ADVOCACY KNOWLEDGE COMMUNITY

DEVELOPMENTAL DISABILITY wa

Members' Issues Register

July 2023

Forward

This Members' Issues Register has been developed by Developmental Disability WA to keep a record of the many issues faced by people with developmental disability, their families/carers and service providers in the community. The issues have been gathered in a variety of ways from members, board members and staff since November 2019.

The Register aims to inform federal, state and local government, as well as the general public, about the issues faced by people when navigating all of the systems in our community. We hope it will inspire relevant agencies to take steps to resolve the issues or at least reduce the impact of these issues on people with developmental disability.

This Register does not seek to explain why an issue may be occurring or what potential solutions may be required, as issues are multi-layered and require further exploration around the causes before a solution can be found.

Lastly this Register is a "live" document, so that as new issues emerge, they are being recorded. On the rare occasion when an issue is resolved, we can celebrate the win and then remove the issue from the Register.

Please feel welcome to contact me at any time should you wish to raise an issue for potential inclusion in the Register, email mary.butterworth@ddwa.org.au

Mary Butterworth
CEO

Contents

1.1 – Self advocacy skill development for people with intellectual disability appears to be comparatively under-developed in WA, for example, not recognised in ABLESWA curriculum. People with intellectual disability often do not learn self-advocacy skills due to learned acquiescence (i.e., they learn to do as they are told) and need to be explicitly taught about their human rights and how to effectively stand up for themselves.

1.2 – The specific needs of people with intellectual disability do not appear to be sufficiently differentiated from the general disability community. Furthermore, the needs of people with intellectual disability can often be homogenised, so those with comparatively low support needs are not differentiated from those with very high support needs.

1.3 – There is no specialist, independent individual advocacy service for people with developmental disability including:

- People who can behave in challenging ways when they have unmet needs,
- People with Foetal Alcohol Spectrum Disorder,
- People with Pathological Demand Avoidance (a form of Autism).

1.4 - There can be issues for people with intellectual disability, high support needs and/or communication impairment not having their close family members recognised as their joint or proxy advocate without legal status.

2.1 – Some parents of children and young people who may at times behave in extremely challenging ways, are resorting to emergency departments and hospital admissions where they are often inappropriately admitted to an authorised mental health inpatient unit, in order to demonstrate the need for services for their children. Support is often provided in the form of medication to alter behaviour - that may also have a sedative effect.

2.2 - There is no independent oversight of the widespread 'off-label' prescribing of psychotropic medications. Section 6(b) of the NDIS (Restrictive Practices and Behaviour Support) Rules 2018 defines chemical restraint as: 'the use of medication or chemical substance for the primary purpose of influencing a person's behaviour. These are known as Psychotropic medications that affect the mind, emotions and behaviour. For children and young people, Psychotropic medications are often prescribed 'off-label', Off-label prescribing occurs when a medical practitioner prescribes a medication approved by the Therapeutic Goods Administration (TGA) for a purpose or in a manner other than that specified in the approved Product Information. The Chief Psychiatrist only provides independent oversight regarding 'off-label' psychotropic medication prescribed by specialist public mental health services.

2.3 – Many NDIS funding plans offer limited support and focus on the family, where the family has a member who behaves in very challenging ways. Furthermore, there is inadequate funding for implementation of a plan or ongoing maintenance support following the period of the behaviour support plan.

2.4 – Many families do not receive adequate funding for 'implementation' of their family member's NDIS Behaviour Support Plan.

2.5 – There is a thin market of support workers with the skills and experience to support people with complex needs who can behave in challenging ways when they have unmet needs. For those Support Workers who do have more advanced skills and knowledge, they are not recognised or financially compensated adequately for working at a higher level, nor are disability service providers funded to employ more highly skilled staff.

2.6 – There appears to be insufficient recognition that challenging behaviours displayed in group homes (that are not pain related), often come from the individuals being frustrated about their living environment and not having their individual needs met.

