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# The ILC landscape: a snapshot

Informing Investment Design:  
ILC Research Activity

Erin Wilson & Chris Brown, 2021

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## Summary

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This paper reviews data from recent public consultations and academic literature related to the broad aims of the Information, Linkages and Capacity Building (ILC) grants program. This is a scene-setting exercise to succinctly summarise the policy and programmatic context surrounding the ILC grants program, and the current needs and priorities of people with disability in Australia.

### Key points

#### Achieving the Purpose of the ILC

The logic of the ILC design has been described in two main ways:

1. as a vehicle to deliver on government strategy, and
2. as an underpinning mechanism to contribute to the sustainability of the NDIS.

For these logics to be fully realised/implemented, however, a need to map the complex State and Federal funding and strategy landscape has been identified in public consultations, in order to ensure maximum co-ordination and complementarity and to identify gaps.

#### Understanding the Needs of People with Disability in Australia

Significant needs remain in relation to inclusion for people with disability in Australia. Issues prioritised through recent public consultations such as those for the National Disability Strategy, the National Disability Employment Strategy, and the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, include:

- negative attitudes, including stigma and discrimination, particularly for people with intellectual, psychosocial, sensory and hidden disabilities and women with disabilities;
- limited employment and economic participation, including a lack of job opportunities and inclusive workplaces as well as insufficient personalised employment supports;
- numerous barriers to inclusion in mainstream services, including inadequate provision and/or inaccessibility of services as well as a lack of disability knowledge of mainstream practitioners, with this gap among health practitioners being a particular priority;
- a range of barriers to community inclusion, such as a lack of recognition of autonomy and in/inter-dependence, inaccessible environments and a lack of culturally appropriate support;
- intersectionality, particularly the experiences of women with disability, Aboriginal and Torres Strait Islanders with disability, children with disability, culturally and linguistically diverse people with disability and LGBTQIA+ people with disability.

Whilst the needs and issues highlighted are broad and far-reaching, an evidenced priority remains the lack of inclusion in mainstream services/sectors. As a consequence, the role for the ILC as a lever for systemic/social change would appear to remain a valid one.

#### Other priorities

The ILC focus on people with disability who are not participants of the NDIS is of agreed importance across public consultations referenced in this report. It has been recommended that the Productivity Commission undertake a gap analysis of supports and services in each State and Territory that are available to people with disability who are not eligible for the NDIS (Brotherhood of St Laurence and Mission Australia, 2020). The ILC could then align to these gaps.

According to a range of commentators (e.g. IAC, 2021), a focus on building the capacity of user-led organisations is highly valued in light of the recognised role they play as key and trusted supports for people with disability and their carers, and the decrease of other available funding sources for these organisations.

# 1. Introduction

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The Centre for Social Impact (CSI), Swinburne University of Technology, is conducting a gap and needs analysis to assist the Department of Social Services to build an evidence base for the Linkages and Capacity Building (ILC) Program. The study includes a review of grants information, surveys and interviews of grantees and sector informants, and a desktop review of literature on current identified needs and priorities to achieve inclusion/equity for people with disability.

This document presents a summary of available literature that captures the priorities and needs in contemporary Australia relating to disability and inclusion, specifically on the topics within scope for the ILC grants program. To do this, a wide range of literature has been reviewed including:

- government policy and strategy documents including various ILC policy (NDIA, 2015), strategy (NDIA, 2018) and investment documents (NDIA, 2016) to explain the original intent of the ILC;
- recent (between 2017 and 2021) national public consultations such as those related to the National Disability Strategy, the National Disability Employment Strategy and the Royal Commission (RC) into Violence, Abuse, Neglect and Exploitation of People with Disability;
- research literature such as academic publications in peer reviewed journals and research and evaluation reports. Fifty-five publications were sourced via an academic data base search for publications from 2015 onwards, using the terms 'Information, Linkages and Capacity Building' or 'ILC'.

To organise this literature, we have drawn on the various logics that have underpinned the design of the ILC grants investment or been used to subsequently describe it. Across authors, contexts and timeframes, various logics have been used to provide a rationale for this investment. These logics have been collated from a range of sources, largely related to ILC policy and commissioning. They offer a starting point for organising data on ongoing priorities, gaps and needs for Commonwealth investment in this arena. (This document does not seek to judge the extent to which these logics have actually guided grant program design or funding allocation). The logics have been organised into two broad categories, those that see the ILC as a vehicle to deliver on government strategy and, related to this, those that see the ILC as a fundamental element of the sustainability of the NDIS. Within each are a range of sub themes that emphasise different elements:

Logics of ILC investment design:

## **1. ILC as a vehicle to deliver on government strategy.**

This set of logics emphasises the alignment of the ILC with Commonwealth and State and Territory strategies, and the need to design a grants program that explicitly complements government programs and activity. Several themes are apparent in the literature and policy documents:

- Alignment with and supporting implementation of the National Disability Strategy (NDS);
- Alignment with State/Territory inclusion plans;
- Supporting interface and interdependencies with, not duplication of, other policy and programs across jurisdictions.

## **2. ILC as an underpinning mechanism to contribute to the sustainability of the NDIS.**

This is most frequently referred to in terms of building the capacity of people with disability and carers, and making mainstream services and community supports and activities more inclusive and relevant to people with disability (so as to minimise the need for funded supports). Again, a range of themes drive the logic of ILC investment:

- Addressing the needs and priorities of people with disability and carers including the causes of exclusion and marginalisation and supports to address these. Within this is an explicit policy focus on specific areas of need in the logic of ILC grants design:
  - Increasing the relevance, accessibility and inclusiveness of community and mainstream activities, programs and services (so as to reduce need for funded supports to mediate barriers to inclusion), and recognising the contextualised, place-based nature of these needs;
  - Providing supports to the wider cohort of people with disability beyond those eligible for the NDIS (particularly in the context of withdrawal of State/Territory funded supports previously accessed by this population), and to families and carers;
- Building the capacity of user-led organisations in recognition of their role as central supports and representative bodies;
- Cultivating a healthy market of disability service providers to deliver ILC outcomes;
- Building and sharing an evidence base of inclusive and capacity building practice, fostering innovation and generating co-investment in activities.

