

Submission to the WA Parliament Inquiry into Child Development Services



South West Autism Network

www.swanautism.org.au

Acknowledgements

SWAN acknowledges the traditional owners of the land on which this submission was produced, the Wardandi Noongar people. We acknowledge the deep spiritual connection to this land and extend our respects to community members and Elders past, present and emerging.

Submission preparation

This submission was prepared by South West Autism Network Inc. In order to write this submission, we listened to the views and concerns of autistic people, their families and advocates, and the wider community. We listened to parents and child development service providers throughout the south west community about their experience with accessing and using child development services. To aid in gathering quantitative and qualitative data, SWAN created a survey and invited people state-wide to participate. We had an overwhelming response to this survey, with 136 responses received in 11 days. People throughout WA responded, and our survey was shared on Facebook 54 times, with many people urging others to participate as an opportunity to have their voice heard on this important topic.



Figure 1: A word cloud featuring the most common postcodes of survey respondents

Introduction - About Us

The South West Autism Network (SWAN) is grateful to the Parliament of Western Australia for making available this opportunity to provide feedback on child development services in the state.

SWAN is a not for profit, charitable organisation supporting autistic individuals and their families living in the south west region of Western Australia for the past 12 years. We are a Disabled Persons and Families Organisation (DPFO) who are currently delivering two Information Linkages and Capacity Building (ILC) projects. We have almost 2000 registered members, with hundreds more people with disability and their families accessing support from SWAN. All staff, volunteers and Board members either have a disability, or are the family member of someone with disability.

Our role in the community is to provide information, peer support, advocacy, and connection to mainstream and disability services, building the capacity of people with disability and their families to navigate Government and non-government systems in order to meet their needs and participate in their local communities. We support people seeking diagnosis, post-diagnosis, and across the lifespan.

Access to Child Development Services

SWAN is extremely concerned about the lack of available assessment, therapy, and support services for children, teens and adults in the south west and regional Western Australia. For the purpose of this submission, we will focus on services for children and adolescents.

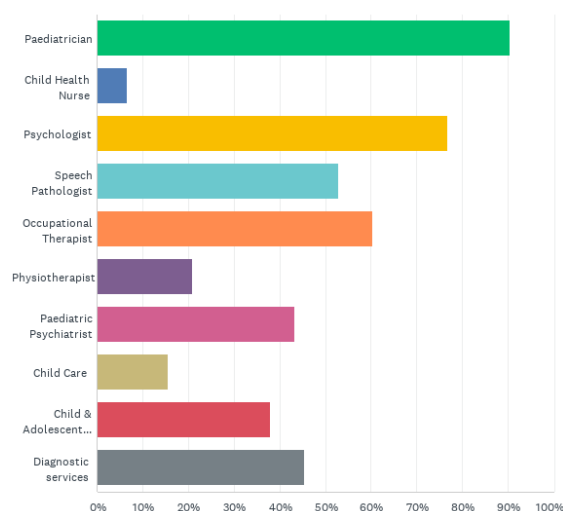
Prior to the rollout of NDIS in Western Australia, access to child development services was extremely limited, or non-existent outside the Perth metropolitan area. Most locations throughout the south west region had no child development services available, other than child health nurses and early childhood education. Whilst limited allied health services were available through some local hospitals, the therapists were often experienced primarily in aged care and rehabilitative services, with limited or no experience in child development.

The rollout of NDIS in Western Australian saw significant growth in the availability of child development services as families gained access to funding to address their children's developmental needs. Unfortunately, huge gaps remain in access to quality child development services. NDIS has served to highlight the high level of need in the community for access to a large range of child development services. This high level of need will continue to grow as our population grows, and significant change is needed to address the issues of access to, and quality of child development services.

Respondents to our survey were asked if they had experienced delays or difficulty accessing any of the following child development services:

- Paediatrician (90.30%)
- Child Health Nurse (6.72%)
- Psychologist (76.87%)
- Speech Pathologist (52.99%)
- Occupational Therapist (60.45%)
- Physiotherapists (20.90%)
- Paediatric Psychiatrist (43.28%)
- Child Care (15.67%)
- Child & Adolescent Mental Health Service (CAMHS) (38.06%)
- Diagnostic Services (45.52%)

Q2 Have you had delays / difficulty accessing any of the following child development services? (please tick all that apply)



Graph 1: Delays / difficulty experienced accessing specific child development services

When asked to rate the availability of child development services in their town, feedback received from our recent survey found that 86% of respondents felt that availability of services in their town was poor. Of the 136 survey participants, 62.5% advised that they waited more than 12 months to gain access to a child development service, with 37.5% of participants reporting wait times in excess of 18 months.

Here are some of the comments made by survey respondents related to accessing child development services:

“We can’t access anything! Every service has either closed their waitlist, or their waitlist is 12 months plus. What on earth are we supposed to do? I’m not a therapist, my son needs help!”