2.7 – Whilst there is paid training for Positive Behaviour Support Practitioners, there appears to be limited training within the education, health, mental health and disability sectors in how to best support people who can behave in challenging ways, particularly amongst support workers. Reward and consequence behaviour strategies are still commonplace.

2.8 – Some disability service providers have limited knowledge or understanding about Foetal Alcohol Spectrum Disorder (FASD) and are therefore not able to respond to people in appropriate ways.

3.1 - The International Declaration of Communication Rights is not formally recognised in Western Australia, in particular how this applies to the Disability Act and Disability Access and Inclusion Plans of state and local authorities.

3.2 – Supported decision-making processes to give consent (which recognise the different levels of decision-making capacity) do not appear to be well developed for people with complex communication needs. This is particularly important in health settings where people need to give informed consent to treatments/procedures.

3.3 – It appears that people generally have very limited awareness of how to communicate with people who have complex communication needs i.e., understand gestures, signs, switches, Alternative and Augmentative Communication (AAC) systems, which significantly limits the number of communication partners available to support them.

3.4 – There appears to be a lack of robust knowledge of keyword sign/use of AAC by staff working within the health and disability sectors, including speech therapists, which directly increases clinical and life risks.

3.5 – There is a limited range of Easy Read and AAC resources readily available in WA for people with intellectual disability and complex communication needs.

3.6 – There are no specialist, individual advocacy services for people who have complex communication needs (CCN) and/or use Alternative or Augmentative communication (AAC) devices.

3.7 - Mandatory mask wearing created additional communication difficulties that were never successfully resolved and will re-ignite if COVID levels once again mandate masks.

4.1 – Many trainee teachers and education assistants have not been adequately trained to develop key skills in supporting students with disability. This appears to be particularly the case for teachers supporting students who can behave in challenging ways when their needs are unmet.

4.2 - There is a shortage of specialist education support teachers and no system funded intensive program to upskill teachers. The shortage of skilled staff is even more apparent in rural and isolated settings.

4.3 – There is no specialist, individual advocacy service for the families of students with developmental disability who are dealing with issues in various education systems i.e., State, Private and Catholic (See Beyond Complaints report).

4.4 – Students with intellectual disability cannot access and participate in university life like students in other parts of Australia.

4.5 – There are differences of opinion and resource gaps between NDIA and state Education Department in relation to support for students who can behave in challenging ways.

4.6 – There appears to be insufficient information provided to schools on the level of funding available to support students with developmental disability and the process for applying.

4.7 - The process for obtaining extra school support for students with imputed disability while they are waiting for diagnosis, can be very onerous and result in the student and the school not having the benefit of essential resources.

4.8 – There appears to be poor educational outcomes for many students with disability, particularly those with complex communication needs, resulting in them leaving school illiterate and having reduced life opportunities. The onus is often on families to drive post-school planning without input from the school, and without utilising those final few years of school to develop the necessary skills and experience for post-school success.

4.8 - Access to schools by therapists for students with disability appears to be inconsistent. Principals interpret guidelines in different ways, resulting in therapy providers having to negotiate school by school, as to the parameters of their access. This appears to affect student outcomes considerably.

4.9 – There are a lack of onsite occupational and speech therapists who can support better social, emotional and education outcomes, for children with developmental, intellectual and neurological conditions.

4.10 – There needs to be more community-based support to help with the transition out of school.

5.1 – Local, state, federal and non-government organisations do not appear to be sufficiently utilising job customisation processes to employ people with intellectual and other developmental disabilities.

5.2 – People with intellectual disability are the only group of people in Australia who are legally permitted to be paid less than the minimum wage.

5.3 – Services provided by Disability Employment Services (DES) for people with intellectual disability has decreased from 80% to 3.3% nationally DES Reform submission (inclusionaustralia.org.au). DES providers have had very limited success in supporting people to obtain employment. DES providers are not required to support people who request assistance.

5.4 - Some people with developmental disability are unable to access a wide range of employment options during and post-school, including mainstream employment, self-employment /micro-enterprises, traineeships /apprenticeships and working at an Australian Disability Enterprise (ADE).

