

**STAND
BY ME**



The Gaps are Getting Bigger for People with Disability in NSW

NSW Disability Advocacy Alliance



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All case studies in this report are real cases from our disability advocacy services. Many of the names have been changed.

We wish to acknowledge the Traditional Owners of the land on which we work and pay respect to Elders past and present. We also acknowledge the work of all of the Stand By Me team.



Disability Advocacy: The Numbers



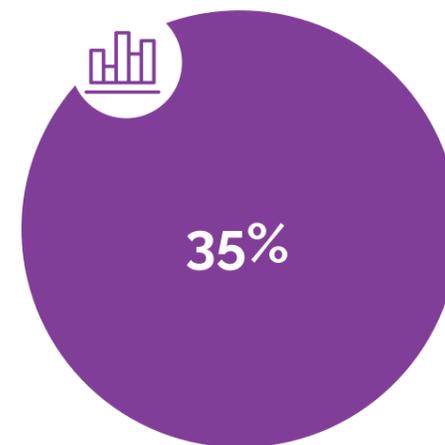
Value of independent advocacy in 2017

The value of independent advocacy was \$589,498,000 across Australia.



Return on every \$1 spent on advocacy

An estimated benefit of \$3.50 is returned for each dollar of cost spent on advocacy services in Australia.



People with disability report poor health

35 per cent of people with disability report poor or fair health compared with 5 per cent of people without disability.



What is happening?

- Disability advocacy cut in NSW
- Huge demand for disability advocacy
- People with disability falling through the gaps in NSW

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"We need advocacy organisations more than ever... advocacy organisations play a critical role in telling people their rights and then helping them to enforce them."

Mr Alastair McEwin, Disability Discrimination Commissioner

People with disability have the same drive and need as everyone else to belong, and to contribute our talents in the places where we live, work, love and play. But for many people with disability, life can be hard not because of the disability, but because of the way society responds to the disability.



53 per cent of people with disability of working age are in the labour force, compared with 83 per cent of people without disability.

People with disability can be excluded, mistreated, or seen as a problem first and a person second. When problems arise, it can be hard for people with disability to do the everyday things other Australians take for granted: go to school, see a doctor, catch a bus, get a job, or pay bills.

In 2020, less than two years away, the NSW Government will be no longer fund any independent disability services that provide advocacy, representation or information to the 1.3 million people with disability who live in NSW and face barriers to having an equal life. At the same time, big changes associated with the NDIS are rolling out for the 10% of people with disability who are eligible.

Case Study

Jeff is person with disability who is blind and lives with multiple sclerosis.

He also has a tumour on his spine. Over the years, he has reached out to a regional disability advocacy service for help with everything from a compensation claim, to accessibility issues in town, to a review of his plan under the NDIS.

If the disability advocacy service was not available in his regional area, Jeff would have an eight hour drive to Sydney to access help.

He says that he doesn't know who he would turn to if his disability advocacy service wasn't there

Case Study

Katie was living in an apartment building on the third level with stairs only, no lift. After her leg was amputated, she was unable to leave her house for many months.

This affected her overall health significantly as she became isolated, could not leave her house to do everyday tasks like going to the shops, paying bills or visiting friends and family. She only left her house twice for health appointments, which required an ambulance.

Katie has a NDIS Plan. Her Support Coordinator contacted a disability advocacy service who were able to provide advocacy through a support letter, liaising with NSW Housing and an occupational therapist.

With continuous follow up by the advocate, Katie was able to move into an accessible home within a few short months.

She can now access the community, making the most with her NDIS Plan: doing activities that she likes, receiving the care she needs. She says that she has a new lease on life, and she is very grateful for the disability advocacy service.



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The NDIS was never meant to be an oasis in a desert. People not eligible still need programs and supports. There should never be a cliff outside the scheme. We need strong leadership by all our governments to ensure that no one falls through the gaps.

Every Australian Counts

Case Study

A disability advocacy service worked with domestic and family violence services across NSW, in partnership with Domestic and Family Violence NSW to develop resources to encourage more accessibility.

They are now working with five domestic and family violence services across NSW for the next few years to improve their services to ensure women with disability have access to these services, just like their non-disabled peers.

The disability advocacy service is employing local women with disability to do disability access audits in each area who then report back to the disability advocacy services about how this access is progressing.

