



## 2020: The Reality of FASD in Aotearoa

This report has been compiled by FASD-CAN Incorporated, a non-profit registered charity established with the objective “to unite caregivers, strengthen families, support individuals and educate about FASD across our communities”.

More and more it is evident that in strengthening families we must engage with policy makers to ensure the best possible services are offered and delivered to our families. With the expiry of the 2016-2019 FASD Action Plan we felt there is a need to canvass our membership to see if anything has improved and what things need serious attention.

We asked our families to contribute their stories to inform a document that will detail parent/caregiver concerns across the life-span of individuals with FASD. The purpose of this document is to share what families, whānau and individuals with FASD are **really experiencing**.

Throughout this document are the real-life experiences of a number of families and individuals living with Fetal Alcohol Spectrum Disorder (FASD) in Aotearoa. There are common threads that link all of these stories together. Sadly, most of these links are the experiences of frustration, exhaustion, isolation and hopelessness as most have unmet needs across all sectors. There are also some glimmers of hope in the pages that follow where appropriate supports have led to better outcomes for individuals and, by connection, the well-being of their entire whānau.

There are four major over-arching concerns in this report.

1. A lack of diagnostic capacity
2. Road blocks to access disability support services due to DSS eligibility criteria
3. A lack of trained front line professionals across all sectors
4. Inconsistency of service and support across all sectors

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## Statistics:

21 individual cases participated in the questionnaire.

81% had a diagnosis of FASD

43% had an intellectual disability

### Age demographic:

> 10	10%
10-14	24%
15-18	29%
19+	38%

## The Questions:

Describe your experiences with:

1. Diagnosis
2. Education sector
3. General health practitioners
4. Oranga Tamariki, care partner NGOs, PCSS
5. Justice Sector
6. WINZ, NASC and sourcing supported/independent living options
7. Mental Health and Addiction services

How would recognising FASD as a disability help?

Describe what you have set up for the individual with FASD to ensure safety and support into the future, when you are no longer here to help them. What steps must be taken to ensure that their money, housing and health is managed right across their life span?

Do you think that the FASD Action Plan has delivered any help or benefit to you and your family?

What would be the first thing you would like addressed in the next steps of the plan?

## Experiences with Diagnosis

Pathways to diagnosis varied. Many of the participants paid privately to have assessment completed. A limited number accessed diagnosis through teams based in DHB with some having assessments paid through Oranga Tamariki and the Justice sector. Some remain undiagnosed because, with patchy diagnostic capacity across the country and long waiting lists, the only alternative is to get a private assessment which, for many, is cost prohibitive. What is consistent is that all families were in crisis at point of diagnosis.

Most articulated a feeling of relief post diagnosis and felt that the assessment reports were useful in helping advocate for their children.

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*“For us the diagnosis was both a relief – having been criticised by so many for our parenting skills – and a realisation we had just been given a life sentence”*

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Many noted the wide array of appointments and tests and diagnosis they had to under-go before finally reaching FASD conclusions. This only serves to waste time and provides intervention suggestions that are not helpful.

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*“A never-ending array of appointments, agencies, and suggestions from professionals ... ADHD, ADD, Autism, RAD, PTSD...”*

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The most common advantage of diagnosis is increased understanding of both the deficits and strengths their children have and the ability to learn and parent differently.

One of the biggest frustrations is limited follow-up post diagnosis. This lack of support creates feelings of helplessness and isolation for parents.

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*“Individually and as a family, we had become isolated. We badly needed respite”*

*“Follow up after diagnosis was very limited. It would be good to have a key worker who advocates alongside the family for a period of time”.*

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## Experiences with Education

The experiences described within the education sector highlight a huge area of frustration for parents and caregivers. All parents described having to advocate for their children at school with many feeling as if they were not listened to. Experiences are again a mixed bag with success depending on the engagement and understanding of individual teachers. It should also be noted that those in a permanent placement within the foster care system have access to financial supports through PCSS. However, most parents described a lack of funding to provide teacher aide

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*“Towards the end of primary school, he started to mis-behave with a specific teacher. His ‘naughty’ behaviour resulted in punishment in class. That teacher told him, at age 8, that he would end up in prison”.*

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support for their children with some paying privately to have the additional help for their children. There is a general feeling noted that teachers lack the insight and training to understand and work

with children with FASD. Parents feel burdened with the need to up-skill teachers.

