Data Analysis January – June 2022

Submission by the
Queensland Independent Disability Advocacy Network
(QIDAN)

Department of Seniors, Disability Services and Aboriginal and Torres Strait Islander Partnerships

July 2022

About the Queensland Independent Disability Advocacy Network

The Queensland Independent Disability Advocacy Network (QIDAN) is comprised of core members which are organisations delivering individual advocacy services to Queenslanders living with disability. These organisations are the Aboriginal and Torres Strait Islander Disability Network Queensland; Aged and Disability Advocacy; Amparo Advocacy Inc; Capricorn Citizen Advocacy; Independent Advocacy in the Tropics; Mackay Advocacy Inc; People with Disability Australia; Queensland Advocacy for Inclusion; Rights in Action; Speaking Up For You; and TASC National.

QIDAN has three aims:

- Systemic advocacy: to take coordinated action to address systemic issues experienced by people with disability,
- Member support: to provide a collaborative space for the exchange of information, resources and issues affecting disability advocacy organisations, and
- Sector advocacy: to promote the importance and value of independent disability advocacy on a local, state and national basis.

QIDAN's core members provide an array of independent disability advocacy services across Queensland, including general disability advocacy, specialized individual advocacy (including National Disability Insurance Scheme appeals and Disability Royal Commission advocacy), citizen advocacy and systemic advocacy. These experiences inform QIDAN's understanding and recommendations.

QIDAN's recommendations

QIDAN recommends the Queensland Government:

1. Provide a minimum of $15 million annually to expand disability advocacy service.

2. In the alternative, provide a minimum of $10 million annually to adequately resource existing disability advocacy service.

3. Provide an ongoing commitment to independent advocacy funding and aligning Queensland Disability Advocacy Program funding contracts with the Commonwealth Government included extended contract lengths.

4. Investigate and resource various complementary models of disability advocacy to work alongside individual advocacy including Citizen Advocacy and Family Advocacy.

5. Continue adequate funding for interpreters for both spoken language and Auslan past June 2023.

Introduction

In 2021, disability advocacy organisations in Queensland campaigned for the continuation of disability advocacy funding. The Queensland Government committed to providing disability advocacy funding until June 2023. During the launch of QIDAN and the newly established statewide information and referral service, Pathways, on 01st April 2022 Minister Craig Crawford, MP acknowledged the work that disability advocacy organisations do:

> *Everyday people with disability, their families, [and] their carers, reach out to advocacy services somehow to help them speak out, understand their rights and overcome barriers. Our government is proud to support organisations now who help others. We've provided $5.9m to fund 11 organisations across the state, to help deliver disability advocacy support services… Can I say a huge thank you to everyone who has put today together, can I thank each and everyone of you for being a part of this journey and knowing the significant difference you will make out there with families. It's not always going to be the big-ticket things that you resolve, it might just be something really really small, but that really small thing, will have a profound difference.*[1]

While the State Government made a commitment of $8.9m over two years for independent advocacy,[2] the reality has been a reduction in advocacy service's capacity statewide. This is due to a reduction in funding from the prior commitment of $9.2m from the previous two financial years,[3] as well as a reallocation of the funding across more services to include specialist cohorts and the Pathways information and referral service. Previous 'top up' funding, that allowed for rural and remote outreach in many instances was not renewed. QIDAN appreciates the additional needs specialist cohorts have and the information and referral service being a centralised point of up-to-date information to stop the many phone calls people with disability often need to make to find a disability advocate, however, the funding received from the Queensland Government simply does not meet the need.

QIDAN also appreciates the current recognition of independent disability advocacy through commitment to funding independent disability advocacy until June 2023. This funding has given us the theoretical opportunity to support people with disability no matter where they are in Queensland. QIDAN is now calling upon the Queensland State Government to commit to providing **ongoing** and **increased** independent disability advocacy funding to meet the ever-increasing demand from Queenslanders with disability. Additionally, to enable the disability advocacy sector to apply appropriate business considerations and practices that enable it to focus on the work at hand, QIDAN members respectfully request that funding contracts be brought into alignment with the Commonwealth National Disability Advocacy Program (NDAP) contracts, which are longer in duration and end in 2025.

---

[1] The Hon. Craig Crawford, Minister for Seniors, Disability Services and Aboriginal and Torres Strait Islander Partnerships, 01 April 2022, at the *Queensland Disability Advocacy Network and Pathways* launch.

[2] The Hon. Craig Crawford, Minister for Seniors Disability Services and Aboriginal and Torres Strait Islander Partnerships, 23 March 2021, *Palaszczuk Government committed to supporting all Queenslanders through advocacy support*, https://statements.qld.gov.au/statements/91774

[3] Stand with us!, 23 March 2021, Palaszczuk Government commits to continued funding for advocacy support, https://www.standwithus.com.au/

QIDAN is calling for the Queensland State Government to understand and acknowledge the work that advocates and advocacy organisations do to protect, defend, and promotes the human rights, safety, and wellbeing of people with disability, including the enormous downstream benefits for family, friends, community, and government. We remind the Queensland Government of the 2017 Cost Benefit Analysis completed by the Disability Advocacy Network Australia (DANA) which found that the cost benefit ratio of disability advocacy is 3.5 to 1, meaning every dollar spent on advocacy returns $3.50 in value.[4]

Independent disability advocacy services are critical for all Queenslanders living with disability, both participants of the National Disability Insurance Scheme (NDIS) and the vast majority who are not eligible to access the NDIS.[5] Whilst the NDIS is a complex system that present its own issues for people with disability, which often requires individual disability advocacy support, the Queensland State Government must not forget the myriad of issues faced by people with disability, whether they are NDIS participants or not. These issues include:

- Attitudinal barriers such as stereotyping, stigma, prejudice, and discrimination,
- Social barriers such an underemployment, access to healthcare, access to education, and a much higher experience of violence, abuse, neglect, and exploitation,[6]
- Accessibility barriers such as poor access to environment, communication, and inclusion in everyday life,
- Policy barriers such as the denial of access to programs and services; denial of opportunities to engage in co-design of services intended to address needs related to lived experience; and options to participate in the wider fabric of community discourse, and
- Systemic barriers such as systems and structures treating people with disability unfairly, or legislation failing to appropriately recognise or address the needs of people with disability.

These issues and barriers are present across all aspects of life e.g., housing; education; employment; child protection; health; transport; and service provision, all which are responsibilities of the Queensland state government. Statistics show that from 2015 to 2018 there was an increasing trend of people with disability reporting having experience discrimination with 2.6% and 9.6% respectively.[7] In 2018, over 33% of Australians aged 15 years and over living with disability reporting having avoided situations such as visiting family and friends, going to the shops or visiting restaurants, cafes or bars due to their disability in the previous 12 months.[8] For people with profound or sever limitations this experience was over 52% and even higher at 67% for people with psychosocial disability.[9]

---

[4] Daly, A, Barrett, G & William, R, 2017, *A cost benefit analysis of Australian independent disability advocacy agencies,* Disability Advocacy Network Australia (DANA), https://www.dana.org.au/wp-content/uploads/documents/Disability-advocacy-CBA-2.pdf p. 43.

[5] 107,365 Queenslanders were NDIS participants as of 31st March 2022 - National Disability Insurance Agency, 2022, *Explore data,* https://data.ndis.gov.au/explore-data, retrieved 15 July 2022.

[6] Centre of Research Excellence in Disability and Health, March 2021, *Nature and extent of violence, abuse, neglect and exploitation against people with disability in Australia,* https://disability.royalcommission.gov.au/system/files/2021-11/Research%20Report%20-%20Nature%20and%20extent%20of%20violence%2C%20abuse%2C%20neglect%20and%20exploitation%20against%20people%20with%20disability%20in%20Australia.pdf p. 9.

[7] Australian Bureau of Statistics, 24 October 2019, *Disability, Ageing and Carers, Australia: Summary of findings,* https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/2018

[8] Ibid.

[9] Ibid.

Access to independent advocacy support is a crucial form of early intervention for people with disability that:

- Addresses serious issues of discrimination, violence, abuse, and neglect of people with disability,
- Represents the rights and interests of the most vulnerable in our community who do not have a voice, or close family or friends who can support their aspirations, or speak on their behalf,
- Builds the capacity of individuals with disability and their family members to understand their rights, make informed decisions and to speak up about what is important to them,
- Supports timely access to essential information, mainstream services and disability supports so people's fundamental needs are met, and rights upheld,
- Prevents an escalation of the person's issues and vulnerability,
- Has long-term cost benefits and saves government and public resources,
- Seeks to build and repair close relationships around the person, an important safeguard for all of us, but especially people with disability,
- Identifies systemic failures and brings these to the attention of those in positions of power and influence in governments and community,
- Supports the Queensland Government to meet its National Disability Agreement (NDA) obligations as part of the National Disability Strategy (2021-2031),[10]
- Encourages services to work in ways that are truly person-centred and culturally responsive, and
- Provides a level of accountability which is necessary in all healthy democracies.

In less than six months since the beginning of the new Queensland disability advocacy funding agreement (01st January 2022 – 31st May 2022), QIDAN member organisations have provided 2330 advocacy services and had to turn away 612 requests for disability advocacy support. The data shows that the inability to provide advocacy services to Queenslanders living with disability is occurring across the State, highlighting the need for a state-wide increase in disability advocacy services.

Advocacy Services Data Analysis

The current model of funding for disability advocacy in Queensland theoretically funds advocacy in all geographical locations in addition for specialist services for, Aboriginal and Torres Strait Islander people with disability, culturally and linguistically diverse people with disability, and children and young people with disability (0-18 years).

Due to the nature of advocacy work and the barriers that people with disability experience, extensive face to face advocacy is often required. In larger regions and rural areas, face to face advocacy requires extensive travel and time. Advocacy is often seen as the 'last resort' when people with disability are banned from other services meaning that a lot of time is spent building relationships. In many areas, advocates work closely with government agencies, such as the Office of the Public Guardian (OPG), Public Trustee of Queensland (PTQ), and Child Safety (DoCS) and receive direct referrals from these departments. Additionally, in regional areas advocates are often required to provide face to face support to people accessing mainstream services that do not have a physical presence in the local region (for example, the National Redress Scheme, or Department of Housing). These mainstream services are

---

[10] Commonwealth of Australia Department of Social Services, 2021, *Australia's Disability Strategy 2021 – 2031,* https://www.disabilitygateway.gov.au/document/3106.

reliant on disability advocates to help breakdown information and communication barriers and act as an accessibility conduit.

