

National Disability Insurance Scheme

A Framework for Information Linkages and Capacity Building

Submission

Children with Disability Australia
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INTRODUCTION

Children with Disability Australia (CDA) welcomes the opportunity to provide feedback on the framework for the Information, Linkages and Capacity Building (ILC) component of the National Disability Insurance Scheme (NDIS).

CDA is the national disability representative organisation for children and young people aged 0-25 years. It receives its core funding from the Department of Social Services and presently receives additional funding from the Australian Government Department of Education. CDA has over 5000 members nationally.

The NDIS was introduced due to a national recognition that the disability service system was grossly inadequate. CDA hears daily of the exasperation that children and young people with disability and their families experience due to the constant and often insurmountable barriers within the disability service system to receiving adequate services and supports. Prolonged advocacy and community action from people with disability, families and advocates led to the Productivity Commission undertaking the Inquiry into Disability Care and Support. The Inquiry found that the disability service system “is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports.”¹ This led to the remodelling of the disability services system with the establishment of the NDIS.

The core principles underlying the NDIS are to:

- support the participation and inclusion of people with disability in social and economic life;
- provide certainty around disability services and supports;
- maximise the choice and control of people with disability around supports received; and
- support people with disability to achieve their goals and live independently.²

To date, the majority of attention regarding the implementation of the NDIS has centred on the processes and procedures around participants of the Scheme with an Individual Funding Package (IFP). It is estimated that 410,000 people are likely to access the NDIS as participants through having an IFP.³

The ILC Framework will be of relevance to the largest number of people with disability, with it being potentially accessed by the 2.5 million people under the age of 65 known to have a disability.⁴ ILC needs to incorporate a flexible process for accessing services and supports for people with disability, families and carers. Many people with disability will require, and in some cases desire, disability specific services as well as there being a critical need for many mainstream services to be inclusive of people with disability. The needs and wants of every individual will differ. The ILC Framework should therefore facilitate a service system for people, families and carers that provides the necessary safeguards and choice to access necessary supports. It should not result in processes, services and supports being imposed on people.

Further, the ILC Framework must generate community-wide change that promotes the inclusion of people with disability in an organic way, rather than through bureaucratically driven processes. CDA

¹ Productivity Commission 2011, *Disability Care and Support: Productivity Commission Inquiry Report Overview and Recommendations*, Commonwealth of Australia, Canberra, p. 2.

² *National Disability Insurance Scheme Act 2013 (Cth)*, part 2.3.

³ National Disability Insurance Scheme 2015, *A Framework for Information, Linkages and Capacity Building*, Department of Social Services, Canberra, p. 3.

⁴ *Ibid*, p. 3.

recognises that this process of reform is highly complex, however this submission raises significant concerns about the proposed ILC Framework.

GENERAL COMMENTS

The NDIS is an extremely complex and challenging social reform, involving ongoing consultation and agreements across jurisdictions. CDA recognises that there is an ongoing need to balance a multitude of considerations as the Scheme is established. It must embed a fundamental cultural and policy shift to the Scheme's guiding principles and establish a new system for the funding and accountability of disability services where the person with disability is at the centre. Underlying these changes is the need to ensure the long term sustainability of the Scheme and the time imperative for implementation. The Department of Social Services and the National Disability Insurance Agency (NDIA) should be commended for their work to date. Below are CDA's comments on a number of general themes and issues presented in the ILC Framework.

Consultation Process

It is the view of CDA that the consultation process for the ILC Framework has been problematic.

- There has been insufficient time for the public to consider the Framework, with there being less than one month for consultations and late availability of an Easy Read version of the Framework.
- Promotion of the consultation appeared limited and the process was not promoted through channels easily available to the NDIA such their e-newsletter. Further, the ILC webpage on the NDIS website was difficult to locate and required people to know what they were looking for to find it.

Language

- The consultation paper is not clearly written and is difficult to understand. It uses highly bureaucratic language and jargon throughout. Examples include 'social insurance model,' or 'systemic level' supports.⁵ While the examples of services and supports provided within each of the streams provided some clarity around meaning, it would have been useful for the Framework to provide definitions of key terms used.
- While 'inclusion' is mentioned throughout the Framework, it is never clearly defined and there appears to be varying understandings of the term presented. Inclusion is a complex and highly debated concept. It requires recognising impairment as one of many forms of human diversity, and welcoming and viewing diversity as a resource rather than a problem.

Often, inclusion is referenced in the Framework as something that can be inserted or retrofitted into existing services or organisations. This is reflected in the repeated focus on "enhancing the inclusiveness of people with disability"⁶ of organisations and services. However, inclusion needs to be inherent in community-based valuing of diversity and premised on a genuine view that all members of the community contribute and are valued. Extensive discussion around the concept of inclusion (in the context of education) occurs in CDA's issues paper, *Inclusion in Education: Towards Equality for Students with Disability*. This paper is available at <http://www.cda.org.au/inclusion-in-education>

⁵ National Disability Insurance Scheme 2015, *A Framework for Information, Linkages and Capacity Building*, p. 1.