Decades of expertise, built up across NSW, particularly in rural and regional areas, will no longer be available to the NSW Government after 2020, or to people with disability, to make sure that our state becomes truly inclusive of people with disability or that people with disability can access the services they need, including mainstream services.

Each level of government has a role to play in making sure that all aspects of society, including public services, are accessible for people with disability. Transport, housing, health and education are just some of the areas where people with disability often miss out on equal access.

People with disability need independent, effective, expert advocacy, representation and information services, including those run by people with disability.



The weekly median income of people with disability is \$465, less than half that earned by those without a disability



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“Our services will decrease due to the capacity building program for people with disability being shut down”.

Ethnic Community Services Co-operative



Disability advocacy services get, on average, 41% of their total funding from the NSW Government. Cutting this funding will force many disability advocacy services to close.

The NSW government has shut down the disability services sector, closing down the Department of Ageing, Disability and Homecare (AHDC) in June 2018. This leaves 90% of people with disability in NSW with no access to disability services.

Our 22 member services, from across NSW, have been working hard to make sure people with disability are ready to transition to the NDIS, and also fighting to find services for those people with disability who will not have access to the NDIS. Our funding will come to an end in 2020, less than two years from now.

By cutting our funding, the NSW government is neglecting a core piece of disability support infrastructure. It will create a giant gaping hole for millions of people with disability (including family, friends and carers) to fall through if the NSW Government doesn't change its mind.

How did we get here?

- The NSW Government has shut down all of its disability services as of June 30, 2018.
- People with disability who are not eligible for the NDIS, now have no disability services.
- Disability advocacy is trying to fill the gaps, but funding ends in 2020.

Case Study

A disability advocacy service has worked for a number of years to highlight the poor health outcomes of people with intellectual disability.

They launched a campaign in 2017 with members and supporters to raise awareness of this issue and to press the NSW Government to provide funding for intellectual disability health specialists across NSW.

After a year and a half of campaigning and support from disability advocacy organisations, the June 2018 budget saw the NSW Government commit to \$4.7 million in ongoing annual funding to put intellectual disability specialists into more health teams across NSW.

Case Study

Linh is a 12 year old child with autism and intellectual disability. Her family has a Vietnamese background with limited English and no computer literacy skills.

The family required support to access NDIS funding and to navigate the system. A disability advocacy service provided a Vietnamese bilingual advocacy worker who assisted the family throughout the NDIS process.

The support offered included helping to complete registration forms, conducting a preplanning session to prepare the client for the planning meeting, gathering supporting evidence and quotes of activities and services to be included in the plan, attending and providing advocacy for the family at the NDIS planning meeting, and contacting the NDIA to apply for a review as the NDIS package received was insufficient to cover the supports that Linh needed to achieve her goals. The disability advocate also worked with the family to build up their confidence to undertake self-advocacy.

The family is now able to contact service providers through an interpreter instead of asking a disability advocate or support worker to do this on their behalf.



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“A big part of the advocacy, information and referral services will be cut and our Community Voice and rights based information sessions will drop. About 16 staff members of the 28 will lose their job.”

Multicultural Disability Advocacy Association

Case Study

Disability advocates supported a young Aboriginal woman in a nursing home to get an NDIS package and suitable accessible housing to be able to relocate to community and reconnect with her immediate family.

This process alone took over one year and without the intensive individual advocacy support of Aboriginal disability advocates to navigate the processes and government agencies, this woman would still be residing in a nursing home.

This facility was totally unsatisfactory and did not support her Aboriginal cultural needs for safety, health and wellbeing outcomes.

Independent disability advocacy, information and peak representative organisations play a much greater role than just assisting people to access the NDIS, though the need for advocacy has increased across all our organisations due to the implementation of the NDIS.

Organisations such as ours assist people on broader issues such as access to education, justice, finances, abuse and discrimination, health, accessing the physical environment, housing and employment.

Different organisations focus on different areas. Some organisations specifically support families, others support people with intellectual disabilities, or particular physical disability. Some focus on making the system better as a whole, while others primarily help individuals.

But whether we're making things better one person at a time or by winning changes that will help thousands, our work is essential.



Disability advocacy services provided over a hundred submissions and consultations to the NSW Government last year.