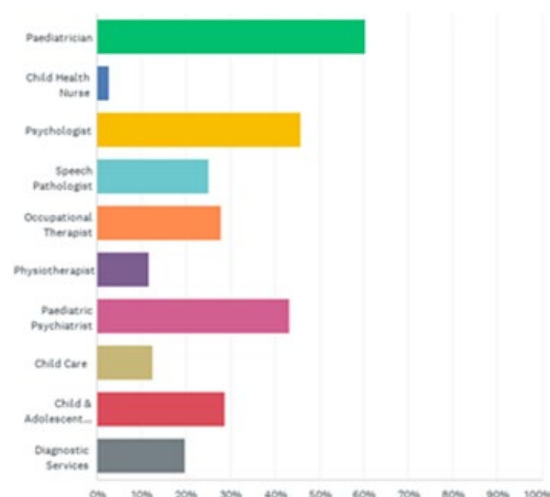
“There are none available, have to travel to appointments, the lack of physio and OT has caused great delays in my son and to look at travelling to appointments the cost in fuel plus time off school is not viable on a pension as there is no spare money, and he can’t afford to have so much time off school as if I could get an appointment there is over 130km round trip to the closest that have not had any vacancies for over 2 years.”

“There are more services in our town now, but the population has also grown. And with NDIS so has demand. It’s nearly impossible to access services. The wait time is horrific!”

Concerningly, respondents to our survey also advised that they had been completely unable to access some child development services:

- Paediatrician (60.36%)
- Child Health Nurse (2.70%)
- Psychologist (45.95%)
- Speech Pathologist (25.23%)
- Occupational Therapist (27.93%)
- Physiotherapists (11.71%)
- Paediatric Psychiatrist (43.24%)
- Child Care (12.61%)
- Child & Adolescent Mental Health Service (CAMHS) (28.83%)
- Diagnostic Services (19.82%)

Q7 Have you been unable to access any of the following child development services?
(please tick all that apply)



Graph 2: Inability to access specific child development services

Paediatrician Services

When seeking an assessment for their children due to developmental concerns, 60.36% of parents surveyed reported that they have been unable to access a paediatrician. One parent advised that *“Four month’s wait was the earliest appointment the paediatrician could see our sick son.”* In most cases, families are waiting between eight months and two years for an appointment to see a paediatrician, with some waiting more than four years before aging out of the system without access. Many families are attempting to access Paediatricians from outside of their local region – seeking referrals to paediatricians in the Perth metropolitan area with considerable inconvenience and additional expense involved in doing so.

A concerning high number of parents have advised that their only option to access paediatrician services has been TeleHealth with an eastern states’ practitioner. This comes with other issues. While TeleHealth enables access to the specialist service, physical examination is not possible, and parents have reported that when presenting to WA pharmacies with prescriptions made by interstate paediatricians, that they are not able to be filled. These are prescriptions that cannot be written by General Practitioners (GPs), forcing parents to join the bottom of the waitlist to access a WA paediatrician purely for gaining access to medication(s) already prescribed, including access to repeat prescriptions for long-term medications. This issue has also been reported to SWAN by families who have moved to WA from interstate.

Comments from respondents to our survey included:

“Our referral went lost for 4 years, even when I called and paed sent new referral....by then she was “too old”.”

“Paediatrician... I’ve given up trying to get an appointment even with referral and correspondence from school psych of urgent need.”

“Waiting over 4 years for necessary services and only got it because of fighting for it after 4 years.”

“Waited over a year for my daughter to see the Pead at PCH for rare disease assessment and genetic testing she clearly had the disease took so long then the genetic testing results took over six months to get the results - we deserve better in our great city of PERTH. She now needs a neurologist assessment as part of her rare disease diagnosis as she is at risk for seizures and other issues still four months nothing.”

“We have a 13 month wait to see a paediatrician for the first consultation”.

“Moved from Darwin and cannot get scripts for my diagnosed children because we are waiting to re-engage with a paediatrician in WA.”

“Waited 8mths then got covid had to cancel a week before then rescheduled for 8mths later.”

“My GP referred us to a paediatrician and feeding team. 2 months later the referral was passed onto the child health nurse (who I have already seen regarding issues) without contact from a paediatrician or feeding team. Unable to get an appointment at any point.”

A recurrent theme reported by parents is their desperation in trying to access paediatrician services for their child(ren). Parents report going to the GP for a referral to a paediatrician, only to discover that the paediatrician is not taking new clients, or their waitlist is longer than eight months. Parents are then returning to their GP for another referral to a different paediatrician, only to experience the same issue. The most common request for support SWAN has received over the past 18 months has been from parents seeking a paediatrician for their child.

“Wait times have been out of this world. Lucky I have the knowledge and capacity to be a squeaky wheel. From the perspective of an EC Teacher (20+ years), things have been a nightmare trying to access support. Everything escalated following the NDIS rollout. We have students entering Year 1 and just getting in to see a paediatrician. EC teachers want and need to work closely with allied health services, for the success of their children, but the support is so delayed.”

Quote from survey respondent

In addition to concerns raised by families about difficulties accessing paediatrician services, SWAN also received comments about difficulties accessing paediatric neurologists, Ear, Nose & Throat specialists, Genetics, and other paediatric specialist services. Particularly for families living in regional Western Australia, access to all paediatric services is seriously limited.