5.5 - There is no specialist, individual advocacy service for people with developmental disability seeking or maintaining employment.

5.6 – The incentive to work can be limited for a person with disability because the threshold of what a person with disability can earn before their disability pension is affected is low. This is particularly the case for people with intellectual disability who occasionally obtain blocks of casual employment.

5.7 - There are a limited number and variety of workplaces which employ people with developmental disability (especially those with high support needs).

5.8 - People with developmental disability on the supported wage system are receiving a payslip which does not reflect the minimum wage, because their income is supplemented by the disability support pension. This practice occurs in both supported and open employment.

5.9 - There are systemic barriers to mainstream employment for people with developmental disability which result in underemployment and restricted employment pathways. These include the manifest criteria and income threshold for receiving the disability support pension, a lack of specialised disability employment services providers and Centrelink income reporting obligations.

5.10 - The current NDIS funding model restricts the job and career opportunities available to people with developmental disability in both supported and open employment.

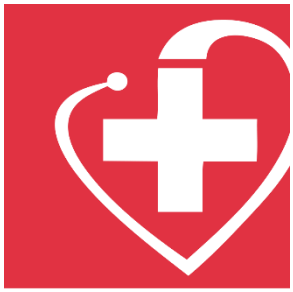
5.11 - Employers looking to employ people with developmental disability struggle to do so because there is limited knowledge of:

- how to recruit,
- a lack of incentives (financial and otherwise) to change current, process/workplace,
- ongoing staff training requirements (including training specific to meet the person with developmental disability's requirements),
- the need for workplace modifications,
- uncertainty and confusion around wage and reporting structures,
- systems to access assistance for employers looking to employ people with developmental disability.

5.12 - Lack of awareness by employers that they need to use Disability Employment Service providers to employ people with developmental disability, not mainstream employment providers.

5.13 - There is often insufficient funding for schools to allocate support staff to assist students to have individually tailored workplace experiences and to try a variety of workplace options prior to leaving school. There appears to be limited funding for both planning and actual support in the workplace.

5.14 – Greater representation on the media with positive role models and meaningful jobs is required.



6.1 - There is no specialist, individual advocacy service for people with developmental disability, complex communication needs and/or challenging behaviour.

6.2 – Whilst ambulance and hospital services may have protocols or resources for supporting people with disability, complex communication needs and/or challenging behaviour, there appears to be very little practical application of policy in everyday practice.

6.3 – People with intellectual disability and challenging behaviour and/or complex communication needs, have generally poor health outcomes when accessing health services and mental health services. Whilst hospital staff have the expertise to support their medical needs, many do not have the time, specific skills or experience to support their behaviour in a positive way, their communication or their personal care e.g., feeding and toileting.

6.4 – Some foster parents of children with suspected Foetal Alcohol Spectrum Disorder are being refused permission to access diagnostic services by Child Protection/ Dept of Communities. Delays in diagnoses ensure crucial early interventions are unable to be provided.

6.5 – Some people with complex needs are being discharged from hospital to unsupported and unsafe settings such as backpacker hostels or back to supported accommodation with regular staff who do not have the necessary medical training and skills.

6.6 – When a person with developmental disability passes away unexpectedly, doctors appear to attribute death to the person's disability rather than seek an autopsy. Most unexplained deaths require an autopsy by law.

6.7 – The Special Needs Dental clinic has a two-year waitlist for dental work under a general anaesthetic. No emergency appointments are available.

6.8 – No funding/system of support for people with intellectual disability and their families to undertake health planning. Little recognition of the supports required for people with intellectual disability to access health care i.e., preventative care not included in NDIS plans.

6.9 – There is no health literacy training for support workers available in the TAFE course.

6.10 – People with developmental disability are at higher risk of chemical restraint and psychotropic polypharmacy (i.e., when more than one psychotropic medication is prescribed).

6.11 - There is lack of understanding by health professionals regarding when they should trigger a State Administrative Tribunal application for guardianship.