These logics provide thematic areas under which evidence of the current issues in the Australian disability landscape are organised. This is an original way to organise and consider data in relation to the rationale for the ILC grants program. As such, not all areas were found to have strong evidence in current public consultations and research.

## 2. Current evidence aligned to the proposed logics of ILC investment design

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### 2.1 ILC as a vehicle to deliver on government strategy

#### 2.1.1 Alignment with and supporting implementation of the National Disability Strategy

In 2020 the ILC grants program was transferred from the NDIA to the Department of Social Services explicitly 'to realise benefits of greater integration and better alignment with the National Disability Strategy (NDS) and other Commonwealth services and programs' (Commonwealth of Australia, 2020, p. 2). As described by the Department of Social Services, a 'key aim of the NDS is to influence the focus of mainstream programs and services to be more inclusive of people with disability, and to support broader community inclusion. The ILC provides a key program lever to give effect to this aim and to the achievement of NDS outcomes' (Commonwealth of Australia, 2020, p. 8). This is consistent with the original intent of the ILC Policy (NDIA, 2015): 'ILC will build on areas of policy action under the National Disability Strategy 2010-2020' (p. 5). However, the ILC Commissioning Framework (2016) clarified this further:

*ILC is not intended as a funding source for organisations looking to meet their obligations under the National Disability Strategy. It is the responsibility of government, business and the community to make sure that their programs, services and activities are inclusive and accessible. ILC will not provide funding for this responsibility. But we will use the funds we have to build the capacity of organisations to better meet the needs of people with disability (NDIA, 2016, p. 13).*

In this context, the ILC appears to demonstrate a consistent logic of alignment with the NDS, though how this alignment is driven and reported against is not clear.

Recent commentary (e.g. Walsh, 2021) highlights the gap in suitable mainstream supports for people with disability and therefore the increasingly critical role of the NDS as the vehicle to deliver these. Walsh (2021, p. 7) recommends that 'the development of mainstream and community capacity must be seriously restored and embraced by all Australian governments through a strong and robust National Disability Strategy 2020-2030', which suggests that the ILC focus on mainstream capacity building cannot be designed without reference to the role and associated investment/activity of the NDS.

#### 2.1.2 Interdependencies with, not duplication of, other policy and program areas across jurisdictions, including alignment with State and Territories

The relationship of the ILC to other Commonwealth and State and Territory programs has been a complex one. When part of the NDIA, the ILC was understood in the context of the 'Applied Principles and Tables of Support that guide the interaction between the NDIS and mainstream supports (e.g. health, mental health, justice, education, transport, housing, and aged care sectors)' (NDIA, 2015, p. 1). Notably, the NDIS cannot fund activities that are the obligation of other jurisdictions and mainstream services, as discussed above: 'ILC supports may assist jurisdictions and mainstream sectors to meet their agreed responsibilities, but will not replace mainstream support delivery for people with disability' (NDIA, 2015, p. 18). This is later articulated in the ILC Commissioning Framework in the following way:



*Governments, businesses or organisations have a responsibility to be accessible and inclusive and meet the needs of people with disability. ILC funding cannot and will not be used to fulfil that obligation. What we want ILC funding to do is build capacity – not replace other services or systems or fill gaps within mainstream services (NDIA, 2016, p. 21).*

In a similar vein, the original ILC Commissioning Framework also identifies individual and systemic advocacy as activities excluded from ILC funding (NDIA, 2016).

The need for advocacy support ties to identified gaps in mainstream service provision which are reported as priorities by people with disability, carers and families. In turn, these gaps impede the attainment of ILC outcomes. Gaps in and poor performance of mainstream services is an ongoing and common theme in recent public consultations and inquiries summarised in sections below. The Brotherhood of St Laurence and Mission Australia (2020) submission to the NDS consultation notes these ongoing gaps and calls for greater systemic action and alignment of investments in the NDS, the National Disability Agreement (NDA) and the NDIS, 'to ensure all three key policy frameworks are mutually reinforcing and do not create gaps in support' (p. 4).

While it is broadly argued that the ILC has interrelationships across mainstream services and parts of the NDIA, a range of key interfaces for the ILC have been identified in various reports as listed below:

- **The Local Area Coordination (LAC) program** of the NDIA (\$332M in 2019, \$120M ECEI) is considered as strongly complementary to the ILC grants program, particularly as they both initially sat within the same ILC Policy (NDIA, 2015). To date, while Partners in Community (LAC and ECEI) have been required to allocate 20% of their time to community capacity building activities, some argue this has not occurred due to their role in enrolling participants into the NDIS (Brotherhood of St Laurence and Mission Australia, 2020). The Independent Advisory Council (2021) similarly notes 'the inadequacy to date of a Local Area Coordination (LAC) strategy to support people with disability to be included in the community' (p. 4). The Department of Social Services suggests that the introduction of the Independent Assessment process (since shelved), the Early Childhood Early Intervention reset, the Participant Service Guarantee and completion of NDIS rollout and planning activities, will lead to a reorientation of the LAC role to encompass increased community connections and capacity building of both individuals with disability and community and mainstream organisations (Commonwealth of Australia, 2020). Certainly, there is broad support for the LAC role to be reset to 'manage the gateway for participants on the cusp between tiers 2 and 3' (i.e. those on the border of accessing funded supports through the NDIS) as well as supporting opportunities for individuals to access mainstream and community supports (Walsh, 2021, p. 8).

