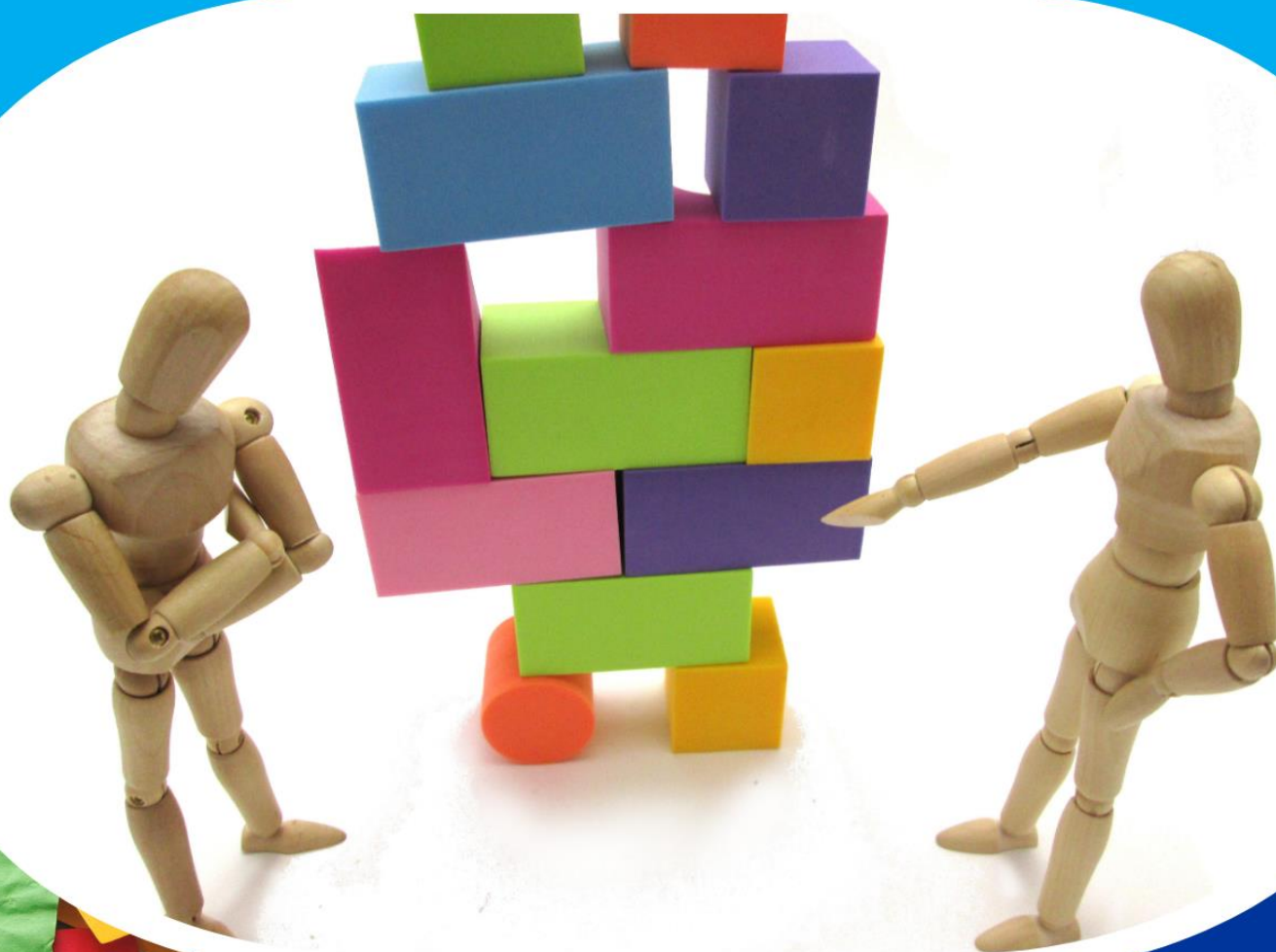


Submission on Foundational Supports



www.swanautism.org.au

Executive Summary

The South West Autism Network (SWAN) supports the introduction of General Foundational Supports but expresses significant concerns about the proposed rollout's practicality, pace, and potential risks. This submission highlights the importance of a co-designed, inclusive, and equitable approach that places people with disability and their families at the centre of all planning and implementation.

Key concerns include:

- Insufficient timeframes for meaningful co-design and consultation.
- Lack of clarity and information about the structure and delivery of Foundational Supports.
- Severe workforce shortages, particularly in regional and remote areas.
- Risks of inequity and unintended harm from proposed delivery in school settings.

SWAN proposes practical, participant-led solutions to ensure the effectiveness of General Foundational Supports. These include slowing down the rollout to align with the Independent NDIS Review's recommended five-year timeline, establishing sustainable funding for grassroots peer support organisations, prioritising workforce development, and creating robust evaluation mechanisms to monitor and improve outcomes.

Our recommendations provide a clear roadmap to deliver equitable and high-quality supports that meet the diverse needs of people with disability across Australia. By adopting these recommendations, the Government can avoid costly errors, reduce harm, and foster trust within the disability community.

December 2024

Introduction

South West Autism Network (SWAN) is a not-for-profit, charitable organisation that has been supporting autistic individuals and their families in the south-west region of Western Australia for the past 15 years. We are a Disabled Persons and Families Organisation (DPFO) with more than 2,000 members, and we provide free information, capacity building peer support and advocacy to many more people with disabilities and their families. All staff, volunteers, and Board members either have a disability or are family members of someone with a disability.

Our primary role in the community is to provide information, peer support, advocacy, and connections to mainstream and disability services. We build the capacity of people with disabilities and their families to access and navigate government and non-government systems to meet their needs, and participate in their local communities. We support people seeking diagnosis, post-diagnosis, and across their lifespan, and provide autistic-safe space group programmes for autistic children, teens, and young adults through our AutStars and YES Programmes. We also deliver Youth Mental Health First Aid training to the wider community.

This submission outlines SWAN's position on Foundational Supports. SWAN has significant concerns about the practical implications of the introduction of Foundational Supports. We are particularly concerned about the speed of the proposed timeline, lack of information and co-design, insufficient workforce and subsequent risk to people with disability and families of rushing the re-introduction of Foundational Supports.

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SWAN's Position on Foundational Supports

Whilst SWAN are supportive of the re-introduction of Foundational Supports, we hold very significant concerns about how Foundational Supports are being explored and rolled out. These issues of concern must be resolved in order for Foundational Supports to achieve the minimum standard required.

