



Queensland Advocacy Incorporated

Our mission is to promote, protect and defend, through advocacy, the fundamental needs and rights and lives of the most vulnerable people with disability in Queensland.

Systems and Individual Advocacy for vulnerable People with Disability

28th November, 2019

Senate Standing Committees on Community Affairs

Effective Approaches to Prevention, Diagnosis and Support for Fetal Alcohol Spectrum Disorder

Committee Secretary

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Dear Committee

Please accept the following submission to this inquiry.

Yours sincerely,

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QAI endorses the objectives, and promotes the principles, of the Convention on the Rights of Persons with Disabilities.

Patron: His Excellency The Honorable Paul de Jersey AC

About QAI

Queensland Advocacy Incorporated (QAI) is a member-driven, non-profit advocacy organisation for people with disability. Our mission is to promote, protect and defend, through advocacy, the fundamental needs, rights and lives of the most vulnerable people with disability in Queensland.

Our Human Rights and Mental Health legal services offer advice and representation on guardianship, administration and mental health matters. Our Justice Support and NDIS advocacy programs provide non-legal advice and support to people with disability in the criminal justice system and the NDIS, and a new service has recently been established to assist people to engage with the Disability Royal Commission. This individual advocacy informs our campaigns at state and federal levels for changes in laws, policies and practices, and assists us to understand the challenges, needs and concerns of people with disability.

QAI's constitution holds that every person is unique and valuable and that diversity is intrinsic to community. People with disability comprise the majority of our board and their lived experience of disability is our foundation and guide.

QAI and FASD

QAI is making this submission out of concern to ensure the provision of appropriate supports for everyone with a disability, including for people who have Fetal Alcohol Spectrum Disorder (FASD). QAI does not provide clinical services and has no role in the diagnosis, prevention or treatment of FASD.

In addition to systemic disability advocacy, QAI is funded by Queensland's Department of Justice and Attorney-General to provide legal advice and representation to people who are on Treatment Authorities and Forensic Orders pursuant to the *Mental Health Act 2016* (Qld) and in relation to guardianship and administration orders pursuant to the *Guardianship and Administration Act 2000* (Qld). We provide non-legal support to people with disability in the criminal justice system, appeals and internal review advocacy support to NDIS participants, advocacy to people who require specific decision support to access and navigate the NDIS, and advocacy support and advice for people to access the Disability Royal Commission.

Each of these services has, at times, contact with clients who have FASD and who do not receive the supports they need to manage their lives better and to live a good life. In this submission we will include learnings from our clients who have FASD, but do so in general terms without including information that could reveal anyone's identity. Our observations and our recommendations come directly from the lived experience of our clients. This submission is relevant to Terms of Reference (g), (i), (j), (k) and (l).



Recommendations

- It is critical that NDIS applicants have advice and support from people who are familiar with the conditions and its effects, nurse educators and the like, who can explain the kinds of therapies and supports that are most appropriate and useful.
- The NDIA has authority to ensure health authorities train and appoint more nurse educators in the field to be available for Participants with FASD.
- NDIA Planners are not likely to be familiar with FASD or its impacts, so it is important that the NDIA issues information and advice to Planners that the person with FASD and or their supporters have the expertise and knowledge about their support needs and the Planning meeting outcomes should reflect this. At the very least, it is important for people to have mentor support during the meeting.
- It is important to focus on the person's *support needs*, even though the client's support needs may not arise directly out of their FASD.
- NDIA Planners and LAC's should utilise the Complex Needs Pathways for Applicants with FASD who require financial support to obtain assessments and reports.
- If an applicant needs supports to develop self-regulation or to decrease behaviours which others find challenging, evidence such as reports from speech pathologists, therapists etc should articulate the triggers or risks.
- It is essential that people are accompanied by someone who not only understands the support needs of people with FASD, but also understands the NDIS planning process.
- Mentors may be the best support: a person who can read moods, and be a 'calendar' to ensure that the person sticks to plans and appointments, and who drives attendance.
- LAC's and/or Planners should link Participants who have FASD to nurse educators and other professionals to assist them.
- The NDIA should abolish Typical Support Plans as incongruent to the diversity of support needs.
- It is essential that if not NDIS-eligible, people with FASD are able to secure block-funded non-clinical supports from mainstream agencies that are funded to provide them.