6.12 – Waitlists for children with disability to access private and public paediatricians have reached extreme levels with families waiting 18 months plus to access services.

7.1 – There appears to be a lack of recognition for the natural guardianship provided by families. Some government and non-government agencies are requiring parents to seek guardianship over their adult family member with developmental disability, which may not be necessary and can be restrictive.

7.2 – People with intellectual disability have limited opportunity to demonstrate their right to vote and participate in government elections as accessible information/systems are not available.

7.3 – The Electoral Act was written in 1907 and does not recognise or make any provision for people with disability or other marginalised groups, except via numerous amendments, which are not core components of the Act.

7.4 – Guardianship and Administration Act 1990 uses outdated terminology which can cause offense, distress and/or confusion e.g., 'mental disability**'.**

7.5 – State Administrative Tribunal guardianship processes are difficult for people with intellectual disability and/or complex communication needs to understand and participate in.

7.6 – The current guardianship model of substitute decision making is not aligned with the more contemporary model of supported decision making.

7.7 – There is limited education for parents of people with disability on how to access appropriate legal guardianship whilst still allowing the person with disability appropriate decision making.

8.1 - Parents with intellectual disability have a very high level of forced removal of children at birth and experience significant trauma. There is no widely recognised pathway of support between health, NDIS, child protection and guardianship services.

8.2 – There are no specialist services for parents with intellectual disability in relation to:

- individual advocacy
- self-advocacy
- case management
- parenting support

8.3 – There are limited training opportunities for pregnant women/new mothers with intellectual disability to learn parenting skills and demonstrate their capacity.

8.4 – Child to parent family violence is not well recognised or responded to by Police, NDIS and Child Protection agencies.

8.5 –There is no proactive parenting support for families with a child with a developmental disability that can at times behave in extremely challenging ways when they have unmet needs. Community services often do not act until the family is in crisis, at risk of child removal or the child becomes known to the Justice system.

RECREATION

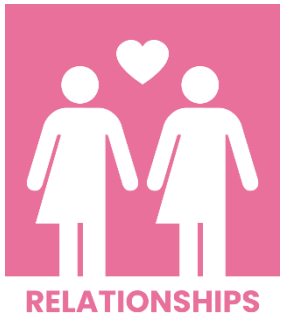
9.1 – Some sport and recreation providers are limiting access to services and facilities by people who can behave in challenging ways, when they have unmet needs. There appears to be limited options for staff to gain the necessary skills and knowledge required to support participation.

9.2 - There is no specialist, individual advocacy service for people with developmental disability, especially people with complex communication needs and/or challenging behaviour seeking to access recreational services.

9.3 – Most sport and recreation providers do not have information or resources to support people with developmental disability and or complex communication needs to access their services or facilities.

9.4 – The costs associated with joining many sporting clubs (eg. membership, transport, equipment) makes them inaccessible to many people with intellectual disability who rely primarily on a Disability Support Pension as their main source of income.

9.5 - Not all online event booking systems enable Companion Card holders/people with disability to specify their seating requirements eg. standard seating, seating next to wheelchair space.



10.1 – There are limited opportunities for people with intellectual disability to learn friendship and relationship building skills.

10.2 – Limited understanding and utilisation of NDIS funding for capacity building around relationships.

10.3 – Limited recognition and funding for sibling support.

10.4 – Misuse of guardianship powers by some parents to interfere with natural relationships between people with intellectual disability.

10.5 – Limited social opportunities for peers with intellectual disability in mainstream settings.

11.1 – There is limited and/or scattered information for people with intellectual disability and/or complex communication needs in relation to:

- Cyber safety - banking, scamming, trolling, sexting
- Personal safety in public - at night, on public transport, at large events
- Physical and emotional abuse
- Emergency preparedness plans
- Hazards - storms, bushfires, floods, cyclone, hazardous material incidents
- Home safety - house fire, chemicals, poisoning
- Health safety – medications
- Workplace safety - bullying, noise, manual handling

11.2 - There are a lack of Family Domestic Violence support options for:

- Mothers of teen boys/adult men with intellectual disability because they cannot both access a women's refuge.
- Mothers of children/women with developmental disability who may behave in challenging ways.
- Mothers of children with physical disability requiring wheelchair access.