Key Concerns

Lack of Information About Foundational Supports

There is minimal information about what Foundational Supports are going to be. People with disability do not have access to practical information about what Foundational Supports will be, and how they will be accessed. State Governments, disability organisations and Commonwealth Government officials also lack information and a meaningful understanding of what Foundational Supports will be. It remains unclear what Foundational Supports will include, and given that budget allocations have already been made, there is high risk of Foundational Supports under-delivering on the promise – particularly in areas of geographic isolation where the cost of providing support is typically higher.

Insufficient Timeframes

The Independent NDIS Review clearly recommended a period of 5 years to codesign and implement Foundational Supports as part of the overall NDIS ecosystem reforms. The Government intends to commence rollout of Foundational Supports from 1st July 2025. This does not allow sufficient time for consultation, effective evaluation of the consultation, development of suitable guidelines, testing or funding arrangements. Further, the pace of changes exceeds the capacity of Department of Social Services (DSS), National Disability Insurance Agency (NDIA), NDIS Quality and Safeguards Commission (NDIS Q&S), State Government Departments and Disability Advocacy Organisations. There are too many changes being consulted on, made and rushed in too short a timeframe to enable quality of the changes and prevent unintended harm occurring to people with disability. Rushed timeframes result in critical errors and oversights, which result in both harm to people with disability and additional costs being incurred to address these issues.

Lack of Codesign

Consultation is not codesign. The Independent NDIS Review's final report recommended that Government *"...should take an individualised and participant-led approach to assessing and responding to risk. Based on this, participants should have access to a suite of general and targeted safeguards to support them to manage the risks they face and build their capacity."* In order to ensure that Foundational Supports deliver on the promise to people with disability and families, are effective and provide quality supports; the structure, processes and delivery of Foundational Supports must be co-developed with people with disability. Consultation alone is not sufficient, and will lead to expensive and ineffective Foundational Supports with far too many people with disability continuing to fall through gaps in support services, and ongoing pressure on the NDIS.

Co-development involves working with people with disability in leadership roles in every State and Territory, with specific inclusion of First Nations people, Culturally and

Linguistically Diverse (CaLD), LGBTQIASB+, regional and remote people, and diverse inclusion of people with different disability types. It is people with disability and families who know where and what the gaps and barriers to support services are – we encounter them every day. Undertaking consultation only and developing Foundational Supports without co-development, testing, evaluation and continuous improvement will result in ongoing systemic failure to address the needs of people with disability – both inside the NDIS and outside of it.

Lack of Workforce

There are very substantial allied health workforce shortages nation-wide (Wait times typically range from 6 months to in excess of 3 or 4 years), and no incentivisation program to increase the workforce. In order to build the workforce to meet the requirements of Foundational Supports, NDIS Participants, Support Needs Assessments, Functional Assessments and the general population, there will be a delay of more than 5 years required to train the necessary allied health workforce (based on minimum timeframe for achievement of tertiary allied health qualifications). This does not allow for allied health professionals to build experience in disability, and there is no requirement of training in disability in any of the allied health qualifications. **It is unrealistic to rollout services requiring high numbers of qualified allied health professionals experienced in a wide range of disability types in less than 7 years.**

Meanwhile, the Commonwealth Government is proposing to commence Foundational Supports from 1st July 2025. There is additional risk to NDIS participants and people with disability outside the NDIS if critical supports, particularly Targeted Foundational Supports, the support needs assessment and functional assessments are performed by unqualified and inexperienced practitioners. **Not only is there the risk of poor, adverse outcomes, but genuine risk to the safety of people with disability of having unqualified and inexperienced practitioners undertaking these roles.**

In regional and remote communities, particularly areas with significant geographic isolation such as WA, Northern Territory and Queensland the workforce shortages are dramatically more severe. SWAN conducted a national survey as part of preparing our [submission](#) to the Commonwealth Senate Inquiry into the Experience of NDIS Participants in Rural, Regional and Remote Australia. We found that in areas of higher population density over smaller geographic areas, such as NSW and Victoria, people wait an average of 1-6 months to access allied health supports. In regional Western Australia, the wait time to access allied health supports are often 18 months to over 3 years, sometimes longer. Many providers specialise in paediatric services, limiting access to therapy supports further for adults.

The combination of budget restrictions and workforce shortages are likely to result in Foundational Supports being limited to a small number of specific schools in regional and remote areas – forcing children with disability and/or developmental delay to travel (often to another town) to access these supports. There is extremely high risk of children and youth with disability experiencing increased segregation in order to access Foundational Supports through schools, as proposed by the Independent NDIS Review's [final report](#).

Additional Barriers in Regional and Remote Australia

Another issue impacting NDIS participants in rural, regional and remote Australia is the narrow scope of clientele that therapy providers typically will see. Many services are paediatric only, leaving adults without access to therapy supports, or waiting in excess of 18

months to 4 years to access supports. There are significant staffing shortages, and many participants and families report being on a provider's waitlist for several months, only to be advised that the clinician has left the provider to return to the metropolitan area, and to join the waitlist elsewhere.

Pre-NDIS, people with disability often moved to Perth to access support services. Due to the housing crisis, however, this is no longer an option. There is no accommodation available to move to. The case study below exemplifies the dramatic difference in access to support services between Perth and regional WA prior to the introduction of NDIS, when there was mandatory provider registration:

Pre-NDIS, Alexa [name changed to protect privacy] and her family were living 4hrs south of Perth. Her 2yr old was diagnosed severely autistic (DSM-4). A relative with autistic kids in Perth told her about how kids under the age of 6yrs in Perth had access to 4hrs of early intervention therapy per week. Alexa was offered 1 visit per year from a psychologist for her toddler, because the family were located outside the metropolitan area. Alexa asked to bring her toddler up to Perth each week to access the 4hrs of early intervention therapy Perth kids benefited from. The State Disability Services denied her request. Alexa continued to advocate, and was forced to threaten to go to the media to be permitted to travel to Perth at her own cost to access early intervention therapy for her child. Permission was finally granted, and Alexa travelled 4hrs to Perth and 4hrs back each week for 3 years. During that time, her second child was also diagnosed severely autistic, and accessed the same early intervention therapy in Perth. Alexa's children were the only WA children outside the metropolitan area to access early intervention therapy during this time.