What are the key issues that disability advocacy services are raising?



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"The information and referral service would be unfunded meaning that we would potentially lose 50% of the staff from our small client services team."

Muscular Dystrophy Association of NSW



People with disability in Australia are more likely to live in poverty. Their income is approximately 70% of those without disability, the lowest of all 27 countries in the OECD.

Without secure long term funding commitments from the NSW Government, people with disability will not have local advocates to turn to when they face issues of discrimination, exclusion or poor treatment. This can happen in any area of life: education, health, justice, transport, employment, accessing infrastructure and community activities.

Disability advocacy services are independent, and are often staffed by people with disability who are experts in the barriers we face to having an equal and ordinary life. Advocacy services are not service providers, housing organisations or support organisations, so can offer resources and information free from conflicts of interest.

Many disability advocacy services are a lifeline in regional and rural areas. Our services have intimate knowledge of other local services that we can refer to and strong partnerships in place to ensure people with disability whom are particularly isolated can receive the supports they need. This local knowledge and partnerships, which can take years to develop, nurture and mature will also be lost moving forward should funding cease, and cost so much more to re-establish in the future.

- Our expertise is cost-effective and saves the NSW Government money overall.
- People with disability face barriers to access mainstream services.
- Independent disability advocacy is vital to make sure people with disability have an equal life.

Case Study

Alok is a person with disability who uses a wheelchair. He had been struggling with his old broken down manual wheelchair and had become isolated and frustrated because getting out and about was very difficult.

Alok applied to the NDIS for a new motorised wheelchair and was approved.

Three months on there was still no sign of the new wheelchair. Alok contacted a disability advocacy service who were able to contact the NDIS.

His wheelchair was promptly ordered and delivered to his home, allowing Alok to easily and safely leave his home and be part of the community.

Case Study

John is 37 years old and has multiple complex disabilities including both physical and psychosocial disabilities.

He is bed bound and can't leave his home. John needs support for all his daily activities. Before the NDIS, John had NSW funded support including home care and personal care support for more than five years. After the NDIS rolled out, John thought he would have a simple transition to the NDIS, with a new plan and the same kinds of supports.

Instead, he was told he wasn't eligible and that he would have to find supports in the health system. John's needs are complex and physically demanding so he had no other option other than to contact an ambulance service and be admitted to the local public hospital.

He stayed in hospital for over four months before being discharged with a temporary support package through the local community health team.

This is not adequate to meet John's needs, but he was unable to stay in hospital any longer. It's not certain what will happen for John next.



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“Both independent individual and systemic advocacy play a critical role in ensuring independent oversight of institutional settings and contribute significantly to preventing and addressing violence against people with disability in these contexts”

Australian Human Rights Commission

Case Study

Wendy called a local disability advocacy service as she was having significant issues with accessing the local school on behalf of her daughter Sally who has a disability.

The family wanted their daughter to go to the local school with her siblings and other friends however the school advised that due to Sally's disability she needed to go to a special school that was some distance from the family.

The disability advocacy service was able to support Wendy and Sally and succeeded in getting the local school to make sure Sally was able to get an education with her peers.

Many people with disability face barriers when trying to access mainstream services, such as health and education. Disability advocacy services can help break down these barriers, and make sure that people with disability have the same access as everyone else.

Without disability advocacy services, many people with disability will fall through the gaps, ending up in hospital, homeless, or in the legal system, creating greater costs for the NSW Government than simply funding our organisations.

The expertise of people with disability, and our advocacy, representation and information services, is relied on by both the NSW Government and many non-Government agencies. This expertise will disappear in less than two years, leaving the NSW Government with higher costs and lower quality consultation.



36 per cent of people with disability of working age have completed high school, compared with 60 per cent of people without disability.



What do disability advocacy services want the NSW Government to do?

- Fund disability advocacy services with at least \$20 million per year.
- Make mainstream services accessible for people with disability.
- Make sure people with disability, who are not eligible for the NDIS, have the support they need.

“

“The Minister is kidding himself. No advocacy will mean a flawed NDIS. We’re creating a funding model. We aren’t solving disability.”

Kurt Fearnley, Paralympian and past NDIS Independent Advisory Council member



Some disability advocacy services have seen a 100% increase in demand over the last two years as the NDIS rolls out, and the NSW Government winds back disability services.

