education. It is recognised in government policy, in the New Zealand NGO disability community and among special education professionals that for children with disabilities to access an education equal to their non disabled peers they must be enabled to be *present* in the classroom, to *participate* in school activities and to *achieve*. These are the same fundamental principles underlying the successful learning of children without disabilities.

2.4. Accommodations needed vary according to the child’s disability support needs. The child may need physical aides such as talking computers and ramps. More commonly as with students with dyspraxia, dyslexia and autism spectrum disorder, they need other supports such as teacher aides working with them in the classroom, specialist support (e.g. psychologist support, speech therapy or occupational therapy), individual behaviour plans and time out spaces. Besides adequate resourcing schools need internal teacher and principal capacity willingness and leadership, external specialist supports and/or personnel to advise, monitor, intervene or otherwise assist to ensure that the learning environment is responsive to the child’s disability.

2.5. If there are failures in the reasonable accommodations needed then the child cannot access an education and is being discriminated against. The Convention on Persons with Disabilities, ratified by New Zealand in 2009, defines a lack of reasonable accommodation as discrimination on the grounds of disability. IHC adopts that view in its advocacy role.

2.6. Barriers preventing reasonable accommodation can be both systemic and school based. Some are beyond the school’s control such as inadequate support and resourcing and the lack of teacher training in inclusive education. Others include: the absence of a school wide inclusive culture led by the Principal, teachers and teacher aides not having been trained to teach inclusively,

2.7. Most of the difficulties described by families who contact IHC concern the lack of provision of any accommodations at all or lack of effective accommodations needed to enable the child to access their right to an education.

2.8. Themes from IHC's online survey of families and educational professionals asking for experiences in the mainstream education system and observations of same include:

- Reductions in funded support when the disabled student is functioning well without the acknowledgement that the funded supports are critical to maintaining success.
- Lack of good information sharing between schools and between the specialists advising schools and lack of sustained implementation of strategies designed to meet the student's disability needs within the learning environment.
- The disabled child and their family always seen as the "problem" with resultant feelings of isolation and judgement for the families and repetitive and sustained anxiety and negative self image for the disabled child.
- Disciplinary processes used to respond to disability related behaviours without identification of what the accommodations were which were are needed at school for the student to manage and grow in the school environment and inquiry into whether such accommodations had been effectively implemented or could be implemented better for the future.
- A focus on the student's behaviour without active and factored acknowledgement that the behaviour is related to the disability and is outside of the student's control. A belief that the behaviour *is* the child and needs "fixing" rather than 'accommodating' in a manner that supports the student and the school.
- School disciplinary processes leading to early/inappropriate disengagement with education or enrolment in segregated "special" school settings.
- Transience - sequenced enrolment at several/multiple schools often with significant gaps between school placements.
- The secondary school environment and challenges with inclusive education given increased numbers of teachers, teaching styles and attitudes towards disability and classrooms each with potential sensory issues to be managed.
- Poor literacy and numeracy outcomes for disabled students.
- Multiple assessments and interventions which may not lead to implementation of recommendations or to the sustained funded support to ensure that implementation of strategies are successful for the child.

- Incident based reactive Ministry of Education funding schemes which are time limited and are unable to support a sustained approach.
- School access to additional support involving lengthy bureaucratic processes and complex decision making criteria which lack transparency.
- Use of medication to manage behaviour in the absence of a funded sustained and implemented whole school behavioural strategy.
- Lack of good interface and information sharing between the education, health, disability and child protection systems who each hold different information about a child but weight it differently and or fail to use information to develop and implement a child centred, child focused, holistic plan of layered and complimentary strategies.

### 3. PREVALENCE

1. A recent World Health Organisation Meeting Report on Autism spectrum disorders & other developmental disorders notes that:

*“Worldwide, people with ASDs and other developmental disorders represent a vulnerable group. They are often subject to stigma, discrimination and human rights violations, including unjust deprivation of health, education and social opportunities. Globally access to services and support for people with developmental disorders is inadequate, and families of those affected often carry substantial emotional economic burdens.”*