Specialist Mental Health Services

Families have been reporting to SWAN for more than two years that there are no private paediatric psychiatrists in Western Australia who are accepting new patients. Families also report extreme difficulties accessing Child and Adolescent Mental Health Services (CAMHS). The desperation and fear that parents experience trying to access these supports for their children and teens is palpable and heart-wrenching. There is strong evidence that early intervention is vital in reducing the long-term impact of mental health conditions on functioning, yet early intervention is often inaccessible or completely unavailable, particularly in regional WA.

Parents report repeated referrals being made to CAMHS by school, GPs, and Psychologists, and still being denied access to the service. SWAN has been contacted by families advising that CAMHS denied access to the service for their child until after there had been multiple hospital admissions and/or suicide attempts.

Comments from respondents to our survey question asking if they have been unable to access a child development service included:

“CAMHS... would not support the child due to living in a refuge which was 'unstable' living environment.”

“Our eldest was denied access to 9 different paediatric psychiatrists. Every paediatrician we contacted refused to see him. Both kids were referred to CAMHS more than 5 times before briefly gaining access, then being ejected so fast our heads spun.”

“CAMHS here in the south west are renowned for turning away people who are in desperate need. As a parent and professional working in mental health, I know first hand of kids who are suicidal being sent home to be cared for by their petrified parents due to insufficient staffing.”

“CAMHS refuse to see my son. School has referred him twice. Our psychologist referred him, and GP referred him too. Surely it's better to see him before he tries to kill himself?”

“We had four referrals to CAMHS from school, psychologist and GP. They won't see him.”

“Paediatricians won't see a 15yr old as a new patient (old paed died). CAMHS say he's too complex & not in crisis despite self-harming daily. No private paediatric psychiatrists taking new patients. Are we supposed to just watch him die?”

“Please fix CAMHS! My son needs to see a psychiatrist but no one will see him. Help us, please.”

“Our child is now 20 years old. When they were six years old, we went on the waitlist for paediatric psychiatry, referral, and we have never heard from them since. Diagnosed in private system with autism age 7, anxiety age 8, ADHD age 9, anxiety and depression, borderline personality disorder age 19. CAMHS refused to see us after the autism diagnosis. Child development services are appalling in this state, we may as well live in India or Africa.”

Of particular concern to both SWAN and the wider West Australian community, is the lack of mental health beds for children and adolescents in the state. There are none available outside of Perth, meaning that in addition to dealing with a mental health crisis, regional and remote children and teens are forced to relocate vast distances from their family and connections in order to access the vital mental health supports they need. This disconnection from their natural family and community supports exacerbates the isolation, stigma, and severity of psychological and emotional symptoms they are experiencing. The south west region has the largest population base outside of Perth, with Busselton recognised in July as the location with fastest selling properties in the state. (Source: <https://www.abc.net.au/southwestwa/programs/breakfast/busselton-fastest-selling-place-in-wa/13985038>) This increased migration to the south west places further strain on already over-stretched child development services in the region.

Psychology Services

There is a shortage of qualified and experienced psychologists Australia-wide, and this shortage is more intensely felt in regional Western Australia. 45.95% of survey respondents advised that they have been unable to access a psychologist for their child. Families report extreme delays in accessing psychology supports, and regional-based families report

significant difficulties sourcing and connecting with psychologists with experience and knowledge in the areas of need for their child / teen. Of particular note, are recurrently identified difficulties finding psychologists with expertise in supporting children and youth with developmental disabilities such as Autism, Intellectual Disability and Down Syndrome; eating disorders; behavioural issues and complex needs.

Families also report difficulty accessing support from school psychologists, particularly where the student has a diagnosed disability. Parents and carers report being informed that their child's needs are "too complex" for the school psychologist, and to use their NDIS funding for this support. Families of children and youth attending private schools in regional WA anecdotally report that there is no school psychologist linked with their school.

It's important to also note the difficulties families are experiencing in paying for psychology supports. Whilst the Covid-19 pandemic measures introduced by the former Federal Government included an increase in Medicare claimable psychology sessions from 6-10 sessions per year, to 6-20 sessions per year, the Medicare rebate for these sessions has not been increased. Families report paying between \$80 and \$130 out of pocket per psychologist session via the Better Access Initiative - Medicare Mental Health Care Plan. For many West Australian families, this cost is simply out of reach – and public mental health services for children and adolescents are under-resourced with enormous waitlists. Some of the free mental health services in the south west advised that their waitlists are currently 18 months to 2 years long.

A further issue with the Better Access Initiative is that there is no Medicare claimable item for seeing a Provisional Psychologist. Access to Provisional Psychologists would significantly improve access to mental health supports for children and young people, however this option is only available to more affluent families able to pay out of pocket, or NDIS participants with psychology supports funded in their NDIS Plans.

As a community, we also need to look at the eligibility criteria for the Better Access Initiative. To be eligible, a patient must both:

- have a mental disorder
- be likely to benefit from a structured approach to the management of their care needs.