Introduction

It is widely accepted that many people who live with FASD, particularly adults, are not aware that they have FASD. Many people with the condition have been not been formally diagnosed, and not least because there are so few specialist clinics dedicated to understanding the condition. It is not uncommon for people to be misdiagnosed with conditions that have overlapping symptoms and behaviours, such as ADHD, Borderline Personality Disorder, Depression and Anxiety.

Some of our clients have only recently become aware that they have FASD. Sometimes the diagnosis of a child triggers awareness and diagnosis of siblings, parents and grandparents. We have supported three generations of a family, all with FASD, who, until recently, were unaware of their common condition. Each was well aware, however, of the challenges they experienced in concentration, learning, planning and focusing, and of the effects on their self-management, communication and social interaction, although none was sure of the cause until, with support, one tried to lodge an NDIS access request. The request initially was rejected, but followed up with efforts to gather better supporting evidence. That supporting evidence confirmed the condition and led to other diagnoses across the generations.

From an early age he realised he wasn't like other kids: he had an interest in learning and tried hard to learn, but was never able to do well at school. He would forget things, could not write well, and could never write essays. He had difficulty understanding the teachers and often got into trouble because he quickly lost interest, becoming frustrated and bored, acting up in class and being cheeky and defiant. His disability has affected every day of his life, and he struggles with the impacts. When he was younger, people just thought he was a really naughty kid, and out of control. He has had several misdiagnoses, including ADHD. He had no control and did not understand the consequences of his actions. He would run away from home and end up on the street homeless. This led to other problems: drugs, stealing to survive, physical and emotional abuse by others.

Now, he receives a disability pension, for which his Mum is nominee. He cannot manage his finances or stick to a budget. Mum makes sure that the rent is paid and other bills are taken care of.

It's still impossible to follow routines because he quickly gets distracted and frustrated. If it wasn't for his Mum reminding him to do things at certain times he would forget and not do them. He needs to be reminded when to attend appointments, and when to take medication.

His inability to regulate his emotions means his aggression levels can go from zero to ten in seconds. When under the influence, this has led in the past to impulsive offending. The result was imprisonment.



Without awareness it is not uncommon for many people with FASD to receive no supports that might mitigate some of the diverse behavioural effects and assist people to live positive, fulfilling lives. An adult diagnosis is also a missed opportunity for early intervention resulting in adult exhibition of many complex behaviours and secondary mental health conditions, poor skills development and patchy employment histories that amount to a secondary disability due to the misunderstanding and mismanagement of the primary disability.

Yet even people who do know they have the condition often are reluctant to disclose it. As with many other avoidable conditions, particularly those associated with a 'pleasurable vice' like alcohol, FASD attracts stigma, and people who have it fear judgement directed at their parents or their grandparents, or themselves.

That fear of judgement often is compounded by fears and anxieties associated with other life circumstances, often traumatic, that may have no direct relationship with their physiological condition. Feelings of low self-esteem, and not feeling 'good enough' stemming from long histories of poor performance in school and in employment, and disconnection because other people have not experienced the traumas of domestic violence, sexual assault, homelessness, imprisonment and alcoholism are often part of the life experience of many people with FASD.

Some people with FASD have received a formal diagnosis, or they strongly suspect that they have the condition, however the condition itself presents difficulties for them to take the steps necessary to mitigate its effects by arranging for behaviour therapies or taking steps to arrange appropriate supports. Others may be aware they have the condition but do not appreciate sufficiently its relevance and impact on their day to day intentions, activities and endeavours, so they are not clear about the kinds of supports that might help them to function more effectively.

Ignorance is not confined to those who directly are affected. Community service providers, support workers and clinicians are often unaware that people they support have FASD, and that can lead to misjudgements about how best to respond or provide support. People with FASD often have to try to explain the condition: no easy task when clinical descriptors include opaque terminology such as 'severe neurodevelopmental impairments in executive function', 'attention and inhibition', 'social skills', 'adaptive behaviours', and 'affect and mood regulation'.