With the complexities of issues and barriers that people with disability experience, it can take many months and in some cases years to resolve matters. In the meantime, advocates are focused on small achievements such as a person having their voice heard at stakeholder meetings, unsupervised visits with their children, or day leave from hospital.

It should also be noted that although the NDIS is a dominating topic of discussion, advocates support people who are not NDIS participants, about issues that are not NDIS related. This can also be seen in QIDAN organisations data, and The Minister has acknowledged this:

> *It's important to note, it's not just about the NDIS, the NDIS will obviously be a big chunk of advocacy, we still understand there are many many bumps, and potholes as we navigate and the NDIS matures, but there are a range of other things outside of the NDIS that is really important from an advocacy perspective.*[11]

Regional Advocacy Services

Between 01st January 2022 and 31st May 2022, regional advocacy services funded by the Queensland Disability Advocacy Program (QDAP), provided 1844 advocacy services. Demographically, services were provided evenly between people identifying as male and female. As the data reports on identifying gender and not sexuality, people who reported as transgender was limited as individuals are likely to identify as male or female.

The majority, 60% of services were provided to individuals within the age group of 36-65. Notably, only 4% of advocacy services were provided to people 65 years and older however, in 2018, approximately 49% of Queenslanders aged 65 years or older were living with disability.[12] While many people over the age of 65 may be able to access services through Aged Care Advocacy, there is a potential gap in service for people aged 65 and over who have a disability advocacy issue.

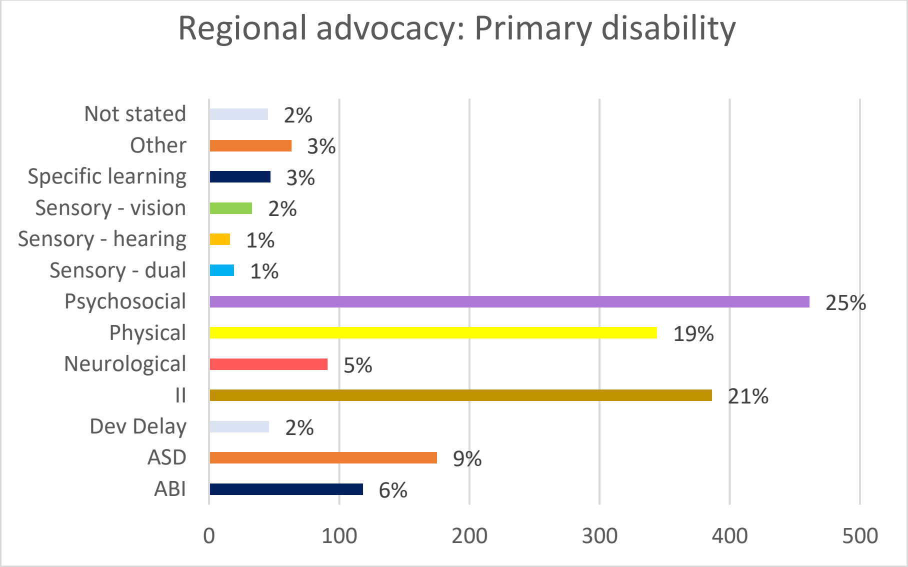
Regional advocacy has continued to provide support to individuals who may also be eligible for specialist advocacy services. A total of 12% of services were provided to young people between birth and 18 years, 12% of services were provided to people identifying as Aboriginal and/or Torres Strait Islander, and 14% of servicers were provided to people identifying as culturally and linguistically diverse.

---

[11] The Hon. Craig Crawford, Minister for Seniors, Disability Services and Aboriginal and Torres Strait Islander Partnerships, 01 April 2022, at the *Queensland Disability Advocacy Network and Pathways* launch.

[12] Australian Bureau of Statistics, 24 October 2019, *Disability, Ageing and Carers, Australia: Summary of findings,* https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/2018.

Graph 1: Regional advocacy services: Primary disability



Most people receiving advocacy services received service face-to-face (55%), followed by 34% receiving services over the phone. Due to the nature of advocacy work, relationship building, communication difficulties and the many barriers to services that people with disability often experience, face-to-face advocacy is the preferred method for delivering support. Due to resourcing, face-to-face advocacy is not always possible and has become increasingly difficult with the large distances that regional advocacy services theoretically provide service to.

It is important to note that 41% of advocacy services were provided to people who are not participants of the NDIS. While only 38% of advocacy issues were regarding the NDIS, of this 38%, 40% relate to access. Considering the high number of individuals with psychosocial disability who required advocacy service this could be indicative of the difficulties accessing the NDIS and other limited state-based supports. Assistance with NDIS service provision comprised 31% of the NDIS issues. Both of these issues, access and service provision, while NDIS related also have significant impact on state-based services such as health, housing, education, child safety and justice.

Graph 2: Regional advocacy services: Breakdown of mainstream and NDIS issues

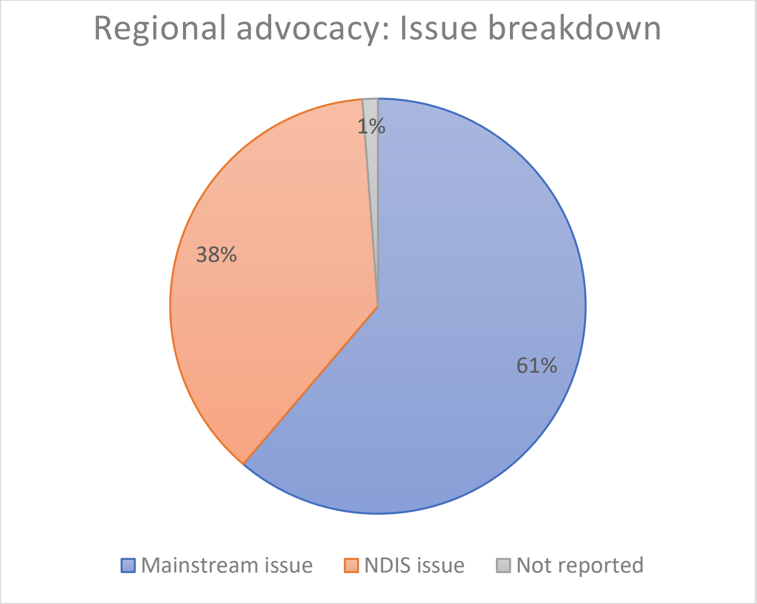
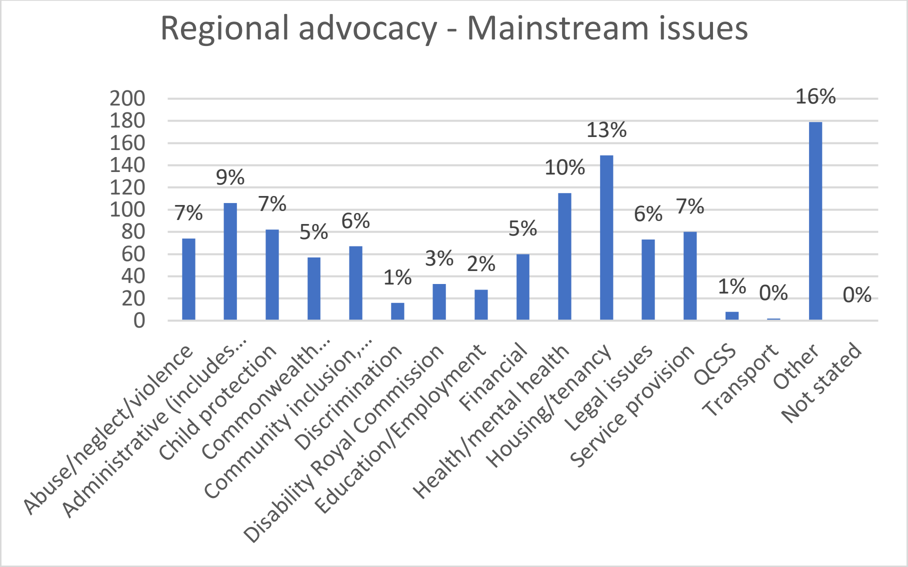


Table 1: Regional advocacy services: NDIS issues breakdown

NDIS Issue	Percentage
Access	40%
Plan review	22%
Decision Making Support	5%
Service Provision	31%
Not Stated	2%

It should be noted that housing/tenancy was the most significant issue, 13%, for people accessing regional advocacy services. This issue appears to be increasing in frequency from quarter 1 2022 to quarter 2 2022. Health/mental health, 10%, and administrative, 9%, issues are also key issues that advocates have been assisting with.

Graph 3: Regional advocacy services: Mainstream issues breakdown

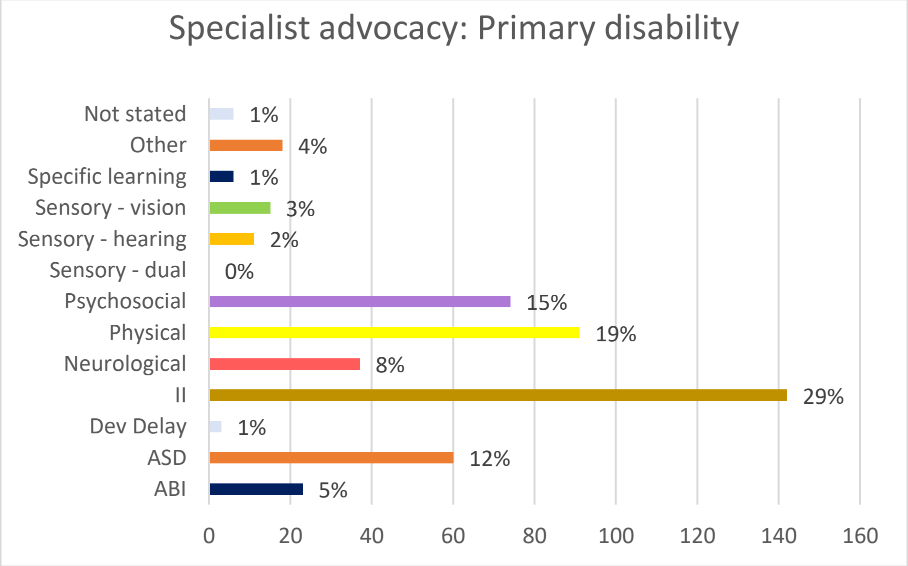


Specialist Advocacy Services

The three specialist advocacy services beginning 01st January 2022 provide support to people with disability who identify as: Aboriginal and/or Torres Strait Islander (ATSI); culturally and linguistically diverse (CALD); or aged between birth and 18 years of age (young people). Between 01st January and 31st May 2022, these programs collectively provided 486 advocacy services.