(Source: <https://www.servicesaustralia.gov.au/better-access-initiative-supporting-mental-health-care?context=20>)

Diagnoses such as Autism, Intellectual Disability and Down Syndrome do not meet this criteria. These diagnoses are neuro-biological or genetic in origin, and are not a mental disorder. Concerningly, Local Area Coordinators and Delegates in the National Disability Insurance Scheme (NDIS) routinely misinterpret the NDIS Operational Guidelines referencing mental health supports (<https://ourguidelines.ndis.gov.au/would-we-fund-it/improved-health-and-wellbeing/mental-health-supports>) to deny funding for psychology supports in NDIS plans, despite the need for this support being directly linked to the disability; and necessary for building skills and capacity. This leaves families in the position of seeking a GP willing to bend the eligibility rules and refer their child to a psychologist under the Better Access Initiative. Assuming of course, that the family has the financial capacity to afford the cost of the Medicare gap fee.

Further comments from respondents to our survey about being unable to access child development services include:

“... The only reason I am able to take him to a psychologist is because of his NDIS funding as the new psychologists here are provisional. This means psychology is unaffordable for my youngest child, who has no diagnosis. ...”

“Children I support in a Domestic Violence refuge who are in urgent need of mental health support cannot get into see a counsellor or Psychologist.”

“Psychologist is in Perth, 3hrs drive away. Couldn't get in locally, so TeleHealth was the only option.”

“Covid hit my 12yr old really hard. She developed OCD and the Eating Disorder ARFID. CAMHS said she was too complex so wouldn't see her so we had to find a psychologist ourselves who could help. The nearest support was in Perth. It cost us a fortune to see an OCD specialist psychologist as we had to drive to Perth each week, had to take a day off work and she had a day off school. I ended up having to resign from my role as her needs were so high and we had appts in Perth each week and work was not supportive. Her school wasn't happy either due to at least 1 day a week missed while we travelled to Perth and her education has taken a big hit in the past 3 years due to school missed while travelling to Perth. When she was diagnosed with an eating disorder, again no one in Bunbury would take her on, no specialists/availability. We had to again go to Perth. We saw a specialist dietician over telehealth which wasn't ideal due to her not being able to sit still because of ADHD and she found it hard to build rapport which is very important in a therapeutic relationship. We had to wait over a year to see a eating disorder psychologist privately, all of this costing us a lot of money. She desperately needed a Child Psychiatrist but none of them in Perth were taking new clients. We have felt very alone and it has been a very scary time for the whole family. I'm not quite sure how we are all still here because suicide for a long time felt like the only way out of the nightmare the whole family was living. Something needs to be done urgently.”

Allied Therapy Services

Access to Allied Therapy Services is also limited in WA, particularly in regional areas. Respondents to our survey advised that 25.23% were unable to access a Speech Pathologist, 27.93% couldn't access an Occupational Therapist, and 11.71% were unable to access a Physiotherapist. Average wait times in the south west to access a private Allied Therapy Service is 6-18months, with some providers having closed their books to new clients due to high demand. For children diagnosed with a developmental delay or disability and referred to NDIS, publicly funded Allied Therapy supports are no longer available. Families of children not eligible for NDIS who access therapy supports through WA Country Health Services (WACHS) frequently report that their child(ren) are only able to access periodic reviews and consultations with parents, rather than actual therapy with the child.

The rollout of the NDIS in WA has led to 21,377 children aged 0-18yrs (as at 30 June 2022) of a total 46,475 people becoming NDIS participants (Source: <https://data.ndis.gov.au/explore-data>) with funding included in their plans for Capacity Building – Daily Living supports. This funding covers all areas of Allied Therapy Services (including Psychology) as deemed Reasonable and Necessary by the NDIA Delegate. For the majority of children and youth with NDIS funded plans, the only supports funded in the Plan are for Allied Therapy Services. This funding has led to a massive surge in demand for Allied Therapy Services, which the industry has been unable to fulfill. The availability of

Allied Health professionals is exacerbated by the shortage of University placements in Western Australia, with no training available outside of the metropolitan area.

Further comments from respondents to our survey about being unable to access child development services include:

“We’ve been waiting 2.5yrs to access an Occupational Therapist. 13 months so far waiting for access to a psychologist, and 2 years waiting for a speech pathologist.”

“... My daughter was referred to WACHS for OT and speech pathology, I don't know how long the wait will be- Last time it was about 6 months. I am waiting on OT availability at the service my oldest child attends for psychology. The only reason I am able to take him to a psychologist is because of his NDIS funding as the new psychologists here are provisional. This means psychology is unaffordable for my youngest child, who has no diagnosis. ...”

“We left another country town to be able to drive to Perth to access services. We still cant find an OT, speechie.”

“There are none available, have to travel for all appointments, the lack of physio and OT has caused great delays in my son and to look at travelling to appointments the cost in fuel plus time off school is not viable on a pension as there is no spare money, and he can't afford to have so much time off school as if I could get an appointment there is over 130km round trip to the closest that have not had any vacancies for over 2 years.”