2. In 1943 Kanner, was the first to describe the shared behavioural characteristics which are still recognised today as being typical of the phenotype of autism: “...*mostly aloof children, with limited, bizzare or absent communication, and stereotypical movements and interests.*” (Steyaert, J and Marche, W, 2008) . The latest edition of the American Psychiatric Association’s Diagnostic and Statistical Manual, Fifth Edition (DSM-5) describes the core symptoms of this disorder as a persistent impairment in reciprocal social communication and social interaction, and restricted, repetitive patterns of behavior, interests, or activities. Present from early childhood these symptoms limit or impair everyday functioning. (DSM, 2013) DSM-5, classifies Autism as a Neurodevelopmental disorder, one of eight more frequently diagnosed in childhood, and introduces a number of changes to the previous diagnostic criteria. The consolidation of the various DSM-IV-TR subgroups of Pervasive Development Disorders including Asperger’s and pervasive developmental disorder into one umbrella term “Autism Spectrum Disorder” represents probably the most significant and contested change in relation to autism. (Lord, C. and Bishop, S, L.2015). Rather than representing distinct disorders, the symptoms of these disorders are now seen as representing a single continuum of mild to severe impairments in the two domains of social communication and

restrictive repetitive behaviors/interests. (DSM-5) This change explicitly recognises the spectrum nature of autism by adopting a dimensional, rather than a categorical approach, and includes the addition of a severity scale operationalised as the degree of support required.

3. Epidemiology studies conducted over the last fifty years indicate that the prevalence of ASD appears to be increasing around the world. (WHO, 2013) Recent epidemiology studies estimate a global median prevalence of 62/10,000: one child in 160 has an ASD and subsequent disability. This represents a 25 fold increase compared with 30 years ago. Steyaert & De La Marche note that the increase is mainly due to improving knowledge about the clinical picture and the broadening of diagnostic capacity. This increase however, exceeds existing diagnostic and therapeutic capacity in many countries. (Steyaert & De La Marche, 2008).
4. According to the 2012/13 New Zealand Health Survey the percentage of children aged 2 to 14 diagnosed with autism spectrum disorder was 1.7%., an estimated 13,100 children aged under 15. Of significance however, is the difference in diagnostic rates between children from the least deprived neighbourhood areas and those from the most deprived areas, with children from the least deprived neighbourhoods being over three times more likely to be diagnosed with ASD. The differences between those identifying as Maori and European/other is also significant with nearly twice as many European/other being diagnosed with ASD than Maori. This suggested that the prevalence of ASD in the child population may be greater than 1,7%.
5. The 2013 New Zealand Disability Survey, estimates that there are 95,000 children aged under 15 living with disabilities (11 percent of all children aged under 15). For a third of these children, the cause of their impairment fell under "other cause", meaning the cause was not identified at birth. Included amongst these children are those with the neuro-developmental disorders; Autism spectrum disorders, dyslexia and dyspraxia. Having difficulty speaking and being understood because of a long-term impairment affected 5% of boys under 15 and 2 % girls. Challenges with communication is a core characteristic of children diagnosed with ASD.
6. Official data which indicates that between 11 and 14 % of the New Zealand school population have disabilities. As at July 2013 the total school roll was 762,400 students, resulting in more than 76,000.00 students with disabilities.<sup>1</sup>

#### **4.BEST PRACTICE**

---

<sup>1</sup> While not all students with disabilities require accommodations to enable their education, the large majority do.

1. Best practice would be understanding that these children are not lacking, they just learn in a different manner. To give these children the chance to access the curriculum in a way that is most productive for them would see a huge change in achievement levels for these young people. In other words adapting to them, not expecting them to adapt to the school.
2. Research evidence shows that all children learn better together. Inclusive education is a basic human right which reflects best educational practice for all children.
3. Best practice for students with ASD is the same as for all children; students with ASD need to be present, participating and engaged in learning, and to have their achievements monitored and valued.
4. In order to access education on an equal basis with their peers students with ASD must have their individual needs recognised, responded to and reasonably accommodated.
5. Parents and Education Professionals have told IHC that significant numbers of students with disabilities, including those with ASD are treated differently and are currently not able to enjoy their right to education because:
  - 5.1. They are declined or discouraged from enrolment
  - 5.2. They are excluded from participation in school curricular or extra curriculum activities
  - 5.3. They are permitted to attend the full day or take part in the full school curriculum only if a family member provides unpaid support or the family pays for teacher aid hours
  - 5.4. They are being taught by teachers who have no or extremely limited training in 'inclusive teaching practices' relating to disability
  - 5.5. They are unable to access the special education support services they need to participate and access the curriculum
6. Best practice is widely considered a whole school approach starting from vision statement to detailed systems that are far reaching and involve every member of staff. They are supported by staff training and accountability. The Ministry of Education Positive Behaviour for Learning (PB4L) initiative provides a good example of how to support a whole school approach. Schools were paid cash to support whole school training and teacher release, key people were given key roles and training.
7. The tomorrows school model does not provide for a consistent approach with many schools not providing well for special needs students, who appear to remain low priority. For this reason students with dyspraxia, dyslexia and autism spectrum disorders are less likely to be identified and teachers who lack capacity, knowledge and skills in teaching disabled children are likely to make false assumptions about disabled childrens "lack of work ethic" and fail to recognise a disability. Parents in many cases are also unable to recognise the reason for the lack of achievement.
8. In the past when I was in a school that had no system, I did unassisted writing samples and spelling tests with all students in years 9 and 10. If they came back low, I brought