Previously, the *ILC Commissioning Framework* (NDIA, 2016) notes that the ILC grants program will not fund 'activities that duplicate the role of the LACs' (p. 20), however, this role is highly variable dependent on locality, provider and level of engagement in planning activity. Given the uncertainty of the context, contractual complexity, and need for workforce capacity building to deliver any change in LAC roles, it is unlikely that changes to LAC roles will pose an area of substantial ILC duplication in the short term. In the longer term, complementarity of focus and activity will need to be managed.

- The **NDIS Participant Employment Strategy** includes proposed activities and aims that resonate with the ILC Economic and Community Capacity Building program. These include, for example, developing and delivering 'cohort specific responses to employment challenges for NDIS participants, such as people with intellectual disability, autism, acquired injury or psychosocial disability' and Investigation of 'cohort specific employment challenges (for example, people with acquired brain injury) to inform ...[response to] specific information and support needs' (NDIA, n.d., pp. 13-14). Guiding this strategy is the DSS/NDIS Participant Employment Taskforce with a focus on

*improving the intersection between the NDIS and other employment supports funded by government ... defin[ing] the right supports for NDIS participants to find and keep a job, reduc[ing] barriers to employment, and assist[ing] employers to reach a level of confidence to employ NDIS participants (NDIA, n.d., p. 24).*

- The **National Disability Agreement (NDA)** covers 'funding responsibilities for disability services not covered by the NDIS, including advocacy, disability employment services, carer support, services for people with psychosocial disability/significant mental health issues and some community access and inclusion programs', but is now out of date (Brotherhood of St Laurence and Mission Australia, 2020, p. 13). Drawing on recommendations from the Productivity Commission's 2019 review of the NDA, the Brotherhood of St Laurence and Mission Australia argue that:

*An updated NDA should hold the Commonwealth and state and territory governments accountable for funding disability-specific services that fall outside the NDIS to ensure there are no gaps in support and ensure consistency across the nation. A comprehensive gap analysis is required to articulate the areas a new NDA should be responsible for and inform a new robust performance reporting framework, aligned to the NDS (p. 13).*

- A number of Commonwealth funded information initiatives may offer areas of duplication or complementarity, depending on scope, for National Information Program and other ILC activities. The **Disability Gateway** (website and 1800 telephone service), funded to June 2022, provides information about supports across life areas and jurisdictions, lists ILC funded National Information Programs (NIPs) where they provide relevant and accessible information services for people with disability, and has links to other ILC projects (Commonwealth of Australia, 2020). Additionally, the **JobAccess** website is the national hub for workplace and employment information for people with disability, employers and service providers. Likewise, the **NDIS Participant Employment Strategy** (NDIA, n.d.) commits to building a 'central, online resource centre for NDIS participants, providers and employers to promote employment initiatives, success stories and links to further information' (p. 13 and publishing 'an annual guide to the available government employment programs and promote these to NDIS participants' (p. 14). The **National Workplace Initiative** (National Mental Health Commission and Mentally Healthy Workplace Alliance, \$11.5M) is developing a new digital portal on mentally healthy workplaces. A further resource, the **National Carer Gateway website** (\$700M over 5 years) aims to help 2.65M unpaid carers get support.

- The **National Disability Employment Strategy (NDES)**, currently under development, will complement the NDS and provide direction for increasing employment participation of people with disability. As of June 2021, the Strategy is still under public consultation. It is not clear how this will interface with the ILC Economic and Community Participation (ECP) program, though recent research identified that the ECP funds employment support interventions targeting demand and supply sides of the labour market, in areas not funded by the Commonwealth (Wilson et al., 2021).
- Similarly, the Economic and Community Participation focus of the ILC has complementarity with both **Commonwealth and State/Territory labour market programs** including disability employment programs (Commonwealth of Australia, 2020), as well as those targeting other cohorts such as young people, mature aged, parents and those targeting specific industries.
- Advocacy is a key area of interest across jurisdictions. The **DSS National Disability Advocacy Program** is funded at approximately \$23M per annum, and **States/Territories also fund advocacy programs** including individual and systemic advocacy (Commonwealth of Australia, 2020). However, the 2020 State of the Disability Sector report identifies that only 20% of disability service providers believe that there is sufficient advocacy for those they support and sees this advocacy as 'vastly under-funded by all levels of government' (NDS, 2020, p. 24). To date, the ILC has focused on building capacity for decision making, self advocacy and peer support, as opposed to individual and systemic advocacy (NDIA, 2015; 2018).
- The **Royal Commission (RC) into Violence, Abuse, Neglect and Exploitation of People with Disability** has produced wide ranging commentary and inquiry into areas broadly having commonality with the ILC program. RC publications to date have been analysed in section 2.2.1 below. Upon conclusion of the RC, it is expected that findings will drive Commonwealth investment over a period of years and to which the ILC will need to consider specific alignment and areas of complementarity.
- The **States and Territories** are a major source of partnership and complementarity in relation to the ILC, particularly in relation to mainstream services across sectors and targeted supports to particular regions or cohorts.
- The First Peoples Disability Network identifies the importance of creating links between disability strategies and the **National Agreement on Closing the Gap** in order to coordinate 'policy and programs at the Commonwealth, State and local levels in partnership with Aboriginal and Torres Strait Islander people with disability and their organisations' (First Peoples Disability Network, 2021, p. 21).
- An interest in **market development** (i.e. disability related service delivery) and stewardship falls across different jurisdictions and portfolios. This includes issues of thin coverage across all Australia and to specific cohorts (Commonwealth of Australia, 2020).
- While the NDIS does cut off eligibility for individual funding packages to those aged over 65 years, it notes the complementarity of supports provided to people in this older age group who are supported by other **Commonwealth (e.g. My Aged Care) and State and Territory systems**. Potential additional integration is suggested in regard to assistive technology by Assistive Technology (AT) For All (2019), an alliance of 25 peak bodies and consumer representatives spanning the ageing and disability sectors, who argue that the Commonwealth Department of Health could co-fund ILC activities to better equip older (and younger) people with disability in the community to navigate systems and supports to access AT.

