



# FASD-CAN

## Aotearoa New Zealand

FASD-CAN submission to Highest Needs Review consultation  
March 2022

### **Introduction**

FASD-CAN is a non-profit, incorporated society providing support to individuals and families who are living with FASD. Our membership is made up of parents, caregivers, and health professionals, including many who are education professionals – RTLBs, SENCOs or teachers in mainstream schools and special schools.

Fetal Alcohol Spectrum Disorder (FASD) is a lifelong neurodisability caused by exposure to alcohol while in the womb. Rangatahi and tamariki affected by FASD experience physical, behavioural and learning difficulties that affect their interactions within education, health and justice settings. There have been no prevalence studies performed in Aotearoa, but studies in Canada, the US and UK indicate the prevalence is likely to be between 2-5%. As such children with FASD are the largest group of neurodiverse children in the community - significantly higher than autism, Down's syndrome and Tourette's. Yet these children remain largely unsupported through the school system. Many families face huge emotional, personal and financial difficulties as a result. Early intervention is key to preventing the secondary disabilities associated with FASD – involvement in youth justice, substance abuse, poor mental health and anti-social activities. Currently FASD is not recognized as a disability in Aotearoa unless there is an accompanying intellectual disability (20-30% of those with FASD). Thus many of our children are unable to access the support needed to enable them to access and benefit from educational practices which accommodate their needs.

We see a need to amend policies, inform educators, change the mindset of Ministers, raise understanding and commitment within schools, and get rid of non-productive assumptions, low expectations, and inappropriate pedagogic and other strategies resulting in significantly poor educational and life outcomes. Instead there should be a recognition of these children as unique children with strengths, passions, aspirations, learning dispositions, contributions and rights, deserving of achieving their full educational potential (with respect, autonomy, friendship, self-determination and a growth mindset).

We welcome the review of the management and education of those children with Highest Needs as an opportunity for the government to redress the inequities and abuse of human rights of individuals with FASD. As a prelude to our response to the specific questions raised in the consultation we ask for the following issues regarding Human Rights and adherence to the National Educational and Learning Priorities, a statutory instrument, to be addressed.

1. Consider the education of these children in the context of the Rights of Persons with Disabilities. In 2016 the UN Committee on the Rights of Persons with Disabilities (RPD) adopted General Comment No. 4 (GC-4) to Article 24 (The Right to Inclusive Education)UNCRPD. The purpose of GC-4 is to provide : the scope of obligations, outline the meaning of inclusive education, and a blueprint for implementing it. This provides the most authoritative articulation of the human right of people with disability to an inclusive education. GC-4 is instructive of the requirements that the Committee will apply in reviewing compliance by individual countries with Article 24. GC-4 stemmed from state parties' reports to the UN (RPD) Committee- raising their "concern that the exclusion in education on the basis of disability experienced by children and adults with disabilities not only constitutes discrimination, but also hinders their meaningful participation on an equal basis with others in all spheres of life".

We are extremely concerned that our children with FASD experience exclusion in education on the basis of their disabilities and the hindering of their meaningful participation on an equal basis with others in all spheres of life. These concerns for individuals with FASD were set out in the Report of the Disability Rights Commissioner and Children's Commissioner to the Prime Minister. Fetal Alcohol Spectrum Disorder: A Call to Action, submitted in 2020. This HNR review gives an opportunity for policy makers and the Minister to address these Human Rights violations.

2. Implement the National Educational and Learning Priorities in respect of individuals with FASD. We are extremely concerned our children with FASD are not experiencing the Implementation of the National Educational and Learning Priorities (NELP) by schools/ teachers. This applies to almost all Objectives and Actions for Schools set out in the NELP: i.e. 'focus (on) their day-to-day work on things that will have a significant positive impact for children and young people. The (NELP) Priorities can be used to help every learner progress and achieve their aspirations '(NELP, Statutory Instrument, Education and Training Act 2020).

