

2e group submission on the needs of children with Dyspraxia, Dyslexia and/or ASD.

27th September 2015

Otago Association for Gifted Children

Q1: What's your story? What would you like MPs to know about children with SLDs?

We are a parent group of 25 families who have a shared experience of raising, and advocating for, children who are both gifted and have a Specified Learning Disability (SLD). In writing this submission, five families attended a meeting and other members who couldn't attend contributed via email.

Within our group, we have children who are gifted with one or more of the following:

- Dyspraxia
- Dyslexia
- Dysgraphia
- Dyscalculia
- Auditory Processing Disorder
- Sensory Processing Disorder
- ASD/Aspergers.
- Significant executive functioning issues/executive dysfunction.
- Slow Processing.

Most of the children have been formally assessed by educational psychologists and identified as intellectually gifted with specific learning difficulties, and have had SLDs confirmed by other clinicians.

The Ministry of Education's TKI website states that "Twice exceptional (or 2E students) are sometimes also referred to as double labelled, or having dual exceptionality. These are gifted students whose performance is impaired, or high potential is masked, by a specific learning disability, physical impairment, disorder, or condition. They may experience extreme difficulty in developing their giftedness into talent.

Gifted students with disabilities are at-risk as their educational and social/emotional needs often go undetected. Educators often incorrectly believe twice-exceptional students are not putting in adequate effort within the classroom. They are often described as 'lazy' and 'unmotivated'. Hidden disabilities may prevent students with advanced cognitive abilities from achieving high academic results. 2E students perform inconsistently across the curriculum. The frustrations related to unidentified strengths and disabilities can result in behavioural and social/emotional issues."

As individuals and a group, we are aware of the difficulties schools have in meeting the needs of children who sit at both ends of the bell curve. In particular, teachers and administrators can struggle to recognise the extreme frustration experienced by 2e students, which often can result in behaviour issues if the child's learning needs are not being met. Most schools will pick up on the behaviour issues first, not the learning needs. Even schools that are generally good at figuring out the source of a child's behaviour issues do not usually consider 2e frustration issues, because it is relatively rare and not well communicated within the MoE. If teachers do not know the reason for the 2e child's in-class behaviour issues, chances are the teacher will not choose appropriate strategies to deal with the negative behaviours and the situation is likely to get worse.

As parents, one of our biggest concerns is underachievement, which has led to many of our children becoming bored, and frustrated with themselves and others. Twice exceptional children can exhibit behavioural issues in the classroom, as well as develop clinically significant anxiety, depression, and even suicidal tendencies. Amongst our parent group we have experienced all of these issues. This impacts on the

whole family environment and is very stressful. When approached by parents, many teachers state that children are “doing fine” because they are meeting National Standards (primary) or getting Bs and Cs (secondary), but parents and educational psychologists, and the children themselves, know that this is not the child meeting their potential. This has caused many of our children to check out of school – either dropping out of high school early, or not bothering while at school. This happens as early as Year One and contradicts MoE policies on inclusive education.

Q2: What screening occurred, and what challenges and costs have been involved?

Screening:

- Early Childhood providers are anecdotally getting better at identifying gifted children, but not so much 2e children. Where a child is identified as having an SLD, there is little knowledge of what can be done.
- One parent reported having a Ministry of Education Early Intervention teacher involved after significant concerns were raised by kindergarten that indicated ASD and dyspraxia, as well as giftedness. The early intervention teacher’s conclusion was that “he is not gifted –gifted children are good at everything” and he was discharged. The child attended his first school for 12 weeks, the second for three terms, then was withdrawn for homeschooling while under a child mental health team. Clearly there was a lack of training in the needs of 2e children to be able to identify the physical and sensory issues that were clearly highlighted.
- Where children have been identified, they have been stuck between the health and education systems, and very few have ended up with access to publicly funded services. Those who cannot afford to pay for assistance are disadvantaged.
- No members of our group have experienced their child being screened for SLDs at either primary or high school.
- Where private assessments have been done (educational psychologists, occupational therapists, audiologists, SPELD assessors etc), schools have frequently resisted doing anything. Many have even questioned the validity of the tests.
- Most teachers haven’t heard of dyspraxia, dysgraphia, dyscalculia, auditory processing disorder, sensory processing disorder, slow processing or executive dysfunction. As they have not even heard of them, they certainly couldn’t recognise them or plan accommodations!
- The screening tool most commonly used by public services to identify children with dyspraxia is limited. The Movement ABC was developed, in part, by Motohide Miyahara. Doderer & Miyahara (2013) state that “The assessment and diagnosis of DCD should involve multiple perspectives from parents, teachers, clinicians, and children to determine the degree of motor delay and the extent of interference with academic performance and activities of daily living. A therapist’s sole reliance on just one or two of the multiple assessment sources would lead to misdiagnosis. Such a misdiagnosis could result in failure to provide sufficient educational and therapeutic support for children in need, to fairly distribute limited educational and clinical resources”. This is especially important, as the Movement ABC doesn’t test for speech or executive functioning issues, and only gives a clinician 20 minutes with a child in a clinical setting.
- The ideal time to make the most of neuroplasticity, and to reduce the ongoing effects of dyspraxia, auditory processing disorder and sensory processing disorder is before the age of seven. Most children aren’t being diagnosed until well after this.

Challenges:

- Public services only use the Movement ABC to screen for dyspraxia, in a single setting over a short period of time, and therefore some children with pervasive dyspraxia aren’t being identified. If they

aren't picked up before the age of five, they aren't eligible for early intervention teams, and paediatric teams are not picking up these kids either. The Ministry of Education, as a rule, doesn't work with children with dyspraxia if it doesn't affect their speech and they are meeting National Standards, so parents must pay \$85p/hr for private therapy, or try and invent their own programmes without clinical support. There are no services available to help children with dyspraxia with their executive dysfunction, unless their emotional regulation issues get to the point of needing mental health services.

- Twice exceptional children don't fully fit into either the traditional special needs or traditional gifted categories, so schools and teachers often do not know what to do with them, even assuming the child has been identified. This puts them at high risk of slipping between the cracks, and, purely due to poor fit, being unintentionally excluded from the school system.
- It is challenging for 2e kids to find like-minds, as even when they are with gifted kids, they can experience frustration in not being able to do things quickly.
- Most parents have had to seek privately funded specialist assessments – at a huge cost.
- Most schools/teachers haven't even heard of the diagnoses listed above. They often question the assessment/diagnosis, professional recommendations and opinions.
- Internationally, dyspraxia is diagnosed via educational psychologist and OT assessments.
- The MoE tends not to provide support to schools and families unless the child is exhibiting extreme behaviour issues. This penalises well behaved children who are struggling.
- Many SENCOs seem under-resourced/under-trained for their role, making it difficult for parents and teachers to access help.
- Motivated teachers are frustrated at not being able to easily access high-quality information about identifying 2e students and developing appropriate teaching strategies. Once teachers have learned about twice-exceptional students, they usually want more information and specific ideas of how to support these students appropriately. There is a small amount of information on the MoE website, but most teachers (like parents of 2e kids) rely on getting more information through word of mouth, if they are lucky enough to find a colleague with an interest in 2e kids. Most teachers do not know what resources are best for different 2e kids or who to ask for more information.
- IEPs are hard to get – in most schools, parents need to really fight to get them. There is the consistent impression that schools are under-educated and under-resourced for SLDs.
- Promises made in IEPs are often not kept – parents need to keep advocating to ensure these are implemented.
- 2e children often hide their challenges and find compensatory techniques that may not transfer to adult tasks. This can make identifying their needs while they are still young very challenging.
- Children who are diagnosed as teenagers are often unable to access any services at all, which often leads to emotional issues.
- Teens who are diagnosed late in the year are unable to access Special Assessment Conditions (SACs).

Costs:

- Educational Psychologist report (all SLDs listed above) - \$900
- Handwriting for Special Assessment Conditions – \$350
- Dyspraxia OT assessment - \$315.
- Follow up OT/physio - \$85 per hour.
- Behavioural Optometrists - \$120 per hour.
- Audiologist - \$250
- Privately funded laptops/iPads \$600-1200, plus software.
- Sensory toys - \$35 per term.