“We waited 10 months for a speech therapist, and still on the waiting list for an occupational therapist 2yrs later.”

“Took us 18 months for our Autistic son to get an appointment to see a Occupational therapist.”

“Child psychology and OT are hard to get into but not as long. It's a long waiting game with minimal support in the interim. I also work in the local school assisting with speech programs alongside the speech pathologist. The wait can be about 9-12 months for these young children to get assessed and program put in place to allow them to “catch up” or assist them to progress appropriately with their peers. Busselton isn't a small town anymore and it is severely lacking in the health support for our young children.”

Diagnostic Services

The public diagnostic assessment service for Autism and Intellectual Disability through the Department of Communities has a waitlist of 6-12 months for children aged 0-6 years, and 12-24 months for children aged 7-17 years. When consideration is given to the wait time to access a paediatrician is 8 months to 2 years in most cases, the delay in accessing a publicly funded diagnosis in Western Australia is unacceptably long. This issue is exacerbated by the fact that diagnosis is the barrier to support services in the Education system, NDIS, and mainstream services. There is little to nothing available in the way of support for the children and guidance for parents during this very long wait period.

The alternate pathway for assessment and diagnosis is via private therapy services. Whilst wait times for private diagnostic services are generally much shorter the cost of \$2000-\$3500 is prohibitively expensive for many families. Access to Medicare rebates for assessments is restricted to paediatrician referral for children younger than 13 years. Such

rebates still require a substantial out of pocket gap fee to be paid by parents and carers. The requirements for autism diagnosis in WA is overly complicated as WA Education systems have not fully transitioned to the process as recommended in the [National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders](#). There are inconsistencies in requirements for Education Support funding in WA public schools, with some schools requiring diagnosis by paediatrician and psychologist or psychologist and speech pathologist, as recommended in the Guideline, whilst other schools require diagnosis by all three diagnosticians. SWAN contacted the Education Department of WA to seek clarification on this issue, and despite numerous phone calls were unable to source clarification on which clinicians must diagnose autism for students to be eligible for Education Support funding.

Once children are finally assessed and possibly diagnosed with a developmental disability, parents and carers must then tackle the long wait lists to access therapy services and try to navigate the NDIS. If their child(ren) are accepted into the NDIS, they are issued an NDIS Plan funded at the Typical Support Package (TSP) rate for their diagnosis – which usually is insufficient to meet their individual needs. In order to prove to the NDIS the impact of their disability on their function, families then need to source a Functional Capacity Assessment (FCA). This involves further stress and waiting to obtain an appointment for this intensive assessment - which not all therapists are qualified to do. The FCA typically costs approximately \$2000 of the child's NDIS funding, noting that most TSP plans for children aged 7-14 years in the south west are funded at \$5000-\$9000 per year (with the average cost for therapy services being \$193.99-\$234.83 per hour, plus travel costs). If the therapist writing the report isn't fully cognisant of NDIS legislation, Reasonable and Necessary criteria and Operational Guidelines, there is risk that the FCA report will be detrimental to the family's efforts to seek an increase in NDIS funding to meet their child's needs.

SWAN regularly meet with parents who talk about feeling frustrated, confused and often quite hopeless that their children will be able to access the therapy and support recommended by the clinicians who have performed various assessments on their child(ren). While the information and recommendations within an FCA report can be very comprehensive and provide guidance on supports and therapy, the onus is then on the parent or carer to attempt to access services to deliver these supports in a timely manner. The majority of school aged children do not have Support Coordination (assistance with accessing services and mainstream activities) in their NDIS plan as it is considered this is the parents role. Parents and carers very quickly become overwhelmed in trying to obtain adequate support for their child and information for themselves.

Unfortunately, the stress experienced by parents of young children is worsened by encountering various clinicians emphasising the urgency of early intervention for their child(ren). When families try to access early intervention services, they encounter waitlists of 8-18 months – intensifying the pressure and distress that parents and carers are experiencing. This perception of urgency for intervention that is generated within children's diagnostic and other therapy reports can lead parents and carers to believe they are failing their children if they do not acquire services quickly. While this has a major impact on families with very young children, parents and carers of older children often experience guilt that their child(ren) were not diagnosed earlier. Parents and carers need to be provided with relevant information and support in these interim periods to strengthen their belief in their own ability to support their children.

Across all child development services, families report an endless, distressing cycle of trying to access the child development services their child(ren) need, as evidenced by the direct quotes from survey respondents below:

“Beyond poor, they’re atrocious. You get sent round and round and round in an endless cycle of specialist referrals, only to be told they can’t assist until a different specialist is able to assess prior and when you go to them, they say they cannot help until the other Person sees the child. It’s time wasting, frustrating and absolutely debilitating.”

“We are restricted to very few paediatric services. Many of which are fully booked and not taking extra patients. You then go out of area and are willing to travel but they say they won’t accept the referral because you are too far away. Another hamster wheel of shame”.

