

Information, Linkages, and Capacity Building Submission

This submission is from People With disabilities WA and Developmental Disability WA in response to the Information, Linkages, Capacity Building Framework paper.

People With disabilities WA (PWdWA)

Since 1981 PWdWA has been the peak disability consumer organisation representing the rights, needs, and equity of all Western Australians with a physical, intellectual, psychosocial, or sensory disability via individual and systemic advocacy. We provide access to information, and independent individual and systemic advocacy with a focus on those who are most vulnerable.

PWdWA is run by and for people with disabilities and aims to empower the voices of all people with disabilities in Western Australia.

Developmental Disability WA (DDWA)

Developmental Disability WA is a not-for-profit community organisation in the disability sector.

For almost 30 years we have been a leader in the disability sector as a strong voice for people with intellectual and other developmental disabilities, their families and the organisations that work for them.

What are the most important elements of ILC?

People with Disabilities Western Australia (PWdWA) and Developmental Disability WA (DDWA) welcomes the recognition that the Information, Linkages and Capacity Building (ILC) framework is an important element of the National Disability Insurance Scheme (NDIS) because it allows for the development, advocacy, engagement and active participation for all people with disability and not solely individuals who are eligible for Individual Funded Packages (IFD).

We acknowledge the ILC framework will provide one of the mechanisms by which the NDIS can influence and shape mainstream services at a systemic level; to provide better outcomes for people with disability, their families and carers. It is important to develop a framework that is transferable and can work across states, the success of which is critical for the implementation of the framework.

We see a focus on increasing the independence and capacity of the person with disability as part of the necessary work to increase participation of people with disability in the community. There is also the added benefit that this can potentially alleviate the pressure on families, carers, and systems that are already over stretched and under resourced.

PWdWA and DDWA agree with the five streams of service identified in the framework, however we think the terms used should be those in the plain English version of the paper as the intent is much easier to understand:

- Stream 1 – Information and Connections
- Stream 2 – Improving mainstream services for people with disability
- Stream 3 – Developing understanding in the wider community
- Stream 4 – Building the capacity of people with disability
- Stream 5 – Connecting communities

It should be a priority that activities that fall under the remit of these streams are developed and implemented with active participation from diverse people with disability and Disabled Person's Organisations. There is an expectation that many elements of what make up the ILC framework should be delivered by Disabled Peoples' Organisations and funded appropriately. A Disabled Person's Organisation is one that is run by people with disabilities for people with disabilities.

In recognition of the key role that families also play in supporting and advocating for their relative with a disability, we would support the need for family capacity building in Stream 4. Engagement with families will bring along a broader population to also assist with developing understanding in the wider community.

It is critical that there is an emphasis on '*meaningful participation as equal citizens*', and that peer support is integral to the implementation of all aspects of the ILC as it supports people with disabilities to be equal citizens. It is also important that all aspects of these five streams are integrated to create seamless services and that they are not operated and managed in silos.

It is essential that the delivery of ILC activities does not become the sole preserve for Local Area Coordination (LAC). The role of LAC should be complementary to organisations who are equipped to reach people with disabilities who do not have individual funding packages (IFP) and can provide, if adequately resourced, the knowledge and expertise to expand capacity building and community awareness.

We agree in principal to the development of a centralised electronic database to convey product and service information. The success of such an initiative will be dependent on information being captured by user led organisations, being available in accessible formats, including linguistically diverse options and being effectively communicated to the intended audience. There must be multiple formats and ways that people with disabilities can get information. Many people are not able to afford internet access and the default of having a website is not the same as effective marketing and communication, or use of multiple access points like libraries, Council offices, NDIA offices etc. We also strongly support the notion of a service/app/website where consumers can share information about providers and rate providers.

It should be noted that organisations like PWdWA provide information and referral services to people with disabilities above and beyond our funding for advocacy. This is because there are many people who need support to access and understand information and there are not many other options if they do not have access to an LAC.

What is missing?

We understand the principles behind the ILC framework, however as organisations that advocate for both the individual and collective voice of people with disability, we question the complexity of the model. The design elements are too complicated and convoluted for many individuals to understand. It is also unclear from the consultation as to how the framework will be implemented. A clear implementation strategy needs to be addressed. An acknowledgement of cultural and linguistic diversity and the diversity of the intersection of aboriginality and disability needs to be addressed. Initiatives which help to address these issues need to be incorporated into the framework. The links with other systems such as Mental Health also need to be explored further.

There needs to be better linkages between the enablers and the ILC framework as illustrated in figure 1 of the document. For example the National Disability Strategy (NDS) demonstrates that all governments are committed to a national approach to supporting people with disability. There are many facets within this strategy that are not covered by the NDIS but would fall under the ILC framework. For instance, an outcome of the strategy under rights protection, justice and legislation is that people with disability have their rights promoted, upheld and protected. Future action ensures people with disability have every opportunity to be active participants in the civic life of the community - as jurors, board members and elected representatives. The ILC framework and its notion of building capacity would facilitate this.