⁶ Ibid, p. 6.

- While it is seen as unintentional, some of the language used in the Framework can be interpreted as positioning people with disability as ‘others’ with some presumptions made about shared characteristics or experiences. For example, one of the service examples listed under stream three is “basic training to individuals...to enable them to more effectively relate to, or work with, people with disability.”⁷ The idea that there is a distinct way in which people need to ‘relate’ to people with disability and that this needs to be explicitly taught is presumptuous and many would find this offensive.

Need to minimise processes imposed on people

- It is important for the ILC Framework to recognise that accessing services, whether through an IFP or ILC, involves compromised privacy and additional responsibilities and accountability requirements. Any person accessing formal disability services and supports has many additional individuals, organisations and systems in their life who know their personal and intricate details. The impact of this is significant. This intrusion and compromised privacy is a stark contrast to the experiences of people without disability. This needs to be a key consideration when thinking about the operation of the ILC Framework. There is a careful balance to be achieved in providing necessary services and supports to enable equal opportunities for participation without unnecessary intrusion into people’s lives.

Role of families

- The role of families of children and young people with disability need to be considered in the ILC Framework. All children have the right to be cared for by family. This right is set out in the *United Nations Convention on the Rights of the Child*. For example, article 18 obliges State Parties to the Convention to:

*use their best efforts to ensure recognition of the principle that both parents have common responsibilities for the upbringing and development of the child. Parents or, as the case may be, legal guardians, have the primary responsibility for the upbringing and development of the child. The best interests of the child will be their basic concern.*⁸

As a society we allow parents and families to have the responsibility for care and protection of their children until they are 18 and to have flexibility around the different decisions made in relation to their children. The role of family needs to be respected and recognised in the coordination of ILC supports. Accessing services and supports for a child with disability should not diminish the roles, responsibilities and relationships of families and care givers. For example, it is important to ensure that the development of Local Area Co-ordination (LAC) involves roles that are complementary to and do not interfere with or undermine the role of families. Services need to be wrapped around the individual circumstances of children and their families rather than participants of the NDIS having to fit in with procedures and roles inherent in the Scheme.

Role of the NDIS

- The ILC Framework should address at the fundamental level how the additional services and supports required by some people with disability can be available in a manner which is as organic as possible. A consequence of accessing ILC services, support and expertise should not be additional processes and requirements regarding planning, participation and accountability in order to access equal opportunities available to citizens without disability.

⁷ National Disability Insurance Scheme 2015, *A Framework for Information, Linkages and Capacity Building*, p. 7.

⁸ United Nations General Assembly 1989, *Convention on the Rights of the Child*.

- The National Disability Strategy (NDS) sets a 10 year reform plan from 2010-2020 for all Australian governments to address the barriers faced by Australians with disability. The purpose of the Strategy is to:
 - establish a high level policy framework to give coherence to, and guide government activity across mainstream and disability-specific areas of public policy;
 - drive improved performance of mainstream services in delivering outcomes for people with disability;
 - give visibility to disability issues and ensure they are included in the development and implementation of all public policy that impacts on people with disability; and
 - provide national leadership toward greater inclusion of people with disability.⁹

The six policy areas covered by the Strategy are:

- Inclusive and accessible communities;
- Rights protection, justice and legislation;
- Economic security;
- Personal and community support;
- Learning and skills; and
- Health and wellbeing.¹⁰

Establishing a new system of delivering and funding disability support was identified as a critical area under policy direction four of the NDS, 'personal and community support.' The NDIS therefore constitutes one aspect of the broader agenda set out in the NDS. However, despite this, the aims articulated in the ILC Framework mirror those of the NDS as a whole. For example, the ILC Framework has the stated aim of facilitating "the social and economic inclusion of people with disability."¹¹ However, this is not the role of the NDIS. It is the view of CDA that the NDIS should not be the 'front desk' organisation that promotes the inclusion of people with disability. It is important for mainstream sectors and the broader community to take the lead in this change. For example, in the area of housing there is currently a critical need to expand the range of flexible and affordable housing options that can meet the needs of people with disability, including the right to inclusion and participation in the community. This cannot be achieved by the disability sector alone, as this runs a high risk of continuing the segregated model of housing for people with disability. Partnerships between disability and mainstream housing services are therefore needed. The NDIS needs to facilitate opportunities and partnerships but should not be the 'director' of all things disability.

- It is noted that the diagram provided of the Disability Support System on page two of the Framework does not include the person with disability or their family. This oversight seems to reflect a theme in the Framework where processes and systems are imposed on people.