Governments frequently fail to take into consideration the additional cost of travel for rural, regional and remote participants – both for therapists to travel to people with disability to provide assessments and therapy, or for people with disability and families to travel to therapists to access therapy. This is hugely problematic for people with disability in rural, regional and remote Australia. Where there are local therapy providers, they very often have closed or extensive waitlists. The only option in these circumstances is to use Telehealth or use therapists willing to travel into the area (or the family travel to the therapists). Telehealth is unsuitable for many people with disability, particularly children; and travelling out of town to access therapy is extremely costly, time consuming, and an additional stressor for people with disability and families who are already time-poor, stressed and often exhausted.

It is crucial that budget allocations for Foundational Supports factor in geographic distances. For example, the budget allocation for Western Australian and Northern Territory must not be allocated based on population alone. This will lead to a worsening of inequity between people with disability in metropolitan areas compared to those living in regional and remote areas.

Who is Responsible?

Which State / Territory or Commonwealth Government Department(s) is ultimately responsible for Foundational Supports?

If the State and Territory Governments have responsibility, will Foundational Supports be spread between Health, Education, Disability, Mental Health; requiring people with disability and families to apply for, understand and navigate multiple complex systems?

Many areas of these Departments had funding reduced or removed entirely as State and Territory Governments channelled funds into NDIS. These systems need to be rebuilt in order to resume these supports – there is no skilled workforce ready to redevelop these systems and deliver quality supports in only 6 months.

Will Foundational Supports be transferrable between States and Territories, enabling people with disability and families to move interstate and retain their existing level of Foundational Supports?

These questions remain unanswered. The Independent NDIS Review suggested that NDIS Participants be supported by NDIS, and people with disability outside of the NDIS be supported by Foundational Supports, rather than requiring them to engage with and navigate multiple complex systems.

It is also important to note that there are people with disability in regional and remote areas of Australia for whom it is closer to travel interstate to access some supports, than it is to access the nearest available support in their own State or Territory. This issue needs to be considered in rolling out Foundational Supports.

Referral Pathways

General Practitioners (GPs), Primary Health, Child Health Nurses, Paediatricians, Psychiatrists, Hospitals, Allied Health Practitioners and Community Services are all referral pathways to accessing supports for people with disability. In Western Australia, wait times to access these services vary dramatically, with Paediatrician and Psychiatrist wait times in particular exceeding 2 years in many parts of the State. Further, there is substantial educative work required to upskill staff in these varied sectors to understand the proposed Foundational Supports, what is and is not available, and how to connect and access these supports.

Impacts of Poverty

43.1% of JobSeeker recipients are deemed to have 'partial work capacity' (have a disability), as shown by [statistics released by the Department of Social Services](#) in June 2022. JobSeeker Payment is [almost \\$225 per week below the poverty line](#). Most of the 43.1% of JobSeeker recipients are not diagnosed with a disability, and typically ineligible for NDIS and/or foundational supports. The Australian Council of Social Service (ACOSS) released a [new report](#) in October 2024, which found that '*..the woefully low JobSeeker payment is just 20% of the average wage.*' People living in poverty are less able to afford access to the supports they require, and are more likely to live in regional and remote areas where rent is marginally cheaper.

Foundational Supports in Schools

The Independent NDIS Review [final report](#) suggested that Foundational Supports for early childhood be delivered in school settings. People with disability (particularly autistic people) and families have raised concerns about this suggestion.

While early childhood, primary and secondary education plays a critical role in the learning, participation and wellbeing of autistic children and their families, the support available in school settings is often sorely lacking and discriminatory. According to the [Australian](#)

[Bureau of Statistics \(2022\)](#) 68.9% of autistic people aged 5 to 20yrs, reported difficulty at school, with the five most common types of difficulties experienced being:

- Fitting in socially (53.4%)
- Communication difficulties (51%)
- Learning difficulties (44.1%)
- Difficulties sitting (27.1%)
- Other difficulties (62.2%)

It was reported by the [ABS \(2022\)](#) that **97.3% of autistic young people aged 5-20 years experienced an educational restriction, an increase of 5% on the 2018 statistics of 92.3% (101,900)**. 45.3% attended a special class in a mainstream school or a special school, and 4.4% were unable to attend school because of their disability. **68.9% experienced difficulty at their place of learning, and 39.3% only achieved completion of Year 10 or below**. These quantitative statistics clearly indicate that nation-wide schools are underperforming in their support for autistic students, but the ABS has not captured qualitative data regarding the issue, and the trauma incurred by autistic children and youth through participation in discriminatory school systems. This issue is exacerbated by the fact that every single Australian teacher will encounter multiple autistic students during their careers, but training on autism is entirely optional. Students studying Education degrees are **not** required to learn about autism or other disabilities in order to graduate.

NDIA captured outcomes data for autistic participants aged 0-14yrs on education outcomes, comparing a baseline for their entry into the scheme with outcomes two years later. As at 30th June 2023, only 65% of autistic participants aged 0-14yrs were attending mainstream schools, compared with the baseline of 72%. Despite 2 years of NDIS funded support, 7% fewer autistic NDIS participants in that age group are now attending mainstream schools. As State-based Education Departments are responsible for support for autistic students within schools (rather than NDIS), this indicates that current school-based supports for autistic students are insufficient to meet needs. As can be seen in the table below, SWAN's extensive interactions with autistic people and families over the last 14 years emphasise the lack of support in WA schools, with enquiries regarding this issue increasing, as shown in the table below.

Enquiries to SWAN about issues with schooling						
2018 6mths	2019	2020	2021	2022	2023	2024 to Nov
12	149	144	488	504	1017	1602

The [Australian Bureau of Statistics \(2022\)](#) reported that over a third (35.4%) of autistic students needed special tuition and 34.3% needed help from a counsellor or disability support person. Of great concern, in 2018 it was reported that almost half the autistic young people aged 5-20 years (45.9%) indicated they needed more support or assistance at school than what they were receiving.

SWAN conducted a survey in 2023 as part of our [submission](#) to the WA State Government Education and Health Standing Committee. Based on the results of this survey, the availability of supports for neurodivergent students in WA schools is significantly lacking. Of the 249 survey respondents who answered this question, only 10% rated availability of support for autistic students in WA as excellent or good. Alarming, 70.7% rated availability of support as poor or very poor. Without a substantial increase in Government support, funding, and investment in training for teachers and support staff, neurodivergent students

are likely to fall further behind than their neurotypical peers, be at greater risk of academic decline, social isolation, and poor mental health. Longer term, there is the risk that insufficient support during school years will impact negatively on an autistic persons' self-esteem and ability to gain and maintain financial independence and autonomy in adulthood; hence the necessity to provide greater support during early childhood, primary school, and adolescence.