them into my learning area and teacher aides put them on a computerised test called LASS. LASS gave me a brief profile of cognitive and literacy abilities. The profile helped identify the reasons for the low achievement and a typical dyslexic profile. I then did individual testing on children on the cues being used in reading and writing to decode and spell. This would indicate the correct remediation programme and also whether they should have special exam conditions /assistive technology.

9. Identification of children with these conditions needs to be led by school SENCO's. All children operating on a lower level could be tested easily for indicators of dyslexia etc. As stated there are even computerised programmes that will test children and identify those who are showing a dyslexic profile. Schools need these things supplying as standard and SENCOS need to be knowledgeable about identification and interventions to adapt the environment. I do not believe they are presently consistently knowledgably across all schools. There is vast differences across schools perhaps because of their self-managing and not mandated processes.
10. Perhaps SENCO's need to pass an exam once they attain a position to ensure they know what to do and appropriate methods. Going to a one off course does not equip SENCOS to deal with these students. They need on the job training and support. Perhaps by organisations outside of MOE such as ours, but monitored and directed/ managed /mandated by the MOE. A partnership approach.
11. Best practise my understanding is there is nothing to define it as schools are self-managing as part of tomorrows schools. While there are some guidelines, these have to be applied to a situation before they will be recognised by schools. Therefore ensuring best practise for an individual with a disability is down to locking the school in by being very informed about terms and what is and is not expected. The biggest that can be done at present is based on parents being knowledgeable and advocating for their own children through ensuring a really good IEP with measurable defined goals, who and what will happen spelt out to the letter in a way you can hold schools accountable.

Example of Typical Practice. – the sort of thing that needs preventing.

'I recently had a colleague ask me for advice as a client's child was given the new 'in class support' funding and had started to receive that in the form of 5 hours in class teacher aide time. Then the school because of its ability to self-manage decided that this teacher aide could be reassigned to start a maths group for 30 kids. The child was to be given support by being withdrawn for some time and one hour of teacher aide time in class to make up the difference. This was done without notifying the parent and without any warning to the child, who was very upset. As the result of the information gained about the way the funding is supposed to be used which has inference from its name and some guideline around it that it is to be used in class support funding, (which is unusual as usually schools can use funding as they see fit.) The parent was very distressed and the teacher was avoiding talking to her as it was her maths group that had stolen the child's teacher aide. Armed with the information I supplied to my colleague the parent emailed the principal. The result was a return of the five hours teacher aide funding, but a new teacher aide which the child was not used to. I advised that all this should have been stipulated to the letter in the IEP. As it was it was changes to the IEP also without consulting with the IEP group that further supported this return of teacher aide time. It had said there would be individual reading support that was now missing. '

The extra work involved and the knowledge needed to know that assistive technology is needed or would be helpful means it is not accessed as much as possible. When I was in school I got laptops free from the organisation my son worked for and used these to run trials for assistive tech or indeed to run trials for special exam conditions.”