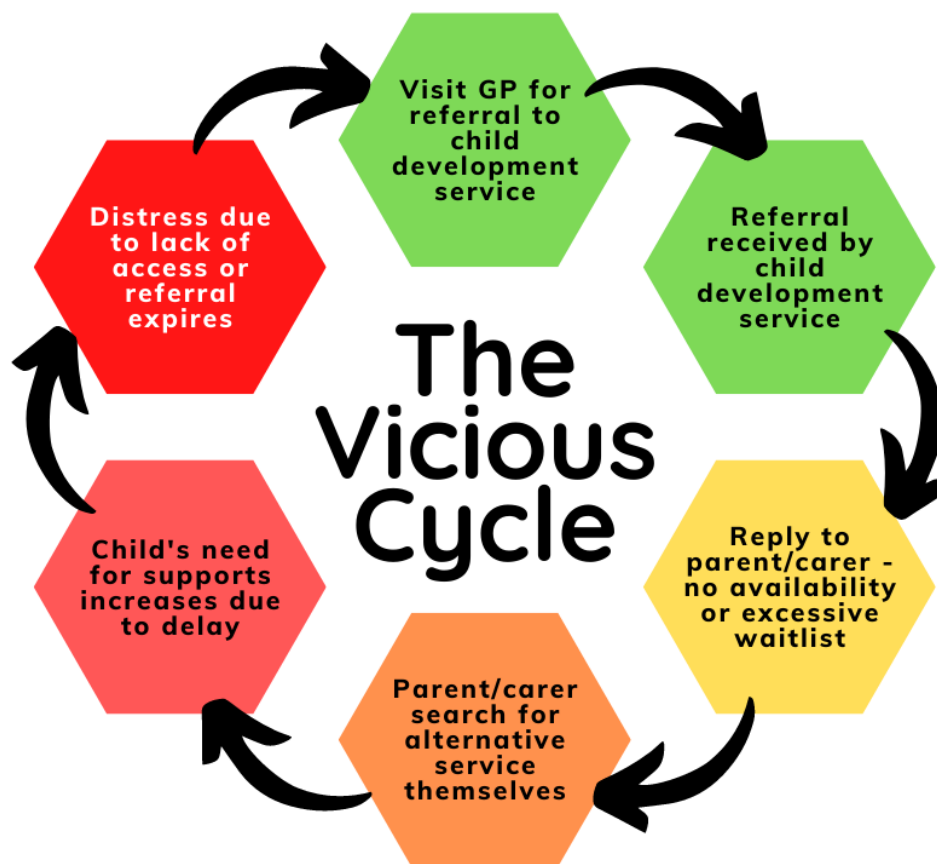


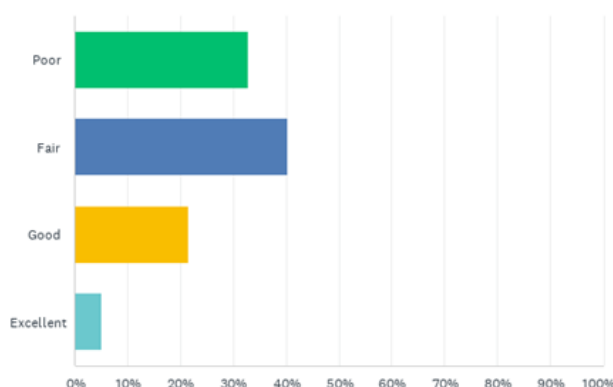
Diagram 1: The Vicious Cycle

Of particular concern to SWAN is the fact that many families simply do not have capacity to do the legwork of trying to find child development services they can access. The lack of readily available access seriously impacts the mental health of the whole family – creating more demand for support services across the lifespan.

Quality of Child Development Services

When asked to rate the quality of child development services in their town, feedback received from our recent survey found that 32.8% of respondents felt services were poor, 40.3% rated services as fair, 21.6% rated services as good, and 5.2% rated services as excellent.

Q6 Please rate the quality of the child development services in your town.



Graph 3: Quality of child development services

Additional comments in the survey noted that once families are able to access a service, the quality of the service is often high, but this is tempered by how difficult the service is to access, and the fact that in many towns, there are simply no child development services available locally. Several survey respondents also raised concerns about providers burning out due to high demand, and leaving the industry – further lessening availability of child development services. This concern is particularly prominent in the Busselton community, [REDACTED]. Below are some of the comments made by survey respondents about the quality of child development services in WA:

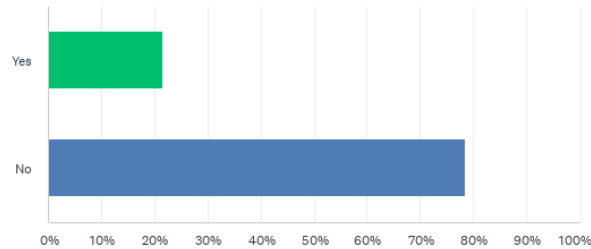
“The quality of the 1 therapist that my child uses is excellent, the overall quality of services in the area is poor as they are over extended. This is not saying that their services are of poor quality, it is saying that they are not being looked after and are in high demand. It is the quality of the spotlight from the government that is poor”.