In light of the identified areas of potential complementarity above, it is not surprising that an evaluation of the early rounds of ILC grants found that 'grant applications spanned the boundary between the activities that are in scope for ILC and those that are the responsibility of mainstream services. These boundaries of responsibility will vary across services and locations' (Argyrous et al., 2017, p. 10). The evaluators noted the need for ongoing contextual judgements about the level of interface, complementarity and duplication. In order to achieve greater coordination across sectors and jurisdictions, the Brotherhood of St Laurence and Mission Australia (2020) call for the establishment of

*a central NDS coordination agency with responsibility for cross-sectoral implementation, data collation and reporting (similar to the approach used for the New Zealand Disability Strategy). People with disability should be directly involved in developing and staffing any NDS coordination agency (p. 6).*

While this recommendation is in the context of the NDS, it highlights a potential mechanism, as used in other sectors (for example the Collaborative Partnership to Improve Work Participation), to resource the alignment and complementarity necessary for the ILC to function effectively. In addition, the National Disability Data Asset (NDDA), under development, will also contribute to meeting the need for data capture, linkage and sharing though its utility in the ILC context is yet to be explored.

## **2.2 ILC as an underpinning mechanism to contribute to the sustainability of the NDIS**

The Productivity Commission (2011) originally designed the NDIS with three tiers. The ILC was initially conceptualised as 'Tier 2' to support all people with disability to have increased linkages to community supports and to foster social change, while Tier 3 provides individualised funding to eligible people with disability to purchase the supports they require to maximise life activities and social and economic participation. 'The original Tier 2 concept focused on providing supports to people with disability outside the NDIS to improve their outcomes, in turn reducing the likelihood they would require support from the NDIS' (Commonwealth of Australia, 2020, p. 4).

The ILC Policy identifies ILC as

*a key component of the NDIS insurance model and will contribute to the sustainability of the NDIS by building the capacity of the community, people with disability, their families and carers which in turn will reduce the need for funding of supports for people with disability through IFPs [individual funding packages] (NDIA, 2015, p. 2).*

Hence, the ILC underpins the Scheme sustainability by fostering the social change needed, because 'a system that responds only to an individual's need [i.e. in the form of individualised funding] is not enough to ensure societal change in inclusion, access and equity of people with disability' (NDIA, 2015, p. 3). The Policy places the ILC as a systemic lever of change:

*ILC will allow the NDIS to influence the delivery of supports at a systemic level to provide better outcomes for people with disability, their families and carers. Over*

*time, this can reduce the demand for, and level of support required through, IFPs (and thereby reduce the cost of the scheme over time) (NDIA, 2015, p. 3).*

Scheme sustainability is predicated on the ILC's attainment of:

- Strengthening mainstream services and supports and community capacity to be inclusive of people with disability;
- Fostering continual improvement and innovation in disability support delivery;
- Minimising the need for escalation of support (largely via the LAC/ECEI program);
- Supporting carers, and;
- Building and promoting individual capacity and peer support (NDIA, 2015).

Figure 1 (below) summarises this commencing logic of ILC to Scheme sustainability.

The ILC Commissioning Framework (NDIA, 2016) reinforces this logic noting that the ILC

*is one of the foundation stones on which the scheme is being built. ILC contributes to the sustainability of the scheme in two ways. By ensuring that people with disability are connected into their communities, using the same services and participating in the same activities as everyone else, it will reduce reliance on specialist supports over time (p. 7).*

Additionally, the Framework argues, 'Providing support to people with disability who do not have an NDIS plan through ILC activities will also mean people will only move into individual funding when necessary' (NDIA, 2016, p. 12).

This logic has been returned to recently in the Independent Advisory Council's (2021) paper on *Strengthening Scheme Reforms to Access and Planning*, with calls to significantly strengthen Tier 2, including the allocation of additional budget. Similarly, John Walsh (a Scheme designer and former NDIS Board member, among other roles) notes the withdrawal of funding from Tier 2 resulting in a near total 'absence of other innovative and appropriate community and mainstream infrastructure and opportunities' (p. 2) demonstrating 'the resistance by governments to the development of an ecosystem of community and mainstream supports for all people with a disability' (Walsh, 2021, p. 1). In Walsh's view, this coupled with withdrawal of State and Territory funded disability services/supports, has led to the over-reliance on the NDIS as the 'all or nothing' system of support (p. 2), contributing to Scheme unsustainability.

Figure 1: Adapted from ILC Policy Framework (NDIA, 2015, p. 5)

ILC will contribute to Scheme sustainability by:

<p><b><i>Strengthening mainstream services and community capacity to meet the needs of people with disability</i></b></p> <p>Contributes to Scheme sustainability by reducing Scheme costs through better utilisation of non-Scheme-funded services and activities. Main strategies:</p> <ul style="list-style-type: none"> <li>• <b>Linking to services:</b> facilitating referral and linkages to and from mainstream service systems for people with disability<sup>1</sup></li> <li>• <b>Making services and community activities more relevant/effective for people with disability:</b> capacity building across communities, organisations, and mainstream service delivery, to influence attitudes and practices to lead to greater inclusion and engagement of people with disability AND to meeting the needs of people with disability their families and carers<sup>1</sup></li> <li>• <b>Expanding services/ activities available:</b> enhance opportunities for local communities to develop local solutions to meet the needs of people with disability.</li> </ul>	<p><b><i>Sustaining informal supports</i></b></p> <p>Contributes to Scheme sustainability by reducing Scheme costs through greater sustainability of informal supports. Main strategies:</p> <ul style="list-style-type: none"> <li>• <b>Providing breaks from care and links to support:</b> linking carers and families to social and recreational activities that provide a break from caring role and connect them with the community</li> <li>• <b>Fostering carer wellbeing activities</b> such as personal development, peer support and mentoring;</li> <li>• <b>Linking to services:</b> linking carers into direct carer support services</li> </ul>
<p><b><i>Fostering continual improvement and innovation in disability support delivery</i></b></p> <p>Contributes to Scheme sustainability by reducing Scheme costs through more efficient funded and non-Scheme-funded services and activities. Main strategies:</p> <ul style="list-style-type: none"> <li>• <b>Improve the quality</b> of support delivery</li> <li>• <b>Promote innovation</b>, leading to improved organisational and personal outcomes</li> <li>• <b>Build consistency</b> across jurisdictions, minimising the risk of the development of multiple service systems</li> <li>• <b>Foster preventative supports</b></li> <li>• <b>Expand gateway to various service systems</b> – link systems (for example, healthcare, aged care, education) to improve support the varying needs of people with disability, their families and carers.</li> </ul>	<p><b><i>Building and promoting individual capacity and peer support</i></b></p> <p>Contributes to Scheme sustainability by reducing Scheme costs through increased capacity of people with disability to access services, negotiate supports and manage services/supports (exercise choice and control). Main strategies:</p> <ul style="list-style-type: none"> <li>• <b>Providing decision-making supports and building individual capacity</b> for people to advocate for themselves (self-advocacy)</li> <li>• <b>Support people with disability to act for themselves and each other</b>, and support families, carers and community members to act for or with people with disability</li> <li>• Support people with disability to <b>lead peer support and promote self-advocacy</b> amongst peers, to support individuals in their capacity to effectively exercise choice and control.</li> </ul>

### 2.2.1 Addressing the needs and priorities of people with disability and carers including the causes of and supports to address exclusion and marginalisation

The 2017 evaluation of the early rounds of the ILC grants rounds proposed a central and ongoing focus on assessing and prioritising needs in relation to ILC outcomes (as opposed to ‘need for services’) to guide the grants commissioning process (Argyrous et al., 2017). The complexity of this work is in identifying ‘needs’ that are fundamental to achieving ILC outcomes. Given the breadth of ILC outcomes, below, we report on a broad set of needs identified and prioritised in various recent consultations, inquiries and research, noting that need is variously discussed by topic, by cohort and by context (e.g. locational disadvantage). To synthesise this, we have further grouped needs in terms of major themes:

- negative attitudes to disability (including stigma and discrimination)
- limited employment and economic participation
- barriers to mainstream inclusion
- barriers to community inclusion
- intersectionality
- provision of supports to wider cohort of people with disability than those eligible for NDIS, and for families and carers.

#### *Negative attitudes to disability*

Headlines:

- negative attitudes to people with intellectual, psychosocial, sensory and hidden disabilities have not improved
- intersectional issues lead to overlaid experiences of stigma and discrimination (e.g. for Aboriginal and Torres Strait Islander people with disability and women with disability).

The 2021 Stage 2 consultation to the next National Disability Strategy (DSS, 2021b) reports the most frequent focus of submissions was in relation to negative attitudes to disability. The earlier 2019 report on the first consultation to the NDS (The Social Deck, 2019) identified that while overall attitudes to disability have improved, this has not occurred in relation to intellectual, psychosocial, sensory and hidden disabilities which remain misunderstood in communities and workplaces (p. 19). This is consistent with past research which identifies that attitudes towards disability are not homogenous and need to be further understood so as to better target interventions. Tan, Wilson, Murfitt and Campain (2019) identify the most prevalent ‘cluster’ of negative attitudes to disability in Australia are those related to knowledge (lacking knowledge and understanding of disability) followed by the competency cluster (characterised by beliefs in the incapacity of people with disability), both experienced to a higher level by people with psychosocial disability and intellectual disability.

The National Mental Health Commission’s (NMHC) (2021) submission to the National Disability Employment Strategy identify ongoing and prevalent experiences of stigma/negative attitudes towards people with psychosocial disability in the workplace. The NMHC identify a need for sustained strategic direction and significant investment in education and information to change attitudes. This needs to go beyond superficial awareness campaigns to systemic strategies such as strengthening rights entitlements and knowledge of rights. Women with Disabilities Australia (2021) and First Peoples Disability Network Australia (2021) both identify the importance of an intersectional understanding of discrimination and negative attitudes. Attitude change strategies must be intersectional, involving disability, gender and race, to address gender based violence (for

example treating women with disability like children in the workplace resulting in being placed in jobs well below their capacity), and high rates of school suspension (leading young Aboriginal and Torres Strait Islanders with disability, sometimes without diagnosis, to experience high rates of school exclusion).

Beyond these consultative papers, the National Disability Research Partnership identifies that only a small amount of published research in Australia (2018-2020) focuses on discrimination, violence and abuse (<https://www.ndrp.org.au/mapping-research>), highlighting a gap in understanding of both incidence and solution.

### **Limited employment and economic participation**

Headlines:

- Limited employment opportunities
- Lack of inclusive workplaces
- Insufficient personalised employment supports
- Employment disadvantage is high (particularly for people with Intellectual Disability, Autism Spectrum Disorder, psychosocial disability, and women with disability).