## 5. SCREENING

1. There is also now a large body of research indicating that early diagnosis and early interventions are critical, with social and functional communication skills having been identified as a key priority. (Steyaert & De La Marche, 2008) The New Zealand Autism Guidelines include key recommendations to this effect. ( MoH, 2008).
2. The Ministry of Education’s 2014 Annual Report identifies that the early intervention service met the 90 day referral target 63.4% of the time, down from 65% in 2013 with the level of demand exceeded the capacity to deliver a service. This is concerning given the short time children spend in early childhood and the acknowledged benefits of early intervention. In addition children with ASD are at risk of developing challenging behaviours resulting from an inability to express their needs and wants through effective communication.
3. Many parents struggle to get a diagnosis of ASD for their child in the first place, particularly for a child who is high functioning. I have worked with many teenagers who were diagnosed between the ages of 11 and 15 years of age. Many of these children were discharged from their local Child Development Centre when they were between 3-6 years with no diagnosis or sometimes with a diagnosis of ADHD. These children have often struggled through school and have been labelled “difficult” or “disruptive”. As with diagnostic teams, mainstream teachers often struggle to identify children with ASD that have mild, less obvious behaviours.
4. A whole school approach should include screening tool and data collected on progress. Separate data is collected on the achievement of Maori and Pasifika children however there is a lack of data collection for children with dyspraxia, dyslexia and ASD and other disabled students. Screening needs to include identifying student individual needs and ensuring the school is equipped to meet them.
5. Special needs students appear to be treated as low priority. The screening needs to include access to assistive technology, teacher aide support, other support systems, IEP’s, Parent feedback, information which specifies attempts to raise achievement with evidence based interventions. This may need to be documented and signed by families too before submitting to the MOE. i.e. agreement of IEP progress and that the plan was implemented. This triangulation of documentation would be self-monitoring and ensure best output by ensuring best inputs.
6. IDEA services Autism specialists comment that there is no prescribed screening route, teachers may raise concerns if they notice something, however unless a child has ORS funding (from early identification) they will need to go on a waiting list for an RTLB or Ministry of Education special education advisory assistance, this can be for an extended period especially if they do not display any aggressive behaviours.

In regards to Dyslexia a lot of children, unless they get a very good teacher also go under the radar for a while as by the time that they start school they have developed very good coping strategies which mask the problems.

## 6. Support

6.1 IHC's online survey confirms that the Special Education 2000 funding framework does not currently provide the support or accommodations needed.

Parents and Education Professionals report that that significant numbers of students with disabilities, including those with ASD are treated differently and are currently not able to enjoy their right to education because:

- o They are declined or discouraged from enrolment
- o They are excluded from participation in school curricular or extra curriculum activities
- o They are permitted to attend the full day or take part in the full school curriculum only if a family member provides unpaid support or the family pays for teacher aid hours
- o They are being taught by teachers who have no or extremely limited training in 'inclusive teaching practices' relating to disability
- o They are unable to access the special education support services they need to participate and access the curriculum

6.2 The funding framework has many components but the main source of individualised funding comes through the Ongoing resourcing Scheme (ORS). The eligibility criteria for the Ongoing Resourcing Scheme remain essentially the same since they were introduced two decades ago. The criteria and benchmarks have not been reviewed since 2001, despite:

- o A substantial increase in the numbers and prevalence of students with ASD. In 1998 the Ministry of Education estimated that just 200 students with ASD would require a high level of support throughout their entire schooling. In 2012/13 at least 13,100 students under 15 had been diagnosed with ASD. The 2014 Ministry of Education briefing to the Incoming Minister again acknowledged the growing incidence of children with neuro- developmental conditions including ASD. There is also acknowledgement that these students will require support throughout their schooling and that other than ORS funding special education services do not generally support students beyond 14.

- o Significant changes in to the DSM-5, one of two international classification systems used by health professionals in NZ to diagnose ASD; having been introduced in 2013. These changes reflect significant advances in our understanding of the nature and aetiology of ASD.
- o A decision having been made during the 2010 Review of Special Education that this was necessary and was to be carried as part of the review. According to information released under the Official Information Act in November 2011;

*“ The outcomes of the Review of Special Education required the prioritisation of recommendations, based on what would make the greatest difference for children and young people, That ongoing prriotisation during July to October 2010 resulted in the decision not to undertake an independent review*

- o Social and functional communication abilities are considered to be a priority for all students with ASD. However, communication services were provided to just 6358 students in 2013. Yet there were an estimated 12,600 school age children under 15 in 2012/13.
- o The Best practice Reviews by Canterbury University of the Communication Initaitive in 1998, 2001 and 2006 have consistently reported that significant numbers of children are not accessing the specialist speech language services they need. Comments from a 1999 paper ‘Review of Best Practice Services in Speech Language Therapy-Key Implications of the review include Ministry of Education has been aware since 1998 that;

*“Of utmost importance is the finding that current services are providing for less than 10% of the estimated number of children who require speech language therapy. Even if only children with the most profound disorders are to be provided for, estimated at 1% or 7,000 children, the current service is grossly inadequate.”*

- o A comprehensive review of the issues relating to the provision of specialist education support services such as speech language therapy should be undertaken. This review should consult all stakeholders and examine all options for service delivery within the context of international best practice.
- o Funding for students with ASD should be based on individual need and should be flexible according to level of need and local conditions. Funding for students with moderate needs should be targeted to ensure equitable access to quality supports.

