

NSW DISABILITY NETWORK FORUM

Independent Advocacy and Independent Information

The NSW Disability Network Forum is pleased to provide this Position Paper to the Ability Links NSW Taskforce to explain the critical role of Independent Advocacy and Independent Information not only to support people with disability and their families and carers, but also to ensure the success of the Ability Links NSW Program and its implementation. The NSW Disability Network Forum believes this is an important consideration in the development of a delivery structure for Ability Links NSW Coordinators. This Position Paper contains a series of advocacy and information stories, provided by the NSW Disability Network member organisations, designed to speak for themselves, to illustrate the positive impacts and outcomes for people, providers and government.

About the NSW Disability Network Forum

Initiated in June 2011, the NSW Disability Network Forum comprises non-government, non-provider peak representative groups whose primary aim to promote the interests of people with disability. The aim of the NSW Disability Network Forum (DNF) is to provide a new avenue to build capacity within and across all organisations and groups so that the interests of people with disability are advanced through policy and systemic advocacy. NCOSS provides the secretariat to the NSW Disability Network Forum.

Introduction and context

The NSW Disability Network Forum contends that Independent Advocacy and Independent Information is essential to the effective functioning of any system of supports that provides robust outcomes for people with disability. This flows from the principles and obligations set out in the United Nations Convention on the Rights of People with Disabilities (UNCRPD).

In NSW, the participation and inclusion of people with disability in their local or chosen communities is the primary aim of the Ability Links NSW Program. The shift towards person centred approaches and individualised funding arrangements to enable personal choice and control will result in a transformation of specialist disability and other supports over time.

The National Disability Strategy seeks to enhance the participation and inclusion of people with disability in all aspects of life not just in their necessary supports, i.e. employment, health, education, housing, transport, law and justice etc. National Disability Strategy Implementation Plans at the National and NSW levels signpost the first important steps towards equitable participation and inclusion of people with disability in everyday life.

INDEPENDENT ADVOCACY and INDEPENDENT INFORMATION

Value for money

NSW Disability Network Forum members have agreed that many people with disability and their families will be effective advocates for their own situations. But increasingly, people with disability want information from a source where there is no reason other than to provide the best possible information to support the person. Equally, people with disability and their families at times want the expertise of advocates to assist when they are overwhelmed or feeling “dismissed”, with negotiations or when larger issues /situations arise. This kind of assistance is often not sought from within the system and an investment in Independent Advocacy and Independent Information will provide cost effective value for money assistance to people with disability external to support pathways.

Further, many people with disability have gained the confidence, through using independent advocacy, to become effective advocates for their own circumstances and concerns.

Safeguards

The provision of external safeguards is critical to the effective functioning of any system to support vulnerable people. The provision of Independent Advocacy and Independent Information is an important and critical safeguard for people with disability in NSW both for their whole of life participation as well as in the existing specialist disability system and the evolving person-centred support pathways including Ability Links NSW Coordinators.

Early warnings

Both at the systemic level and for the individual, there are many gaps in both the existing systems as well as the new systems for people with disability described above. While longer term resolutions are planned over time, these gaps can and do create unintended hardship and unreasonable consequences for a person or group of people.

The support of timely, non-aligned, Independent Information and/or Independent Advocacy allows issues to be handled with expertise that avoids costly escalation that could make the service or system work better by identifying failures or opportunities for improvement, or by simply solving a problem for a person when there is nowhere else to go.

Levels of government and cross agency issues

Independent Advocacy and Independent Information has long expertise in responding to people with difficult and/or complex issues, especially across a broad range of government agencies, e.g. ADHC, housing, education, health, transport etc. both at the individual and the systemic levels. This experience is important in navigating the complex levels of federal, state and local government responsibility, as well as departmental/agency responsibilities at state level. In this way, Independent Advocacy and Independent Information can be an important asset to both Ability Links NSW as well as the “support pathways” for person centred approaches.

Broad options and non-systems issues

NSW Disability Network Forum member organisations were clear that the flexible advocacy and information provided was not confined to government agencies and services. Importantly, the support of independent advocacy and information is required in dealing with everyday issues do to with housing, budgeting, managing the household, personal decisions, accessing professional supports etc. While often not seen as imperative in the scheme of support services, these can be critical factors for the person and may be critical inhibitors to inclusion and participation or a good life. Independent advocacy and information can have the flexibility to address these everyday issues in the short and longer terms at the individual and systemic levels.