In formulating our response we have not attempted to detail the specific practices which would make a difference to the education of children with FASD. There is extensive literature and many guidelines on this, including the MOE's own TKI resource on FASD. As a general guidance on educating those with neurodiversity we draw your attention to the following report: Martin-Veitch B, Talota N and Schmidt L (2020). Responding to neurodiversity in the education context: An integrative review of the literature. Dunedin: Donald Beasley Institute.

In February 2022 we surveyed families with children with FASD on their experiences in the education system. Twenty-two families provided detailed responses. The children were in a range of education settings: mainstream schooling, special classes, Te Kura, special schools and care and protection residences. They were asked a series of questions relating to their experiences – description of the school settings, school awareness and accommodation, how the schools awareness of FASD or lack of it had affected the child's education, reasons for their choice of schooling, access to funding, success and difficulties and their view on what needs to be done to improve the educational outcomes of those with FASD.

The accounts described years of parents and caregivers battling for their children, having to move children between schools, being turned down for funding, the children being misunderstood, punished and excluded from the education system.

The results of this survey have been used to inform this input into the Highest Complex Needs Review.

### **Scope Area 1: The Journey Through Education System**

The Review will include how children and young people access supports, regardless of where they are learning, by including the journey children and young people take through the education system, from early learning through to leaving secondary school. This includes transitions throughout a child's learning journey and transition across different education settings.

Our response includes families at all stages of schooling from primary age to those who have left formal education. Most children had been educated in mainstream schooling initially, but as they progressed many had to move to special classes, special schools, alternative education settings or correspondence schooling.

Within the FASD community there is no one journey through the education system and no 'one size fits all'. It is largely dependent on age of diagnosis/if there IS a diagnosis, access to funding, how the FASD presents (also hugely individual) at different ages/stages. When the demands get higher as children move through the school system, non-coping behaviours can escalate as the child struggles to keep up with expectations and demands.

Primary - Children with FASD seem to be more 'successful' within the ECE setting and mostly through primary school...this seems to be due to the holistic approach that serves as a wrap around support to children. Play based learning is conducive to a child's well-being. Many of those with FASD do not have an intellectual disability and are able to cope well at this early stage. However two families had faced their first school exclusion when their child was 6.

End of primary schooling denotes where the gaps between neurotypical children and those with FASD become more marked, especially around aspects such as dysmaturity - one of the characteristics of this neurodisability.

Intermediate - The responses here reflect the differences between different schools and teachers. For some intermediate was a positive experience, for others it was the beginning of troubles for their child in school.

High school - high school generally is a less structured environment, relying more on the organisation skills of the maturing child. Those with FASD frequently have deficiencies in these areas - difficulty in complying with start times, finding their way around. They may also be at a more vulnerable stage in terms of getting involved in antisocial activities, where they may need a greater level of oversight to protect them from being involved in those who are poor social influences, bullying and inappropriate sexual interactions. School refusal at this stage was frequent amongst the families who participated in the survey, with many children dropping out completely by early teenage years.

One family reported an extremely positive experience at Kingslea Special school after many years of their child being disengaged from education. They described 'a simply amazing teacher and staff at this school'. Another family with a child at this school reported it does individualised plans though often the plans can't be implemented because "the provision in residence is massively limited and at too low a level. Mostly in residences the work offered is very limited to basic literacy and maths or badminton - so not a broad curriculum. Kids in residences are often denied education for long periods of time".

Several reported school exclusions and expulsions. One 14 year old had been expelled 5 times in two years, even though the school had been supplied with her diagnostic report (which the school had not read).

Many children have spent considerable amounts of time outside the school system - often because the system is not responsive to their needs; they have found it too stressful or there is inconsistent or no TA support. Some families have found their child thrived better within a home/correspondence environment.

Two families had managed to access residential special schools: others had tried to do so and failed. It is recommended that these schools be easier to access for those with FASD, including those with behavioural issues. In one case the decision to place their child in a residential special school was given as "Our daughter cannot attend a state high school as she is still at emergent reading & writing level, and is very easily influenced and gullible. She would not respond well to demands and expectations pitched at her year group. It would be like sending a 7 yr old to high school....RSS is the only safe option for our child... She could not cope with attending a learning support class within a high school as they still have to integrate with other high school kids and the year level curriculum - and all the expectations etc that this comes with."