6.3 Currently, students gain funding to support their learning, either through the Ongoing Resource Scheme (ORS) or through the Special Education Grant (SEG). The SEG is part of a school's operational funding and is determined by the school's roll, together with a base amount.

The Education Review Office report on the Special Education Grant (SEG) identifies that;

- Data is increasingly driving much of what takes place in schools, yet there does not appear to be any information about how many children in each school access the SEG. Nor is there any information freely available about how the funding is used, or the wait times faced by learners and their families to access specialist services, such as speech language therapists. Graham Stoop is quoted as saying that “only 82% of children ... [receive] help within 90 days of being referred” (Jackman, 2015, para. 15).
  - The number of children who are unable to access their local school/centre or the school/centre of their choice is also unknown. This information, which should be recorded by the Ministry of Education, is critical to measuring success and the impact of current funding.
  - Up to 8,000 children at any one time are eligible for the Ongoing Resource Scheme (ORS) funding which supports students with high special education needs (Ministry of Education, 2015). The exact number of those students who require this funding miss out due to the artificial ceiling on support is unknown.
  - The Ministry of Education acknowledges that 30,000 learners have high special education needs (Ministry of Education, 2012). It is unclear if this includes students who receive ORS funding. Those students who do not receive ORS funding have to be supported by the SEG, which must also cater to the estimated 40,000 – 60,000 learners with moderate special education needs (Ministry of Education, 2012). The SEG also supports those students whose needs are classified by the Ministry as minor.
  - It has also not been determined to what extent families/whānau are financially supporting schools, through paying for teacher aides and other costs.
  - The cost to individual schools/centres of supporting learners with special needs is also unknown. Many schools are using local funding in addition to the SEG to support students with special education needs. This additional funding is often used to pay for property modifications, ICT or increased teacher aide hours (Education Review Office, 2015b).
4. It is difficult to see how individual schools can meet the requirements of the United Nations Convention on the Rights of Persons with Disabilities where “persons with disabilities receive the support required, within the general education system, to facilitate their effective education [and] effective individualised support measures are provided in environments that maximize [sic] academic and social development, consistent with the goal of full inclusion” (United Nations, (2006), as cited in Education For All, 2014, p. 3), without further support from the Ministry of Education, including keeping statistics about the levels and effects of funding. As there is no baseline data to work from there is no

way of knowing if the objectives can be met. “Advocates for the disabled [also] cite the lack of data pertaining to disabled children as a key issue for them because the lack of baseline information makes it difficult to advocate for better policies and services” (Child Poverty Action Group, 2015, p. 3). It is difficult for the sector to do ‘more with less’, as expected under Better Public Service goals (State Services Commission, 2015) in the absence of data.

5. An Idea services Autism specialist states that “there is very little support available especially when students are in the initial years of schooling in the way of learning adaption’s, unless a school is supportive a higher functioning student who could also be extremely high achieving is getting average or below average grades in assessments due to lack of learning adoptions. I have seen a child get 25% in a maths exam, but when reworded they got 100%, however this was not able to be recorded as it was not to the exam specifications. Bottom line, not enough support, or funding to provide the support for the majority of children who require it to access the curriculum to the best of their abilities”.
6. Children who do access ORS typically now only get 10 hours Teacher Aide time per week, leaving the class teacher to manage and teach the child the remainder of the time.
7. Whether children with ASD gain 1:1 Teacher Aide support or not, many of them struggle to sit still, to understand and follow verbal instructions, struggle with the co-ordination for hand-writing, struggle with the executive functioning needed to plan tasks and with many other expectations of them within the classroom.
8. A large proportion of children with ASD suffer from additional anxiety. They may be more anxious in a group or when there is a lot of background noise.
9. Children with ASD struggle socially, particularly in unstructured activities. At break and lunch times children tend to have even less support from teachers which is precisely the time children with ASD are likely to struggle the most.
10. Communication between the School, Special Education and parents is often poor. Parents often report feeling left out of processes and decisions made about their child with ASD. The ASD Guidelines and all the research highlights the importance of working collaboratively with parents in a strength-based way.
11. The philosophy of the school and the support network provided for the teacher has a massive impact on how well he/she is able to manage her class and the varying abilities of all children successfully.
12. For assistive technology it is necessary to prove a child will have a barrier removed by inclusion of this device. An example is a camera given to a secondary school boy with dyslexia. It changed his life. He would photo teachers notes, or a class mates notes. Print out and stick in his book as he could not spell. He was taught to read to a reasonable level so was then able to access the work. He went from being self-harming to having friends, being more outgoing and generally happy. He was lucky his mother pushed him to the schools attention.
13. Many students do not get this help if they come from low socio-economic areas and have a less skilled SENCO or parents who have so many problems they cannot or don’t know how to advocated for them. It’s a lot of paper work to get the assistive technology application and trials have to be run to prove its needed. Even then it is not guaranteed,