Similar trends can be observed with the gender data for these services however, the age data identifies that 46% of services were provided to people from birth to 18 years. Interestingly, 15% of specialist advocacy services were provided to people aged 65 and above. Another key difference is the primary disability recorded with intellectual impairment accounting for 29% of the services provided.

Graph 4: Specialist advocacy services: Primary disability



As expected, there was a high number of services (69%) provided to people who identify as culturally and linguistically diverse. While the numbers of services provided to people who identify as Aboriginal and/or Torres Strait Islander was 20%, there are a number of reasons for this. As the specialist advocacy program for people who identify as Aboriginal and/or Torres Strait Islander is a new program it has taken time to develop using co-design, and to build trust within community. The growing demand for this service is evident in the increasing number of services each month.

There is a substantial difference in NDIS status between the regional services and specialist services. The specialist services reported 73% of advocacy services provided were to people who are NDIS participants. Similar to the regional advocacy services, 56% of services were provided face-to-face and 33% via phone. Specialist advocacy programs have reported substantial difficulties providing state-wide culturally appropriate and responsive in-person advocacy due to the limited funding restricting outreach. Again, face-to-face advocacy service is often the preferred method due to the complexities of the situation and experiences, especially considering the intersectionality of these cohorts.

The issues advocacy assisted with vary substantially between specialist cohorts. For both the CALD and young peoples cohorts, mainstream issues made up 66%. However, this was reduced in the ATSI cohort with NDIS issues making up 55%. Data from the ATSI cohort demonstrates the need for NDIS access assistance for Aboriginal and/or Torres Strait Islander people. Inadequate NDIS supports for culturally and linguistically diverse people and young people have a broader impact on state-based services as they attempt to have their needs met by mainstream and community programs. Additionally, service provision is a consistent issue across all cohorts, all regions and regardless of NDIS status.

Graph 5: Specialist advocacy services: Breakdown of mainstream and NDIS issues

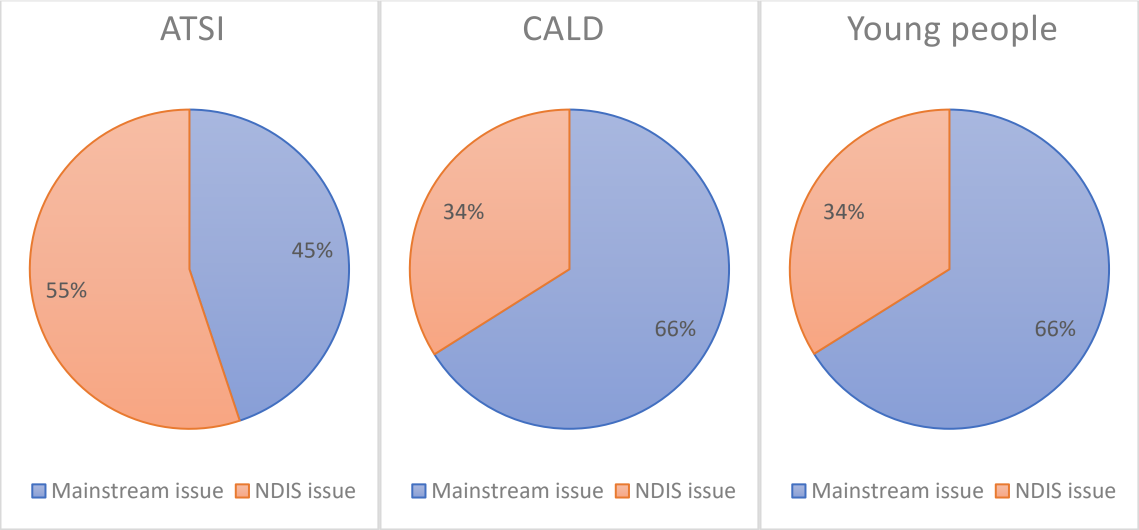


Table 2: Specialist advocacy services: NDIS issue breakdown

	Key NDIS issue - 1		Key NDIS issue - 2		Key NDIS issue - 3	
ATSI	Access	46%	Service provision	33%	Plan review	15%
CALD	Plan review	47%	Service provision	30%	Access	23%
Young People	Plan review	65%	Service provision	20%	Access	15%

Overall, the most common issue for specialist cohorts was housing/ tenancy and service provision, both at 19%. However, when each cohort is analysed separately, there are clear differences based in cohort need. Housing/ tenancy and service provision was a key issue for both ATSI and CALD cohorts, however education was by far the biggest issue for young people. Notably, there was engagement from young people involved with child safety to have their voice heard.

Table 3: Specialist advocacy services: Mainstream issue breakdown

	Key mainstream issue - 1		Key mainstream issue - 2		Key mainstream issue - 3	
ATSI	Housing/ tenancy	30%	Service provision	23%	Administrative	14%
CALD	Service provision	22%	Housing/ tenancy	21%	Health/ mental health & community inclusion	13%
Young People	Education	61%	Child protection	18%	Community inclusion	13%

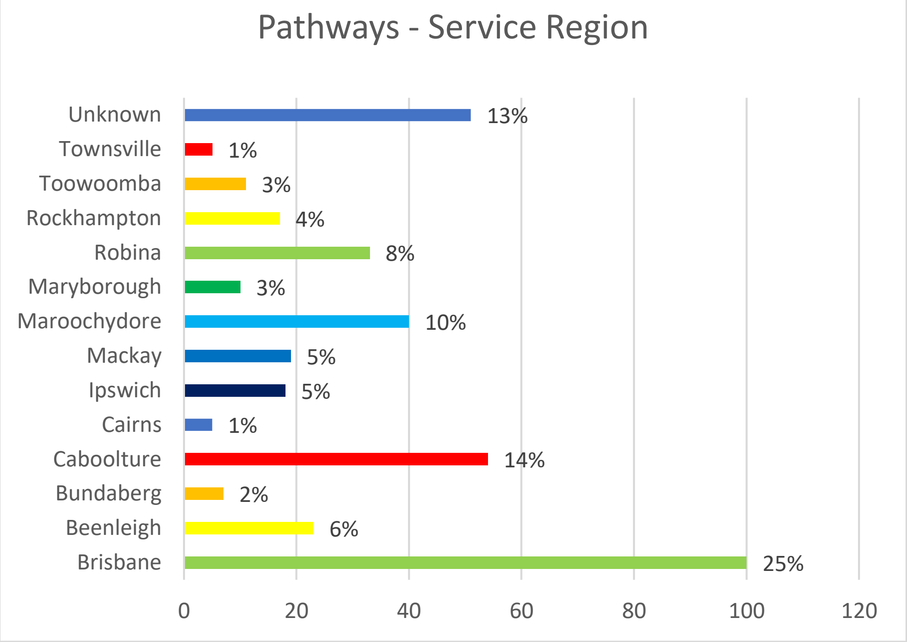
Pathways

Pathways was established in January 2022 as the 'Hub', funded by DSDSATSIP, to provide information and referrals to people with disability, their families and supports. As the 'Hub', Pathways maintains systems and processes for reporting and monitoring service capacity across QDAP organisations. This ensures, as much as possible, that people with disability seeking advocacy assistance are not on a constant 'referral-round-about'.

It should be noted that most enquiries received to Pathways would meet advocacy criteria, however, when Pathways is aware that there is no capacity in the region or with specialist programs, alternative referrals are made where possible. People with disability are often referred onto other supports that may be able to assist, such as community legal centers and community supports. Whilst these services are able to provide advice and, in some cases, ongoing support, they do not replace the need for individual disability advocacy and in some cases, individuals have returned seeking advocacy support after engaging with non-QDAP community-based services.

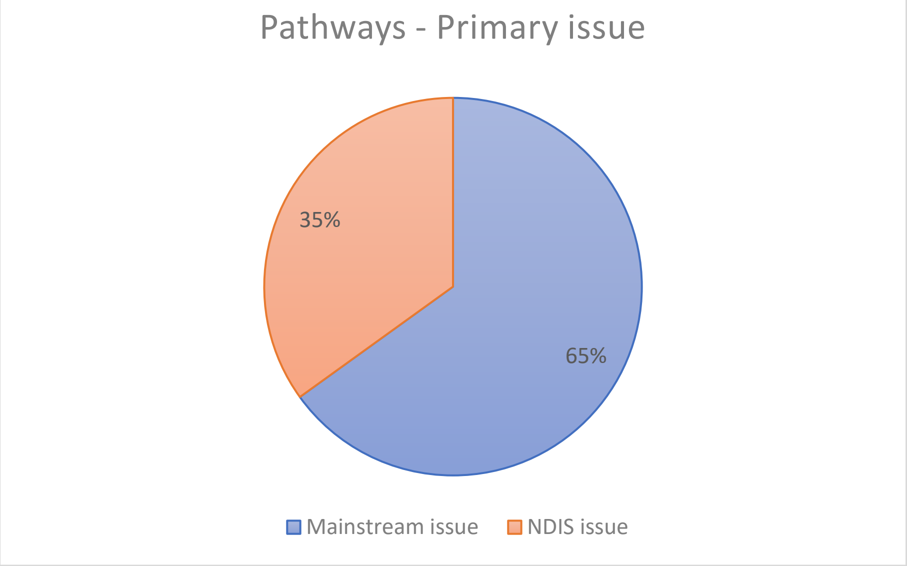
Between 01st January 2022 and 30th June 2022, Pathways provided 395 information and referral services. Most services were provided via phone to people across Queensland.

Graph 6: Pathways: Breakdown of service region[13]



In many instances, people contacting Pathways have a range of issues they are seeking advocacy in relation to. Due to limitations in the reporting only the primary issues are able to be captured. Between 01st January 2022 and 30th June 2022, 65% of services were provided for mainstream issues, while the remaining 35% were NDIS issues.