“Overall, I think they are good (with some being excellent) – you just can’t access them!”

“Difficult to change provider if they’re not suitable or good enough as the wait to get in is so long – you’re stuck with whoever you can get in to and then terrified you’ll lost the service”.

As noted in the last statement above, we are aware that people are so desperate for services that they are taking whatever services they can get, and are reluctant to complain or seek alternate services, because child development services are so limited.

Q10 Do you know how to complain about child development services you have used?



Graph 4: Knowledge of child development services complaints processes

SWAN were deeply concerned to note that when asked in our survey if participants know how to complain about child development services accessed, 78.52% of respondents answered 'No' and 21.48% answered 'Yes'. In response to this question, we also received comments such as:

"If I complain, we lose access to services for my son".

"I don't feel comfortable complaining because we have such limited services, so we just remain silent".

Families in regional WA have raised concerns with SWAN that in order to meet demand, some providers are employing new Allied Therapy graduates, not sufficiently experienced or supervised to provide the support required by children with complex needs. This issue is particularly experienced by children and teens with limited or no verbal communication and/or requiring Positive Behaviour Support services. Families of children with these needs report to SWAN their experience of being turned away by each provider they approach for supports, because the needs of their child are "too complex".

Training and Qualifications for Providers of Child Development Services

Medical and Allied Health University courses are predominantly only available in the Perth Metropolitan area, meaning people in regional WA are forced to relocate to Perth in order to obtain appropriate qualifications to provide specialist services. A degree in Psychology used to be available at the Edith Cowan University Bunbury Campus, but Nursing, Primary School Teaching and Social Work have been the only University qualifications with some relevancy to child development available outside of Perth for more than a decade.

Many people, particularly parents with children, are unable to relocate even if it were financially viable. Housing shortages throughout Western Australia add another barrier to people being able to gain the necessary qualifications. To further exacerbate the issue – once people are qualified, they are unlikely to be able to move to the South West region as the housing shortage in the area is dire, and private rental costs have ballooned with the high demand. Even where training is available online or externally, all medical and Allied Therapy qualifications have requirements to attend campus in-person at specific times (exams, specific classes, Masters and PhD studies). Due to Covid-19, people with disability

and chronic illness at high risk of death or serious complications are completely locked out of University training in medical and allied therapy specialties.

NDIA delegates frequently fund Capacity Building – Daily Living (therapy) supports at a lower than needed rate, on the assumption that participants can stretch their budget by using therapy assistants. NDIS also requires that these therapy assistants be directly supervised by the therapist, and have a minimum qualification of Certificate IV in Allied Health Assistance. For families living in much of regional WA, including the south west, this is simply not an option. The Certificate IV in Allied Health Assistance is currently only available in Perth and Albany. NDIS do not take this into consideration when funding plans, however, so many participants are left with insufficient funded support to meet their needs.

Respondents to the survey made some of the following comments related to training and qualifications for providers of child development services:

“Please make training for these services available outside Perth. We are desperate for support for our kids.”

“We are seriously lacking in paediatricians, psychiatrists and all allied health professionals. ECU in Bunbury used to offer Psychology as a degree, but they dumped it. South Regional TAFE refuses to introduce the Cert IV in Allied Health Assistance, despite NDIS expecting people to use therapy assistants rather than therapists. We need the Bunbury ECU Campus to offer Psychology, Occupational Therapy and Speech Therapy as a bare minimum, and need the South Regional TAFE to provide the Cert IV in Allied Health Assistance training. People are desperate, waitlists are enormous. Our kids are falling through the cracks.”

“There is a lack of training outside of Perth for people wanting to work in this area. There is not enough allied health services available.”

“Can you bring in therapists and paediatricians from overseas? Can you make the training available outside of Perth?”

Our Recommendations

- Fund Education support for students in public schools based on need, rather than diagnosis. Develop an assessment process within the Department of Education for school psychologists and School of Special Education Needs (SEN) professionals to identify students at risk and in need of Education support services, and fund these supports on the basis of student needs rather than delaying supports until families are able to access formal diagnosis (often a wait of two years or longer for children aged 7 years and over).
- Subsidise the cost and increase University placements for students to study to become paediatricians, paediatric psychiatrists, paediatric medical specialists (including Neurology, Ear Nose & Throat and Genetics), psychologists, occupational therapists, speech pathologists and physiotherapists.
- Improve access to University training and bridging courses for regional and remote residents, both online and in-person at regional University campuses such as ECU Bunbury.