Employment has been identified as one of the major concerns for people with disability in Australia, where poor employment outcomes have not seen improvement between 2001 and 2016 (Emerson et al., 2017). HILDA data identifies that unemployment inequalities have worsened between 2001 and 2018 for people with disability aged 15-24 years (Centre for Research Excellence in Disability and Health, 2021b). Survey results reported in the 2019 report on the consultation to shape the next National Disability Strategy (The Social Deck, 2019) identified that employment and career opportunities were the biggest issues for people with disability. Heightened disadvantage was reported to the Royal Commission (RC) into Violence, Abuse, Neglect and Exploitation of People with Disability, particularly for people with psychosocial and intellectual disability. People with intellectual disability were reported as being 'among the most disadvantaged in the Australian labour market' and less likely to be employed full-time compared to people with other types of disability (12% vs 32%) and people without disability (55%). Similarly, respondents to the RC reported only 8% of people with psychosocial disability had employment (in 2015) (RC, 2021a). People with Autism Spectrum Disorder were reported as being three time more likely to be unemployed than people with other disabilities (RC, 2021a). Women and girls with disability have experienced no increase in labour force participation whereas this has improved for men and special measures are needed to accelerate economic participation for women and girls (Women with Disabilities Australia, 2021). A range of research has identified the fundamental and ongoing structural impediment of the limited supply of jobs for people with disability 'that meet their diverse needs, capabilities and aspirations' with the need to raise understanding about and expectations of the work capability of people with disability (Centre for Research Excellence in Disability and Health, 2021b, p. 5).

Employment is not only an issue in its own right but intersects with other experiences of marginalisation and disadvantage including socioeconomic hardship, with the consultation for the National Disability Strategy noting insufficient money to pay for daily living as the second largest issue (The Social Deck, 2019). Likewise, the RC (2021a) has noted how unemployment contributes to mental health challenges and lack of self-worth, which can be self-perpetuating.

Responses to the RC Employment issues paper (RC, 2021a) also address a range of barriers to employment including 'transition' issues (pp. 7-12). Transition from school to work, and gaining the



requisite work experience prior to and during transition, is an identified gap (Centre for Research Excellence in Disability and Health, 2021b). Likewise, transition to employment for young people has been identified as a priority in the National Disability Employment Strategy Consultation Paper (DSS, 2021).

The first stage consultation to shape the next National Disability Strategy (The Social Deck, 2019) identified a need for more inclusive workplaces. Response to the Royal Commission's Issues Paper on unemployment (2021a) notes that where employment is gained, experiences of ongoing segregation, low pay and abuse remain (pp. 5-6). Similarly, the Mental Health Commission (2021) identified stigma/negative attitudes towards people with psychosocial disability in the workplace, noting employers and work colleagues as one of top three sources of discrimination experienced by people with psychosocial disability, requiring a strong focus on attitude change.

A range of research and evaluation studies report poor performance of Commonwealth labour market programs for people with disability (for example Boston Consulting Group, 2020). The bulk of Commonwealth programs do not reference people with disability and as such are not designed for their inclusion particularly where people with disability are able to work only a small number of hours per week or cannot work full time. For example, the New Enterprise Incentive Scheme offers support to people wishing to start their own business but participants must be able to work full time, whilst the National Work Experience program is only available to those in DES, Jobactive or Transition to Work, and its short duration disincentivises employers from investing in work accommodations (Wilson et al., 2021). This research identifies a range of gaps in the provision of employment supports and services, both in terms of eligibility for Commonwealth labour market programs, and in the limited range of intervention designs used in these programs, leaving a gap filled largely by ILC funded community-based interventions with precarious funding (Wilson et al., 2021). Further, employment services targeting people with disability are repeatedly criticised by people with disability and advocacy groups (for example, throughout submissions to the NDES). DES (and Jobactive) services are identified as inadequate and potentially harmful to people with psychosocial disability (National Mental Health Commission, 2021) and are not being utilised by the full cohort of people with disability, with young people under 34 years under-represented in DES (Centre for Research Excellence in Disability and Health, 2021b). Likewise, Women with Disabilities Australia (2021) recommends reform of DES and Jobactive to better address the particular needs of women and the barriers they experience in relation to employment, including stigma and sexual harassment. Research identifies a shortage of a skilled workforce to provide employment supports, both to job seekers and employers, and including those working in Commonwealth employment services and the community based sector (Centre for Research Excellence in Disability and Health, 2021b).

A range of submissions to the National Disability Strategy identified a need for increased and different employment supports to better meet the needs of different groups of people with disability. The National Mental Health Commission (2021), in this context, identified the need for a focus on gaining and maintaining employment across a longer time span. Similarly, the first stage consultation to shape the next National Disability Strategy (The Social Deck, 2019) identified a need for more and personalised employment supports. Valued Lives (2021) identified a lack of available support for microenterprise and for people with significant disability to access employment and self employment.

## **Barriers to inclusion in mainstream services**

Headlines:

- inadequate provision of services
- inaccessibility of services
- lack of disability knowledge of mainstream practitioners, particularly health practitioners
- critical function of inclusive mainstream services in NDIS sustainability.

As identified by the Brotherhood of St Laurence and Mission Australia (2020)

*many mainstream services—including health, education and training, housing, employment services, justice, housing, transportation—continue to be inaccessible or non-inclusive. Their built environment, information provision and service practices too often present barriers to people with disability in meeting their needs to the same standard as others using these systems (p. 8).*

In addition to inaccessibility, service systems can be difficult to navigate, hindering their ability to be 'mutually reinforcing and interconnected' (Brotherhood of St Laurence and Mission Australia, 2020, p. 9).

Inclusion also emerged as a key theme from the second round of consultations for the National Disability Strategy (The Social Deck, 2021). Inclusion was considered important 'across all outcome areas, but particularly in education and health' and calls were made for 'stronger actions to change the way people with disability are treated and included' (p. 36) including application of the social model of disability and universal design, more inclusive education systems, targets and requirements in education, business, health, justice and other mainstream settings.