One family found the good fit for their children with FASD was a deaf pre-school, even though the children did not all have hearing loss, as the school was accustomed to work with children with additional needs.

There was some experience with alternative education. Whilst this setting may provide a quieter and more 1:1 experience it was also reported that it may apply a reward and consequences approach - which is not successful for those with FASD.

A common comment was concern about the safety of the child within the school setting, particularly as some of these children were described as 'wanderers'. For example " When our son is stressed he runs away from school which is dangerous and very scary. The

school has installed a high quality gate system and our child hasn't run away since this has been installed even though he is capable of opening it. It seems to give him a layer of "thinking time" before leaving".

What is happening in your community that is working well?

Half of the families reported the school had recognized FASD. In several cases this was due to the intervention of the parents – to inform and train school staff on this disability.

Many respondents praised individual teaching staff and those who 'got it'. However the lack of understanding by some staff was correspondingly likely to lead to adverse outcomes. "Issues with ADHD becoming apparent towards the end of this time and then confrontation with one teacher in particular at intermediate. By high school he was only intermittently engaged with learning and his behaviour was becoming more challenging'.

Difficulties ensued when a child was viewed through a behavioural lens and only taking account of their chronological age.

One family reported a positive experience of a special class: "There were no other options and we felt lucky to get in there - as there are limited to no options. She could no longer survive in mainstream classes. We tried a mainstream high school where you have to go from class to class and she would not be able to navigate herself around the school with no support. Or she would be late and be told - you are late - no accommodations or understanding . The Auckland schools are just too big to support the level of inclusive support that would be needed and should be expected."

One respondent highlighted the difference between a decile 8 school and a decile 1 - and the understanding of school staff at the 2 schools: At the decile 8 school the child, who is part Maori, was a minority at the school. The school assumed they were another family with a difficult child. After 3 years they changed to a Decile 1 school where she is mixed with children of similar or other challenges and is thriving. The teachers and the school overall have catered to her needs, understand, are non-judgemental and work at her strengths. They have set a routine for her and the class setting supports her.

The positive aspects were noted as:

- Having teachers/teacher aides who are FASD informed
- Having staff who are prepared to be flexible and change things to accommodate the needs of the child
- Having a fluid environment where the child is allowed to work at their own pace and is accepted for who they are.
- The school working closely with the family to understand the child and the accommodation needed to help them settle in school and learn.
- Small class setting with low stimuli classrooms (many children with FASD also have sensory issues) and quiet spaces
- Lots of physical activities
- In some cases, the availability of special classes or special schools which give a more personal approach, appropriate for the needs of the children.

### What do you want to see happening in this area?

Children with FASD are not able to access funding for the most part unless they are under PCSS (Oranga Tamariki) or have an Intellectual Disability. We would like to see expansion of the support available which would enable those with FASD to get the interventions they need to remain supported within the education system..

Teachers and staff need to be trained to understand FASD and how to accomodate the needs of our children - this needs to be part of the teacher training programme and part of ongoing professional development.

We draw your attention to the recent study on the awareness and understanding of FASD amongst education professionals which highlighted the need for training in FASD to increase competency in working with children with FASD. Of the participants in the study only 45% reported that they received training the last 5 years related to FASD or to other neurodevelopmental disabilities (noting many of the participants were a self-selected FASD-informed group).

Respondents to our survey reported that education professionals often ignored the diagnostic reports (which describe the specific brain injury and also the areas of strength). These need to be read and understood by frontline professionals.

We recommend that the MOE has a structured workforce planning approach which recognises the extent of the need for training in this area, and responds to the very high proportion of children who are estimated to have FASD in Aotearoa NZ (2-5% based on research in geographies which have similar drinking cultures to our own).

### How might barriers for learners with the highest support needs be removed?

If FASD were to be recognised as a disability then those able to get a diagnosis would be able to get funding for learning support. However we recognise that this is beyond the scope of the current review.