NDIS SUPPORTS

12.1 – Some people with intellectual disability are missing out on NDIS support because there are virtually no services to assist with:

- gathering evidence for NDIS registration
- the pre-planning process
- the costs of initial reports/assessments
- access to health professionals to undertake the assessment (wait lists of over 12-18 months)

12.2 - Some NDIS Planners do not read, understand, or utilise information in diagnostic, therapy and equipment reports.

12.3 - All reports for a planning meeting need to be submitted to enquiries@ndis.gov.au six weeks prior to the planning meeting, however at the planning meeting planners will often not have the reports available and ask for them to be re-submitted.

12.4 – It appears the planning tool used by the NDIS to assist people with Autism is inappropriate to identify actual needs, particularly related to behaviour.

12.5 - Participants with comparable needs receive vastly different funding. For example, twins with Autism received different funding to the extent that the more able twin received more funding than the twin with higher support needs.

12.6 – Where there are multiple people living in a group arrangement, the planning process is not undertaken at the same time, so the needs of each person sharing the home are not considered in the context of the household.

12.7 - Where there are multiple family members with disability in the one home, the planning process is not undertaken at the same time, so the needs of each family member are not considered in the context of the whole family.

12.8 – People living in group homes with intellectual disability and no verbal speech skills are still at high risk of having no choice and control in their lives. Many people do not have access or support to use a communication device.

12.9 – Some people have been persistently underfunded, despite endless documentation and reports seeking additional funding. The outcome on each occasion has been the individual has then been moved out of home, into other accommodation, as the family are burnt out or the situation has escalated. Supporting people outside of home has been at a much greater cost to NDIA, than any supports that were requested to keep them at home.

12. 10 - Despite most service providers traveling to provide services, NDIS continue to not acknowledge or fund travel expenses. Many people in group homes only get funded for community access hours, no travel, this results in their community access hours being reduced each year to accommodate travel incurred. For those who do receive transport funding, it is often not enough to cover costs.

12.11 - No long-term support strategy for families who experience challenging behaviour i.e., the DDWA Side by Side community is only project funded to June 2024.

12.12 – NDIS plans are not being reviewed by the participant and mutually agreed.

12.13 - When support workers cannot be recruited (particularly in regional areas), it is extremely difficult for parents to be paid for short periods of time even with safeguards put in place to reduce the risk of vulnerability or exploitation. Parents cannot work because they do not have support workers to care for their family member and cannot be paid to provide the support themselves, creating a poverty spiral.

12.14 - People are underutilising their NDIS plans because they cannot find suitable staff (private or provider) and then getting penalised for this via reduced funds in their next plan.

12.15 - Despite being funded to provide information and support, some LAC's refer people with disability and their families to Disability Representative Organisations (DRO's) like DDWA for specialist information, yet the DRO's are not funded to provide this service. Many DRO's are reliant on project grants to operate and do not have core funding for basic information and support services.

12.16 - When families are self-managing support worker teams (for a participant) they are expected to upskill their staff and coordinate team meetings without any funding to cover these costs. Furthermore, funding is allocated based on direct hours of support, but does not consider the additional staff time needed for follow up meetings such as with Positive Behaviour Support practitioners.

12.17 - Families who have no Support Coordination funding are not getting essential information from LAC partners. By comparison during COVID, participants were able to access Support Coordination through their Core supports budget which ensured participants were more likely to get information and relevant support in a timely manner.

12.18 – Most support workers do not obtain key skills in how to support people with complex communication needs and/or challenging behaviour when completing TAFE courses or inhouse training programs.

12.19 - There is no recognition or incentive for skilled/experienced support workers i.e., higher pay rates when they work with people who are more difficult to support for example, a person can behave in challenging ways when they have unmet needs.