As community run, non-profit organisations we already do a lot with a little, and we’re experts at stretching out a dollar.

But we’re struggling to meet community demand with existing funding. Our services need to be fully funded into the future or it will have dire impacts on the lives of people with disability, their families and friends.

Demand has increased for our organisations with more people with disability living in NSW, the closure of NSW Government disability services, and the roll out of the NDIS. A recent survey of our alliance members found that workloads had increased 50-100% over the last two years.

We need secure, permanent funding so we can invest in building the capacity of people with disability. Many of our organisations are run by people with disability, and have many people with disability who work as advocates. We need certainty, so we can build a successful future for us all.

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“Essential services for people with disability, such as information, peer support and our regional outreach services, will all stop if these funding cuts by the NSW Government go ahead. Our organisation will lose ten staff.”

Spinal Cord Injuries Australia

“We will no longer be able to provide the NSW Government with policy expertise from people with disability for consultations, committees and Government decisions. Our specialist work in making sure that people with disability who live in boarding houses are ok, will stop if these funding cuts go ahead. What will happen to people with disability living in boarding houses then?”

People with Disability Australia

Case Study

Jim's parents contacted a disability advocacy service concerned that he wasn't getting the medical treatment he needed for an issue with his foot.

Jim had attended a specialist appointment about his foot as it was affecting his mobility and causing significant pain. The specialist would not undertake the recommended operation as he felt this would be too disruptive to Jim and the hospital staff because of Jim's disability.

The family previously had no luck with changing the specialist's discriminatory approach and due to being regionally isolated they had limited ability to seek a second opinion.

The disability advocacy service provided advice and support on relevant legislation and standards as well as helped the family prepare a letter to the specialist that strongly encouraged Jim having access to the medical treatment that he needed. Jim was successful in getting the operation.



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“The effects of funding cuts on our service are catastrophic. The Bathurst, Coffs Harbour and Armidale offices will close, with six advocates lost. The Newcastle office will lose two advocates. Each of these advocates helps at least 100 people with disability every year.”

Disability Advocacy NSW

Case Study

When Emma and her husband, a person with disability, began the process of applying for the NDIS, they found the information confusing, and that made them angry.

Emma attended a disability advocacy service information session and found that not only was it informative, but the presenters were living examples of how a good life was possible with the NDIS.

The advocates had lots of local knowledge and were able to put Emma and her husband in touch with local services.

Emma believes that we can't afford to lose the specialist knowledge provided by disability advocacy services.

Ongoing funding should be designed and allocated to ensure that disability advocacy is trustworthy and successful. This means it must be:

- Independent: no financial conflict of interest
- Specialist: run by and for people with disability, with deep expertise in the unique challenges and possibilities faced by people with disability
- Long-term: here to stay, something every person who needs it can count on

We also need the NSW Government to keep their oversight measures, such as the NSW Disability Ombudsman and Community Care and Support Program, and commit to implementing the National Disability Strategy.



Disability advocacy services work is 36% NDIS related, and 64% non-NDIS related.

What will happen if disability advocacy services aren't permanently funded?



- Our disability services are very cost effective and save the NSW Government money.
- There will be greatly increased costs for the NSW Government if people with disability don't get the right services.
- Expensive consultants can't replace the hundreds of years of expertise in disability advocacy services



"Never has disability advocacy been more important than in the roll out of the NDIS and state governments need to maintain their ongoing funding."

Jane Prentice, former Federal Disability Services Minister



Disability discrimination matters account for the highest volume of complaints to the Australian Human Rights Commission.

NSW Government departments would lose access to the input and expertise of disability advocates who participate in departmental and Parliamentary committees and help government 'get things right'. Disability advocacy helps government understand the needs of people with disability and stem problems before they blow up into preventable tragedies.

We also provide input through face to face consultations and many written responses to Parliamentary inquiries, State policy and regulation reviews. All this expertise will disappear in 2020 without permanent funding.

Economists Professor Anne Daly and Greg Barrett took a rigorous approach to identifying and assigning values to the costs and benefits arising from the work of independent disability advocates.