However barriers could be removed by changing learning support funding criteria to include those with behavioural issues or an FASD diagnosis (or probable). Unless the needs of those with FASD are recognised early in the education pathway and appropriate intervention and accommodations are put in place, then support is only available when behavioural problems have become significant. Early support would avoid the need to access funding at crisis point e.g. HCN and IWS. It would also mitigate the risk that some children with FASD drop out of the education system around early teen years, and get involved in the activities associated with the secondary effects of FASD - substance abuse, involvement in youth justice, anti-social activities.

Sometimes children with FASD need additional help with communication and these types of support should be more easily accessible e.g. A child who had difficulties writing, thrived when it was recognised he was good at typing and speaking and so was provided with the appropriate technology to help him communicate.

We need an alternative path that works for our children who can't cope in the mainstream. This could be in the form of Special schools, satellite classes, or a completely alternative education system. Inclusiveness does not mean acceptance into mainstream if it doesn't meet the needs of that individual - options should be available.

### **Scope Area 2: Access to Supports**

The Review will consider how supports and services are accessed. This includes reviewing the current rigid and deficit focused criteria and application processes for identifying when children and young people experience significant barriers to accessing the curriculum on an equal basis with others, the level of support required, and the length of time support is provided

Nearly all families in our survey had applied for funding through the MOE. None were successful except for one family where the child also had an autism diagnosis. Children with FASD may not meet the learning level criteria for ORS funding. However one caregiver noted that the child she was caring for had enough trauma in his background to make a case for ORS, but the SENCO was not responsive to applying for it.

Two children received High and Complex Needs funding. However this was only given when the circumstances were extreme. The first case was a child who went 'from no support in intermediate to managed out in the first term of high school as her needs were too complex to manage with a robust support package'. As a 15 year old she was placed in a care and protection unit after years of lack of accommodation, recognition and understanding of her complex needs, leading to school exclusion, truancy and then social vulnerability . In the second case, in the words of the caregiver, "the people waited until he was criminalised before he could access such individualised provision"....."honestly to get this he had to nearly die several times over - he had to fail first big time and had to place himself at risk of being harmed and getting into trouble first - otherwise there was no way he would have got this funding. He was denied all other options before this. He got funding at 14 years for c. 2-3 years".

MOE funding was not available for most of the families – nearly all had tried and failed to secure ORS funding or been turned down by their SENCO as not worth the effort. One child, who had attended several schools, had been turned down for ORS and HCN support - because she could read and did not have a physical impairment so was not considered high risk enough.

Those who had children placed through them via OT had access to PCSS, which was used to fund teachers aides. However they noted that this had to be re-applied for every 2 terms and was only available when the children were diagnosed. The wait for diagnosis can be long (some were still waiting), meaning that support was not readily available at a time when intervention is most effective.

International research has shown that early intervention mitigates the secondary effects of FASD – addiction, involvement in crime, mental health issues etc. The need for parents to keep reapplying indicates the lack of awareness that this is a life-long brain disability and removal of supports when they are effective is a failure to recognize that these children will need support throughout the education system. Furthermore it places huge stress on the

parents and caregivers of these children, who are already stressed from supporting a child with this neurodisability.

Some families had to resort to private funding, private schools to get the appropriate educational support and setting their child needed.

What is happening in your community that is working well?

Nothing really appeared to be going overly well in this area!!

Out of twenty three responses fifteen had access to funding and eight did not. The funding came predominantly through PCSS. Other funding was from RTLB services, respite hours from PCSS, and high and complex needs as noted above.

Many of the families in our membership are foster families and Home for Life carers, and therefore have access to support services which do not represent the broader FASD community. In many cases of children with FASD, support will not be available unless they have an ID.

What do you want to see happening in this area?

There needs to be much greater access to funding on an individual basis for children with FASD, taking into account the child's present and continuing needs which will only increase with time in terms of FASD.

Some children who have been lucky enough to access supports have flourished. However the consequence is the removal of the support. The idea that a child is now deemed successful and removing TA support (which is WHY they were 'successful'), is short sighted and sets our children up for failure.