Helping the “system” work better

Building Independent Advocacy and Independent Information supports at this early stage alongside the development of the *Living Life My Way* support pathways, including the roll-out of Ability Links, will ensure that there is flexible assistance for people with disability and their families and carers, especially where that system has no capacity to respond. This ensures that issues for the person with disability do not needlessly escalate, that gaps or program/system response issues can be identified quickly, that misunderstandings are competently and objectively managed and that whole-of-life issues are handled with care.

Complementary to Ability Links

The role of Independent Advocacy and Independent Information is quite separate and distinct from Ability Links NSW Coordinators. According to the original Ability Links tender documents, Coordinators will assist people not now in the disability service system to access their local community for the support and services they need to exercise their choices in life, just like anyone else. There are concerns that the very high workloads of these 248 Coordinators (between 129 and 103 per annum each) plus their required community development functions could mean that their time with each person with disability could be limited, or that the people with more difficult or more complex issues are referred to other places. At present, the other parts of the “support pathways” system are not currently being established and will, in any case, have specific functions for identified target groups.

Independent Advocacy and Independent Information will provide more flexible and non-aligned support unrestricted by support pathways requirements and complementary to the Ability Links role. This also applies to the proposed Access Points as well as the other parts of the planned *Living Life My Way* support pathways. In fact, DNF member organisations report that the ADHC regional offices often contact NGO information and advocacy organisations for advice or to make referrals. Therefore the roles are clearly distinct as Independent Advocacy and Independent Information sits outside but adjacent to the support pathways system and will assist with other parts of the person’s life at the same time.

Stories of Independent Advocacy and Independent Information

The NSW Disability Network Forum believe it is important to let the work of Independent Advocacy and Independent Information demonstrate its critical purpose. Accordingly, the following short stories from member organisations have been collated to give effect to the points made in this Position Paper. This section includes stories on Independent Advocacy, and there are a number of stories that are contained in the next section on **Independent Information**.

Note the wide variety of people with disability in the stories, the wide variety of issues described and the wide variety of outcomes achieved. And this is just the tip of the iceberg... The NSW Disability Network Forum was overwhelmed by the number of stories submitted for this Paper just from amongst its members, and the challenge was in selecting just a few.

Help to make the right move

An advocate has for some time now been supporting a man with intellectual disability who lives independently in the community; particularly in undertaking more complex tasks associated with a Housing NSW tenancy. Recently the advocate was contacted by a Housing NSW representative who had come to know that the man receives support from Side by Side Advocacy. The man had to move house because he had been living in a property leased by Housing NSW from a private owner; and the owner wanted the property back. Advocacy assisted the man to understand that he was going to have to move, why and what the process would be. Advocacy supported the man to express his needs clearly and used knowledge of his needs accumulated through various advocacy actions and through speaking (with permission) to the man's family to ensure that only appropriate offers of alternative housing were made. The man's family drew attention to the fact that while living in a previous house, the man had been a target of abuse from neighbours. The advocate supported the man throughout the offer, acceptance, lease signing and organising for Housing NSW to pay for the cost of the move. He is now settled in his new home. Advocacy has also provided some guidance with respect to tasks that have to be done when a person changes address and what to do if there is a problem with any of the neighbours.

Talking to the boss

Advocate supported and created opportunities for a young man to express his feelings about his workplace role and responsibilities. The employer of 7 years had not recognised or given any consideration to this man's workplace support needs and his anxiety was overwhelming.

The two meetings that consequently took place were structured to enable the young man to lead and guide discussions. This young man is currently enjoying his work and future review meetings are planned to review and maintain what has been achieved.

Due to the support of the advocate, there is improved understanding, support and enhanced relationships within his workplace.

We need the support of our own people

When we think about disadvantage, living in a remote community in western NSW and having a child with disability, who requires multiple medical interventions daily, this is the reality for many Aboriginal families in trying to live a good life.

Mum is a strong black woman who is a survivor of the stolen generation, who cares for multiple people in her household with disabilities. To be able to use Aboriginal advocacy support has sustained her life. Recently the family needed to navigate the medical system in Sydney and without having individual advocacy support they could not have been able to succeed in the outcomes they wanted. The social and professional language is very different for an Aboriginal person from a geographically isolated area and real needs can get lost within frustration and anger.