Graph 7: Pathways: Primary issue

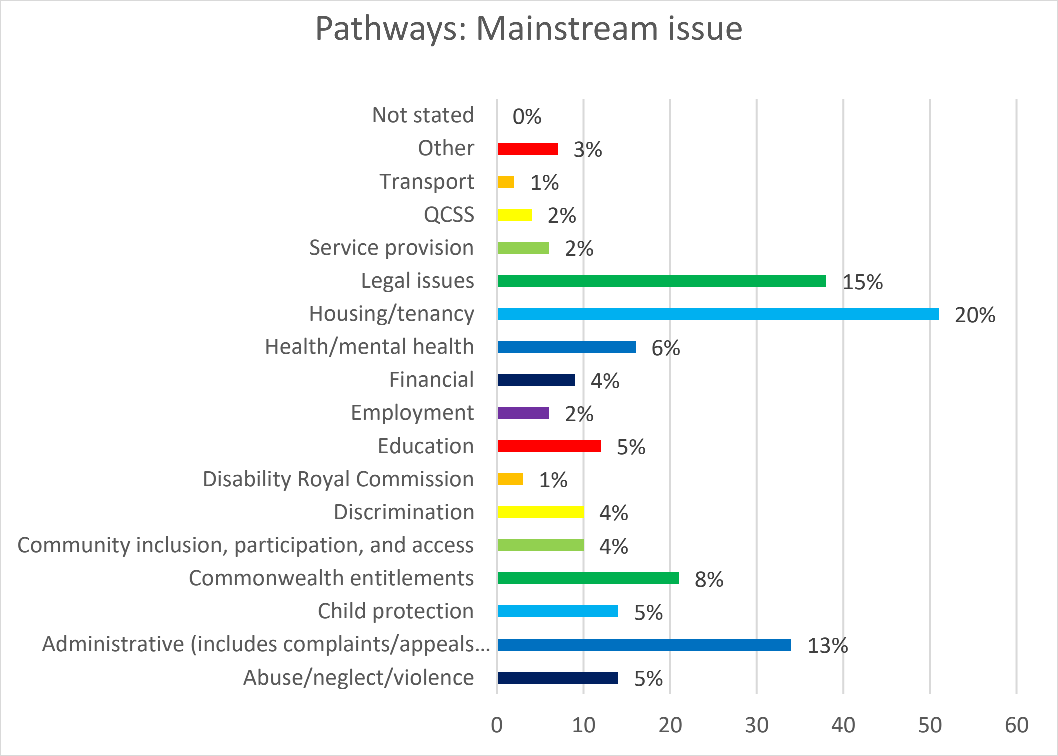


---

[13] The service region reflects where the individual requesting information and referral services lives and is reflective of the QDAP funded regions.

A further breakdown of the mainstream issues highlights that housing/tenancy, 20%, is a key issue for Queenslanders with disability. This is followed by legal issues, 15%, administrative issues, 13%, and commonwealth entitlements 8%. These trends are similar to those seen in the services provided by advocacy organisations.

Graph 8: Pathways: Mainstream issue breakdown



NDIS issues are also broken down in the following table. It is interesting to note that 38% of NDIS issues relate to access to the NDIS, and this often interacts with State systems such as health, education, and justice.

Table 4: Pathways: NDIS issue breakdown

NDIS Issue	Percentage
Access	38%
Plan review	29%
Decision Making Support	10%
Service Provision	16%
Not Stated	7%

Between 01st January 2022 and 30th June 2022, 35% of referrals from Pathways were made to QDAP providers. A breakdown of these referrals is shown below. A total of 25% of Pathways services resulted in 'no referral' and people were provided with information to assist them to self-advocate. This is often as a result of advocacy organisations lack of capacity. Although information was provided to these individuals, it does not provide the assistance that individual advocacy would and provide the desired outcome of ongoing assistance.

Graph 9: Pathways: Referred to

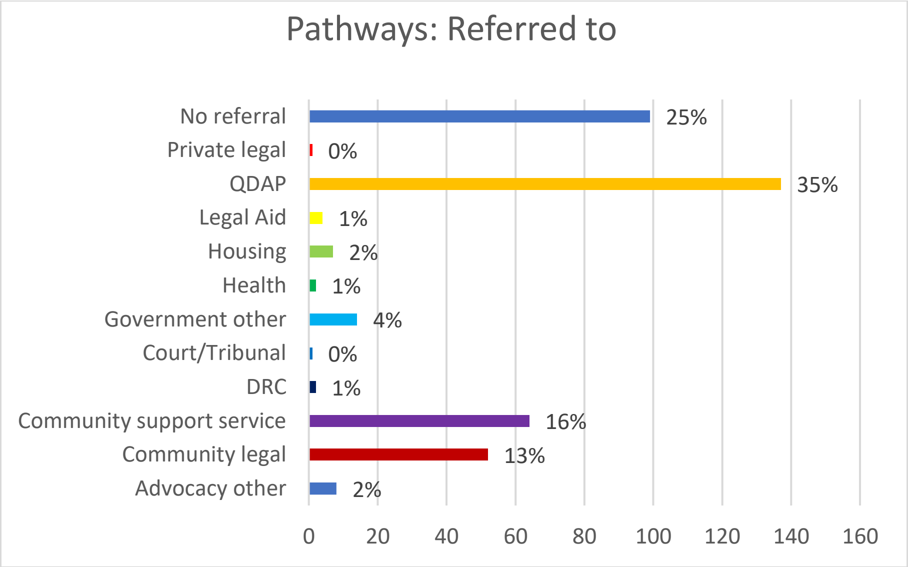


Table 5: Pathways: Referrals to QDAP providers

QDAP Provider[14]	Number of Referrals
Aboriginal and Torres Strait Islander Network of Queensland	8
Aged and Disability Australia	18
Amparo Advocacy	0
Capricorn Citizen Advocacy	0
Independent Advocacy North Queensland	2
Mackay Advocacy	8
People with Disability Australia	52
Queensland Advocacy for Inclusion	118
Rights In Action	0
Speaking Up for You	50
TASC National	26

It is important to note that when a referral is made to a QDAP provider, the service referred to may not be QDAP funded. For example, a referral to People with Disability Australia may result in support provided by their NDIS appeals service, or individual advocacy that is funded by NDAP.

The time in which QAI had to set up Pathways was limited as the service needed to be operational from 05th January 2022 which is the first day back after the Christmas/ New Year break. This provided limited

---

[14] Aboriginal and Torres Strait Islander Disability Advocacy Network of Queensland, Amparo Advocacy Inc and Queensland Advocacy for Inclusion provide specialist advocacy services.

time to develop the processes for Pathways which have now been successfully developed, although are going through constant transformation and improvement.

Another issue experienced with Pathways is the ability to backfill staff when sick or on leave. This has been exacerbated by the impact COVID19 and general illness has had on the wider community. The skills and knowledge a staff member must have to effectively complete the information and referral role is high, meaning an individual must go through rigorous training. Staff must know which organisations operate in which region, the differences in advocacy services (such as the differences between QDAP and NDAP services), and the nuances of each individual advocacy service. Additionally, due to the limited capacity in the advocacy sector, Pathways staff have had to acquire the same level of knowledge for the community services sector and community legal services sector. Pathways staff must also stay up to date to changes that occur throughout different areas such as the NDIS, QCSS or housing which is time consuming.

The Pathways staff have undergone extensive training and continue to engage in training and building relationships with both QDAP and non-QDAP organisations to provide the best information and referral service possible. This has meant that creating outwards facing resources for both social media and the website have been limited as staffing the Hub has been the main priority. It is also very difficult to hire staff who have experience in both phone/web-based enquiries and resource development as these are two very different skillsets. Pathways requires an increase in staff to ensure there is a full roster of individuals with the expertise to complete the work. This would also allow Pathways to complete promotion of the service to raise awareness of its existence and support available which has been limited due to staffing limitations.

Funding for ‘the Hub’, also includes operating QIDAN. The initial set up of QIDAN required extensive work and continues to be time consuming. QIDAN is now operating effectively, however it can be difficult to make decisions when managers are unable to attend meetings due to competing interests, which can mainly be attributed to experiencing capacity issues locally. Operating QIDAN is a full-time position as QIDAN is striving to be an effective peak body. This includes the set up of a Community of Practice for disability advocates across the State and organising support and training to further develop skills and education sector wide as well and the ongoing management of QIDAN systemic issues.

Unmet Demand Data Analysis

An important distinction to make is the difference between unmet demand and unmet need. The data collected for the period, 01st January 2022 to 31st May 2022, refers to unmet demand; that is people who have identified they have a problem and have enquiries about disability advocacy support. There are an exceptional number of people living in closed and hard to reach environments (such as group homes, boarding houses and hostels, rural and remote areas etc.) that either:

- Are unaware disability advocacy existing and could assist with their issue,
- Do not have the means to make initial enquiries to disability advocacy. E.g., they do not have access to a phone, do not use a computer/email/internet,
- Are unaware they are in a situation that could be improved with disability advocacy. E.g., Unaware of their rights to come and go from their premise as they wish, unaware that there is a process to intervene in unauthorised restrictive practices, or that there is assistance to engage appropriate services to meet their needs.

An additional issue with the lack of disability advocacy funding is the inability for services to complete meaningful engagement with individuals face-to-face when they are funded for one advocate (and in many regions, less than one full time advocate) to cover hundreds of square kilometers. This means people who require proactive assistance from a disability advocate are unable to access these services. As the Disability Royal Commission has highlighted, people with disability are more likely to experience violence than people without disability.[15] Proactive outreach to find and support people with disability who fall into the 'unmet need' category is important in upholding an individuals rights.

Unmet Demand - Combined

When interpreting the unmet demand data, it should be interpreted within the current context. There are limitations to this data which means it does not accurately reflect the full extent of the unmet demand. It has become clear that there is inconsistent reporting of unmet demand between services. One of the reasons for inconsistent reporting is due to limited guidance and/ or training provided by DSDATSIP to QDAP organisations as to how to best use the reporting spreadsheet and the definition of different reporting options. This has meant QDAP organisations have created their own internal definitions in relation to what and how to report unmet demand, leading to significant inconsistencies and uncaptured enquires. QDAP organisations also have concern that reporting unmet demand when potentially not meeting work plan obligations (such as number of clients) could cause issues with DSDATSIP.