Currently our children are falling through the gaps as they are not deemed bad enough e.g. not throwing chairs etc, or are achieving academically. However, we need to have access to services to support children with FASD as we know they STILL have needs but at the moment they are only being supported when they get to the bottom of the cliff.

There needs to be more specialist advisors e.g. psychologists trained in FASD.

How might barriers for learners with the highest support needs be removed?

Enable access to support EARLY on...not when a child has been excluded from an educational facility.

Look at the child as an individual and identify their needs: for FASD these needs are never going to go away - they might change over time but the funding and support needs to continue throughout their lives. To truly remove the barriers, the support needs to stop being based on a deficit model as this perpetuates the ambulance at the bottom of the cliff...currently we are waiting for our children to fail before we step in and help. As one respondent said,

*"People waited until he was criminalised before he could access such individualised provision."*

The other barriers that were repeated often were the lack of FASD informed teaching that resulted in school refusal, anxiety and the inability of teachers to adapt the curriculum to suit the child.. children with FASD are expected to fit to the curriculum.

The brain of a child with FASD is often overworked - a typical day at school for a child with FASD may feel like being in the middle of a tornado of thoughts. At the end of the day they are exhausted. Placing unreasonable expectations such as completing homework will not work for these children. Also consideration needs to be given to school hours - "why are kids forced to do 9-3pm when their brains can only do 9-12. Kids need more schools that offer morning education followed by afternoon interesting tailored activities."

We also would like to see the removal of impossible criteria in Special schools such as Salisbury. For some of our children, especially vulnerable early teenage girls, such a school would provide a safe space for them to learn, away from risks which can arise from their emotional dysmaturity, and which enhances their mana because they are learning alongside others at similar developmental stages.

### **Scope Area 3: Responsiveness of Supports**

The Review will consider the responsiveness of support to needs to ensure the system is delivering the right support to address the barriers being experienced. The current system is focused on service delivery by measuring service inputs. Instead, we need to measure the outcomes and how the delivery of supports can help children and young people define and achieve successes

What is happening in your community that is working well?

See response above - some children get some supports.

What do you want to see happening in this area?

*"The going in and out of the mainstream has been difficult and the difficulty in being able to engage my child has been very difficult. Keeping him in school full time has been very stressful and difficult with large periods of time only attending half days. Standowns due to inconsistent TA support "*

As the quote above (from the survey) highlights there appears to be an inconsistency in the support if it is actually provided, which results in elevated school dropout rates amongst the families who took part.

At the moment the service delivery model is failing our children. This is because it works on the assumption that behaviours etc can be 'fixed' by a piece of work delivered by an RTL or similar for ten weeks. This does not work in children who have a lifelong brain based disability as their behaviours are simply symptoms of an unmanaged disability. They are not something that can be fixed and measured. Often tamariki/rangatahi will repeat the same

'behaviours' again and again despite appearing to have initially made progress. This is because of the damage to the part of the brain that is responsible for decision making/consequences/thinking things through/impulsivity.

The consequences of failure of early intervention have been documented by research internationally. These include involvement in the criminal justice system, substance abuse and addiction, family breakdown, poor mental health, greatly increased suicide rate, homelessness. The economic value of intervening in education at an early stage has not been researched in New Zealand (there is no prevalence data collected in NZ) but some very basic economic analysis demonstrates the high cost of unsupported FASD within our communities. Therefore, in relation to this section, it is important to consider the cost of increasing support in the broader context of very significant gains to society by preventing the secondary disabilities. Greater access to support is an essential step to improving the life outcomes of these children.

#### How might barriers for learners with the highest support needs be removed?

Expanding the support criteria to include those with a diagnosis of FASD or suspected FASD and those with similar behavioural manifestations.

#### **Scope Area 4: Fluid Boundaries**

The Review will consider the need for fluid boundaries between education settings to help encourage and strengthen positive working relationships where learners and schools can better access expertise held in specialist settings. This includes the need to better share knowledge and expertise.