14. **This situation creates inequitable education for some children.** There needs to be much wider and more certain access by children identified as having a specific learning difficulty such as dyslexia, dyspraxia or ASD. ASD often has comorbid learning and fine motor problems.
15. **Transitions to schools for children with disabilities.** A quality transition support is critical to success in the new school and avoids devastating misunderstandings that can easily escalate.
16. Some RTLB clusters collate data from the primary schools within their region and liaise between the primary and secondary to share data. They give very limited or no support to secondary schools for these students however unless they are individual referrals or the SENCO asks for support for herself. Perhaps this should be made mandatory with some specific expectations for what should be set up with the new teacher to ensure success.
17. **Children on the spectrum really need a good transition if they are to stand a good chance of staying in school. They are left open otherwise to being misunderstood in the play ground or other situation through their behaviours being misunderstood /them being disciplined for something they cannot help. Hence often leading to meltdowns and exclusions.** An IDEA services autism specialist states "I have often been at Board meetings with children who are on the spectrum being excluded for behaviour. I have been made aware of teachers taunting children with autism for their behaviour and attitude as they have made assumptions around its intention and meaning".
18. **Many teachers do not understand the behaviours of children on the spectrum. They often assume children with dyslexia are lazy. Compulsory initial and ongoing whole school training and development with regular review and monitoring of the progress of their identified ASD and other children with specific learning difficulties is required.**

" I have witnessed many incidents of misunderstood behaviours by ASD children even in special schools. i.e 'shouting at the teacher to write it on the board and not to do dictation because of auditory processing difficulties which was ignored and the class were told, ignore him let us keep going, which resulted in a huge meltdown and tables flying.' ' teachers not understanding why a child is guarding the pencil sharpener,' 'why an autistic girl keeps staring at their faces and occasionally asking them if they are angry.' ' covered ears during a distressed situation responded to with speaking louder and assuming the child is being rude.' These children are fragile and prone to mental health issues because of consistent elevated stress and the torment of these situations they are forced to endure. Ensuring they are identified is the first hurdle and that all teachers understand them is the second. **It is ESSENTIAL they are identified and that all teachers understand how they function**".
19. **Special Exam conditions.** In order to be eligible for special exam conditions there has to be proof provided about the specific learning disability - It cannot be global. Hence you need some way to prove your cognitive ability is above your achievement level and that the barrier will be removed by special exam conditions. Example being dyslexia where you cannot read or learn to read despite years of remediation, you can apply for a reader for all tests, apart from tests that measure reading.
20. AN IDEA specialist reports that "One school I know of is a school that is known to have an extremely high level of learning problems and behavioural problems to match. It only

had three students receiving special exam conditions last year. Two I identified while I was there, and one I identified and did a free report for since I left. None were identified by staff and no more were put through as even SENCO's don't have the training to know how to identify these children, how to process their applications, how to effectively help them and there is so much extra work involved anyway, it does not get attempted.