The NDIA has the authority and power to work with jurisdictions and health authorities to equip the professionals with knowledge and expertise in this area. In Queensland, despite a high population of people who are likely affected by FASD, there are only two clinics with this specialist knowledge. QAI recommends that there be concerted and intentional training about FASD with all health professionals and an increase in the number of positions of nurse educators with FASD expertise.

NDIS Pre-planning and Planning

Getting the right diagnosis is necessary to establish the disability requirements for NDIS eligibility, but there is no cure for a permanent brain injury like FASD. Every effective approach is about



finding the right mitigating and skills-building therapies, and, most importantly, about avoiding a 'one-size-fits-all' approach to finding the right supports for the particular person. It is beneficial to have a completed WHODAS functional assessment prior to the planning meeting for time-saving purposes, but it is important to impress upon the NDIS planner where a person is required to obtain assessments or reports as evidence of their condition, they utilise the Complex Needs Pathway in order to do so.

A common mixture of supports for people with FASD includes:

- core supports to help the person function better in the home;
- community access supports for budgeting and finance, shopping, banking and taking part in social and community activities and events;
- capacity building supports that help with developing living skills;
- capital funding for equipment and assistive technology;
- support coordination to assist in finding the appropriate supports in that person's geographical area;
- plan management to pay respective support bills;
- therapeutic and capacity skills support including psychology and counselling;
- an Occupational Therapist for functional capacity development; and
- programs for people with addictions, past or current, who need to learn life and living skills without the addictive substance/s.

Planning meetings

Conveying to the uninitiated the diverse effects of FASD and its varied behavioural and mental impacts is a huge problem. NDIS Planners are not likely to be familiar with FASD or its impacts, so it is important that the NDIA issue to all Planners information and advice about FASD, but more importantly, advise Planners that the Participant with FASD and/or their supporter is the expert in their condition and support needs. At the very least, it is important for people to have mentor support during the meeting and Planners and LACs should anticipate this and organise such support if the person has no-one to support them.

It is easy for Planners to get a false impression based on a person's presentation. Superficially people with FASD can appear to be confident and competent, having reasonably expressive language and appear to understand the conversation, but the reality often is that their comprehension does not match. It can depend on the day, and even the time of day, but when the applicant appears to be confident, as opposed to unresponsive and confused, these observational impressions may direct a planner in their decision-making. Underneath a competent presentation, it is not uncommon to find poor verbal reasoning and problem solving, extremely low range verbal processing speed and severely impaired auditory attention that can sometimes cause severe anxiety in social situations.



It is critical that NDIS applicants have advice and support from people who are familiar with the conditions and its effects, nurse educators and the like, who can explain what kinds of therapies and supports would help the most. It may seem trite to mention it, but everyone is different, and for many, FASD is one of a number of conditions in relation to which the person needs support. It is important to focus on the person's *support needs*, even though the person's support needs may not arise directly out of their FASD.

A person with FASD may, for example, have difficulty waking up at a predetermined time, showering daily, and carrying out ordinary everyday domestic duties. This may not be because it is physically impossible to perform such tasks, but because execution of such tasks may be an insurmountable organisational challenge. Mood, mental acuity, memory and concentration can interact together to make simple tasks like learning a new public transport route, household budgeting or financial management impossible. Cumulative failure to achieve simple goals can undermine self-esteem, and trigger paranoid thoughts and feelings of inferiority towards other people in the person's social sphere, who the person may perceive as superior because they appear not to have the same challenges. This can lead to so-called 'challenging behaviours'.