This report focuses on the unmet demand since the reallocation of Queensland disability advocacy funding which occurred in January 2022. However, there has been a long history of disability advocacy not being able to meet the demand and this report highlights this ongoing issue. During period 01st January 2022 – 31st May 2022 the disability advocacy organisations operating in Queensland have been unable to provide service to 612 individual enquiries. At least 16% of these enquiries were refused service due to lack of capacity in the organisation and 4% due to having no specialist skillet.[16]
It is acknowledged that 26% of the reason for being refused service were due to "not being an advocacy issue", however this can be explained by advocacy organisations having to reduce their scope, to ensure they can provide consistent services to the most vulnerable people with disability. There are many issues that disability advocacy has previously assisted with, however due to the increased demand and reduced serviceability due to funding restraints, have had to turn away. Disability advocacy organisations have also had to refer matters on to other services such as community legal services due to capacity, whereas if they had the capacity, they would assist with the issue.

Many organisations are not reporting when they complete information and referral work as this is onerous and organisations are not funded to capture this data. Admin, intake and in some cases, advocates can spend significant time on the phone (and follow up emails) explaining processes to

---

[15] Centre of Research Excellence in Disability and Health, March 2021, *Nature and extent of violence, abuse, neglect and exploitation against people with disability in Australia,* https://disability.royalcommission.gov.au/system/files/2021-11/Research%20Report%20-%20Nature%20and%20extent%20of%20violence%2C%20abuse%2C%20neglect%20and%20exploitation%20against%20people%20with%20disability%20in%20Australia.pdf p. 9.

[16] No specialist skillset refers to a more appropriate funding stream such NDIS appeals.

individuals who enquire for advocacy support and due to having no capacity, provide information and referral to assist the individual as much as possible. It is difficult and somewhat awkward to ask individuals for information that DSDATSIP is requesting as part of the unmet demand reporting when an organisation is turning them away.

Additionally, if an advocate provides a ‘one of advice’ or short-term advocacy, whereas the person would like ongoing support, but the organisation does not have capacity, this is also not being captured in unmet demand, rather only in individual advocacy services delivered. This type of work is also being completed by advocacy organisations across the country (described as ‘little advocacy’ by the Victorian Council of Social Services) and is often completed because the alternative is no support at all.[17]
Many of the organisations have also advised they are not reporting when they are completing what is referred to as ‘passing the buck’ work. This is when referrals are made to advocacy organisations when the referrer should be completing the work. This is work that takes time to explain to the individual and the referrer what the next steps are and why the referrer should be completing the work. For example, employment services referring individuals to advocacy service to fill out disability support pension paperwork. There is an opportunity to develop the disability sectors knowledge and skillset, however advocates do not have the capacity to do so.

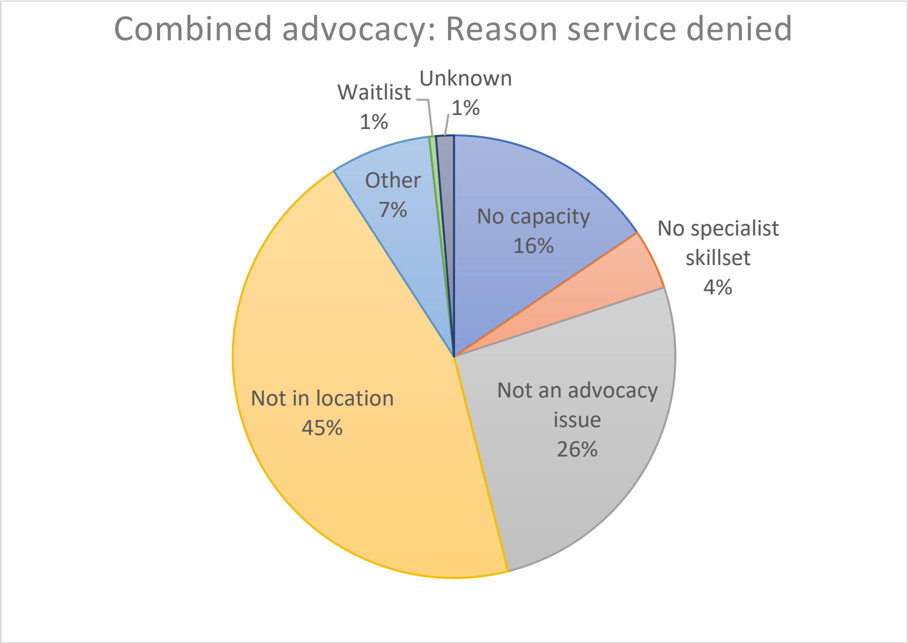
One of the concerns that is shared amongst disability advocacy organisations is an individuals’ ability to reach out for support repeatedly. When an individual is advised the organisation is unable to assist due to lack of capacity, the likelihood of the person calling back to request support appears to be diminishing. This lack of capacity then also influences advocacy organisations raising awareness of their services, including completing proactive outreach to find the most vulnerable as the actual unmet need is unknown. Advocacy organisations do not want to raise their profile, and have individuals reach out assistance, only to turn more people away.

The largest reason for people being turned away by advocacy organisations is because the individual is not in the location they service (45%). However, when an advocacy organisation is unable to provide services due to the individual not living in their service region and almost all advocacy organisations are at capacity, this translates into unmet demand due to lack of capacity.

---

[17] Victorian Council of Social Services, July 2022, *Building a stronger foundation: VCOSS submission to the National Disability Advocacy Framework 2022-2025,* https://vcoss.org.au/wp-content/uploads/2022/07/2022-VCOSS-National-Disability-Advocacy-Framework-Submission.pdf, p. 9.

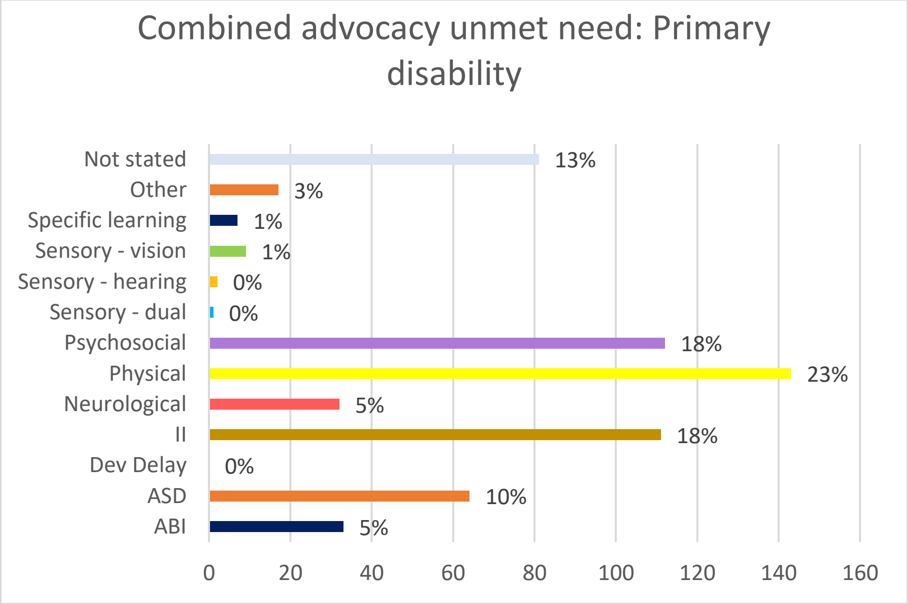
Graph 10: Combined advocacy services: Unmet demand reason



Advocates are often working beyond capacity and take on more and more clients when it is clear the person is extremely vulnerable, and this is not reflected in the unmet demand. The data instead shows that advocates are delivering more services without understanding the context as to why.

Another concerning trend is the number of people living with physical disability being turned away from advocacy services. Twenty three percent of people who were unable to be provided with disability advocacy reported their primary disability being a physical disability. Unfortunately, those who may be deemed able to self-advocate are often turned away from advocacy services, regardless of whether they have the capacity to self-advocate at that point in time. Although all advocacy organisations will foster self-advocacy where possible, it must be acknowledged that our current society is not accessible and inclusive and even the most skilled individuals may require advocacy support.

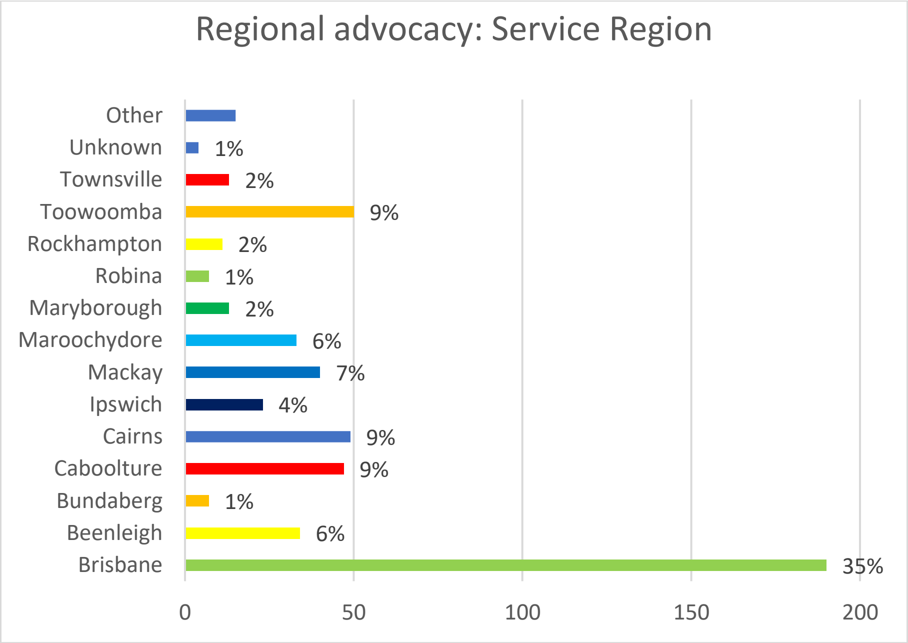
Graph 11: Combined advocacy services: Unmet demand primary disability