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*“Nothing was ever good enough with educationalist grasping at straws. ... All I remember is the many car trips home everyone in tears – including me”.*

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It was noted that one-on-one learning environments produced good results but often this type of help was offered too late. These children are victims of bullying and they become entrenched in a system that delivers consequence and punishment in attempts to modify

their behaviour. As a result of a mis-informed education sector and teachers turning a deaf ear to parent’s concerns, these children are leaving school with no qualifications and often with huge self-esteem issues. The education sector has a huge influence over the trajectory of all children and when it presents as years and years of unmet expectation, punishment and isolation, the path is inevitably one of self-destruction. One size does not fit all.

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*“However, once our son was considered at high risk of hurting himself (following suicidal thoughts and mental health inpatient care), he was assigned a full-time teacher aide. It was in the last term of his schooling but the one-to-one tuition worked very well and he achieved some NCEA credits in that time. It is just a shame that he did not receive this level of support throughout his school years. It would have set him on a different trajectory”.*

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## Experiences with General Practitioners

Generally, experiences with GP's highlighted a lack of training and knowledge of FASD. Most caregivers described their GP's inability to see or suggest further testing for FASD with some noting that their GP's did not know what it was at all – "he googled while we sat in his office". This inability to recognise and understand FASD in the primary healthcare sector means that the pathways to diagnosis are not open and often families are led in the wrong direction gathering a raft of incorrect diagnosis along the way.

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*"We approached our doctor when our daughter was three with concerns that she had FASD. His response was that she did not have the facial features so she did not have FASD. We did our research and paid for a private diagnosis which concluded that she did have FASD".*

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*"My grandson was born with a cleft palate, hernia, jaundice, a hole in the heart and differences on the body from one side to the other – ears, fingers, thumbs different plus the shape of his head bulged on one side. Red flags should have been raised from birth regarding possible FASD."*

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There are a number of families who describe serious physical impacts of FASD. Whilst these physical issues were addressed well within the health system, it leaves families wondering why, when involved with so much medical intervention, no-one raised concerns about neuro-development. "They don't see what they're not looking for".

There were some who described their children being referred to mental health services and becoming mental health inpatients without GP understanding that the mental health symptoms were a feature of FASD. The primary issue is not addressed or understood in a mental health setting.

## Experiences with Justice Sector

For many families, contact with the Police is nothing new. Often when children with FASD are acting out at home, there is no-one else to call for help. This is a last resort as phoning police is not a natural parental response to their child's behaviour.

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*"Our daughter has a red alert on the national data base. Police have been called to our home numerous times due to her violence towards us. They have been fantastic and very kind to us".*

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Many parents/caregivers carry a heavy burden of guilt, embarrassment and sadness having felt that the only place left to turn for help is law enforcement.

Of those who responded to this survey, one third had serious interaction with the justice sector with charges ranging from petty theft through to assault and threatening to kill. Many described the pressures of peer influences and social situations that contributed to impulsive behaviour.

As is consistent with all service providers, there is serious inconsistency in how those with FASD are treated in the Justice sector. Some reported the Police to be heavy handed and unsympathetic and others telling of how the Police had handled the situation with compassion and understanding. Some

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*"Our lawyer advocated hard for leniency due to the fact that this was a first offence and mitigated by having FASD. The Judge said that he did not need to hear about FASD, he had sentenced people with Bi-polar Disorder before!"*

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described FASD being considered as a mitigating factor in sentencing and others described intolerant Judges who did not want to be FASD informed. Some had experiences of leniency and others of consequences that were difficult for a person with FASD to adhere to without intense parental support.