SPECIFIC COMMENTS

STREAM 1: INFORMATION, LINKAGES AND REFERRALS

- Families of children with disability have consistently articulated that information provision regarding availability, quality and accessing services and support is a significant issue of concern. This was a dominant theme in the community consultation undertaken by the

⁹ Council of Australian Governments 2011, *National Disability Strategy 2010-2020*, Commonwealth of Australia, Canberra, p. 9.

¹⁰ Ibid, p. 9.

¹¹ National Disability Insurance Scheme 2015, *A Framework for Information, Linkages and Capacity Building*, p. 1.

Productivity Commission for the Inquiry into Disability Services and Support. It was frequently remarked that the services system is highly fragmented and difficult to navigate. The establishment of the NDIS was envisaged as a more centralised, coordinated and comprehensive services system. However, it is unclear from the proposed ILC Framework how the Scheme will facilitate this. The Framework does not provide information as to how needs and gaps in service and support provision will be identified and met and how supports will be funded. Overall, it is unclear how what is proposed in the ILC Framework differs from current practice.

- It is important for the NDIS to co-ordinate supports relating to ‘Information, Linkages and Referrals’ with existing pools of knowledge around service and support provision and best practice. CDA’s experience is that family and parent networks are extensive, rich sources of information and experience which presently are an integral part of the information and support available. Generally people are highly generous with sharing their experience and knowledge. A key focus of the ILC Framework should be on how this existing knowledge can be supported, extended and enriched. In addition, local knowledge about services and support available in particular regions should be considered in stream one. Further, knowledge from mainstream sectors, such as education, housing or health is a further source of information that should be drawn upon.
- The ILC Framework does not clearly identify the roles and responsibilities of the NDIA, states and territories, local government, non-government organisations, people with disability and families and care givers.
- Stream one does not provide details about whether a single or multiple gateways for NDIS participants to access information, linkages and referrals are envisaged and if so, how this will operate in practice. It is unclear how ILC will differ from current practice in this regard.
- The experience of children and young people and their families as the Scheme is in the initial establishment phase is that many services and supports are being scaled down or in some instances ceased in anticipation of the full implementation of the Scheme. It is critical to identify where this is occurring and how any service gaps will be addressed as the Scheme is rolled out fully.

STREAM 2: CAPACITY BUILDING FOR MAINSTREAM SERVICES

- This stream is central to the aim of meaningfully affording people with disability rights, equal opportunities and the development of a truly inclusive community. However, CDA is concerned that this stream contains minimal substantive information about how it will be achieved in practice.
- In stream two, one of the strategies identified is to enhance the “inclusiveness of people with disability”¹² in mainstream services and providers. However, this places responsibility for ensuring mainstream settings are inclusive with the NDIS. As previously stated, it is critical that mainstream services and portfolios take the lead in promoting a culture of inclusion. The ILC Framework should focus on interface issues between the NDIS and other areas, rather than looking to drive this change.

¹² National Disability Insurance Scheme 2015, *A Framework for Information, Linkages and Capacity Building*, p. 6.

- The examples provided in this stream are confusing and their practical application is unclear. One example is “enhancing ‘best practice’ in service delivery,” however there is no explanation of what this involves.

STREAM 3: COMMUNITY AWARENESS AND CAPACITY BUILDING

- The objective of ‘Community Awareness and Capacity Building’ is “getting organisations... and people within communities to be inclusive of people with disability.”¹³ Again, this takes the view that inclusion can be retrofitted into communities. As previously stated, inclusion is a more complex and organic process that cannot be ‘added on’ to existing structures and communities.
- This section states that “the NDIS has a key role in supporting and strengthening effective local initiatives by community groups and businesses to address disability issues in the community (e.g. social isolation).”¹⁴ The categorisation of social isolation as a ‘disability issue’ infers that disability is the cause, when in fact it is barriers within the society which make issues such as social isolation a common experience for people with disability.
- Currently, we see culturally and historically embedded discriminatory attitudes in many areas of the Australian community. These attitudes, or ableism, position disability as an inability, rather than a positive aspect of a diverse culture. In CDA’s experience, it is common place for children and young people with disability to be referred to as a ‘burden,’ ‘problem,’ ‘broken’ or ‘sick.’ It is critical to address the attitudes in the broader community, rather than having focus on particular attributes presumed to be typical or common traits of people with disability. This will be a complex process, requiring commitment and input from all areas of community life. While leadership from the NDIS is important, it is critical to note that the broad cultural changes required cannot be driven by a single sector.
- In addition, it is important to note that bureaucratically-driven awareness raising campaigns are rarely organic drivers of change. One of the examples of programs provided under stream three is “public campaigns to improve the community’s general disability awareness and understanding.”¹⁵ However, there is a risk that such campaigns would promote a charity model that relies on ‘feeling sorry for’ people with disability, rather than challenging ableist attitudes. Again, the focus needs to be on changing discriminatory attitudes as a community, rather than increasing ‘awareness about disability.’
- A critical time for the development of cultural preferences, such as attitudes towards disability, is during childhood. It is important to ensure that disability is experienced within the community as a usual part of diversity to encourage the development of mutual values of equality, respect and participation. Leadership and commitment to inclusion within the early childhood and school education sectors is critical to achieving this, rather than just disability services.