<u>Unmet Demand - Regional Individual Advocacy</u>

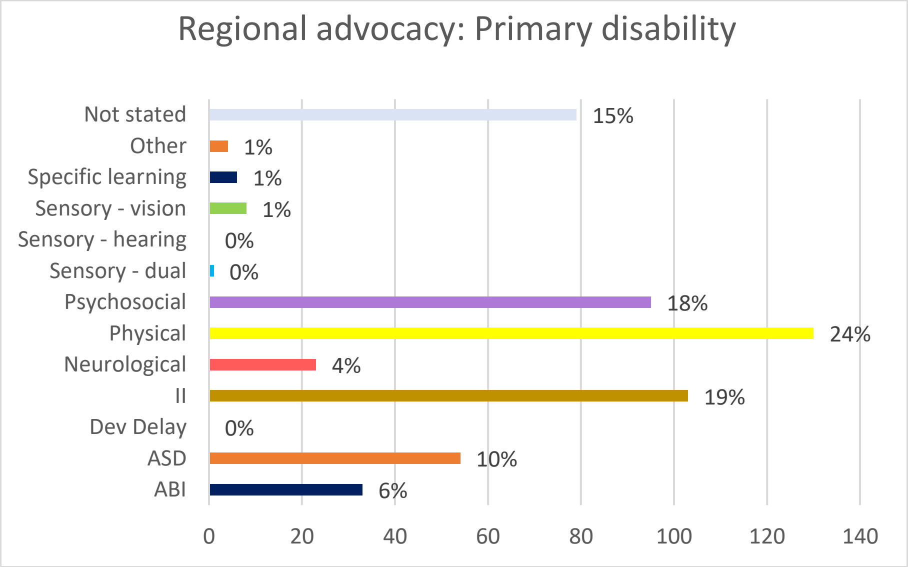
With the re-allocation of funding in January 2022, some services experienced significant changes in their service area. This has resulted in some confusion amongst the community leading many to reach out to organisations that were previously in the area. This was most experienced in Brisbane. The unmet demand is significantly higher in Brisbane due to the number of individuals seeking to access disability advocacy support. However, it should be noted that all regions are experiencing unmet demand, showing that there is a need for increased advocacy funding across the state. 536 requests for services were unable to be met by regional advocacy services.

Graph 12: Regional: Unmet demand service region



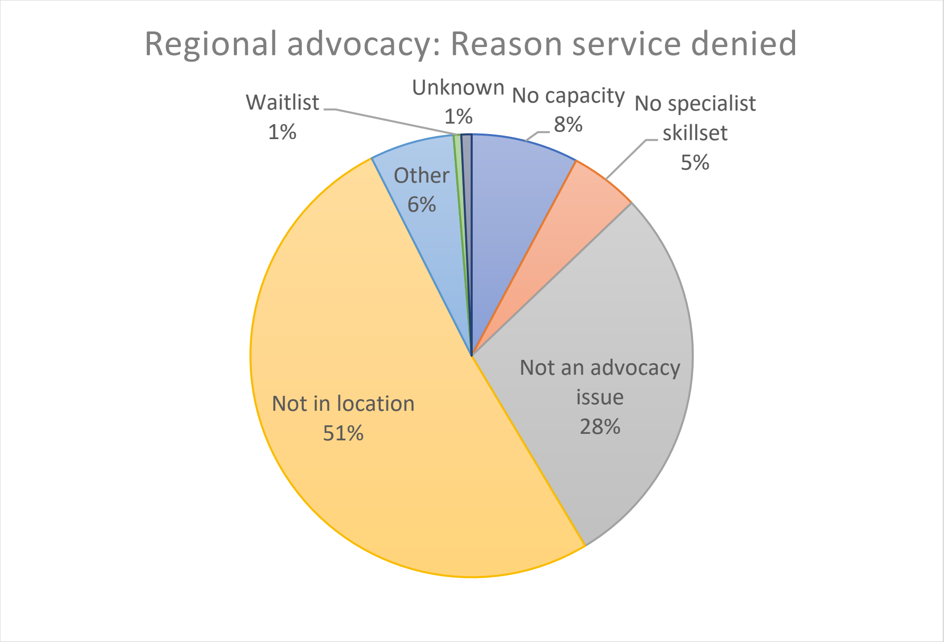
The regional advocacy organisations have similar trends to the combined advocacy services for unmet demand, as regional advocacy makes up a large portion of the unmet demand data. Similarly, people living with physical disability were the individuals to be turned away from advocacy services. Twenty-four percent of the unmet demand reporting their primary disability as physical, there is also a high rate of people with intellectual impairments (19%) and psychosocial disability (18%) being unable to access advocacy.

Graph 13: Regional: Unmet demand primary disability



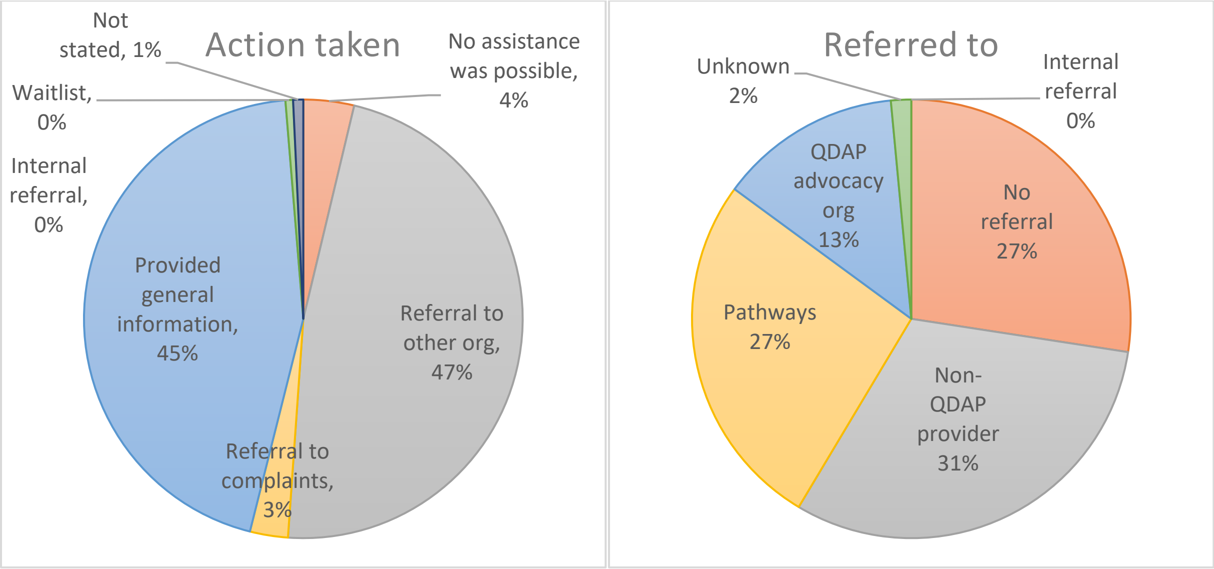
The most common reason a request for advocacy was unable to be provided was because the individual did not reside in the areas the organisation covered (51%), with the second most common reason being ‘not an advocacy issue’ (28%). However, as discussed earlier, when an advocacy organisation is unable to provide services due to the individual not living in their service region and almost all advocacy organisations are at capacity, this translates into unmet demand due to lack of capacity.

Graph 14: Regional: Unmet demand reason



When faced with being unable to provide advocacy services, many organisations provide referrals to other organisations (47%). As there is limited geographical overlap of disability advocacy services only 13% of referrals were made to QDAP organisations, with the majority either being referred to non-QDAP providers (31%) or Pathways (27%) for alternative options.

Graph 15: Regional: Unmet demand action taken and referred to



<u>Unmet Demand - Specialist Cohorts</u>

With the re-allocation of funding and introduction of specialist services in January 2022, new services were established for Aboriginal and Torres Strait Islander and children and young people cohorts. In establishing the Aboriginal and Torres Strait Islander specialist service, ATSIDNQ worked with local communities to co-design the service, build trust and relationships. Significant time and resources have also been put into establishing and promoting the children and young peoples specialist service by building relationships with key stakeholders for referrals. As these services are still evolving, we suggest the unmet demand should be analyzed month to month, to show the increased demand.

Table 6: Specialist: Unmet demand breakdown month by month

Month/Org	January	February	March	April	May
ATSI	0	1	1	5	2
CALD	12	0	21	12	18
Young People	0	0	1	1	1
Total	**12**	**1**	**23**	**18**	**22**

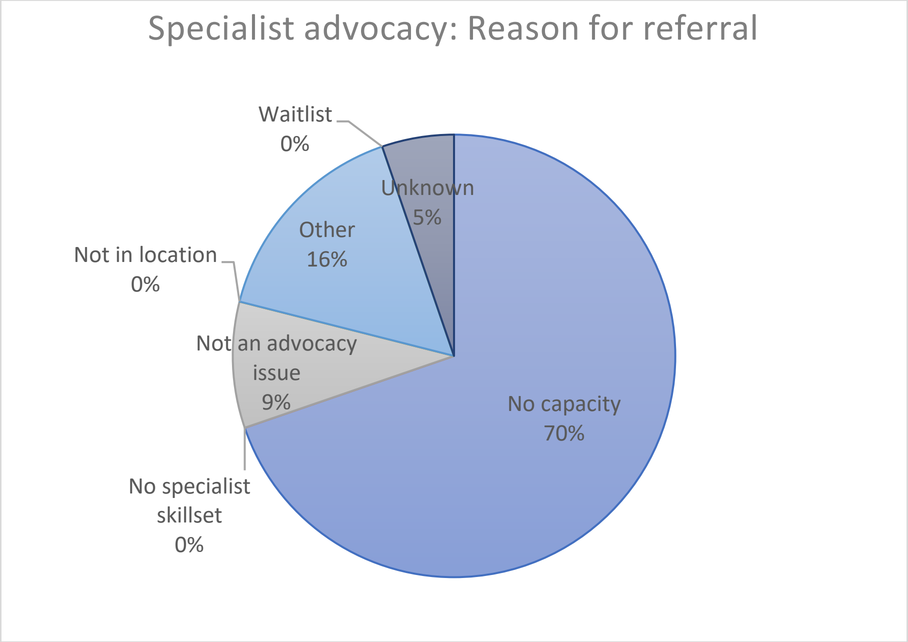
For the period, 01st January – 31st May 2022, 76 services were reported as unmet demand. A considerable amount of the unmet demand was recorded in the Brisbane region, 41%, followed by Ipswich 16%, and Beenleigh 13%. It is of note that 16% of these services do not have a recorded location. It is also important to note, that 27% of the unmet demand was people from birth to 18 years, 5% of the unmet demand were people who identified as Aboriginal and/ or Torres Strait Islander and 76% identified as culturally and linguistically diverse.