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*"Whilst he engaged in the FGC's he attended and strongly expressed his intent to comply with the agreed conditions, he was unable to see it through. He couldn't keep to a curfew."*

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## Experiences with Mental Health and Addiction Services

Caregivers described the anxiety, depression, self-harm, suicidal ideation and attempts, together with some who displayed threatening behaviours towards family and friends. Many also described tendencies towards the mis-use of drugs and alcohol. Child and Adolescent Mental Health Services

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*“Our son has been an inpatient at an adult mental health facility three times across his teenage years. This was due to self-harming and suicidal ideation. Unfortunately, we did not feel as if the staff had any training or understanding of FASD. He was medicated and kept safe whilst there but that was the extent of the intervention. In fact, one psychiatrist told us if we believed in God, then we should pray.”*

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appeared reasonably well equipped to work with young people in a combination of ways with a focus on anxiety and panic attacks. Adult services were largely inadequate particularly as issues increased as the children aged. Reports from addiction services are also varied with most confirming that these services did not know about FASD and how to work with those with FASD. The most common premise for addiction services is that you must want to change and must demonstrate this by attending meetings

as specific times, dates and places. Success has been experienced when this standard model is altered so that pressure to make decisions and be on time in a clinical environment is removed or reduced.

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*“Our son recently had a further evaluation for drug addiction. The counsellor questioned why a 22-year old would have their mother in attendance. When I said he had FASD and may not be able to understand, despite being articulate and appearing aware, the counsellor said, “FASD, what’s that?”. Given the greatly enhanced risk of drug addiction in individuals with FASD this level of ignorance is unacceptable.”*

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Further to the concerns around individuals with FASD and engagement with mental health and addiction services, is the fact that many parents and caregivers also experience mental health issues – depression, anxiety and PTSD. These aspects of FASD are often hidden as

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*“My mental health is poor. I cry all the time and some days I just do not want to carry on living as I know that I am going to be abused at some stage, so I am always hypervigilant and just waiting...”*

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parents and caregivers mask the impact that their children are having on their own well-being. Not all harm is physical and many parents describe issues with fatigue, impaired decision making, isolation, fear and relationship issues and break-downs simply through the stress of raising someone with FASD.

Again, families described individuals who were “outstanding support” from nurses to behavioural specialists to community based AoD programmes. These are like “pockets of hope” but sadly all do not get to access these.

**These pockets of hope look like this:**

*“Our foster daughter has been an outpatient of our DHB Child and Adolescent Mental Health services for the past 4+ years. She has had excellent care from a Child Psychiatrist and a Psychologist specialising in anxiety”.*

*“I’m pleased to say that addiction services through a community-based kaupapa Maori health provider have been excellent. The difference with this service and the DHB is that they are prepared to meet the person where they are – literally and figuratively. Meetings can be at your home or at the beach. The focus is on risk mitigation and taking a whole person approach which extends to the family supporting the young person. Again, there was limited knowledge or understanding of FASD but, by comparison, there has been an eagerness to learn about it and an adjustment to approach as a result”.*

## Experiences with Oranga Tamariki, PCSS and Care Partner NGO's

Parent Caregivers described their involvement with Oranga Tamariki which was mostly through fostering or adoption. Some described going to Oranga Tamariki in search of help. There was nothing positive of note in anyone's recount of their experiences with Oranga Tamariki. Parents repeatedly told of having their skills and abilities called into question by ill-informed social workers. Many experiences involved broken promises by Oranga Tamariki and others shared stories demonstrating appalling communication skills by our

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*"If the public really saw what life with an FASD child looked like, no one would ever foster a child. This is why there needs to be much greater support for families taking on children through Oranga Tamariki. We need to look after these innocent victims but who looks after us?"*

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state department established for the care and protection of children. Parent Caregivers are definitely aggrieved by the way they have been treated by Oranga Tamariki and not without reason. Most had entered into caregiving arrangements without full knowledge of the background of the children or the high likelihood that they would have FASD. Many placements are at serious risk of breaking down, to the serious detriment of both the child and caregiver's wellbeing.

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*"We approached Oranga Tamariki for some help. We were traumatised, exhausted and out of our depth and needed some time out. We felt that she was unsafe and we were also unsafe. A senior Social Worker told us that Oranga Tamariki are not a therapeutic resource."*

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PCSS on the other hand, was mostly viewed as positive. Caregivers who were able to access support through PCSS reported helpful, supportive relationships with the social workers and noted various types of funding that assisted them in their everyday lives, for example; paying for diagnosis, follow up counselling, training, Teacher Aide hours. However, not every caregiver can access PCSS so this system is not designed to meet need but is very prescriptive in access criteria.