The following example illustrates the difficulties

"I am just doing a special exam conditions application for a boy who is hard of hearing as a part of alports syndrome. He has autism, does not speak much, has huge comprehension problems but is good at maths. He was not diagnosed with hearing impairment until he was in year 6, which is a demonstration of what is and is not picked up by teaching staff in schools. As a result it has been an extremely complex issue to test and identify his needs for special exam conditions. The school had continued to progress him on reading tests guessing he knew the answer to comprehension questions from his one or two word answers. They have now had to put him back to age 5 to 7 reader and we now have to explain that in an ORs application that was failed because of the schools inaccurate testing. On the WISC he has a huge deficit in the verbal comprehension range which without very detailed and skilled assessment could not have been justified to MOE for him to have a reader, extra time and separate accommodation. As the school say, how can you ask for a reader for a boy who is hard of hearing. There are a number of web pages that parents can look at and teachers on the MOE site. This child apart from teacher for the deaf support gets nothing to help him and it is possible he will lose his kidney function, hearing and eye sight, while he is already very difficult to communicate with as he does not understand concepts or anything abstract".

6.21 Although most schools are supposed to collect data to avoid the expense to the parent of an individual psychologists report, most do not have the knowledge and expertise to do this. Most schools don't do this thus leaving parents having to find \$1000 approximately for private psychologists reports to recommend special exam conditions. This means that only the well off parents can afford this and poorer families cannot access this support for their children.

## **7. TEACHER EDUCATION AND CAPACITY**

1. No it does not. I have worked with first year teachers with some students I support and have had to provide them with education myself as they were unsure of what ASD is, let alone able to support a student adequately. Professional development opportunities are available but funding prevents the majority of teachers from accessing it.
2. My understanding is there is very little teacher training on things such as dyslexia. Back in 2005 I was asked to teach the paper on catering for diversity at Auckland University. It was an 8 session course that I had to fit everything into. This included something on reading failure, behaviour management, developing social skills, supported reading / adapting strategies, adapting for children with disabilities and SE 2000 the special needs framework and what could be accessed. These were post grad secondary teaching students. As such they were not taught how to teach reading even, never mind adapting and intervention. I know teachers who are training now and feel the situation is the same. There is low priority on deepening teachers knowledge of special needs such as ASD, Dyslexia and Dyspraxia, which are often comorbid.

3. There is tips for autism but that just includes one teacher from the school, the parent and a specialist. It does not include other staff and teachers who come into casual contact with the child and could react without understanding. MOE need to put some priority on the expectation teachers will attend PD in school on these topics and be accountable for implementation.
4. There are other teacher PD courses for those with enough interest to go on them. This is too piecemeal and there needs to be more whole school emphasis on gaining knowledge, skills and interventions for children with ASD, dyslexia and dyspraxia. Most PD requires teachers to listen and then implement the learning without any guidance. It would be better to have on the job training. RTLB can do this but there are too many referrals and schools do the referring and I would say mostly refer their behavioural students and not just those who are finding learning or the environment difficult.
5. More teacher education time should be devoted to diverse learning needs to give teachers a good basis to build on once they start teaching.
6. The percentage of people in prison who have dyslexia is known to be high. The impact of having these disabilities without appropriate supports is clear in relation to education, employment and quality of life.
7. I have done lots of training over the years for teachers and other staff around dyslexia and ASD. Staff are always amazed to hear of the differences in the thinking of children with Autism. They need to develop in depth understanding of how and why children on the spectrum function in the way they do, not just surface knowledge of what they should do for these children. Understanding is needed to ensure flexibility in implementation of strategies is applied and the ability to generalise the new learning to other children on the spectrum.
8. Our service, RTLB or similar could provide this to schools, alongside individual interventions to ensure success. There does however need to be direction from the MOE for schools to be even interested in making this a priority and implementing this suggestion.
9. All too often, Class Teachers do not have the time, energy or occasionally the interest to cater to the specific needs of a child with ASD. Many children with ASD appear to cope, learn and communicate well on the surface and many Class Teachers over-estimate a child's ability to cope and underestimate the importance of supporting their sensory needs to prevent 'sensory melt-downs' and 'disruptive' behaviour.
10. While training courses such as TIPS for Autism and support for Class Teacher's such as LLI (the Learning and Language Initiative) can be helpful, the Teacher needs to be willing, able and responsive to the information received. The key to working with children with ASD is to be able to problem-solve and think 'outside the square' about what will work for a particular child. Some teachers are excellent at adapting their teaching style, others refuse to incorporate well-researched and proven strategies such as using a reward system into their teaching methods.
11. The Education for All group (made up of NGOs and DPOs committed to inclusive education) of which IHC is a committed member has developed the following priorities and recommendations in relation to teacher education and capacity