- Develop a program to pay out HECS / HELP debts for child development service and medical practitioners, conditional on working in regional Western Australia for a minimum of 5 years.
- Advocate to the Federal Government to add Medicare items for provisional psychologists (with sufficient training) to be claimed via the Better Access Initiative Mental Health Care Plan.
- Create Government incentives for paediatric specialists and Allied Health to work in regional WA.
- Introduce and promote a subsidised Certificate IV in Allied Health Assistance course at South Regional TAFE (Bunbury / Busselton / Margaret River). Introduce and promote a subsidised online / external Certificate IV in Allied Health Assistance course accessible to prospective students throughout regional WA.
- Prioritise building a specialist in-patient mental health treatment unit for youth in the south west region.
- Determine a specialist to population ratio for each child development service type and each region, mapping population growth and migration to plan for future needs. Ensure that the number of Government employed child development service practitioners are monitored and the specialist to population ration maintained.
- Collaborate with the Federal Government and professional regulatory authorities to streamline the process for overseas practitioners to immigrate to Western Australia and provide child development services. Provide fully subsidised programs of support to immigrants to enable them to meet regulatory requirements to practice in WA, accessible regardless of the location they reside in. Subsidise immigration costs for practitioners to move to regional Western Australia. Fees to be reimbursed to the Government if the immigrant does not engage in practice in regional WA (exemptions to apply for female immigrants requiring maternity leave) for at least 5 years.
- Advocate to Federal and interstate Governments for prescriptions to be fillable anywhere in Australia regardless of the location the prescription was written.
- The WA and Federal Governments to invest heavily in the construction, repair, and purchase of affordable housing options throughout Western Australia. If affordable housing is not available or accessible, there is little incentive for child development service practitioners to relocate to areas of need, and the pressure on existing services will continue to grow.

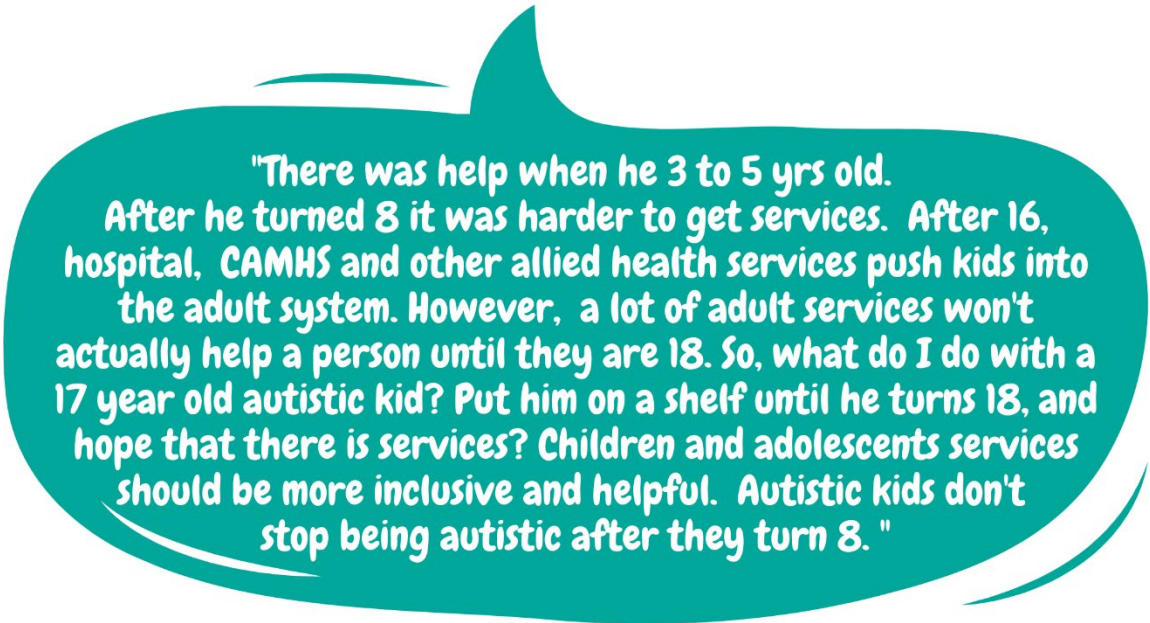
"Access to child development services in the south west is disgraceful. There is little to no availability, and the services that exist are stretched to their limits. Children are waiting far too long to access ALL services, and this is often incredibly damaging for those in need."

Conclusion

As an organisation with more than 13 years' experience negotiating, advocating, and working in the disability sector, supporting and advocating for thousands of people with disability living in regional WA, SWAN has an excellent understanding of the availability and quality of child development services and the disparity of access between metropolitan and regional WA.

As the peak body supporting autistic people in the south west region of WA, we would be happy to discuss the issues further with the Members conducting the Inquiry. It is very clear that whilst availability of child development services in WA has improved over the last several years, demand continues to far outstrip availability. Without significant investment in training and support for child development services in Western Australia, waitlists will continue to grow, and increasing numbers of children will fall through the cracks – requiring substantially more support from State and Federal Governments as adults.

Thank you for investigating these issues. Investment in child development services is an investment in the future of Western Australia.



"There was help when he 3 to 5 yrs old. After he turned 8 it was harder to get services. After 16, hospital, CAMHS and other allied health services push kids into the adult system. However, a lot of adult services won't actually help a person until they are 18. So, what do I do with a 17 year old autistic kid? Put him on a shelf until he turns 18, and hope that there is services? Children and adolescents services should be more inclusive and helpful. Autistic kids don't stop being autistic after they turn 8. "



"Investing in children's health and wellness is an investment in a better future."

Quotes from survey respondents

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