In addition to the lack of support availability, survey respondents also reported issues with the quality of support in WA schools. Of the 248 survey respondents who answered this question, **no one** rated the quality of support for autistic students as excellent. 11.3% rated the quality of support as good, and concerningly, 65.7% rated the quality of support for autistic students in WA schools as poor or very poor. We note also that 40.9% of school staff responding to this question rated the quality of support as poor or very poor, and only 28.7% of school staff rated the quality of support in schools as good.

The proposal to deliver Foundational Supports to children with developmental concerns and disability in school settings is deeply concerning. SWAN are likewise concerned that budget constraints and the rushed timeframe will lead to these supports being delivered by under-qualified and under-experienced practitioners, with high risk of doing more harm than good. Further, there is high risk of exacerbating the inequity between children with developmental concerns and disability in regional and remote areas and their metropolitan peers.

Information and Capacity Building Support

The provision of information and capacity building support to people with disability and families is best delivered by peers – people with disability and family members who are experienced in navigating the multitude of complex systems that people with disability are required to navigate. This lived experience is crucial, and the level of expertise required takes many years of practical experience to accumulate. Concerningly, the DSS Engage questionnaire on Foundational Supports excluded disability peer support organisations from the list of sources of information and capacity building support for people with disability and families. This is a significant oversight, especially in consideration of the fact that the Independent NDIS Review [final report](#) recommended that General Foundational Supports “...includes information and advice and peer support.” The word “peer’ appears 35 times in the report.

The consultation questionnaire on DSS Engage asked:

“What sources of information and advice do you currently use, or are most likely to use? (You can select as many as you want)

- *Disability Gateway*
- *Carers Gateway*
- *Phone lines (such as the 1800 numbers provided through the Disability Gateway site)*
- *Other government websites*
- *Non-government websites*
- *Online platforms (e.g. websites) to find disability providers*
- *Disability advocacy organisations, including their websites or phone lines*
- *Local government information*
- *Information from community organisations in my area*
- *Disability service providers*

- *My GP or other health professional*
- *Talking to other people with disability and/or carers*
- *None*
- *Other”*

The Disability Gateway is centralised to the east coast of Australia, lacking expertise on services available in local communities in each State and Territory. Commonly the Disability Gateway staff contact disability peer support and representative organisations such as SWAN, seeking information about services available in local communities. Staff from the Disability Gateway have contacted SWAN on more than one occasion to seek advice on services available in Sydney NSW, despite SWAN being located in regional WA. It is clear that the Disability Gateway, NDIS Partners in Community, Carer Gateway and numerous other mainstream and disability services rely on disability peer support organisations to provide crucial information and capacity building support to people with disability and families. However, 173 of these organisations lost all or most of their Information, Linkages and Capacity building (ILC) funding in the most recent ILC grant round, which decimated the sector. SWAN note that not one autism peer support organisations received funding in that ILC grant round, and Western Australia was allocated less funding than the minimum required for population alone.

The Carer Gateway is facilitated by State-based Carer representative bodies with some (limited) expertise on services available in local communities. Outside of metropolitan areas, the Carer Gateway often refer people to local disability peer support organisations where available. Whilst the Carer Gateway offers significantly more types of support services than the Disability Gateway, the wait times to access these supports (eg. free counselling) varies dramatically. People in crisis being required to wait in excess of 10 months to access these support services poses a significant risk to the health and wellbeing of the carer, and in some cases, the safety and wellbeing of the person with disability. Carer support services are not always accessible to disabled carers, further marginalising this cohort.

Options involving websites and other digital resources overlook the substantial digital divide present in many parts of Australia, particularly in regional and geographically isolated areas, marginalised groups, and particularly people living in poverty. People experiencing poverty often cannot afford to live in cities, where access to information and support services is more readily available. The only device they own may be a phone and many are unable to afford sufficient (or any) internet access. This leaves people with limited access to the internet via public libraries and community resource centres, which aside from the lack of privacy, may not be located within travelling distance.

Digital resources are often inaccessible to many people with disability, requiring high levels of literacy, understanding of technology and vision. These resources are rarely accessible to screen-readers, are not typically written in Plain English; and Easy Read and Auslan versions of these resources are even less common. This lack of access to digital resources often impacts the people who most need access to information.

Disability advocacy organisations are funded through the [National Disability Advocacy Program](#) grants (which is closed to new applicants) and are often not disability-led. Many disability advocacy organisations prioritise employment of staff with social work or related degrees rather than lived experience. This leads to advocates who do not understand the complex systems people with disability are required to navigate, such as the NDIS.

While Local Governments may have a Community Development Officer, many do not, and knowledge of disability and relevant supports is often very limited. Most Local Governments have a Disability Access and Inclusion Plan (DAIP), and some have a DAIP committee. However, this is not regularly available and maintained - there is a lack of consistency of knowledge, and minimal (if any) support available to people with disability.

What Does “Good” Look Like?

Disability peer support organisations, including SWAN, have a long history of providing information, capacity building and peer support to people with disability. These organisations prioritise lived experience and local expertise of the mainstream and disability supports and services available. To ensure positive outcomes of General Foundational Supports, it is crucial that people with disabilities and our small, grassroots peer support organisations lead codesign of General Foundational Supports.

Existing small, grassroots peer support organisations were established to address gaps in support available to people with disability and families; to provide information, capacity building, peer support and advocacy. Typically, these organisations support individuals to connect with and navigate existing Government and non-Government services to address needs; and develop complimentary programs and resources to fill gaps in support services, based on feedback from the individuals they serve.

Small, grassroots peer support organisations are incredibly efficient, providing an extremely high standard of service delivery at very low cost. Their disability-specific and local expertise is impossible to replicate at large scale. Services are individually tailed to meet the needs of people contacting the organisation, and are specific to the addressing the needs, barriers and gaps experienced by people with disability and families living in the local region. Large scale, singular service models are ineffective at addressing these needs, due to adopting a one-size-fits-all model of service delivery. The needs of people with disability in regional WA are very different to the needs of people with disability in Melbourne Victoria, for example.

The key to successful Foundational Supports is to invest in small, grassroots disability peer support organisations to deliver flexible, individualised support to meet the needs of people with disability and families in the region being serviced, with scope to adapt to the changing needs of the community through codesign.