- 11.1. Teaching approaches and practices are situated within a human rights framework, underpinned by social model understandings of disability, and based on evidence for the effective delivery of Te Whaariki and the NZ Curriculum.
- 11.2. Nationwide provision of whole school professional development and mentoring to support every school to develop and sustain a culture and practices needed to ensure the learning, achievement and success of **every** student
- 11.3. Graduating teacher standards to include a compulsory specific competency on how to include and teach students with disabilities, demonstrated knowledge of the likely impact particular disabilities may have on student participation and learning, Teacher education providers partner with disabled people to provide this training, Registered teacher criteria include a demonstrated ability to respond effectively to students with disabilities, all registered teachers are required to undertake professional development in inclusive education as part of the registration process.
- 11.4. New Zealand teacher education providers, schools, teachers and teacher's aides receive professional development on how to plan and teach for diverse learners, including principles and practices of Universal Design for Learning (UDL)

### **8. Review the implementation of the 2008 NZ autism spectrum disorder guidelines recommendations specific to education to assess progress**

8.1 I do not feel these have been implemented. I have had to show some schools these and point out that the optimal way in working with a child with ASD is including their family. I have given teachers printouts of this as they have not even heard of it.

I feel this is just a list of guidelines that I feel are so vague and non specific it is unlikely to be fully read and digested by a wider audience. There needs to be written as the rights of people with autistic spectrum disorder for schools etc to listen and observe what is needed.

8.2 ASD specific behavioural services should be looked into. **Our ASD team could do this if given more funding and would be well placed to carry this out. We have already developed education packages and workshops that could be used to support interventions for individuals referred and educate the people that deal with them in the community.** We are able to cover all aspects of his including working in the education sector.

### **9. CASE STUDIES**

**Case Study of a 6 year old Year 1 student – unfortunately this type of scenario is not uncommon.**

This family have a 6 year old boy with Autism Spectrum Disorder. The family are easy to work with and want the best for their son, however they have had a terrible first year at school for the reasons below. This child has recently been pulled out of school as a result of physical force used by teachers that the parents never agreed to.

- The child's class teacher does not understand ASD and refuses to treat him any differently to any other children (despite repeatedly agreeing to in public forums such as the IEP meeting). In this case, appropriate training would likely be futile.

- The class teacher believes this child has age appropriate comprehension and as such his behaviours are all intentional (despite being repeatedly told by professionals that he only has single word understanding and has huge sensory issues).
- The class teacher, the acting principal and a representative for Special Education met without the parent's knowledge or consent to lay out an 'Interim Behaviour Support Plan'. This plan was implemented despite the parents expressing they did not agree with the strategies and did not want it to be used.
- Despite his parent's wishes, the child was taken to time-out at the office 35 (recorded) times over a 6 week period. This was for an unspecified amount of time and if the child was unwilling to go, he was physically forced to go by 1 or 2 teachers picking him up and/or dragging him to the office. Time out is a strategy used in the school charter for all children but there was no allowance made for this child's sensory issues or lack of comprehension.
- The family have followed all the correct procedures and have repeatedly addressed their concerns through the formal IEP process, directly with the Class Teacher, the Teacher Aide, the Acting Principal and 3 Special Education workers (SEA, SLT and OT).
- Several meetings regarding 'behaviour management' of this child have taken place between the school and Special Education without the parent's knowledge or consent.
- The class teacher has ignored suggestions, strategies and advice from the parents and several professionals - including the 0.1 ORS Teacher, the Occupational Therapist, the Speech Language Therapist and myself.
- This child has started hand-biting, hitting other children and has suffered from constipation (only during term-time).
- The acting principal 100% backs the class teacher and when the child was pulled out of school her only comment was "I don't know what to do about the situation."
- The lead worker for Special Education (the SEA) is related to the Acting Principal and tends to back what she and the class teacher say over the parent's wishes.
- The Teacher Aide has been hauled into a meeting with the Acting Principal. She has been accused of passing details of how behaviours are being managed in the classroom onto the parents and she has been told under no uncertain terms that she is not to talk to the parents about school (despite her supporting the family with respite care outside of school hours). The Teacher Aide has since resigned as a result of how she has been treated over the last year.
- This child has been pulled out of school and is currently at home with no education until the issue is resolved.
- The parents have been exhausted by this whole process. In particular, the mother's emotional well-being has suffered and she has had difficulty sleeping for several months.

## **9.CONCLUSION**

## **10. BIBLIOGRAPHY**