What this means at each state level is that a State's Disability Plan (which is meant to be how the state is implementing the National Disability Strategy) should be directly connected to the ILC framework. This is particularly important in Streams 2 and 3 where state government departments and local governments have a very important role to play in including people with a disability.

Research and innovation is a key enabler that should be explored further particularly as the NDIS is founded on an evidenced based model. PWdWA promotes the need for products and services to be developed based on robust research and best practice. We strongly recommend that research is conducted by user led organisations and that appropriate funding is awarded to ensure that research involves active participation, is consumer led and is based on contemporary models of inclusive research. The ILC framework through its initiatives around peer support, personal networks and community activities will help to achieve this.

In terms of funding, the framework makes suggestions on the types of ways funding might be envisaged, however there is no emphasis on Disabled Peoples Organisations and the role they can play in peer support, capacity building, and increasing the capacity and understanding of main stream services. Many people with disabilities participate freely in advisory groups and many Disabled Person' Organisations and advocacy organisations play a representative role in co-designing policy and advising many different departments and local governments on how to be inclusive of people with disabilities. This representative and co-design work should be acknowledged and funded.

There is also a case for block funding of services to support people with disabilities to be included in the community. The funding may be a combination of funding from partnerships between local government, the NDIA, state government etc. but can be provided for things like shared community transport options and services like Travellers Aid (<https://www.travellersaid.org.au/our-services/travellers-aid-access-service-taas>).

It is unclear how the role of the LAC will provide outreach and engagement with people living isolated lives on society's fringe. Without a very active process of outreach and relationship building, individuals in this situation are unlikely to see the potential benefit of the NDIS or seek assistance from it. These are also likely to be the people who do not need (and may not be eligible for) funded packages but do need substantial disability support in times of crisis or transition and/or adhoc disability support with month to month problems. People who are already in the justice system or at risk of being in the justice system, people living in private hostels and people with mild intellectual disability and co-occurring psychosocial disability are some of the types of people who need this direct support through ILC.

The ILC Framework is an essential element of the developmental and preventive safeguards for people with disabilities. This needs to be acknowledged as it is through capacity building and connection with mainstream that people with disabilities can safely take risks to learn and grow and experience good lives. Ensuring mainstream services like consumer affairs are working with people with disabilities and Disabled Person's Organisations brings the safeguards the rest of the community use into the disability sector and could strengthen those safeguards for the whole community eg, understanding contracts in plain English. The ILC should also therefore be funded and implemented properly as an acknowledged part of the Quality and Safeguarding Framework.

How will we know the ILC streams are meeting their objectives/vision?

There is a need for a robust and independent quality assurance framework with a monitoring and evaluation element. This should be supported by an annual review process focused on the analysis of outcomes. This will identify gaps and

weaknesses which can be addressed. It is important to again ensure that people with disabilities are included in this process and consulted on evaluation methods.

We suggest some of the early indicators to success may be the quality and abundance of information available in alternative formats, the numbers of people with disability in the justice system, and increased options for people with disabilities in their communities e.g. employment, recreation facilities. An annual review or tool similar to the “Closing the Gap” report would provide some specific targets and indicators for success.

https://www.coag.gov.au/closing_the_gap_in_indigenous_disadvantage

What would be the implementation challenges?

We firmly advocate the need for adequate financial resource to implement the many initiatives identified in the framework. It is important that capacity building and community awareness are fully costed and integral to budget planning and are not considered as voluntary arms and ‘good will gestures’ of the community sector. To achieve robust, relevant and effective capacity building requires sound investment into the community infrastructure through appropriate funding and support. An approach which is too slow will mean that people remain isolated with support in their homes if ILC change isn’t keeping pace with the NDIS rollout. Achieving a balance between a prevention focus and a development focus, while moving away from a deficit focus, is essential for the success of the ILC framework. Likewise there needs to be a focus on long term capacity building strategies and not just a short term fix.

We consider that a major implementation challenge will be targeting priority groups. To be truly and fully engaged with the disability community will take time and flexibility and the framework needs to adapt to this to allow individuals to develop capacity and become empowered at different timeframes. Engaging a majority of people will be challenging especially in regional and remote areas. In addition how best to support people who have minimal networks of support, different levels of understanding and ability to cope with change will all pose challenges. It is therefore extremely important the ILC framework is implemented and delivered by people with disabilities and the organisations who can best represent them. This will not only provide better support for people with disabilities in decision making but also make the ILC framework more credible.

Another barrier to implementation will be the attitude and willingness in mainstream services to develop services that are inclusive. For example, the slow pace of change in the built environment and physical realm of access will create real challenges for implementation. Also the lack of access and change to technology by mainstream services which increases access and inclusion for people. There needs to a fully funded training and education resource to raise awareness of disability in the public realm

There are currently many good examples of programmes that delivery quality and effective outcomes for people with disabilities, KidSport in WA (<http://www.dsr.wa.gov.au/docs/default-source/file-funding/file-individuals/kidsport-infographic.pdf?sfvrsn=2>) being a prime example and which also recognises poverty as a major factor which contributes to isolation and non-inclusion. These programmes are often funded through other agencies and not specifically targeted at people with disabilities. There is a risk that by introducing a specific funding stream to develop community infrastructure, programmes like kids in sport will reduce their amount of funding attached to such initiatives in the belief that it will be funded elsewhere. It is vital therefore those new funding channels complement existing ones and that they do not replace them.