Please see the attached [Addendum 1](#) for an example of the information, capacity building and peer support available through SWAN. Support is provided via the preferred communication method of the individual (phone, email, social media, SMS, in-person, Zoom/Microsoft Teams). We start by listening to the individual about their concerns, support them to prioritise the issues, and arm them with information, connections and strategies to support decision-making and self-advocacy. Where people require more intensive support, we provide it. [Addendum 2](#) provides case studies of people with disability and family members we have supported.

We strongly recommend exploring the supports and services available through other disability peer support organisations around Australia to gain an understanding of the types of Foundational Supports that are sought by people with disability and families, as well as what “good” looks like.

To deliver “good” Foundational Supports requires sustainable, long-term investment in peer support organisations and groups to enhance their capacity and capability to meet the needs of autistic people and the broader disability community. These organisations must be adequately resourced and funded with ongoing support to effectively serve their communities. The current short-term, one-off project-based grant funding available through the Information, Linkages and Capacity building (ILC) program is insufficient for providing the Foundational Supports needed by the disability community. The short-term, one-off project based grant funding for ILC has directly resulted in the huge gaps in access to information, capacity building and peer support experienced by people with disability and families. The need for this support remains unchanged, but funding is cut off due to the project-based nature of the funding, and the requirement that projects be “innovative and new”, rather than a continuation of the required support service.

New peer support organisations which emerge over time to address gaps should also have equitable access to funding – this should not be a closed system in the manner of the National Disability Advocacy Program (NDAP).

Additionally, the system must be streamlined to allow peer support organisations easier access to long-term funding options, with reduced administrative burdens and less time-intensive reporting requirements. Alternative systems are needed to replace the [Department of Social Services’ DEX \(Data Exchange\) system](#), which is overly complex, inaccessible, and lacks training support. DEX is also highly labour-intensive, requiring double data entry due to organisations being unable to retrieve data entered into DEX, thus requiring them to maintain their own Client Records Management (CRM) systems as well.

Compounding these challenges is the requirement to collect identifying and demographic data for DEX reporting. This prevents access to anonymous information and support, which deters people from accessing support before a trusted relationship is established. This is particularly important for people who have institutional trauma from attempting to access and navigate inaccessible and discriminatory systems (eg. people with psychosocial disability, and people who have trusted providers with private information which has then been used against them). There are further concerns about data sovereignty and integrity - who owns the data - and the risk of private and identifying data being breached.

It is crucial that reporting and data capture be simplified to enable disability peer support organisations to prioritise the most important work – providing information, capacity building, peer support and advocacy to people with disability and families.

Co-development of Foundational Supports

To ensure that Foundational Supports deliver on the promise, it is crucial that Foundational Supports are co-developed by a steering committee comprising a minimum 50% people with disability. The committee must comprise of people from diverse backgrounds, including representatives from each State and Territory, geographically isolated people with disability, First Nations, CaLD and LGBTQIASB+ representatives. The steering committee should guide the co-development of Foundational Supports, ensuring that the voices and needs of the most marginalised people are included and considered. This steering committee should oversee the implementation of Foundational Supports, assessing the effectiveness, identifying and addressing gaps, evaluation and continuous improvement.

Referral Pathway

Whilst the Disability Gateway is not fit for purpose, and Carer Gateway is limited, there is potential for both Gateways to be repurposed as a vehicle to connect people to Foundational supports in their local communities. Ideally people would have a choice of collaborative organisations to contact for Foundational Supports. People could phone or visit the Disability Gateway website and enter any of the following details:

- Postcode
- Disability
- Type of support required (eg. advocacy, information, peer support, navigation support etc)

The Gateway would then provide a list of options for accessing information, capacity building and peer support. This provides access to localised and/or disability-specific expertise, and enables the individual to have choice and control over who provides this support.

Importantly, however, these Gateways should not be the only referral pathway. A 'no wrong door' approach must be adopted.

Evaluation Mechanisms

To ensure the success and continuous improvement of General Foundational Supports, SWAN proposes the following evaluation mechanisms:

CoDesign Evaluation

- Establish a steering committee comprising at least 50% people with disability and their families from diverse backgrounds, including representation from First Nations, Culturally and Linguistically Diverse (CaLD) communities, LGBTQIASB+ groups, and regional/remote areas.
- Conduct quarterly reviews of the co-design process to ensure inclusivity and responsiveness to feedback.
- Evaluate the extent to which the co-design process influences policy and implementation.
- Use a 'feedback loop', to ensure that the steering committee and all individuals involved in codesign receive regular updates and reports to advise what changes and improvements have been made as a result of their advice.

Outcome Measurement

- Define clear, measurable objectives for Foundational Supports, such as:
 - Reduction in wait times for allied health services.
 - Increased access to supports in regional and remote areas.
 - Improved satisfaction among people with disability and families regarding support quality.
- Use baseline data from the Independent NDIS Review and other sources to measure progress.

Accessibility and Equity Audits

- Conduct biannual audits to assess:
 - Geographic coverage of supports, particularly in regional and remote areas.
 - Accessibility for diverse groups, including those impacted by poverty and digital divides.
- Ensure budget allocations consider geographic and demographic inequities.

Workforce Monitoring

- Track workforce development initiatives to address shortages in allied health professionals, especially in under-served areas.
- Measure the percentage of practitioners with disability-specific training and experience.
- Evaluate the effectiveness of interim measures, such as telehealth and support from less-qualified practitioners.

Stakeholder Feedback

- Implement a continuous feedback loop involving people with disability, families, service providers, and advocates.
- Use surveys, focus groups, and interviews to gather qualitative and quantitative data.
- Publish annual reports summarising stakeholder feedback and outlining adjustments made.

Service Quality Assessment

- Develop quality benchmarks for Foundational Supports delivery.
- Regularly assess services against these benchmarks through user feedback and independent evaluations.
- Include lived-experience peer reviewers in quality assessments.

Information and Capacity-Building Evaluation

- Measure the effectiveness of peer-delivered information and capacity-building supports through user satisfaction surveys.
- Track engagement levels across different delivery methods (e.g., online, in-person).
- Evaluate the impact of these supports on users' ability to navigate systems and advocate for their needs.
- Measure feedback from disability peer support organisations on identified support needs, ensuring flexibility of funding to enable organisations to pivot to address emerging needs.

