

Seeking feedback on critical issues

This submission by the Fragile X Trust (NZ) is made on behalf of the many New Zealand families affected by fragile X syndrome. Fragile X is a complex genetic disorder that causes mild to severe intellectual disability, a wide spectrum of learning delays and difficulties, anxiety disorders and autistic behaviours. About one third of children diagnosed with fragile X are on the autistic spectrum. Fragile X affects around one in 4000 individuals and around one in 260 women and one in 800 men are carriers of the genetic mutation that causes fragile X.

The Fragile X Trust is a parent-led charitable trust that provides support, advice and advocacy for New Zealand fragile X Families. As there are no professionals specialising in fragile X syndrome in New Zealand, the Fragile X Trust also provides expert advice to families and to the professionals working with fragile X children and adults. We have a close working relationship with leading international authorities on fragile X in the United States and Australia.

For more information on our organisation, our activities and fragile X syndrome, please visit our website: www.fragilex.org.nz

About us:

1. Are you responding as parent or caregiver or family of a child with special education needs?
Yes – The Fragile X Trust is a parent-led charitable trust aimed at supporting families with fragile X syndrome.
2. Are you a student with special education needs?
No
3. Do you work in the health or disability sector?
Yes – See above
4. Are you responding on behalf of a community or other non-government organisation?
Yes – See above
5. Do you work in the education sector?
Yes – We provide workshops and training to parents, professionals and paraprofessionals who are supporting children with fragile X syndrome

This submission has been compiled by Chris Hollis, Chairman, Fragile X Trust. **The Fragile X Trust would also like to make an oral submission to the panel.**

Email: c.hollis@paradise.net.nz
Tel: 04 938 0552

Schooling

Q 1a What is needed to help schools succeed?

1) Provide ongoing teacher education

Teachers require extra knowledge about the individual learning needs of children they teach. Information will make a difference if it is relevant to the individual needs of the child, family and teacher. *Tips for autism* is an example of a programme that provides schools with relevant information about an individual child with ASD. We recommend that this programme continues to be supported by the Ministry of Education and that the programme is used as a model to provide information for teachers working with children with other disorders such as fragile X syndrome.

2) Information online

Provide ongoing teacher education through online education modules. Topics covered would cover basic theory, teaching strategies and give curriculum design and delivery examples. Similar modules are already being developed by the Autism Guidelines Implementation team and the tips for autism team. We recommend that these initiatives are extended to cover a wider number of topics.

3) Use of existing knowledge

Schools working with students with fragile X syndrome work in isolation. At present there is no method of sharing strategies between schools around the country. Establish online networks where teachers can support each other.

4) Provide pre-service training

Teachers need more training in special education, especially in methods of curriculum delivery to individuals with diverse learning needs such as visual learners, tactile learners and learning through play.

5) Models of Assessment

Provide schools with clear models and expectations of alternative assessment frameworks for children with special needs. For example the narrative assessment model developed at Canterbury University by Missy Norton and colleagues.

6) Nationally standardised training and qualifications for para-professionals

Provide training and qualification requirements that are standardised throughout schools nationally for all para-professionals (including teacher aides) working with children with disabilities.

Q 1b How could schools work together to succeed?

In Auckland where many special schools exist, parents of fragile X children are often actively discouraged from enrolling their child at their local school by their local school principal. Schools are more willing to take on fragile X children in regions where there is no option of placing the student elsewhere.

ORRS Students verified with Very High Needs have needs that are unique and are sometimes hard to provide for in a mainstream setting. Some of these students need access to an environment that can only be provided in a special school setting.

A few special schools offer services that are unique and cannot be provided elsewhere. Examples include Kimi Ora in Wellington, Hohepa in Hawkes Bay and Sarah Cohen School in Dunedin. These schools should not be closed.

Position special schools as resources for regular schools particularly in teacher education and support and resource gathering for ORRS teachers. Additionally create networks for ORRS teachers to work together at a national level to share knowledge, resources etc.