In regard to help and support from other NGO's, some parents described success with community-based organisations working in a kaupapa Maori way.

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*"This organisation has been excellent at not boxing in individuals to fit some weird criteria for help and in taking a collective, whole-family approach focused on strengths."*

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## Experiences with WINZ, NASC and sourcing supported living options

Most families have had experience with WINZ whether that be to access the disability allowance, unsupported child benefit or supported living benefit. As expected, there are mixed reports on how effectively this Government Department handles and interacts with people with neuro-disability and their families. A common thread was that those with co-morbid conditions such as intellectual disability received quicker and better service. Some described a long period of time where the young adult with FASD was given Job Seekers benefit and continually asked to report to WINZ offices and renew medical certificates whereas others were put directly on supporting living benefit without having to jump through hoops.

Some caregivers also noted their inability to work due to the high demands of raising a child with FASD and the financial strain this puts on the family. Others spoke of their gratitude for a flexible workplace.

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*“If I didn’t have a work situation that allows flexibility and a workplace that has been very generous to my situation, I would have lost my job and likely been on a benefit”.*

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**NASC** interactions painted a dim picture. Many noted that they were not eligible for NASC services and others who did qualify because of co-morbid intellectual disability also found the service provision and communication poor.

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*“It could take months for our NASC to return phone calls or emails and often work was not done due to staff changes..”*

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Those that did qualify for respite hours also reported a lack of suitable places for their children to go where the caregivers were FASD informed. The NASC providers themselves also appear to lack any real

understanding of the difficulties of FASD and a number of families noted that they were told on multiple occasions that they were not supporting FASD but a child with an intellectual disability. The caregivers unanimously said that the help they needed was for FASD, not the intellectual disability.

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*“We were repeatedly told that they would fund her intellectual disability, but not her FASD. Our NASC person told us that we needed more evidence that our daughter was violent at home and if we wanted more funding then we should call the Police when we were being assaulted. We followed this advice and had armed defenders turn up one time and another time our daughter was taken away in handcuffs as she was self-harming.... We stopped phoning the Police because we did not get any more funding, just a more traumatised child”.*

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Those with young adults had varying stories of “independent” living. Some had attempted to live in flats supported by their parents but mostly this had not worked because of their vulnerability. Stories of these young adults being taken advantage of in the community having things stolen or people moving in to their flats (squatting). Families who had successfully found supported living options were able to access this due to intellectual disability diagnosis.

## Lifespan Approaches

Families described a sense of worry they live with in regard to the long-term outlook for their children and what and who will be available to support their children when they are no longer able to. Some freely admitted that they had not yet thought about what adulthood might look like for their child, others had given it considerable thought. One grandmother's response is worth copying verbatim.

I am very aware that at the age of 63 with a teen who has FASD, that I am raising a child that will need life-long supports. If all goes well I will live till he is 30, but I will be 80 at that time. He is not going to achieve full independence, he will need supported living and I am working hard now to think about how he is going to survive without me.

1. Financial management supports, **he doesn't have any sense of money, so trusted others may have to manage his money in life**, I am currently working with him to see what he can and can't learn. If he sees money he spends it. If he has an EFTPOS card he gets easily talked into using his money by others etc.
2. Work and Income in the future – **he will need supports to maintain a continuous job** but I am trying to figure out how to ensure that he will have meaningful work in the future. He can physically work hard but his attention span, memory, thinks people are laughing at him and other issues let him down. He likes group activity, he likes camaraderie, he likes working hard but maintaining a consistent pattern is very difficult for him.
3. **Trusted people in his life** – I have identified two key people going forward who have a deep love and care for my grandson who can be guardians for him in the future but who may not be able to be his caregiver.
4. **Personal health care – he is going to need supports to maintain his personal health care otherwise he is oblivious to it.** he is currently unable to do things without constant reminders eg brush teeth, have a bath, clean room, feed himself. Systems are important for him but then he forgets systems. He will need reminders by a trusted person and assistance at times. He cleans well in a co-cleaning situation but otherwise is oblivious. He can follow written instruction. We are building a good relationship with the GP now that he has a diagnosis. The GP is very good.
5. **Assisted Living – he will need to live in an assisted living home with others or he may manage if he is in a small flat beside extended family.** He likes to be social, but he will make poor choices in friends including kids who beat him up if he is not surrounded by a safe network of friends.
6. **Police need to be clear about FASD and have an FASD protocol.** I have several close relations in the police force in our town. I have been educating them as much as possible about my grandson and that he may come to their attention. I educate them about the condition generally and internal training has started in the police force about FASD. So I proactively work across the social services and other sectors to educate them that my grandson has difficulties. I am getting to know as many of the youth justice people as possible so they can contact me early or get someone from the family there.
7. **Whanau, marae and hapu network – General education needs to be happening for everyone on FASD.** I am educating as many people as I can about my grandson so they can understand him, many of these people are nurses, teachers etc so they do look out for him. In our whanau