Data-Driven Continuous Improvement

- Use anonymised data from support interactions to identify trends and gaps, utilising efficient reporting mechanisms (other than DEX) to ensure organisations are able to prioritise service delivery.
- Conduct annual reviews to refine support offerings based on emerging needs.
- Implement a secure and accessible data reporting system that minimises administrative burdens for support organisations (not DEX).

Budgetary Oversight

- Ensure funding allocations are reviewed biannually to confirm alignment with identified needs, particularly for regional and remote areas.
- Assess the adequacy and utilisation of funds allocated to peer support organisations.

Public Transparency

- Publish evaluation findings in accessible formats, including plain English summaries and Easy Read versions.
- Host public forums and webinars to share results and gather feedback on proposed changes and improvements.

Long-Term Impact Studies

- Conduct longitudinal studies to assess the broader social and economic impacts of Foundational Supports.
 - Examine metrics such as school retention rates, workforce participation, and quality of life improvements among beneficiaries.
-

SWAN's Recommendations

1. Extend the Timeframes Implementation of Foundational Supports

- Slow down the rollout of Foundational Supports to allow sufficient time for meaningful collaboration with the disability community, including co-development and consultation processes.
- Use this time to ensure policies and implementation strategies are participant-led, well-informed, and thoroughly tested to avoid harm and costly errors.
- Align the timeline with the Independent NDIS Review's recommendation of a five-year codesign and rollout period to build trust and deliver quality outcomes for people with disability.

2. Adopt a Comprehensive Co-Design Approach

- Establish a steering committee composed of at least 50% people with disability and family representatives from diverse backgrounds, including First Nations, Culturally and Linguistically Diverse (CaLD) groups, LGBTQIASB+ communities, and individuals from regional and remote areas.
- Ensure the co-design process is ongoing and prioritises participant-led insights to shape every stage of implementation, from policy development to delivery and evaluation.

3. Ensure Accessibility and Equity

- Allocate funding based on geographic and demographic needs rather than population alone to address inequities in regional and remote areas.
- Improve accessibility of digital resources by providing content in Plain English, Easy Read, and Auslan, and ensuring compatibility with assistive technologies like screen readers.
- Incorporate provisions to address the digital divide, particularly for people with disability in poverty or geographically isolated areas.

4. Invest in Disability Peer Support Organisations

- Provide sustainable, long-term funding to small, grassroots peer support organisations that have proven expertise in delivering tailored, high-quality supports to people with disability and families.
- Streamline funding application and reporting processes to reduce administrative burdens and allow organisations to focus on service delivery.
- Include peer support organisations as a recognised component of General Foundational Supports, ensuring their role in information and capacity building is formally acknowledged and adequately resourced.

5. Address Workforce Shortages

- Implement targeted incentives to increase the allied health workforce in under-served areas, with a focus on disability-specific training and experience.

- Introduce interim measures, such as telehealth, supported by robust training programs for practitioners to ensure quality services are delivered in the short term.
- Develop and fund pathways for training and recruitment in regional and remote areas to reduce wait times and increase access.

6. Embed Robust Evaluation and Continuous Improvement Mechanisms

- Implement the proposed evaluation mechanisms, including regular stakeholder feedback loops, biannual accessibility audits, and outcome measurements aligned with clear, measurable objectives.
- Ensure evaluation processes are transparent and findings are published in accessible formats, such as Easy Read summaries and public reports.

7. Prioritise Training Over School-Based Foundational Supports

- Avoid implementing Foundational Supports within school settings, recognising the risks of inequity and potential harm due to under-resourced and poorly trained systems.
- Instead, focus on significantly increasing investment in mandatory training for teachers and school staff to improve their understanding of autism and other disabilities, ensuring that schools become more inclusive and supportive environments for all students.

8. Develop Clear Referral Pathways

- Redesign and expand the functionality of the Disability Gateway and Carer Gateway to act as effective referral hubs for accessing localised and disability-specific Foundational Supports.
- Provide training to referral pathway professionals, such as GPs, allied health practitioners, and community workers, to enhance understanding of Foundational Supports and reduce access barriers.

9. Strengthen Policy and Accountability

- Clarify roles and responsibilities between Commonwealth and State/Territory Governments to ensure seamless delivery of Foundational Supports.
- Develop a centralised framework for monitoring and reporting, allowing for ongoing assessment of progress, effectiveness, and alignment with participant needs.

10. Guarantee Long-Term Sustainability

- Introduce multi-year funding cycles for Foundational Supports to reduce service disruptions caused by short-term project-based grants.
- Establish pathways for new peer support organisations to access funding and participate in the delivery of Foundational Supports.
- Simplify the reporting requirements for funded organisations and replace inaccessible systems, such as DEX, with more user-friendly alternatives.

11. Foster Transparency and Continuous Improvement

- Regularly share findings from evaluations and audits with the public to maintain transparency and build trust in the system.
- Use feedback from people with disability and families to refine and adapt Foundational Supports continuously.
- Include independent lived-experience reviewers in quality assessments to ensure the supports meet the needs of the intended beneficiaries.

12. Mandatory inclusion of disability training tertiary qualifications

- Require Universities and TAFEs to include relevant, codesigned training on disability in many of the qualifications they offer, including, but not limited to:
 - Allied Health qualifications
 - Education (primary, high school and tertiary)
 - Medical (both Doctors and Nurses)
 - Community Services
 - Mental Health
 - Require mandatory codesigned professional development training on disability for existing professionals in the above fields and for frontline mainstream service staff.
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Conclusion

The implementation of General Foundational Supports represents a critical opportunity to address significant gaps in support for people with disability. However, rushing this process without thorough co-design, consultation, and preparation risks undermining its potential and causing harm to the very people it aims to support.

SWAN urges the Government to slow the rollout and engage meaningfully with the disability community to co-design supports that are inclusive, effective, and sustainable. Addressing workforce shortages, investing in peer support organisations, and prioritising equity for regional and marginalised groups must be central to this process.

By taking the time to collaborate, evaluate, and refine, the Government can ensure that General Foundational Supports achieve their intended goals - empowering people with disability to live with dignity, independence, and equitable access to the supports they need.

Addendum 1: Information, Capacity Building and Peer Support Available Through SWAN

FREE support with NDIS, seeking diagnosis, mainstream and disability supports available to meet your / your child's needs and much more.

SWAN receive [Information, Linkages and Capacity building](#) (ILC) funding from the federal government. We are a Disabled Persons and Families Organisation (DPFO), providing peer support to autistic people and their families throughout the South West of Western Australia and beyond. We also provide support to people with any disability type.