We support **Option C - Special schools as resource centres** with the addition of retaining special schools that provide a unique service. Special attention must be given to ensure that children with very high needs are appropriately catered for.

Transitions and agencies working together

Q 2 What needs to be done to make transitions work better

1. Provide for flexibility and best practice models for transition from Pre-school and School.
2. Use and extend existing successful programmes such as the Christchurch Lead School Transition Service Pilot to support transition to work and further education to all areas of the country.
3. Provide a clearly defined pathway to transition students to work, further education and living away from home that can be understood by students, parents and professionals.
4. Successful transitions require access to communication and behaviour specialists to provide support to solve difficulties experienced in the post school setting
5. Teach students life skills and independence from an early age
6. Transition plans should focus on student strengths and interests.

Q 3 How could services be better coordinated and focused on the needs of students and families?

We have found that families within the fragile X community experience different levels of service, largely depending on where they live. All children with disabilities should receive the services they need to best reach their potential wherever in New Zealand they live. National coordination is essential to ensure that service provision is consistent across the country and that families, care-givers, and professionals are well informed.

Lead agencies and/or lead workers need to coordinate between with all providers involved with the student to develop a plan for delivery of service that is consistent with national guidelines and meets the needs of the student.

Funding and resource use

Q 4 What arrangements for funding, decision-making, verification, and fundholding should we have?

1. Replace the ORRS system with a system where verification is decided by educational professionals at Ministry of Education regional office level, in close consultation and engagement with teachers, parents and care-givers.

ORRS currently provides individualised funding, which best meet the needs of the student and provides for a greater opportunity in education for the individual.

However, the ORRS verification system is not effective in understanding the child's needs in a school environment. The process asks those who know the child if they can fit the child into a tightly defined box. Some children fit easily. Children with fragile X syndrome do not fit well into verification criteria despite often having high learning needs. Children with high needs who are not verified are not adequately catered for by the current system. These children and their families fall through cracks of inadequate service provision.

The decision to verify high and transitional needs should be made by the educational professionals who know the child best having worked with the child for an extended period of time (the lead practitioner currently completing the ORRS applications). The relevant educational professionals would meet together to decide who to verify. The number of places available for verification of high and transitional needs children would be decided by population and socioeconomic weighted bulk funding – similar to ESW and teacher aide moderation. The decision to grant verification of Very High Needs could also be made regionally but would need to be funded nationally. This would streamline the process and the decision would be made by the educational professionals who know the child best. Ministry of Education offices would be able to identify the children in their area in most need and provide adequate support for those children.

2. Retain the current ORRS system but change criteria 8 and 9

Children with fragile X syndrome have high *“needs arising from a severe disorder of both language use and appropriate social communication”* (Criterion 8) and *“needs in moderate-to-high learning needs in combination with two other needs at the moderate-to-high level. The three needs inter-relate to significantly reduce a student's ability to access the curriculum.”* (Criterion 9) however fragile X children may not be verified because their impairment profile does not match the verifiers' expectations for these criteria.

Criterion 8 states that: *“these students usually distance themselves from social situations and seem to be largely unaware of people around them although they may respond positively to their parents and other very familiar people”*.

Fragile X children are usually very aware of others and are often socially motivated however suffer extreme social anxiety and have very poor social and communication skills. A child with communication skills (both expressive and receptive) which are at or below the level of a two year old would not meet this criterion if they show awareness of others. Very few children (even with a diagnosis of ASD) fit this very specific description if they have received appropriate Early Intervention. This is especially true since Barry Prizants SCERTS programme – now being used across New Zealand, which specifically attempts to address children's awareness of others

Criterion 8 also requires students to be *“difficult to engage in almost all learning and social activities”*. This is a description of a child with a severe intellectual disability and should not be required for a child that meets criteria 8. Children with a severe disorder of both language use and appropriate social communication may engage meaningfully with a wide range of material that is of interest to them through free solitary play in an early childhood centre. Children with fragile X syndrome may develop splinter skills in areas such as number, shape, colour and letter recognition despite very limited receptive or expressive language. These children require specialist teacher time to access curriculum in a school environment. If a child has received appropriate Early Intervention, he or she will only fit this very specific description if suffering from a severe intellectual impairment.