A study of the priorities of people with spinal cord injuries and post polio in two Australian states (Wilson, Campain & Hayward, 2019), identified three mainstream areas in greatest need of capacity building (including changes to resources and infrastructure, knowledge, attitudes, policy): 1. health, 2. the built environment sector, and 3. transport. The Productivity Commission (2021) likewise identified barriers to inclusion in mainstream services in relation to access to public transport, where 15.6% of people with disability reported they could not use, or had limited use of, public transport. A common theme is the lack of inclusion knowledge and skills of mainstream practitioners, across mainstream sectors which affected both their capacity to identify exclusionary barriers as well as the solutions to these (Wilson, Campain, Hayward, 2019). Similarly, the Productivity Commission (2021) reported 27.7% of people avoided services that involved interaction with service staff, due to their disability.

A high proportion of survey respondents in the 2019 consultation for the NDS (The Social Deck, 2019) identified ongoing poor health, and inaccessibility of health services and supports (including deficits in health personnel knowledge of disability and suitable approaches). Participants involved in Stage 2 consultations on the National Disability Strategy also raised similar concerns regarding a lack of disability awareness and understanding from health professionals (The Social Deck, 2021). This theme is also found in research with people with spinal cord injury and post-polio (Wilson, Campain & Hayward, 2019) where the area of health was rated as the top priority for mainstream capacity building. It was noted that health services were frequently inaccessible for this cohort, with many health practitioners having little knowledge of patient needs with negative attitudes towards the patient's own expertise in their condition. In addition, assistive technology was often missing from health care settings (Wilson, Campain & Hayward, 2019). More broadly, access to

cost of assistive technology (AT) was rated as the third highest issue in survey results reported in the 2019 report on the consultation to shape the next NDS (The Social Deck, 2019) with some participants identifying a need for greater information about emerging AT.

Barriers to health care are particularly acute for people with cognitive disability and can include: communication and physical barriers; cost and funding; rural and remote access; lack of training of health and mental health professionals (RC, 2019a, p. 3). Inadequate health care for this cohort includes 'diagnostic overshadowing – where a health professional attributes symptoms to a person's disability rather than to a health issue; delayed diagnoses/misdiagnoses; prescribing practices, over-prescription, and restrictive practices; lack of sexual and reproductive health care', often underpinned by the attitudes and assumptions of health care practitioners towards people with cognitive disability (RC, 2019a, p. 3). Appropriate receipt of health services is further complicated and limited by interactions between health systems and the NDIS, including gaps in funding and supports (including support workers and communication supports), lack of coordination, inconsistent information between systems, and delays in hospital discharge and planning (RC, 2019a, p. 3). Overall, public consultations noted that 'to improve outcomes in health and wellbeing, people must first have basic living needs and arrangements taken care of' (The Social Deck, 2021, p. 18).

While the ILC policy has received validation in its focus on mainstream services, it has also received criticism that 'there is no detailed or sustained engagement on the question of how to systematically enhance mainstream services to make them more responsive to the intersecting inequalities experienced by many people with disability' (Thrill, 2019, p. 698). Similarly, the recent Independent Advisory Council to the NDIS (2021) calls for an increase in funding to the ILC and for it to be

*redesigned to focus on delivering improved accessibility of government services and raising awareness of the services throughout the community of people with disabilities to support DSS's responsibilities for the NDS while maintaining alignment with broader NDIA objectives (p. 14).*

In a similar vein, recent commentary blames both the unsustainable increase in costs of the NDIS, along with a reinforcement of an unwanted medical model approach to disability, on the 'lack of investment in community and mainstream supports and capacity building infrastructure' (Walsh, 2021, p. 7).

### **Barriers to community inclusion**

Headlines:

Inclusion prevented by:

- negative attitudes and ableist discrimination
- lack of recognition of autonomy, in/inter-dependence
- inaccessible environment
- lack of culturally appropriate support.

The National Disability Strategy 2010-2020 (Commonwealth of Australia, 2011) includes 'inclusive and accessible communities' as one of its six primary outcomes defined in the following terms: 'People with disability live in accessible and well-designed communities with opportunity for full inclusion in social, economic, sporting and cultural life' (p. 29). However, the RC's Issues Paper on

Promoting Inclusion (2020a) notes a range of barriers to inclusion. These include negative attitudes, ableist discrimination, lack of 'recognition and respect for autonomy, independence and interdependence', 'inaccessible environments' and a 'lack of culturally appropriate supports' (p. 3).

In its submission to the NDS consultation, the Brotherhood of St Laurence and Mission Australia (2020) identify that community organisations, such as sporting and leisure clubs and businesses 'require investment in their capacity to be inclusive' including resources, supports, capacity building and education (p. 8). In this context, they highlight the need to:

*Build community inclusion by (a) specifying clear community capacity building outcomes in the NDS outcomes framework; (b) aligning these outcomes with the NDIS's role in community capacity building via Partners in the Community (PITCs) and Information, Linkages and Capacity Building (ILC) grants managed by the Department of Social Services; and (c) requiring regular reporting on community capacity building outcomes (p. 5).*

### **Intersectionality**

In policy settings, intersectionality is replacing a focus on the concept of difference as seen through ideas of cumulative or 'double disadvantage' with an understanding of the 'simultaneous lived experience of multiple facets of social identity and the ways in which it is shaped by interlocking and mutually constitutive social relations of power and privilege' (Thrill, 2019, p. 692). This draws attention to the iterative and inseparable identities people hold and how they shape inclusion and exclusion. Intersectionality attends to the 'lived experiences of marginalisation' without limiting these through pre-determined categories of difference (Thrill, 2019, p. 693). It is an emerging approach to social policy and one strongly underpinning Disabled Peoples Organisations (Thrill, 2019). In her analysis of how intersectionality is dealt with in NDIS policy, Thrill (2019) argues that by marginalising 'the voices and experiences of particular people and groups ... this process contributes to human rights abuses and service delivery gaps' (p. 690). In the absence of an intersectional approach,