Support is available via phone, email, social media, SMS, Zoom, Microsoft Teams or in-person.

We can assist people with disability and families with FREE information and support about:

Seeking autism diagnosis

- The requirements for autism diagnosis for each age group.
- How to access diagnosis, including the public vs private pathways, and associated costs.
- Finding diagnosticians.

What to do after diagnosis

- Financial support available from [Centrelink](#), the [National Disability Insurance Scheme \(NDIS\)](#) and other systems.
- Assistance to apply for NDIS Access.
- Supports available through mainstream and disability services, and how to access them.
- Supports available at public / private schools, TAFE, University and with employment.

Information on what disability and mainstream supports are available to meet your needs, and support to access them

- **National Disability Insurance Scheme (NDIS)** – our team are extremely experienced and knowledgeable in all things NDIS related
- **Education** – information about supports available in public or private schools, TAFE and University, and how to engage with these education services to improve flexibility and inclusion.
- **Employment** – information and support to connect with employment supports, including Disability Employment Services (DES), Microenterprise, Customised Employment and School Leavers Employment Supports (SLES).
- **Community Services** – information and support to connect with community services in your local area to meet your individual needs.
- **Mental Health** – we provide Youth Mental Health First Aid training in addition to information and support to connect with public (free) and private (at cost) mental health support services.
- **Recreation and social connection** – information and support to connect with community activities that match your / your child's interests and needs.
- **Advocacy** – empowering you to self-advocate, connecting to advocacy services, and SWAN can also provide some advocacy support to people as needed. SWAN are not funded for advocacy, however we are able to provide advocacy support in some circumstances thanks to the generosity of our benefactors, Greg and Kathy Walsh.

- **And more** – our team have a wide range of knowledge and experience, and are more than happy to assist. If we don't know the answer to your question, we'll research and get back to you.

Person-Centred Planning & Goal-Setting Sessions

SWAN provide **free** person-centred planning sessions using a range of visually attractive and interactive tools and strategies. The person with disability is central to the planning process, and we work to empower you to think about:

- Each session is designed around the communication needs of people attending.
- Available **FREE** to people with disability (family &/or supporters are welcome to also attend) and carers of children with disability.
- The goals and plans developed can be shared with NDIS, school staff, extended family, support services etc (with the permission of the person with disability).

[Download Person-Centred Planning & Goal-Setting Poster](#)

Accessing the National Disability Insurance Scheme (NDIS)

- We can assist with filling out the forms to apply for NDIS Access, gathering supporting evidence, and all things NDIS related – completely **free**.

Preparing for your / your child's NDIS Planning meeting

- How NDIS works.
- What supports are available.
- Intensive pre-planning session to help you prepare for your / your child's NDIS planning meeting, so that you can be confident in knowing your rights, what to ask for to meet your / your child's individual needs, what to expect and more.
- Our aim to empower you with knowledge at every stage of your NDIS journey.

Understanding the NDIS, and how to use your / your child's NDIS Plan

- NDIS processes and how to navigate them.
- Reasonable and Necessary – what this means for you / your child.
- What supports are the responsibility of NDIS / Education / Health / Mental Health and other mainstream services.
- Understanding your / your child's NDIS Plan.
- How to use the NDIS Plan flexibly to meet your / your child's disability-related needs.
- Finding and connecting to supports.

Self-Managing NDIS Funding

- All of our team are currently Self-Managing NDIS funding (between 1 and 3 NDIS plans each).
- We can advise you on how to Self-Manage NDIS funding, navigate the NDIS Portal, employing your own supports, managing providers and more.

Support with Variations, Reassessments and Internal Review of Decisions

- Support to prepare for your / your child's End of Plan Reassessment.
- What to do if you don't have enough funding to meet your needs.
- Understanding the different types of NDIS Reviews / Variations / Reassessments, and information to help you decide how to proceed.
- Gathering evidence for appealing your funding (Plan Reassessment or Plan Variation).
- Support with seeking an Internal Review of Decision.
- Support with seeking a Change of Circumstances Reassessment.

SWAN also provide two peer support groups on Facebook, and a public page where we share information daily:

- [SWAN public Facebook page](#)
- [SWAN Peer Support Group](#) for autistic people and family members
- [Disability Peer Support WA](#) for people with disability and family members

All supports above are available entirely FREE to all people with disability and their families, regardless of disability type. Please [contact us](#).

Please contact us by emailing info@swanautism.org.au or phone / SMS **0499 819 038**. Please note that we are unable to answer the phone when we are meeting with clients, so please send an SMS or leave a voicemail if you are unable to get through.

Systemic Advocacy

SWAN provide advocacy to improve or change State and Federal Government systems in order to improve access, inclusion and supports for people with disability. You can find out more about our systemic advocacy [here](#).

Other supports provided by SWAN:

(click on the links below for more information and to see costs)

- [YES Program for teens and young adults](#)
- [AutStars for primary school aged kids](#)
- [Youth Mental Health First Aid \(YMHFA\) training](#)

Addendum 2: Case Studies

Kwang

(name changed to protect her privacy)

SWAN were initially contacted by a multicultural service in early 2022 regarding a new client who had been attending their 'English as a second language' classes. Kwang is a 47-year-old woman originally from Thailand. She moved to Australia with her Australian husband and their then 8-year-old son. Kwang sought help from a Women's Refuge after fleeing long-term domestic violence from her husband. He had a new partner and had withdrawn from any contact or support for Kwang and their son, including withdrawal of sponsorship for their application for permanent residency in Australia. The multicultural service referred Kwang to SWAN as she understood her son was autistic but was unsure whether he had received a formal diagnosis, or what supports they may be eligible for.

SWAN met with Kwang and a representative from the Women's Refuge. As English is Kwang's second language, she required additional support to be able to communicate effectively. Initially it was unclear whether her son had been formally diagnosed with autism or if he needed to be diagnosed. We were unable to source any information about the NDIS available in the Thai language, but were able to link Kwang to the [Positive Partnerships website](#), which features Google Translate, enabling the entire website of information and resources about autism to be translated into Thai. SWAN explained that to be eligible for the NDIS, her son would need to be either an Australian citizen or a permanent resident.

Approximately 2 months later the multicultural service contacted SWAN to say that they had been contacted by Kwang's immigration lawyer. The Government were going to refuse permanent residency on medical grounds due to her son's autism diagnosis. We provided more information about his diagnosis and immigration requirements, and referred Kwang to a Perth-based disability advocate experienced in working with people from Culturally and Linguistically Diverse backgrounds and issues of immigration and residency in Australia.