and marae he is happy and supported. But I am careful to not set up situations where he fails in these situations.

8. **Strengths based training and care** – I proactively set up situations for my grandson with the help of extended whanau so they can see that he can achieve in positive ways, if he is in the right environment. For example, he is very good on the marae working in the kitchen and dining room so he can excel and get lots of praise. If I put him into the situation for more than 2 days however he will fail so I have to manage everything to get the success. He is excellent in group work situations, where the whole whanau is working.
9. **He need supports to maintain his need for physical movement**– because of his ADHD he spends hours a day playing basketball, scootering etc, his body needs to move for several hours a day so am finding activities that keep him focused otherwise he uses his energy like he is caged up.
10. **He will need ongoing supports in Education as an adult** – From my research I see that our children do not always understand certain things in life until their 40s. We do projects at home based around his learning, his reading level is good because I read to him from 6 months old and he has a good reading level.

## How would recognising FASD as a disability help?

Some families described being able to access support due to their child or children having an intellectual disability. The support they received had been by way of respite hours, teacher aide in school, access to community support organisations providing mentors or key workers, therapeutic services, and supported housing options. The inequity in this is not lost on parents/caregivers where their children do not have an intellectual disability, but do have significantly impaired function, and access to services (or access to assessment) is denied.

For most the benefit was seen as having access to disability support services (DSS). These services would be the same as mentioned above.

There was also a strong view that recognition as a disability would 'raise the profile' of FASD community wide and eventually help all families because of the increased awareness and understanding. Families are feeling worn down by continually having to educate about FASD where ever they turn for help. The inadequate education and understanding of frontline professionals, across all sectors, causes an added layer of stress to parents and caregivers who, along with managing their complex children, must then educate those who are meant to be helping them. Some simply don't have the energy.

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*“Financial support for people with disability is vital to the health and wellbeing of the individual and the whānau that support them. When FASD is recognised as a disability it will give it validation that this neuro-disability has ‘special needs’ that require special help and support. Currently those who do not have an intellectual disability get NO support – it is a basic human rights issue.”*

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## The FASD Action Plan

Every person who provided a response said that the 2016-19 FASD Action Plan had not contributed anything positive to them or their family.

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*“The failure to address and understand FASD across all sectors is devastating not only for the individuals with FASD but also the entire family/whānau and wider community. We need to take a strengths-based approach with those with FASD to ensure that they can live with a positive sense of self-worth. Trying to fit them into ‘main stream’ just strips their self-esteem and leads to many other difficulties such as mental health and addiction issues. We need to engage with the business community and work out how those with FASD can be supported in the work place. Given the right type of support, those with FASD can be active, contributing members of society”.*

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### What would you like addressed as the next step in the Plan?