- Lost income as often one parent needs to work part-time or stay home full-time to dedicate their time to researching their child's needs, advocate for them, meet with the school (often weekly or daily if clinicians aren't involved), or homeschool their children.
- Few clinicians are in the regions, so travel, lost income and accommodation costs apply.
- The MoE requires Ed psych and SAC reports must be renewed every three years, increasing the cost.
- Statistically, where one child in the family has SLDs and/or is gifted, siblings will be too. The Gifted Development Centre noted that out of 148 sets of siblings, 1/3 were within 5 IQ points of each other. A child is 50% more likely to have dyslexia if their sibling also has it, than a child with a neurotypical sibling (Shaywitz & Shaywitz). This may mean that a family needs to get one or more children assessed every year.

Q3: What works when teaching children with SLDs?

- Having genuinely quiet spaces (that can't be used for group discussions) to work in, enabling children to concentrate. Alternatively, noise cancelling earphones.
- Grouping children with similar strengths and challenges together – providing like minds, peer support, and reduces isolation.
- Project based learning – children can express their learning through a means that works for them..
- Strengths based learning – teaching a child with a genuine focus on their strength gives them the self-esteem to tackle the tasks that they find challenging (especially when they know everyone else can do those tasks without thinking).
- Emphasizing process over product for 2e students, as they benefit from celebrating real learning (process), not just achievement (product).
- Where a child who is identified and is getting average marks, recognise that they might still be struggling. Particularly if they are struggling in an area that is identified as their strength by either historical school records or educational psychologist testing.
- Alternatives to timed tests – gifted children are frequently held back due to slow processing eg children who can quickly do complex maths but are slow at processing basic facts – they must be able to calculate if they can do complex equations quickly!
- Communities of schools – primary and secondary schools working in partnership to test children at the right level, then being able to develop a curriculum that suits their strengths. We find this also helps with their SLD.
- Providing standing desks for children who need to move/have trouble with sitting balance.
- Recognise that children with SLDs are working twice as hard as neurotypical children to just keep up (a bit like being in a classroom where you don't speak the language fluently). Their performance may be inconsistent (they have curriculum areas where they excel and others where they struggle; or even have days when they excel in one curriculum area, then struggle in it the next).
- Provide flexibility in how work/a task is done, and chances to rest the mind and body.
- Taking time to genuinely listen to children when they talk about their challenges and frustrations – don't assume they are lazy, or disrupting the class for no reason.
- Flexibility in testing
 - Divergent thinkers may not give an expected answer in a comprehension test, but doesn't mean they aren't able to read or comprehend at that level.
 - Different learning styles must be provided for eg Visual Spatial Learners will not test well in a sequential way – they need to be able to go straight to the big picture and work backwards.
 - National Standards don't work for these kids!!! Either they get a message that they are 'below' or they test 'above' and their movement within that category may not be tracked – they may be so far above that a nosedive in achievement due to their SLD is missed. We depend on an individual teacher's ability to test above level and to track it.

- These children need more 1:1 time – this is why so many families (an increasing number) choose to homeschool.
- Understanding executive functioning issues – not labelling as lazy, but providing strategies to help with:
 - Sequencing thoughts/tasks
 - Awareness of time and space (incl moving around a school from class to class).
 - Ability to initiate and terminate tasks
 - Ability to transition from one task to another.
 - Ability to regulate emotions.
 - Working memory incl remembering to bring things to school eg homework.
- Providing workshops for teachers and administrators to truly understand the experience of children with SLDs – the more experiential the better. Anecdotally, those teachers that provide well for these children have usually had a direct previous experience with 2e children.

Q4: What has been provided?