12.20 – There is no apparent strategy to utilise redundant equipment for example, children's wheelchairs, when still in good condition.

12.21 – It appears some specific services would be better suited to block funding (such as equipment for growing children, behaviour support/counselling for people with intellectual disability related to sexuality issues), so that services can be provided in a timely and cost-effective way.

12.22 – Many service providers indicate they are using their reserves to fund NDIS services for both people with very high support needs (especially if restrictive practices are in place) and low support needs. Some service providers are being forced to only provide services to people with mid-level support needs to remain viable i.e., "cherry pick" who they serve. Many smaller to medium providers have had to merge to stay in business so less choice and control for participants.

GENERAL SUPPORTS

12.23 – There is no provision for people with disability to phone their nearest local Centrelink branch and have follow-up conversations with the same staff member, if needed. Many people with intellectual disability have difficulty in understanding and using complex choice making processes on the phone.

12.24 - Some children being provided respite by Dept of Communities due to their complex behaviours are receiving this respite in Airbnb's or motel rooms. There appears to be no routine or consistency of staff, adding further to the distress of these children.

13.1 – It appears that 17-year-olds with disability, who will be leaving foster care when they turn 18, routinely lack access to independent advocacy to support them when the state seeks to appoint a guardian.

13.2 – There appears to be limited transition support services when children with disability transition from paediatric to adult health services. Hospital services require children to transition to adult services once they turn 16 years.

13.3 – Some state appointed guardians appear to have limited disability-specific knowledge in relation to 'choice and control' in the context of clinical and life risk.

13.4 – Lack of supports for transition periods, in particular:

- Starting school
- Starting high school
- School to post school
- Family home to own home

14.1 – People with intellectual disability are especially concerned about their personal safety on public transport, particularly at night.

14.2 – There is no financial assistance for people to purchase vehicles that can accommodate wheelchair access modifications. Whilst people can get assistance with vehicle modifications, the additional cost of purchasing a larger vehicle, makes owning a vehicle prohibitive.

14.3 – The School Bus Service for students with disability:

- Is in some cases not responsive to the needs of individual students.
- Harnesses some students in seats so they are unable to escape in an emergency.
- Requires some students to wear continence pads for a long time on bus.
- Does not provide drivers and/or aides with adequate disability awareness training and support e.g., regulation partner.
- Requires parents to pay for cost of assessment for behaviour support plan with no review process.
- Can dictate/limit choice of which school, based on bus routes i.e., not always able to access ed support nearest to home.

14.4 – Accessible taxis in regional areas are limited or not available even in some tourist destinations/regional centres for example, Broome.

14.5 – There needs to be greater recognition of the long distances rural people have to travel to access services and how much of the plan is eaten up with support workers travelling to and with their participant to activities.

14.6 – Public transport is not very accessible for people with intellectual disability because:

- Signage is not in accessible language, for example, mostly has letters which people cannot read, does not have picture symbols.
- Everyday language is not used in all communications.
- It is hard to understand real time communication e.g., information displays, audio announcements, timetables, 24-hour clock.
- Website and Apps do not meet Cognitive Accessibility guidelines and are not always tested by people with cognitive disability.
- Printed information is hard to find except at central stations.
- Can't always get tickets at point of access, so need to go to retailers.
- Automatic tag off not in place for people who forget to tag off.
- Inconsistent training for transport and security staff across taxi, rideshare, train and bus services.
- Alternative options for ordering and paying for rideshare services (such as Uber or Didi) are not available.

15.1 – Single people with intellectual disability are typically only eligible for a one-bedroom public/community housing unit, which can leave many feeling vulnerable, lonely and isolated. It appears there is limited visibility of policy and practice around providing a two-bedroom unit, so that co-resident models of support can be considered.

15.2 – People with developmental disability continue to be channelled towards shared/group living arrangements by NDIS planners.

15.3 – Limited support for people with disability when they do move into their own home with skill development in budgeting, planning routines, cleaning, cooking.