- Social workers, health and education professionals are trained in FASD so they have the knowledge, skills and competence to be helpful.
- Increased diagnostic services
- Recognise FASD as a disability and open pathways and access to services
- Increase supported living options
- Improved access to respite for parents/caregivers with adequately training caregivers
- A single, co-ordinated, disability support service
- Parent/caregiver training
- Funding for research

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With shared strength, guidance and wisdom, those with FASD CAN grow and achieve

## Closing Comments (verbatim)

*The key things that have kept me sane are:*

- *Finally getting a diagnosis and understanding that there are set limits to what my grandson can do and all of it is normal as a result of brain injury.*
- *FASD-CAN, Grandparents Raising Grandchildren and the support groups that have helped me to advocate and gain understanding of the condition and how to try to navigate my way to get help.*
- *My own online research and reading of Canadian research.*
- *Whanau supports, who have also had to grow to understand FASD and once they do, are a good source of help*

*But I hope no others have to deal with what we deal with without the clear understandings.*

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*Both our kids are extremely resistant to accepting their disability and therefore are not cooperative with having supports put in place on their behalf. We have spent many years parenting by stealth when working with agencies. Some have understood this issue and worked with us, others not all. The workload of dealing with up to half a dozen different services at a time for 2 individuals has been excessively taxing and has, in addition to living with our FASD people and their daily issues, put huge pressure on our marriage and our health. Streamlining services around the person, in my mind is a must.*

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*Our daughter HATES having FASD. It is frustrating for her in every part of her day. It affects the way she goes about her daily tasks, her schooling, her social interactions, her ability to self-regulate, her ability to moderate her response to the environment, her ability to embrace the highs and lows of life and her ability to 'keep up'. She didn't choose this and her mother didn't choose this either. The alcohol industry has to take some responsibility for this serious and preventable disorder.*

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*It is a human right abuse to not recognise FASD as a disability. My child is being denied their right to have their disability recognised and appropriate supports put into place in legislation*

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*NO child chose to be born with this lifelong disability – why do we treat them as if they chose this disability and then why do we treat this disability as if it's something people with FASD can just turn on and off, as if they have control over their brain impairment. We stigmatise and discriminate against those with FASD and we blame them for being born – disgusting.*

*Someone needs to seriously address the appalling billion-dollar business that the alcohol industry is – killing our children before and after birth with poison marketed as if it is not addictive and does no harm. Shame on New Zealand.*

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*Looking back, if she was diagnosed at an earlier age, life for her and us would have been a lot easier. We could have been educated earlier, the schools could have been able to assist better with knowing what is required for a child with FASD. If it wasn't for her having such bad behaviour and being referred to the Intensive Wraparound Service we wouldn't have been referred for FASD assessment and we could have still been struggling trying to understand how we could help her. Upon receiving the diagnosis it was like a weight off our shoulders as there was so much reading resources available that assisted us as a whanau and the school with understanding her more and strategies that we needed to put in place for her wellbeing, education and care.*

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*Raising a daughter with FASD is increasingly having a significant impact on employment. As a mother I have never been able to work more than 2 days a week and at times it is a challenge to even do this. And the impact of constant appointments / stress is impacting fulltime employment of my husband, with minimal understanding by the employer*

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*Financial impact as we look for other options that may help. EG: we have recently investigated and have started undergoing Biofeedback therapy in the hope of 'rescuing a sinking ship'. It's not a well-researched modality but one we are trying in the hope of making a difference in the trajectory our daughter is currently on. Personal impact is significant: not only on our other children but on ourselves: health issues, need to go on separate weekends away for respite, impact on marriage, loss of friendships, letting go personal dreams of travel etc*

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*FASD is a condition not fault of the child, we are only humans as caregivers and sometimes as parents /caregivers it can be challenging at times where we may lose ourselves.*

*There are some amazing caregivers out there and the stories I have heard or read, makes me sad especially when they are screaming out for the support and help they need.*

*I believe with the recognition that FASD gets, the programme for those to understand the condition will be beneficial. OT will need to ship shape and work further with the families and children who have the FASD, not throw them on caregivers who out of the goodness of their hearts take on an innocent child with no support.*

*It takes a village to raise a child, and with FASD we need villages that work together, collaborate through govt agencies to work with those who have opened their homes.*

*We only have 1 child, but it was clear to me from the conference that it takes more than a 2 parent family to raise a child like this, just like our home if we hadn't had Miss 7 father, my husband, I and her adult siblings to support her and brother we would have been a wreck. I was fortunate enough that I could dedicate my time to read about it and chase up MOH and school about her and even said down with the adults at home and discuss our approaches with her and the younger children needed to change. It has its moments but it definitely has its rewards, without the support of the adults at home and older children it would be tiring.*

**Please help, SOS**