STREAM 4: INDIVIDUAL CAPACITY BUILDING

- This section does not provide a clear definition of ‘capacity building’ and what the aims of capacity building are. CDA understands ‘capacity building’ to mean that people have a better understanding of services and supports and are in a better position to access them. This involves a self-advocacy role so that people are aware of their rights and can challenge the

¹³ National Disability Insurance Scheme 2015, *A Framework for Information, Linkages and Capacity Building*, p. 6.

¹⁴ Ibid, p. 7.

¹⁵ Ibid, p. 7.

assumptions in the community that create a culture of low expectations for people with disability in a range of life areas.

- The language around ‘capacity building’ imposes processes and planning on people with disability. For example, the ‘Individual Capacity Building’ stream aims to be “effective in supporting an individual with planning.”¹⁶ However, there is a need to be aware that formal planning out of one’s life is an artificial process that people without disability do not necessarily undertake in their daily lives. As previously discussed, the ILC Framework needs to acknowledge the intrusion that formal disability services have on people’s personal lives and ensure that these processes are not imposed.
- Another aspect of this stream is that programs are “adapted to be inclusive or particularly responsive to people with disability.”¹⁷ As previously discussed, this is problematic as it implies that the NDIS is trying to retrofit inclusion.
- A further example of supports provided through stream four is “parent breaks and programmes to provide parents with skills and information about disability.”¹⁸ However, this implies that children are defined by their disability, rather than being seen as a child first. Rather than providing disability-specific parent support groups, access to support and information should be provided through mainstream family services and programs that have an inclusive culture.
- As in previous streams, the proposed precise role of the NDIA in providing supports related to ‘Individual Capacity Building’ is not defined. It is also not established how the NDIA will map areas of need and existing provision to identify priority areas. It is unclear to CDA how this will differ to practices currently in place, apart from the centralised funding model of this NDIS.

STREAM 5: LOCAL AREA COORDINATION (LAC)

- It is stated that “LAC will ensure that people with disability, their families and carers, are able to make full use of the mainstream and other services...available to them.”¹⁹ This language presumes that people with disability and families will want to use LAC services. The language of the Framework should clearly indicate that people can elect or opt in to LAC.
- A number of points made about the role of LAC are unclear. LAC will “promote community inclusion”²⁰ however no clarification is provided as to how this will occur. The role of LAC also involves “prevention, capacity building and locally based practical solutions which are fundamental to ILC and the concept of a wide entry gateway.” This sentence is ambiguous, with it being unclear what is meant by ‘prevention’ and what a ‘wide entry gateway’ is intended to lead to.
- It is stated that Local Area Coordinators will work “with people with disability, their families and carers to consider their immediate and future goals and how these might be best achieved.”²¹ As discussed in relation to stream four, the establishment of goals is a process

¹⁶ National Disability Insurance Scheme 2015, *A Framework for Information, Linkages and Capacity Building*, p. 8.

¹⁷ Ibid, p. 6.

¹⁸ Ibid, p. 7.

¹⁹ Ibid, p. 8.

²⁰ Ibid, p. 8.

²¹ Ibid, p. 9.

that most people do informally. Again, it is essential to be mindful that people without disability do not need to undertake these processes in their daily lives.

INTERSECTION WITH MAINSTREAM SERVICES

- This section describes special schools as a 'mainstream system,' however this is incorrect. Special schools are segregated, disability-specific settings.

CDA is mindful that this submission has focused on the limitations of the proposed framework and limited feedback has been included as to how the framework could be improved. This is partly due to the limited time frame in providing submission.

As emphasised, throughout this submission, CDA recognises this is a very significant and important component of the NDIS, and would very much welcome the opportunity to contribute to any further work or consultation that occurs around the future development of the ILC Framework. Further consultation which allows input from a range of stakeholders is viewed as essential. Please do not hesitate to contact us if you would like to discuss further any aspects of this submission. Thank you for the opportunity to provide a submission to this consultation.

Contact: Stephanie Gotlib, Chief Executive Officer
Suite 3, 173 Queens Parade, Clifton Hill, VIC 3068
Phone 03 9482 1130 or 0425 724 230
stephanieg@cda.org.au
www.cda.org.au