Case Study

A disability advocacy service has advocated for over ten years for lift access on the Sydney Harbour Bridge, and in 2016 funding was announced but was then shelved in the budget the following year.

A media and awareness campaign was initiated by the disability advocacy service, emphasising how important it is for people with disability, parents with prams, the elderly, or anyone who is unable to climb steps to have access to the Bridge.

Funding was restored, and lift access is due to be completed by October 2018.

Case Study

Joan acquired a spinal cord injury and a brain injury due to a fall. As a result, she had significant health and mobility issues.

After finishing her hospital stay and rehabilitation, Joan had to return to the same accommodation despite it not being accessible. She had to negotiate a flight of stairs in order to access her unit and it was only due to the physical assistance of her partner, that she was able to do this.

This left her in a very difficult position as she was isolated and unable to leave the home independently. Our disability advocacy service negotiated with NSW Housing, but they wouldn't reconsider Joan's housing.

The disability advocacy service then sent letters to Joan's local MP and the Minister, who acted on her behalf and assisted Joan to move into an accessible flat where she can use her wheelchair and be able to get out and about independently.



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Our advocacy services will be significantly impacted by these cuts, with the loss of up to two advocates that assist families of people with disability. We would also lose some of the basic office infrastructure that keeps us going.”

Family Advocacy NSW

Case Study

Sarah, a young woman with an intellectual disability, had her son removed from her care by the NSW Department of Community Services. This was done quickly, and without consultation or warning.

Sarah's family, who were actively involved in supporting her and her child, weren't told about why this happened, and were shocked and upset.

Disability advocates worked with the family to get the child returned into Sarah's care. This involved supporting Sarah and her family through the court system, working with stakeholders, obtaining legal representation, getting support through local family services and negotiating with FACS on an ongoing basis.

Seven months later, Sarah has been reunited with her child and she continues to successfully care for her son to this day.

The economists found investing in independent disability advocacy leads to a range of benefits including improved educational and employment outcomes, that it frees up resources in the justice system, health and accommodation services and helps to relieve the load on carers and service providers.

This analysis found that independent advocacy delivers substantial economic benefits far exceeding its costs. The Net Present Value of independent advocacy is \$589,498,000 in 2017 dollars indicating that an estimated benefit of \$3.50 is returned for each dollar spent.

This is a very high ratio of benefits to costs and shows that independent advocacy represents a highly effective use of resources.

Without disability advocacy support, the 10% of people with disability provided with an NDIS funded plan, won't have access to an independent champion to help them navigate the fledgling NDIS system. The introduction of the NDIS is creating significant change in the sector and for people with disability, resulting in a greater need for independent disability advocacy.

For the 90% of people with disability not receiving NDIS funding, the loss of disability advocacy will mean an even greater gap in access to supports and being included in their community.



Disability advocacy services provide expertise to the following committees, groups and bodies:

- ABC - Audio description for public events
- Aboriginal Ability Linkers Advisory Group
- Aboriginal Children's Advancement Society
- Advisory board for NDIA CALD engagement strategy
- AIME reference group
- Armidale Dumaresq Council Street trading policy (disability access)
- Australian Bureau of Statistics
- Australian Communications Consumer Action Network (ACCAN)
- Australian Electoral Commission
- Australian Inclusive Publishing Initiative/Marrakesh Treaty Forum
- Australian Network for Universal Housing Design
- Board of the Federation of Government Schools
- Boarding House Expert Advisory Group
- Building Access for Women with Disabilities to Domestic and Family Violence Services Project (BACOP)
- Central and Eastern Sydney Primary Health Network Disability Network
- Change the Record Steering Committee
- City of Sydney Council Way Finding Committee
- Closing the Gap Advisory Board
- Commonwealth Ombudsman Community Roundtable
- Council of the Ageing (COTA) Advisory Committee
- Disability Advocacy Network Australia (DANA)
- Domestic Violence Reform Implementation Group
- DPOA Alliance Committee
- EnableNSW
- Energy and Water Consumers Advocacy Program (EWCAP)
- Energy and Water Ombudsman Consultative Council
- Greater Sydney Commission Social Panel
- Guardianship Board Advisory Group
- Guardianship Tribunal Stakeholder Reference Group
- iCare Lifetime Care and Support Reference Group
- Joint Transport for NSW and City of Sydney Council Access Advisory Group (Sydney Light Rail and Pedestrianisation of George St)
- Juvenile Justice Advisory Committee
- Kinchela Boys Home Corporation Advisory Committee
- Minister for Innovation's Social Innovation Council
- National Disability Carers Advisory Council
- NCOSS Assistive Technologies Community Alliance NSW (ATCAN)
- NCOSS Disability Network Forum (DNF)
- NCOSS Forum of Non Government Associations (FONGA)
- NCOSS Health Policy Advisory Group (HPAG)
- NCOSS Transport Policy Advisory Group (TPAG)