#### What is happening in your community that is working well?

1. What currently doesn't work IS the transition from primary to intermediate/high school. This is because of the change of environment to one of constant change e.g. between classes etc and expectations of independence - for children with FASD this is not a realistic goal. Our children are working towards interdependence and cannot cope with the constant changing of classes/ following timetables and getting to places on time. This needs to be recognised - there needs to be a multi modal support system wrapped around our children.
2. There needs to be a transparent sharing of information with whanau placed at the centre and their own knowledge and expertise acknowledged.
3. In order to address the barriers, there needs to be a recognition of FASD as a disability and then measures taken to address this. The expertise in the area of FASD often lies with the family and people who look after them, but the reception to families was varied as shown in the quotes below.

*"They let themselves down by assuming we were another family with a difficult child."*

*"Schools (we attended 3 are now at our 4th) had no idea and wouldn't listen to me as his carer, because physically he looks "normal" they rejected me as an obsessive "mum" "know*

*"it all" I received reports of his behaviour and would try and share how to manage and engage with him to learn and was told "oh so you're a teacher too now"*

4. We do not expect all teachers and learning support staff to be experts on FASD. But we believe it is essential for all frontline workers to have some awareness and knowledge of FASD and access to those who are able to advise. We would also like to see greater promotion of the TKI guide and of the Te Pou FASD learning module for strategies for frontline professionals (only 10% of the respondents to the University of Auckland survey of education professionals had completed that course).
5. Children with FASD that are in supportive schools that have an IEP in place that identifies their unique strengths and areas that they need support in and,

***"The student is recognised as an active, capable learner. IEPs are a way of adapting the school programme to fit the student rather than expecting the student to fit the school programme." (Collaboration for Success, MoE 2011).***

#### What do you want to see happening in this area?

We believe it is important to recognise that not all neurodisabilities are the same. Those supporting people with FASD understand there are specific accommodations needed for those with FASD. However there are some strategies suitable for different neurodisabilities e.g. use of visuals for ASD are suitable for students with FASD.

We would like to see a greater understanding of FASD among the community at large. Many parents and caregivers reported their children were bullied. Worryingly, many also reported the lack of understanding and tolerance of other parents and their influence on the outcome of their children within the school setting. Increased societal understanding of this disability is needed to address these types of issues – would someone bully a child in a wheelchair because they slowed their exit to the school gate?

Punitive measures for those with FASD must be stopped. The use of punitive measures and consequences based approaches are hugely damaging for these children. Punitive measures such as standdowns should not be used when there is a clear correlation with the neurodisability.

There needs to be equity of treatment within education for those with FASD. One parent noted:

*"There were courses for pupils with autism. There were training days in advance for the non-verbal pupil with Down Syndrome etc. In each of 2 schools, I saw hundreds of thousands of dollars spent to make the school accessible for children with physical disabilities. But for FASD . . . nothing."*

Some specific recommendations are:

- Training in FASD
- A recognition of the difficulty in transitioning from primary to more unstructured education settings and putting in place individual plans to address this. This includes

recognising that the independence which is encouraged and expected of neurotypical children is not appropriate for those with FASD, and may actually put them in danger.

- An alternative pathway that avoids unnecessary transitions between schools.

#### How might barriers for learners with the highest support needs be removed?

- Awareness, understanding, training, accommodation

#### **Scope Area 5: Support for Adults Across the Network**

People at all levels of the network need ongoing support to build knowledge, understanding, and capability to identify and respond at the earliest opportunity when a higher level of support is needed. This means children and young people, family/whānau/aiga, educators, school leaders, school boards, resource teachers, specialists and Ministry of Education staff working together to i) share expertise, ii) make plans that include strengths, aspirations, and learning goals and iii) navigate pathways for additional help together if needed. The provision of professional learning development about specific needs is included in scope of the Review