While 15% of specialist individual advocacy services were provided to individuals with a psychosocial disability, 22% of the unmet demand recorded is for people with a psychosocial disability. There are also high rates of unmet demand for people with the primary disabilities of physical 17%, autism 13%, neurological 12%, intellectual impairment 11%. Seventeen percent of people recorded as unmet demand recorded a primary disability as ‘other’.

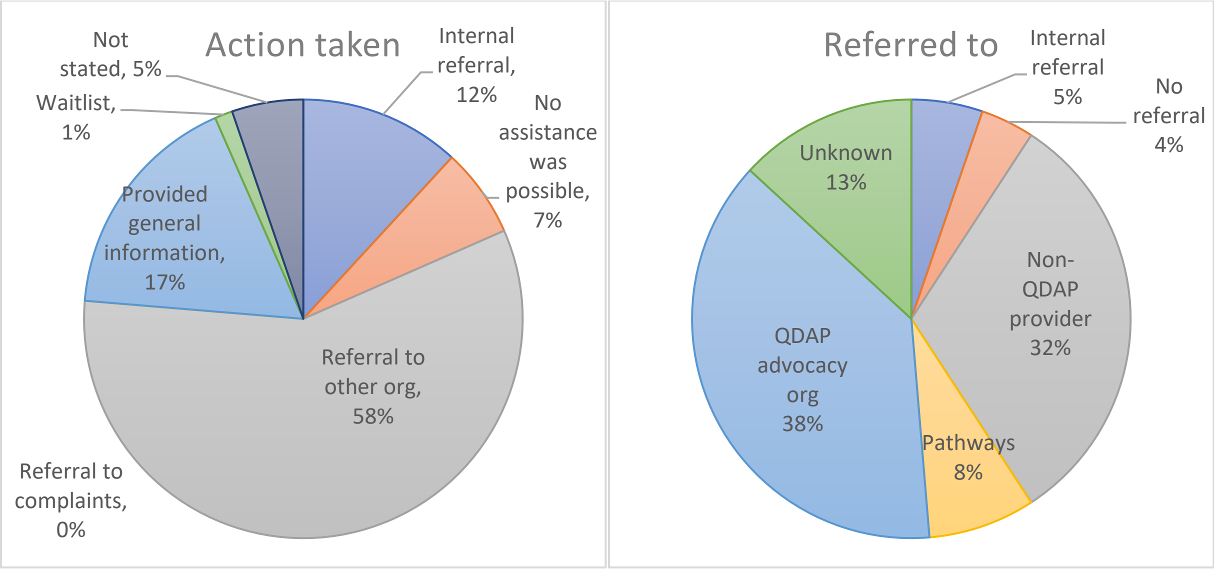
The majority, 70%, of unmet demand services were recorded due to a lack of capacity within the service. It is likely that this number is higher, as it has become evident from discussions with organisations, the ‘Other’ category is being used in situations where; advocacy is not available within the required timeframe. Where advocacy services were not able to be provided, 70% of people received a referral to another organisation. Of this 70%, 38% were referred to QDAP organisations. While it is difficult to know if the referral was accepted, with the lack of capacity within the sector, it is unlikely these referrals were successful. Another large portion of the referrals, 32%, were for non-QDAP providers which again includes community legal services and other community supports. While these services may have been able to assist in some way it does not replace the need for independent disability advocacy.

We suggest that two of the options for reporting; ‘provided general information’ and ‘no assistance was possible’, should be interpreted collectively as no advocacy assistance was provided.

Graph 16: Specialist: Unmet demand reason for referral



Graph 17: Specialist: Unmet demand action taken and referred to



<u>DANA Intake Project Data</u>

Disability Advocacy Network Australia (DANA) have kindly provided QIDAN preliminary indications of the data from their recent Intake Project. The DANA Intake Project was a 12-month project funded by the Department of Social Services (DSS) running from 01st July 2021 to 30th June 2022.

The project involved DANA exploring intake and prioritisation processes used by disability advocacy organisations, as well as how waitlists and demand are managed. The aim of the project was to capture a picture of unmet demand, and to highlight if and where processes can be streamlined across the sector.

Over the course of six months 80 disability advocacy organisations, that provide a range of advocacy services including individual, systems, citizen, self, and legal advocacy nationally, were invited to submit data relating to how they managed workflow given the enquiries they have received in each of the six months. The data was collected using an online survey and 49 orgnisations responded to the request for data. The data was analysed independently by two project officers to ensure the accuracy of the data and the analysis undertaken. In all, comprehensive data was gathered from 39 orgnisations who provided data for *each* month between September 2021 and February 2022. The following analysis is based on these 39 organisations.

The table below provides a breakdown of the participating organisations by state / territory. Three of the participating orgnisations provide services across state / territory borders; Victoria/ New South Wales, New South Wales / Australian Capital Territory, New South Wales / Queensland.

Table 7: Location of participating agencies by state / territory [18]

State/ Territory	Frequency	Valid Percent
Victoria	10	25.6
New South Wales	8	20.5
Queensland	5	12.8
Australian Capital Territory	2	5.1
South Australia	5	12.8
Northern Territory	2	5.1
Western Australia	5	12.8
Total	39	100

Disability advocacy organisations receive funding from multiple sources including DSS and state/ territory funding and the data provided analyses the unmet demand across all funding steams.
Some limitations of the preliminary indications include:

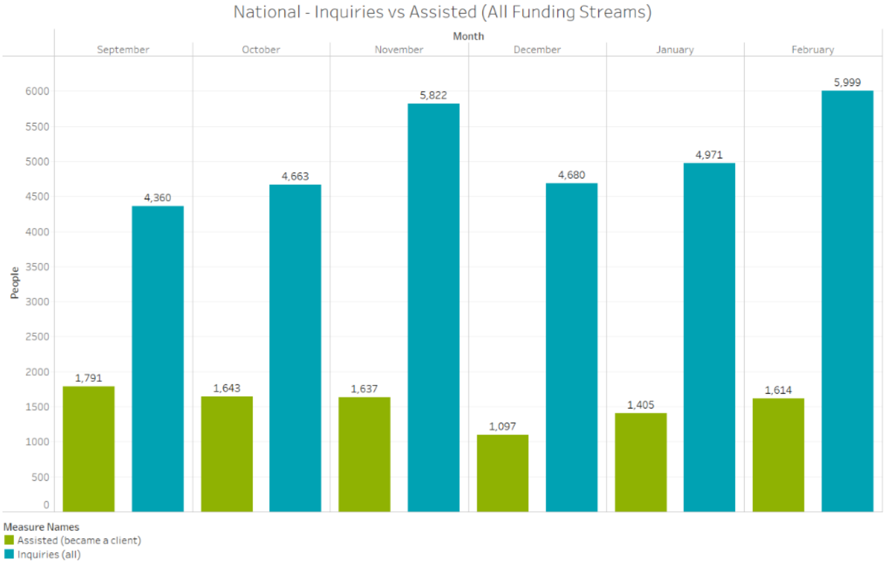
- There is only six months of survey data, including the December/ January holiday period, which makes it difficult to determine clear trends around increasing demand over time. To achieve this, a 12-month data collection period may be more appropriate,
- During the data collection period there were significant changes to Queensland state funded disability advocacy organsiations. Some of these organisations may have been establishing new services or making transition arrangements,
- Survey questions had limitations and additional information could be beneficial such as the length of waitlists,
- Organisations manage demand in varying ways and may not consider their processes as ‘waitlisting’,
- Only a portion of the sector engaged with the project.
-

Preliminary indications of the data demonstrate a constant and increasing demand for advocacy services in Queensland that is unable to be met with current funding arrangements. The National data has been included to show the consistencies across the country with Queensland data.

---

[18] Disability Advocacy Network Australia (DANA), 2022, *Intake Project unpublished data*.

Graph 18: National: Comparison of inquiries and assisted (All funding streams)



Graph 19: Queensland: Comparison of inquiries and assisted (All funding streams)

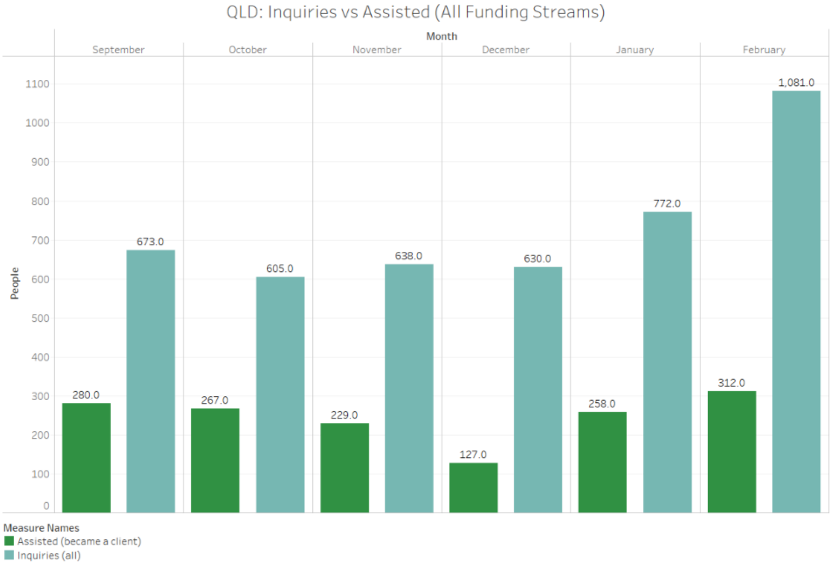


Table 8: Queensland: Funding type breakdown of assisted and unmet demand

	September		**October**		**November**		**December**		**January**		**February**	
	Assisted	Unmet	Assisted	Unmet	Assisted	Unmet	Assisted	Unmet	Assisted	Unmet	Assisted	Unmet
QDAP	5	15	86	88	66	63	39	70	59	50	69	39
NDAP	46	33	56	31	24	18	20	15	41	18	68	27
NDIS Appeals	42	35	38	61	53	47	37	23	46	25	108	32
DRC	12	3	12	5	11	4	8	1	8	4	13	2
Decision Support	10	1	6	2	3	0	1	0	6	0	2	2
Other	165	19	69	5	72	0	22	0	98	0	52	15

We note that there is a portion of enquiries that are not categorised as assisted or unmet demand. QIDAN submits that anyone who contacts an advocacy organisation seeing advocacy and is unable to be assisted is therefore unmet demand.

Additionally, individual disability advocacy funding is provided through QDAP, NDAP and other streams. We therefore suggest that the unmet demand figures for these funding steams should be consider together i.e., September unmet demand for individual disability advocacy services was 67 people.