To have one of their own kin, from the disability advocacy network, to lean on in times of extreme stress and moments of vulnerability, is not only comfortable and non-judgmental, but it also eliminates the need to explain why.

This family has a need for ready and available advocacy provided by one of their own and its success can only be measured in the outcomes that have been attained by having someone at hand, only a phone call away.

Mary avoids a nursing home

Mary was a 26 year old woman who was holidaying in the UK when she had a major stroke leading to locked in syndrome and significant physical disability. She was brought back to Sydney for rehabilitation. Soon after, her father had a heart attack and died.

Mary spent 3 months in rehabilitation but made little progress. The rehab centre recommended to Mary's mother that she look for a nursing home placement for Mary.

Mary's mother's friend contacted an advocacy agency for assistance.

The advocate assisted the friend and mother to mobilise Mary's friends and family into a circle of support. This provided a vehicle to channel their love and concern in a practical way. Under the guidance of the advocate the circle of support

- Guaranteed that Mary's mother would not go to meetings with Rehab staff alone
- Committed that Mary would go home
- Kept friends involved by coordinating their visits so that Mary would have maximum social contact

In addition, the advocate helped Mary obtain an Attendant Care package and to negotiate a Community Participation package. Eight months later, Mary went home.

The right treatment at the doctors - Adjustable height examination tables

Research has shown that people who cannot access adjustable height examination tables are more likely to not have access to either acute medical care or preventative medicine. In addition, they are also at risk of misdiagnosis or non-detection of potentially serious conditions. However, not only patients are at risk, but also doctors, nurses and carers assisting patients onto fixed height tables or physically supporting people in wheelchairs. In addition, adjustable height tables are also vital for older people and other people with temporary limited mobility due to accident or illness.

Organisations and individuals:

- *Built on previous work.* Following on from the 2006 survey of GPs by Access for All, (to determine the number of adjustable height examination tables in surgeries), and the Open Letter from the Australian Human Rights Commission issued in 2007, Physical Disability Council NSW (PDCN) conducted a survey of people with disability in 2008-2009 to gain more information and further insights about the extent of availability of adjustable height tables
- *Worked collaboratively,* including: Royal Australian College of General Practice; Women with Disabilities Australia ; Australia Human Rights Commission; NSW Council on the Ageing; and People with Disabilities Australia
- *Participated in advisory committees,* including provided information to the Standards Committee of the Royal Australian College of General Practitioners
- *Prepared submissions and reports*
 - Involved in the preparation of a joint submission for the RACGP Review, with People with Disabilities, Women with Disabilities Australia, and NSW Council on the Ageing. Final submission was signed /endorsed by more than 130 organisations/people
- *Gave presentations and interviews*
 - The PDCN Research was the subject of a presentation by Graeme Innes AM from the Human Rights Commission at PDCN's Annual General Meeting in October 2009
 - Issued media releases and raised issues with a number of state and commonwealth government agencies
 - Provided information to people with disabilities about the survey results, and the RACGP review via newsletters, website and community consultations
 - Promoted the value of height-adjustable treatment beds to General Practitioners using wide distribution of a flyer, and information to Divisions of General Practice.

The work by PDCN and other organisations and individuals resulted in The Royal Australian College of General Practitioners (RACGP) making the installation and use of adjustable examination tables in the rooms of General Practitioners mandatory (flagged) in October 2010.

A keyboard opens up possibilities

An advocate has been supporting a young man with intellectual disability and autism who lives at home with his mum. The man does not speak. However it has become clear through therapy that he has a good understanding of what is going on around him and he has begun to communicate using a keyboard.

The Advocate approached ADHC in several ways to ensure that the man's ability and potential is known and to raise the question how resources could be dedicated to the man's development on a consistent and permanent basis.

Through a third Community Participation appeal (Mum had previously appealed twice) the service provider of the man's Community Participation program was compelled to provide an additional computer and to set aside time each day to support him in improving his communication using the keyboard. Previously the man would only type with the support of his mother. He now spends 15 minutes each day at the service at a computer with the aim of gradually improving his concentration and extending that time. Although it remains to be decided whether a higher level of CP funding will be allocated to the young man, it was very interesting and different to attempt an appeal based solely on something positive about the person and that has already produced a great result.