Kwang contacted SWAN again more than a year later to advise that she and her son had been granted permanent residency, and were seeking support to connect with support services they are now eligible for as permanent residents of Australia. SWAN met with Kwang and supported her to complete a NDIS Access Request form for her son. We provided information about developing a plan with the NDIS for her son, once his application had been received. SWAN also provided a list of therapy providers in the region and suggested she join the waitlists as soon as possible (approximate wait time at paediatric therapy providers in the region was 8-18mths).

Once Kwang's son's application for NDIS was approved, SWAN used the services of a Translator over two meetings to support Kwang to prepare for her son's first NDIS planning meeting. Kwang and her son were no longer living in the refuge, but were living in unstable accommodation where they were confined by the homeowner to a small bedroom they shared. After explaining options via the translator to Kwang, SWAN contacted the NDIA to request that her son be restreamed to the Complex Support Needs Pathway. We then supported Kwang at the planning meeting, and supported her to connect with a Support Coordinator and Plan Manager to start using her son's NDIS plan.

During these meetings, we also identified that Kwang was not yet eligible for Centrelink parenting and carer payments until she had passed the minimum permanent residency period. Kwang was struggling to financially meet her son's needs due to a severe back

injury limiting her ability to work, and not having informal support for her son to allow her to work and earn an income. They were also at risk of becoming homeless, as the homeowner they were boarding with had no tolerance for any noise Kwang's son made. SWAN connected them with Foodbank, arranged hampers and vouchers to assist financially, and scheduled a meeting to assist Kwang to apply for the Centrelink payments she would be eligible for once the waiting period was over.

Tom

(name changed to protect his privacy)

Tom is a 22 year old diagnosed autistic level 2-3 and has no informal supports after being forced to leave home at 16 years of age. He was referred to SWAN by the Local Area Coordinator (LAC) Partner when he contacted them for help to understand his first NDIS Plan. On meeting with Tom, we learned that he had been advised that he would become homeless again in 3 weeks, and had been alternately sleeping rough, couch-surfing, sleeping in his car or in crisis accommodation for the past 4 years. Tom is a JobSeeker recipient awaiting the outcome of his Disability Support Pension application, He has no informal supports, insufficient funding in his NDIS Plan, which also does not include Support Coordination. Tom is on the waitlist for assistance from the disability advocacy provider, but had not understood how they could assist him in order to choose which of the issues he is experiencing he wants their assistance with (the provider require clients to nominate one issue when applying to the service). Tom is extremely overwhelmed by the myriad of issues he is attempting to deal with at once, the many complicated and inaccessible systems he is trying to navigate, and needs support to make decisions. He also finds transitions extremely difficult to cope with, and urgently needs stable accommodation.

SWAN provided Tom with information about housing and accommodation support services available. We assisted him to fill out application forms for public housing and for the WA Community Disability Housing Program. We wrote a letter of support, and worked with Tom to draft evidence of his needs for his GP to write a letter of support for the Community Disability Housing program.

We explained the eligibility requirements for Disability Support Pension, and that he would need more evidence to support his application. Tom was provided an example letter for his GP to use as a guide to write a new letter in support of the application.

SWAN then supported Tom to connect with a Plan Manager to start using his NDIS plan, and connect with an Occupational Therapist specialising in Functional Capacity Assessments to gain more evidence in order to seek an internal review of decision for NDIS Plan and provide additional evidence for his Disability Support Pension application. Tom has difficulty understanding questions, and was worried about undergoing the Functional Capacity Assessment (FCA) without support. At his request, SWAN will provide peer support during his FCA and support to understand and respond to the assessment questionnaires. We will then support him to review the FCA report and submit an S100 Internal Review of Decision on his NDIS Plan.

Davinder

(name changed to protect privacy)

Davinder contacted SWAN after a Google search. His son was diagnosed autistic in New Zealand and again in India, before they moved to Australia. Davinder confirmed that the family had been granted permanent residency. His son was struggling at school and needed Education Assistance Support, but had been unable to access this support because the school required full diagnostic evidence to support their application for funding. SWAN explained the Education Department's requirements, and advised Davinder to contact the New Zealand diagnosticians to seek his full diagnostic report.

Three weeks later Davinder contacted SWAN again, and emailed through the reports he had been able to source from both New Zealand and India. Unfortunately none of the reports addressed the autism diagnostic criteria or confirmed his formal diagnosis. Each report stated that he had been diagnosed autistic, but the actual diagnostic reports were missing. SWAN explained the diagnostic requirements in Western Australia, and that returning to India for another diagnostic assessment (which Davinder knew would be faster) would not be helpful, as it would not be accepted by the Department of Education. We then provided Davinder with information about how and who could assist with the autism diagnostic assessment for his son, and explained next steps for applying for Education Assistance funding and access to the NDIS.

Jennie and Devon

(names changed to protect privacy)

Jennie is a single parent. She has a degenerative neurological condition and uncontrolled epileptic seizures. Her son, Devon is diagnosed with autism level 3, and is non-speaking. Jennie first contacted SWAN when Devon was a toddler, prior to being diagnosed autistic. Over the six years we have supported the family, SWAN has provided information and support about autism, what to expect from the diagnostic process, what supports are available after diagnosis, and supported the family to access and navigate Carer Allowance and NDIS. We have supported Jennie to prepare for Devon to start school, understand Individual Education Plans (IEPs) and how to advocate for Devon. Like many people living in poverty in the region, Jenny fled a domestic violence situation with Devon and became homeless.

Initially the family were couch-surfing with extended relatives between two towns more than an hour apart, but this negatively impacted Devon's education. Jennie managed to purchase a caravan for them to live in, but they are finding it extremely difficult to manage in such a small space with Devon's support needs, and due to WA law are forced to move to a different caravan park every few months. Due to Jennie's epilepsy she is unable to drive, and reliant on extended family members and friends to assist them to relocate to a different caravan park, which also makes it difficult to get Devon to and from school. If there is an incident at school and Jennie is contacted to collect Devon, she is having to pay for a taxi to collect him – a huge expense for a single family living in poverty when some of the caravan parks are more than a half hour drive away from the school.

Most recently SWAN supported Jennie with gathering evidence of their urgent need for public housing to support their application, and assisted Jennie with drafting her NDIS Access Request Form as the impact of her neurological condition has increased.



Contact

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