Children with fragile X do not meet criterion 9 as the majority of fragile X children who do not have a hearing or vision difficulty therefore must meet criteria 9.4. which is for students *“with moderate to high difficulties with gross and fine motor skills”*. Fragile X children have great difficulty with fine motor skills requiring extensive Occupational Therapist intervention. The cause is difficulty with motor planning which is not recognised in the criterion so fragile X children do not meet the criterion because of the cause of their difficulties rather than what therapy they need or their ability.

Q 5a How can individually targeted services and supports be made more efficient?

Teacher aide moderation is very time consuming and unnecessary for children with ongoing needs. It is appropriate that teacher aide moderation is reviewed periodically based on student need

We agree that five-year-olds who have been supported by special education early intervention programmes and with needs that are well-known to the Ministry of Education should not need to fill in lengthy ORRS applications. This process should be streamlined. The people who are most able to make an informed decision are the Early Intervention Teams that have worked with the child and consulted with parents, care-givers and teachers. These professionals' opinions should be respected. Funding issues exist however these teams already manage capped budgets for ESW moderation.

Q 5b Is the current mix of programmes, services and supports right and does it provide value for money? What changes would you suggest?

No comment.

High quality services and being accountable

Q 6 How can the quality of services be improved?

No comment.

Q 7 How can families and schools be better informed?

Families want their child to reach their full potential and to be happy, included and treated with respect. National standards have little relevance for children with special learning needs who are not expected to achieve at the same level as their peer group. Comparing fragile X children to their class mates is a meaningless and depressing for both child and parent. Parents of special needs children often receive inadequate information about their children's successes as methods of reporting focus on learning outcomes relevant to regular school children. The NZ curriculum states that "Effective assessment is planned and communicated – Outcomes, teaching strategies, and assessment criteria are carefully matched". It is important that schools document and communicate to both children and parents, the learning outcomes achieved by children with special learning needs. Learning stories would be very effective for this.

Q 8 What does successful special education look like and how should we measure it?

Successful special education should meet national standards outlined in the New Zealand Curriculum: Vision, Values, Key Competencies, Learning areas and

Principals. Curriculum below level 0 must be developed to meet the developmental levels of some students.

Q 9 When things do not go well, what arrangements should be in place to resolve issues?

1. Schools should be able to access a **rapid** and a **coordinated** response from educational specialists when things do not go well
2. A formal documented process based on the information provided in the consultation document (page 40) regarding the expanded process should be available to parents, care-givers and teachers.

In closing

Q 10 What is the most important change that would improve outcomes for children and young people with special education needs?

1. Ongoing teacher and paraprofessional education that provides the relevant information about an individual child.
2. Provide pre-service teacher education about curriculum delivery to meet the diverse learning styles of students with special needs.
3. Use special schools as resource centres and retain those special schools that provide a unique service.
4. Use and extend existing successful programmes such as “tips for autism” and the “Christchurch Lead School Transition Service Pilot”. Use them as models for other disabilities, such as fragile X syndrome.
5. Transition plans to work and further education should focus on student strengths and interests.
6. Replace the ORRS system with a system where verification is decided by educational professionals that know the child at Ministry of Education regional office level, or change criteria 8 and 9 so that they include the high needs students they currently unfairly exclude.
7. Streamline service provision whenever possible, such as where the needs of the student are well known and ongoing.
8. Communicate learning outcomes to parents and students in a form that is easily understood by both.
9. Give schools access to a rapid and a coordinated response from educational specialists when things do not go well.