Our Expertise

- Last year, disability advocacy services provided hundreds of expert consultations and submissions to the NSW Government.
- Disability advocacy services provide disability representation and expertise to over 80 NSW Government and non-Government groups.
- In less than two years, all of this expertise and representation will disappear.

- NDIS CEO Advisory Group
- NDIS Pathways Advisory Group
- North Coast Primary Health Network Cancer Screening Collaborative Reference Group
- NSW Advocate for Children and Young People Anti-Violence Campaign Expert Advisory Group
- NSW Anti-Social Behaviour Reference Group
- NSW Apprehended Violence Orders Legal Issues Coordinating Committee
- NSW Civil and Administrative Tribunal Consultative Committee
- NSW Dept of Family and Community Services CEO Advisory Group
- NSW Dept of Family and Community Services Disability Inclusion Plan Implementation Committee
- NSW Dept of Family and Community Services Future Directions Collaborative Forum
- NSW Dept of Family and Community Services Safework Advisory Board
- NSW Dept of Health ILC Project Reference Committee
- NSW Dept of Health Non Government Organisation Advisory Committee
- NSW Dept of Justice Disability Advisory Council
- NSW Dept of Premier and Cabinet NDIS Transition CEO Advisory Support
- NSW Disability Advocacy Network (NDAN)
- NSW Disability Ombudsman Roundtable
- NSW Electoral Commission Equal Access to Democracy Disability Reference Group
- NSW Energy and Water Ombudsman Advisory Group
- NSW Health Care Complaints Commission Consumer Consultative Committee
- NSW Housing Connect
- NSW Housing Federation Exchange
- NSW Insurance Regulatory Authority
- NSW NGO Housing Partners Reference Group
- NSW Pharmacy Council Advisory Group
- NSW Public Housing Repairs Coalition
- NSW Social and Affordable Housing Fund Expert Advisory Group
- NSW Sydney Water Customer Council
- NSW Victims of Crime Interagency
- NSW Women's Alliance
- Our Big Kitchen Advisory Board
- Positive Partnership Advisory Reference Group
- Redfern Statement Alliance Committee
- Social Ventures Aboriginal Service Provider Advisory Group
- Statewide Steering Committee, Joint Protocol to Reduce Contact of people with disability in Supported Accommodation with the Criminal Justice System
- Telecom Institute (Autism) Advisory Committee
- Transport for NSW Accessible Transport Advisory Committee (ATAC)
- Transport for NSW Train Station Signage Testing Advisory Group
- Transport for NSW Way Finding Project Consultative Committee
- University of Sydney Disability Bias Crimes Working Group
- University of Sydney Prepare NSW Advisory Committee
- UNSW Home Modifications Information Clearing House (HMInf.) Advisory Group
- Women NSW Sexual Assault Strategy Expert Advisory Group
- Youth Justice Advisory Committee

Our Members



Ability Advocacy



Action for People with a Disability



Blind Citizens Australia



CAWS

Blind Citizens Australia

Community Access Western Sydney



Council for Intellectual Disability



DeafBlind Association (NSW) Inc.

Council for Intellectual Disability

Deaf Blind Association of NSW



Disability Advocacy NSW



DAISI Services Limited



Ethnic Community Services Co-operative



Family Advocacy NSW



First Peoples
Disability Network



Information on Disability
Education and Awareness
Services



Intellectual Disability Rights
Service



Multicultural Disability Advocacy
Association



Muscular Dystrophy NSW



Physical Disability Council of
NSW



People with Disability
Australia



Radio for the Print
Handicapped



Regional Disability Advocacy
Services



Spinal Cord Injuries Australia



Stroke Recovery Association
NSW



Synapse



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