- Very little.
- IEPs – very difficult to get and not consistently followed.
- Some teachers take time to scribe for children, or accept work finished and typed at home and emailed to them.
- Teacher Aides are not usually available for these children as they are not eligible for RTLB. One parent was told by RTLB “we work with children who throw desks, not kids who just struggle to learn”. We find this unacceptable when there was a \$360m budget for Special Education which was underspent by \$16 “due to lack of demand”.
- 2e children are often discriminated against by Ministry of Education and Ministry of Health services. The assumption is that the children will figure it out for themselves, “they’re gifted, they’ll be fine”. This is unacceptable when children struggle to read, write, hear, sit independently, or remain in the classroom sensory environment. One parent reported not being able to get help from Special Education for a child with dyspraxia who couldn’t sit at a desk to write, participate in PE or use the playground. A second referral was done with all evidence of giftedness removed – two separate IEPs were written, and this request was accepted. Applications for assistance for clinically identified special needs should not be declined because a child is also gifted.
- MoE occupational therapists and physios aren’t able to work with children; they can only consult and develop a programme for teachers to implement. This is unrealistic when a teacher doesn’t have a therapy background and is teaching 25-30 children.
- Children are assumed to get help through the Gifted Education funding pool – this is only \$1.2m and very little goes to providing support for children in their classroom. Gifted education does not provide support for SLDs.
- Applications for special assessment conditions are often declined.

Q5: What recommendations would you make to the Science and Education Select Committee re Supporting Children with SLDs?

- Ensuring that the people who are put into SENCO roles are suitably experienced and qualified, and are well supported by MoE to provide for all children with special needs. This requires ongoing professional development, access to experts (eg audiologists, occupational therapists, educational

psychologists, SPELD assessors) to support understanding and planning, and funding to implement recommendations.

- Strengths-based learning.
- Strong working relationships between teachers, parents, MoE and MoH services, to ensure all needs are met, increasing positive outcomes for children and facilitating inclusion.
- Ensure that Inclusive Education policies are extended to include 2e children; in writing, funding, and service provision.
- Reconsider the assessment process
 - Free screening by a highly educated and experienced teacher, educational psychologist or clinician at age five; either parent or teacher nominated.
 - Where there are indications that there may be an SLD, carry out more than one assessment and allow clinicians time to spend properly observing children in their classroom setting. 20 minutes is not enough.
 - Make educational psychologist assessments available as either fully funded or subsidised, as currently these are only available to people with disposable income and the ability to travel for assessments.
 - Support more people to train as educational psychologists in regions, making them more accessible.
- Needs-based funding rather than diagnosis-based.
- More support for teachers in the classroom, especially when there are children who cannot easily manage a classroom environment, are reluctant to attend school, or can't cope with parents leaving them at school.
- Use IQ testing by educational psychologists. These tests (WISC-IV, Woodcock-Johnson, Stanford-Binet, WIAT 2, and others) are reliable identifiers of a child's learning strengths and challenges, as well as identifying SLDs.
- Set up an independent advocacy service (like the Health and Disability Advocates with HDC) who can guide parents and assist them to hold schools and MoE to account where children are not having their needs met.
- Have a clearly documented process online for getting help for each of the SLDs, including links to local specialists. At the moment parents need to find other parents with children with similar challenges and find out how they accessed the support their children needed.
- Provide more professional development for teachers on the needs of children with SLDs (especially the fact that children can be both gifted and learning disabled at the same time, and the challenges that this presents) – include parents in this, or provide an experiential workshop. An example of a useful workshop is www.youtube.com/watch?v=uYg8sX2fv90
- Provide more training to student teachers on the needs of children with SLDs – include parents in this, or provide an experiential workshop. One and a half days is not enough!
- Provide resources for schools on identifying and providing for the needs of 2e children. Our group subscribes to the 2e newsletter (www.2enewsletter.com), which has lots of useful material, and there are many more articles and books available.
- Provide more IT support for schools to set up laptops and voice recognition software for children with writing difficulties. Recognise that often 2e children will avoid tasks that involve writing, and even "go on strike" in the classroom due to frustration with their needs not being met.
- Encourage schools to take the views of parents more seriously. Parents live with this everyday and have often done a large amount of research and reading into how to provide for these children. Also parents live with the emotional fall-out every evening with children who are struggling at school.
- Advertise that there is an education ombudsman who parents can go to when their child's needs are not being met.