Personal Experiences

H

In October 2020, Rights In Action received a referral from the Indigenous Consumer Assistance Network (ICAN) to advocate on behalf of 'H', a 59-year-old vulnerable and financially disadvantaged First Nations man living on the Atherton Tablelands.

'H' has end stage chronic inflammatory lung disease with severe shortness of breath, fatigue, difficulty walking and a high incidence of hospitalisations due to frequent lung infections. He was receiving the Job Seeker payment and struggling to comply with the Disability Employment Service's program of support and mutual obligations during a time that was exceedingly difficult for him and his family.

Two years earlier, 'H' had made enquiries at the local Centrelink office about receiving the Disability Support Pension but was told he wouldn't qualify. His GP at the Aboriginal Medical Centre had been assisting with Medical Certificates, but 'H' was still required to attend meetings with the DES provider.

Through vigorous advocacy support from Rights In Action, in collaborations with ICAN and the Aboriginal Medical Centre, the medical evidence was gathered and a Centrelink DSP application submitted. In December 2020, 'H' was approved for a Disability Support Pension. He was very happy and relieved.

'H' was assisted to create an Enduring Power of Attorney document so he could identify who will make decisions about his health and welfare if he becomes incapacitated in the future. A referral was also sent to ICAN who helped 'H' gain early access to his superannuation funds.

G

In March 2020, Rights In Action received a referral from a youth service to assist 'G', a 19-year-old First Nations young woman from the Atherton Tablelands with suspected FASD (fetal alcohol spectrum disorder) who was homeless, couch surfing and at a high risk of physical, emotional, financial and sexual abuse. Despite experiencing significant difficulties, 'G' did not have access to disability supports or a disability support payment due to the lack of a formal diagnosis of her disability.

'G' was removed from her mother at birth and raised by a foster family under a long-term guardianship order with Child Safety. 'G' received specialized learning support at school but formal assessments were not completed. She ran away from the foster family and left high school in her early teens. After she turned 18, she was linked with a youth service to transition to adulthood. She was unable to maintain her tenancy at the youth accommodation due to lack of appropriate supports and she became homeless.

When advocacy commenced, Rights In Action worked in close collaboration with ‘G’, the Aboriginal Medical Centre and the youth service.

During 2020, ‘G’ underwent a suite of specialist tests to obtain the medical evidence needed. ‘G’ missed or terminated many appointments due to her lack of appropriate accommodation, declining mental heath and substance abuse.

In December 2020, ‘G’ moved into a Department of Housing unit. She is struggling to maintain her tenancy and is being assisted by the youth service who have limited funding.

In January 2021, the clinical psychologist at the Aboriginal Medical Center provided the formal diagnosis of FASD and a private occupational therapist, with funding from a disability support service, conducted a full functional capacity assessment to identify ‘Gs’’ support needs in day to day life.

In February 2021, a NDIS application was submitted. When appropriate NDIS supports are in place, a Disability Support Pension claim will be lodged.

Sally and John

Sally and John* initially contacted QAI for assistance with Internal Reviews of their NDIS plans. Sally and John have been together for several years and recently married. They have supportive family and a long-standing service provider who had been supporting them to work towards their goal of starting a family. The couple were expecting their first child and had requested additional support from the NDIS to assist them to achieve their goals of becoming a family, including additional help around the home to support them to be new parents. Sally and John had successfully completed several parenting classes and had been working closely with their midwife in the lead up to the arrival of their daughter.

During one of the final check-ups before the birth of their daughter, Sally and John were notified by the hospital that they were making a notification to child safety as they both have intellectual impairments. The QAI advocate assisted Sally and John to arrange legal advice, prior to the birth of their daughter, about their rights, how to work with child safety and the possible processes. The QAI advocate also successfully advocated for a substantial increase in supports funded by the NDIS.

Following the birth of their beautiful daughter Amy, a nursing assistant was permanently stationed in Sally’s room. At this stage Amy was still in the nursery, due her weight at birth. After a couple of days without seeing her child, Amy was finally brought to Sally’s room. At this time the nursing assistant stated her job was only to monitor and refused to assist Sally in any way, such as with the initial breastfeed. This added a significant amount of pressure on the new family. When the family were finally able to return home, they had a wealth of support from their family and NDIS service provider. Child Safety spoke with the family and all of their supports and closed the file. Over time the paid supports

have reduced, and Sally, John and Amy are living happily as family. Unfortunately, the fear of child safety has never left the minds of Sally and John.
** Names have been changed to protect confidentiality*

Andy
Andy* is a young indigenous student in year eight who had been permanently excluded from his school in North Queensland following an incident of verbal and physical escalation. Andy and his mother felt that the incident occurred as a result of a disruption in his daily routine and a lack of preparation around the changes. These are known triggers for Andy due to his disability – intellectual impairment and Autism Spectrum Disorder. Despite the COVID related disruptions in 2020 Andy and his mother considered that his transition to high school had been successful. Andy wanted to return to the school as he felt they had been supportive of him.

Andy's mother was referred to QAI by the Autism Hub for assistance to appeal the exclusion decision. Initially we assisted by;

- discussing the situation and reviewing documentation, correspondence and support plans;
- providing information around the process to appeal the decision;
- drafting a letter of appeal;
- discussing the Principal's response to the appeal; and
- drafting a further response to the Principal's response.

The Principal's decision was amended to an exclusion from the school for a period of four (4) months. Unfortunately, when the exclusion period ended, Andy was not able to easily re-enroll at the school, due to concerns of teachers at the school. Very limited educational support and tools were provided to Andy during this period, and he missed 4 months of schooling.

Andy's mother contacted QAI again after several weeks of communicating with the Regional Case Manager about Andy's education moving forward. The advocate spent another 23 hours working with Andy, his mother, the Autism Hub and the Assistant Regional Director to negotiate Andy's enrolment, appropriate supports and transition to a new school.

Andy is at a new school and has made a new friend. His hours at school are still reduced and his mother is working closely with the school to ensure he is included and has access to appropriate supports at school.

Andy's mother has provided the following feedback
"I really can't thank you enough for all the help and assistance you have provided not only to me by to Andy in being able to finally attend school and get the education he deserves. I will definitely reach out in the future if need be, I'm hoping that's not the case and Andy can succeed at school."

The following feedback was provided by Department staff following the resolution of Andy's matter.
"Just ringing to let you know that Andy has successfully enrolled at [the new school]. He started school yesterday. He had a wonderful day of all reports. I just wanted to thank you for your support in what's

been a really challenging time. We wish all the best for the young person and hope he does well there. The region and both schools have put a lot of support and planning into his transition to this new high school. We wish you all the best for him and his family. Thank you for your support."
* *Name has been changed to protect confidentiality*

Conclusion

Independent disability advocacy services are critical for all Queenslanders living with disability, both participants of the National Disability Insurance Scheme (NDIS) and the vast majority who are not eligible to access the NDIS.[19]

During the launch of QIDAN and the newly established state-wide information and referral service, Pathways, on 01st April 2022 Minister Craig Crawford, MP acknowledged the crucial role of advocacy in achieving positive outcomes for people with disability:

> *There is no doubt about it to me, that the evidence is that it is critical to influencing positive change and the delivery of services and attitudes towards disability. We meet all the time as disability reform ministers, we met just a couple of weeks ago, and there is no doubt that advocacy is a big area of focus right now. We know that a new approach to advocacy recognises that the best advocacy supports require action at multiple levels.*[20]

Master data was provided by DSDSATSIP for QDAP funded services for 01st January 2022 – 31st May 2022 and was used to prepare this report. Through our analysis of the data as well as our experiences providing advocacy services, it is evident that there is significant unmet demand for independent advocacy services.

Increasing the State government funded independent advocacy program, QDAP, to a **minimum of $15 million** annually would allow expansion of disability advocacy across the state. In the alternative, providing a **minimum of $10 million** annually would allow for existing disability advocacy services to be adequately resourced and assist in meeting the current demand.

$15 million annually would enable independent advocacy services to:

- Double the number of advocates across the state enabling greater access to independent advocacy services and renumerate advocates at the appropriate SCHADS award,
- Complete outreach and face-to-face advocacy services in more regional and remote locations that is culturally appropriate,
- Engage with people with disability who are isolated and in ‘hard to reach’ environments,

---

[19] 107,365 Queenslanders were NDIS participants as of 31st March 2022 - National Disability Insurance Agency, 2022, *Explore data,* https://data.ndis.gov.au/explore-data, retrieved 15 July 2022.

[20] The Hon. Craig Crawford, Minister for Seniors, Disability Services and Aboriginal and Torres Strait Islander Partnerships at the Queensland Disability Advocacy Network and Pathways launch on 01 April 2022.

- Expand the scope of advocacy services to provide preventative advocacy such as supporting pregnant women with disabilities to engage with child safety and reduce the long-term impacts on the families and cost to the State,
- Support other models of advocacy such as citizen, peer and family advocacy,
- Increase the Pathways ‘Hub’ services to provide information and referral to a greater number of people, develop resources, and support advocacy organisations,
- Participate in QIDAN for a minimum of 10 hours per month per organisation,
- Contribute to systemic change by addressing localised and statewide systemic issues,
- Facilitate appropriate training and ongoing professional development for the independent advocacy sector,
- Raise awareness of advocacy organisations and the rights of people with disability,
- Build the capacity of mainstream and disability services to become disability informed and support people in a disability responsive manner,

Without this funding and an ongoing commitment to independent disability advocacy, Queenslanders living with disability will continue to have difficulty accessing advocacy services. Additionally, those living in regional, rural, and remote locations will have trouble accessing quality face-to-face advocacy services that are responsive and with localised knowledge. The issue surrounding organisations having limited capacity to provide services will continue.

Disability advocates will be unable to complete proactive outreach to find the most vulnerable people which will result in Queenslanders living with disability continuing to have their human rights infringed upon. Disability advocates will be unable to complete community-based education and capacity building for individuals to self-advocate and will instead spend their time focusing on ‘putting out fires’ rather than ensuring they were not lit in the first place. Disability advocates want to see our communities moving towards being disability responsive, accessible, and inclusive and disability advocates can be facilitators in making this happen. We hope the Queensland Government understands the importance of disability advocates in upholding, defending, and promoting people with disability’s rights and look forward to an increase in funding and ongoing commitment to support the sector.