If an applicant needs supports to develop self-regulation or to decrease behaviours which others find challenging, helpful evidence could include some of the indicators listed below:

- A diary of days and times when challenging behaviours have occurred (if this is recorded);
- The kinds of extra time required to support behaviour management at home, school, or out and about;
- Reports from Speech Pathologists, Occupational Therapists, Psychologists or teachers; about the child's/adult's behaviours and ways of communicating their feelings, needs and wants;
- Evidence of any monetary outlays the family has incurred as a result of the behaviours;
- A list of the risks to the person, other people, and property if the behaviours are not addressed, such as harm to self, harm to others, property damage;
- Including the social isolation of the person if restrictive practices are used, such as being put into 'time out', or shutting the person in a different room, or not allowing the person/child to go on an outing if social interaction is more difficult due to behaviours.
- Potential increase in support costs and needs for extra support staff, and use of other services if the positive behaviour support services are not provided.

NDIS applicants have to challenge planners' use of Typical Support Packages (TSPs) to devise the NDIS plan. Since their introduction in 2017, Typical Support Packages have resulted in less individualisation in plans. At the planning meeting, a participant answers questions and a computer creates a plan with amounts. Before TSPs were introduced, the NDIA built plans from the ground up using spreadsheets. This took a 'little' more time but it was still possible for planners to meet their plan KPIs and the time savings were akin to false economy. Now, with TSPs, getting the right



plan is like winning the lottery. QAI recommends removing TSPs to get better outcomes for participants, reduce internal reviews, AAT appeals and participant dissatisfaction.

TSPs were calculated to ensure decision consistency, equity and sustainability and they vary according to the applicant's disability, age and levels of functional limitation. The only reason a Planner is permitted to go above the TSP is when they need to account for supports that are not generated by the guided questions of the planning program, such as when the applicant has complex circumstances that may include, for example, behaviours of concern and/or involvement in the criminal justice system. If the Planner exceeds the TSP they must look at how they can offset any increase by cutting funds from elsewhere. It is essential that people are supported by someone who not only understands the support needs of people with FASD, but also understands the NDIS planning process.

QAI recommends that the TSP is abolished as this ignores the diversity of support needs of individuals and returns to the outdated and demeaning treatment of people by homogenizing them according to a diagnosis label.

Support

Support may be required in the long term by multiple professionals and, if this is the case, best practice indicates a collaborative, information sharing model. Sometimes intensive behaviour support is not necessary, and support in learning living skills such as cooking and cleaning may be sufficient. Mentors may be the best support: a person who can read moods, and be a 'calendar' to ensure that the person sticks to plans and appointments, and who drives attendance. It is common for people with FASD to have good intentions, but not to follow through on things: not because of laziness, poor compliance or ambivalence, but because of difficulties around organisation, memory, information processing and problem solving.

Again, just as the behaviour manifestations of FASD are diverse in range and in intensity, the person's support needs likewise may need to be diverse. For example, the person may sometimes require ordinary mentoring support, and sometimes more intensive 'therapeutic' support from a person who can read physical and emotional signs, a motivator of compliance, and a 'calendar', and who may collaborate with a psychologist: something like a 'therapist assistant'.

Counselling may not work: what many people need is someone who is willing to go out into the community and implement practical regimes to assist the person to keep to task, understanding that people may require additional time to learn new skills, and need to explore alternate ways of learning. Ordinary support workers may need to be 'trained up' on the specifics of the person's impairments and the mechanisms for management and support.

LACs and Planners should link Participants with FASD to nurse educators or other professionals with expertise and understanding of the condition and its effects.

Supports for the NDIS-ineligible

The NDIS will not necessarily cover all of these supports, particularly supports that sit better with mainstream health services. A significant majority of people with FASD will not get access to the NDIS and likely will receive no formal supports at all, despite having, perhaps with less severity, a similar range of symptoms, behaviours and support needs, and similar experiences of feeling



overwhelmed and an inability to cope with simple day-to-day tasks. It is essential that if not NDIS-eligible, people with FASD are able to secure block-funded supports from mainstream agencies that are funded to provide them.

Finally QAI reminds the Committee that the NDIS was intended to support people with disability, including those who had gone without support or assistance in the past. People with FASD are misdiagnosed, undiagnosed, and often unsupported and are likely to experience marginalisation and/or criminalisation without appropriate or sufficient supports.