Which aspects of a person's life do you think ILC could have the greatest impact on?

PWdWA and DDWA are assured that the intention of the framework is to empower individuals and help them make considered choices. An individual's connection to the community has a great impact. By developing and implementing a user led framework will ultimately bring benefits of improved social and economic outcomes. Better employment opportunities, recreation opportunities, communication, relationships, self-confidence all stem from better connectivity and the ILC framework can impact on this. Even the smallest changes can have huge impacts and decreasing the number of multiple services by streamlining service provision is important.

A very important aspect of a persons life which we hope is impacted, is their relationships, friendships, and value. If implemented well across all areas there should be an increase in the numbers of people with disability seen in the community and who are friends with people in their community.

What are some of the principles that should guide investment across ILC streams?

PWdWA and DDWA see the overarching legislation that should guide investment across the ILC streams being the UN convention on the rights of Persons with Disabilities coupled with the National Disability Strategy and National Disability Standards. At an operational level, a quality improvement process that embraces value for money; choice and control with an outcome that satisfies and individual's needs is recommended. It is important that such a process includes a consultative approach that facilitates growth and personal development, and empowers the individual to make real and considered choices.

We perceive this is an opportunity to consider local solutions to people's issues and create links to local communities through capacity building where there are gaps. There is real scope to engage with local and small businesses to help bridge these gaps, build capacity and raise awareness in the community.

How do you see the interface between ILC functions and activities and the interaction with the mainstream service system? (housing, education, employment, health, family, accessibility and transport)

PWdWA and DDWA advocates that the National Disability Insurance Agency (NDIA) challenges other systems to fulfil their legal and best practice obligations by ensuring the enablers of the disability support system are adhered to fully. It is absolutely imperative that the key decision makers in mainstream areas such as health, housing and local government have an understanding of the need to include people with disabilities and an understanding of their obligations under the UNCRPD.

The person with disability must be the priority and mainstream services must integrate to provide services that are person centric and provide equal access regardless of the type of disability or location of the individual.

It is important to ensure the interface is pro-active not reactive and disability groups are an integral part of the design of systems and programs. Local Area Co-ordinators and other professionals' role should be to facilitate outcomes for the individual who can access user led services and support. The experience of the LAC model in WA is that it has been very good for those that have access to a good LAC, however the model tends to work on a person by person, family by family basis and does not bring people together to learn and support each other. In WA this has meant there is not a strong peer network or peer organisations that have developed to build the capacity of people with disability and this is a risk with over reliance on LAC.

PWdWA and DDWA recognises that Disability Access and Inclusion Plans (DAIPs); a legislative requirement on all State Government departments and Local Governments in WA, are an integral part of the process by which services for people with disabilities are improved. Their remit covers: services and events, buildings and facilities, information, quality of service, through appropriately knowledgeable staff, complaint processes and consultations. This is an effective mechanism for ILC interface with a range of mainstream services. Many Local Governments and State departments now employ disability inclusion or community development officers. It is essential that these officers are working within the parameters of the ILC framework to develop strong networks which broaden the range and increase the reach of people with disabilities to ultimately enhance best practice in mainstream delivery. It is critical that effective training is provided to ensure best practice in mainstream services; PWdWA supports this element of the framework and recommends that a network of trainers is created to ensure training is delivered by people with disabilities or people with experience of disability.

Other comments

Employment of people with disabilities in roles related the ILC framework is essential in creating good outcomes, good role modelling, and jobs for people with disabilities.

PWdWA and DDWA strongly support the role of independent advocacy in the ILC framework. It is important to ensure both the individual and collective voice of people with disabilities is elevated and that service providers and mainstream services are continually challenged to improve through constructive and independent feedback. PWdWA is ideally placed to continue its role as independent advocate at an individual level, evidence provided from this is able to inform and direct systemic change. DDWA creates lasting positive change by:

- supporting people with developmental disability and their families to have a strong voice
- partnering with others to develop more connected and inclusive communities, and
- influencing government and other decision makers

There also needs to be a recognition of the role of Disabled Peoples Organisations in representing the rights and voice of people with disabilities in co-design of policy, on advisory groups and in giving feedback and submissions such as this. We have a broader connection to people with disability and understanding of disability issues than a government department will ever have.

PWdWA is an organisation led and delivered by people with disabilities for people with disabilities. It is already actively delivering pioneering initiatives that cover many of the facets of the ILC framework. The development of peer support groups and work with the NDS to promote the National Standards for Disability Services amongst the sector being two such examples.

PWdWA recommends the establishment of a consultative committee of disability organisations that can influence the development and direction of the ILC framework.