Advocate also assisted and supported mum in expressing her vision for her son that he would live independently in the community and that he can with the right support. Therefore he should be given full consideration for any recurrent package of support offered on that basis.

Cathy lives her own life

Cathy was a 24 year old woman in 1989 when Hornsby Challenge was asked by the Royal Institute for Deaf and Blind Children (RIDBC) to accommodate a young woman who had remained at the RIDBC for 6 years longer than usual because of challenging behaviour (frustration). She had been refused accommodation at all other services, and they were told she would need to go into a Nursing Home if this was not successful. Advocacy from DeafBlind Association was sought and communication solutions were implemented; her accommodation is still secure and she worked in open employment with minimal support, but with advocacy and communication, for the next 15 years before making the choice to remain at home and join other social venues. She is currently a happy person making her own choices.

A student with disability gets the school support he needs

The parent contacted an advocacy agency when her son with disability was suspended for 20 days from school because of behaviour. The parent reported that her son had been suspended 3 times each for 3 days over the past school term and that on each occasion, he had returned to school, the behaviour recurred and he was resuspended.

The advocate gave the parent a copy of the Suspension Guidelines of the Dept of Education and Communities, summarising (s6.2.3) that during the time of suspension, the Principal should use all available school, education and other resources to assist the student modify his behaviour.

The advocate suggested that the parent meet with the Principal to request specialist support to assist the student to change his behaviour, to give the teacher additional skills to reduce the likelihood of the inappropriate behaviour and to assist the teacher to plan so that the student was more engaged in learning.

The advocate assisted the parent to plan for the meeting with the Principal. In addition, the advocate gave the parent contact details of the Behaviour Support teacher at regional office. In turn, the Behaviour Support Teacher offered to remind the Principal of the support that could be provided.

When the parent met with the Principal, he was amenable to the suggestions of the parent. The Principal also agreed that the parent would be part of the initial meeting to brief the Behaviour Support teacher.

Getting my payments sorted

Over a six month period, an advocate was contacted by three people with intellectual or psychiatric disability who had all received letters requiring payment of up to \$4000 owed to Centrelink.

Advocate found that each debt (the whole or a part of it) was the result of factors connected to the person's disability. Two people had, during the time they were overpaid, been struggling to work and study while supplementing their income with an unemployment or student payment. The impact of their disability means they really need to be paid Disability Support Pension if they are to maintain employment and complete their studies. The other person had not recognised changes to their employment income or the need to tell anyone.

Advocate assisted each person to have their debt either waived or reduced. Each person has also received some advocacy support to allow them to begin or continue to be paid the correct rate of Disability Support Pension and work, study or both.

A good education at my local school

When thousands of parents of children with disability were being refused enrolment in regular classes of local neighbourhood schools, advocacy agencies campaigned to change education policy and education infrastructure so that students with disability could expect a quality education together with their peers.

While initial advocacy efforts led to the physical presence of students with disability, teaching practice and school attitudes kept them marginalised. In response, advocacy organisations worked both outside government (through campaigns, letters, articles and discussion papers) and inside government (on working parties and advisory groups) to enable children and young people with disability to have the same opportunities as their peers without disability.

INDEPENDENT INFORMATION

While including Independent Information, much of the above has an emphasis on the provision of Independent Advocacy. The NSW Disability Network Forum wanted to shine a light on the role and importance of Independent Information.

Why is information so important?

The right information at the right time in the right format is what good information provision is all about. It assists people to make sound decisions and choices about their lives.

Information is an integral part of life for all people living in the 21st Century and access to information can often be taken for granted by people who have the skills and resources to obtain it as needed.

- People need good information to make good choices
- Poor choices cost the person their health and realisation of their wants and goals in a truly inclusive community
- Poor choices cost the state money.

Why information services?

- People with disability, like anyone else, want a trusted, credible and reliable source of information.
- They are skilled in collecting, evaluating, producing and disseminating information on a wide range of issues, topics, supports, research and resources that may be of interest to people with disability.
- Information services offer much more just a list or flier – they are problem solvers, connectors and linkers.
- They listen to people and respond to their needs
- They help people to connect the dots and feel more confident about making decisions.

Why is independent information important?