#### What is happening in your community that is working well?

1. In schools where staff are FASD informed our children are doing well but this seems to be hit and miss and very dependent upon the teacher. There needs to be a bigger emphasis on FASD training at a higher level e.g. teacher training colleges/universities. Teachers and staff within education need ongoing support and training so that they can provide programmes that suit individual needs.
2. There needs to be recognition that FASD is not like other neurodiversities and that one of the biggest parts of FASD is the inconsistency and that the underlying brain damage is so often ‘masked’ or hidden due to the ability of a child to be articulate and social.
3. Plans need to be made with whanau at the centre and their voice heard as they are often the ones who are the expert of their child and have ‘lived experience’ of it. However, this was not the case in most of the survey responses. See above.
4. The needs for teenagers and young adults with FASD will be diverse, depending on their own strengths and abilities. For many, altering their education pathway to a vocational one at a stage earlier than for neurotypical students may be an advantage as they may struggle and lose confidence and self-esteem within a mainstream setting. Individuals with FASD can find gainful employment, although this will often only be able to be maintained with the support of an informed and understanding employer. Currently there is no formal pathway to ensure success for these individuals and it is up to the motivation of the child, and the advocacy and support of the caregivers and parents, to ensure that he/she has the best chance.

#### What do you want to see happening in this area?

1. For individuals with FASD overseas research has shown that they are most successful within the education system when there is a multidisciplinary team

approach that is coordinated across agencies. Having a dedicated person available consistently and for all schools, who was responsible for coordinating this and ensuring there was a wrap-around service, would be helpful in achieving this.

2. Having information transferred and given to people involved with the young person so that the whanau does not have to keep retraining teachers/teacher aides.

#### How might barriers for learners with the highest support needs be removed?

1. Provide training at teacher training colleges/universities - there currently is no requirement of those training as teachers to undertake papers in this area. Teachers need to have a thorough understanding of FASD as a brain based disability. It is important that those with lived experience input into the development of this training curriculum. This should be done, paying heed to the demands of those who are experts in the FASD area, so that the curriculum development can be co-designed and consistent. As one respondent highlighted

*"through her whole education from age 5 her disability has been misunderstood. It seems hard for education to understand to believe she can do something one day and not be able to do it tomorrow. Simple understanding of brain difference, that what school consider meltdowns are overwhelm or sensory issues."*

*"Too late for my child, but an understanding of the brain disability caused by FASD is essential for appropriate accommodation of those affected."*

2. There needs to be ongoing access to support for staff school wide throughout the young person's time at school. The recent survey completed by the University of Auckland showed that, the most common resources wanted by those in education were training workshops about FASD (63.5%), FASD-informed interventions and strategies (63.5%), online resources (57.8%), and referral resources/specialist register(50.4%).

#### **Scope Area 6: Alignment Across Agencies**

The Review is an opportunity for increased collaboration, connectedness and cohesion across services and supports funded by different agencies, including the Disability System Transformation.

#### What is happening in your community that is working well?

It appears that when there is a 'team' e.g. SENCO, LSC, teachers, teacher aides around the child then they can remain engaged in their schooling and achieve 'success'.

#### What do you want to see happening in this area?

Most individuals with FASD do not get funded because of the limitations of the disability criteria. We would like recognition that a child with FASD within the education system is treated as are other rangatahi, including consideration of the health, education and social welfare needs of that child.

### How might barriers for learners with the highest support needs be removed?

As noted several times above, the lack of access to disability support means there may not be an involvement of several agencies in a child's life, particularly at early stages of the education system. Where there is eligibility for disability support, there appears to be little to no collaboration between all the agencies that can be involved. A more holistic approach is required for support. This needs to be addressed by identifying a coordinator role - maybe an expansion of the LSC?

### Additional considerations not covered by the review questions

We recommend that consideration is given to the following to enable young people with FASD to flourish in the school system:

- Upskilling of staff – a general need to educate the education sector
- Making funding pathways easier to access – recognizing that anyone with FASD has high and complex needs
- Understanding that early intervention is needed, not waiting until behavioural issues become manifest.
- Considering the physical environment e.g. classroom configuration – “What were the MoE thinking creating multi year and multi roomed class rooms with loads of students. Another fail for our young people”
- Understanding of accommodations required – giving time to change a task, giving a quiet place to de-escalate, breaks, sensory awareness
- Safety plans
- Training in life skills and social skills for these children – many will struggle with adaptive functioning.