Information has to be pure but potent. The person with disability or their carer needs to know the full who, what, where, why and how, of any information data set they want to know about. Informed decisions can only come from having the full picture – you can only buy apples if you are offered apples.

Information that is not tied to service provision or other allegiance due to their independent nature, and values accuracy as its first order principle and does not act as promoter or adviser in any other capacity is critical.

Who uses information services?

- People with disability, their families, support networks, the disability sector, the government and the wider community.
- Information officers in other information and referral services
- Information services play an integral role in connecting many of these people and systems.

It is likely:

- Without good information people will make poor choices
- Without good information people will stay with what they know
- Without good information people will not choose mainstream

Information Services at Work...

Working for individuals

New opportunities

Bob is 33 and lives at home with his family. He rings the information service because he is lonely and bored. He is linked to a community group in his area to try out. Bob excitedly rings back in a few weeks' time to share the news that not only had he enjoyed going to the group but he had met someone there who gave him a job. He was over the moon with the opportunities this has opened up for him.

Personal choices

Rebecca is 24, has an intellectual disability and wants to have sex with her partner. She does not want to talk to her mother about this. Rebecca rings the information service that is able to send her some pictorial information about this. They also give her the details of a counsellor she can talk to about this issue.

Living where you want to

Eric is 44, his mother has just died and his sister now wants him to come and live near her. Eric does not want to do this. He has friends, a job and likes living where he has lived for the last 6 years. He is scared that she will make him move as she has already rung the real estate agent to terminate his lease. Eric contacts an information service as he does not know what to do. He is linked to an advocacy service that helps him to stop his sister's actions.

Working for families and carers

Joining in

Elsie, 76, had heard on the radio there was a forum in her local area about health and disability but the way to find out more information was via a website. Elsie didn't use computers. She rang the information service to see if they could assist. The information officer got some details from Elsie, searched for the forum then printed the information for her. This included enlarging the flyer to A3 size and posting it out to Elsie. She was delighted to receive this information and attend the event.

Welcoming, listening, responding...

Rebecca's child has just been diagnosed with a disability – she is distraught and just does not know where to start to get support. She has tried ringing 5 different government departments and had not been able to get anywhere. She calls the information service – they send her out some information and tips on navigating the system. She is encouraged to contact the information service again, which she does numerous times over the next 12 months. She reports that they are the only ones who listen to her story and does not make her feel stupid for not knowing what to do.

Working for the system

Training in easy-to-read information

NSW CID and IDEAS information services in 2010 had numerous requests regarding creating easy to read information – where could people go to learn this skill? NSW CID and IDEAS partnered to host training in NSW which was attended by a big cross section of professionals. The benefits of this training have been far reaching with many new resources and publications made for audiences that have poor literacy skills. This included information on mobile phone scams, diabetes, complaints, research and health.

Ready resources

A disability service provider contacts NSW CID concerned about a person they are supporting who is going through grief. Thus far they have been unable to find any resources or services to support this person. NSW CID provides copies of easy read information designed specifically for people with intellectual disability from their library collection. Staff is also linked to a psychologist who works in this area and some guidelines around supporting people through grief. In this instance the information has not only directly benefited the person but also served to up skill staff.

Information can be proactive and often it really is a case of a stitch in time saves nine.

CONCLUSION

The NSW Disability Network Forum is continuing to develop additional compelling evidence for the growth of Independent Advocacy and Independent Information into the future.

Should the NSW Ability Links NSW Taskforce require any further information, clarification or wish to discuss any matters raised in this submission, please contact the NSW Disability Network Forum secretariat, c/- NCOSS Christine Regan, ph. 9211 2599 ext. 117 or chris@ncoss.org.au or Val Kors val@ncoss.org.au.

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NSW Disability Network Forum Member Organisations:

Aboriginal Disability Network NSW
Association of Blind Citizens of NSW
Brain Injury Association NSW
Deaf Society of NSW
DeafBlind Association NSW
Deafness Council (NSW)
Institute For Family Advocacy
Intellectual Disability Rights Service
Multicultural Disability Advocacy Association
of NSW

NSW Consumer Advisory Group - Mental Health
NSW Council for Intellectual Disability
NSW Disability Advocacy Network
People with Disability Australia
Physical Disability Council of NSW
Positive Life NSW
Self Advocacy Sydney
Side By Side Advocacy Incorporated
Council of Social Service of NSW