*injustice ...results from people falling through the cracks of categorical approaches to policy and service delivery because these approaches fail to take intersectional experiences into account. For example, since disability service policy neglects gender and gender-based violence policy neglects disability, then both policy fields miss the specificity of gendered disability violence (Thrill, 2019, p. 693, citing Kayess et al., 2014).*

While attending to intersectionality attempts a more complex analysis of 'cohorts' and their experiences, there is 'no clear criteria upon which to decide the specific categories of difference and inequality to examine in any particular policy context' (Thrill, 2019, p. 693). Below, we have presented a summary of needs as articulated from different positionalities, many of which explicitly argue for an intersectional lens, rather than a singular cohort focus. In doing this, we follow Thrill's proposal to let the voices of lived experience guide the construction of categories for intersectional focus (Thrill, 2019, p. 691). A more detailed explanation of the below intersectional experiences can be found at Appendix 1.

### **1. Place-based disadvantage and people with disability living in rural and remote areas**

People in rural and remote areas have different experiences to those in urban areas (The Social Deck, 2019). In particular, people with disability in rural and remote areas experience much higher rates of lack of access to accessible transport, as well as lack of access to sports, arts, recreation and leisure, specialist and health care. Furthermore, families in rural and remote areas experience 'compounding challenges' including a lack of training designed to support inclusive services, limited availability of disability services leading to delayed diagnosis and access to support ultimately resulting in higher levels of undiagnosed children in remote and rural areas (The Social Deck, 2021, p. 29). Families in rural and remote locations have also identified higher needs for support to navigate and access services (The Social Deck, 2021).

### **2. Aboriginal and Torres Strait Islander people with disability**

A range of evidence highlights the increased prevalence of disability among Aboriginal and Torres Strait Islander peoples and poor access to mainstream services (Ferdinand et al., 2019). This is coupled with cultural as well as geographic and logistical barriers to accessing services, along with key infrastructure limitations in some areas such as inadequate housing, lack of accessible and public transport, and lack of suitable assistive technology relevant to living contexts of many Aboriginal and Torres Strait Islander people. Moreover, First Nations people with disability face significant systemic issues such as intersectional racism, discrimination and poverty (The Social Deck, 2019). This is matched by the need for culturally appropriate responses, including trauma informed interventions and those not based on the medical model of disability.

Amidst this context, First Peoples Disability Network Australia (2021) argues that:

- an intersectional lens needs to be embedded into all policy, accompanied by the funding of specialist intersectional discrimination advocacy support/advice.
- strategies and activities need to align with the National Agreement on Closing the Gap to maximise impact, and in recognition of the fundamentally unique position occupied by Aboriginal and Torres Strait Islander people resulting from their historical context (Gordon et al., 2019).
- there is a need for wider screening for disability (especially related to children and young people) and greater equity in NDIS funding allocations for Aboriginal and Torres Strait Islanders.
- support is needed to build community controlled and led disability services and workforce, with locally led programs, staffed and run by Aboriginal and Torres Strait Islander people.

Overall, First Nations people desire a holistic response to needs e.g. housing, health, education and employment via culturally appropriate community-controlled services (Ferdinand et al., 2019).

### **3. People with disability from culturally and linguistically diverse (CALD) backgrounds**

Culturally and linguistically diverse people with disability experience a range of additional barriers relating to service access and social inclusion (The Social Deck, 2019; Royal Commission, 2021d). Language barriers and a lack of interpreters have made it difficult for CALD people with disability to access key programs and support, including the NDIS (Royal Commission, 2021d). A lack of culturally appropriate services has also been identified, with participants involved in the second round of consultations on the next National Disability Strategy suggesting that cultural training for the disability workforce be included in the next Strategy (The Social Deck, 2021). Some people with disability with CALD backgrounds, particularly newly arrived refugees, have experienced significant violence and trauma, and as a result are reluctant to share their stories or engage with

government agencies (Royal Commission, 2020d). In some cases, people with disability from CALD backgrounds are stigmatised and isolated in their own communities, a problem which can be compounded by broader attitudes 'towards disability and cultural and linguistic diversity' (Royal Commission, 2021d, p. 4). However, despite this evidence from consultative mechanisms, there is very limited research in Australia focused on this cohort, with only 1.4% of all academic peer reviewed publications on Australian disability topics (2018-2020) being devoted to this group (<https://www.ndrp.org.au/mapping-research>).

#### **4. Lesbian, gay, bisexual, transgender and intersex (LGBTQIA+) people with disability**

In Australia, there is almost no academic peer reviewed research on this cohort, with only 0.16% of publications between 2018-2020 focused on this group (<https://www.ndrp.org.au/mapping-research>). The limited evidence highlights that people with disability who identify as LGBTQIA+ experience a range of compounding challenges and barriers. In their response to the Royal Commission's Criminal Justice Issues Paper (RC, 2020b), ANROWS note that LGBTQIA+ women are one of the groups who 'are particularly disadvantaged when it comes to accessing supports and services' (p. 11). Responses to the Royal Commission's *Rights and Attitudes Issues Paper* (RC, 2021c) highlighted how LGBTQIA+ people, as well as other intersectional identities, experience 'greater degrees of rights deprivation and attitudinal barriers' (p. 11). Consultations conducted as part of the development of the next National Disability Strategy (The Social Deck, 2019) highlighted concerns around the 'lack of understanding among health professionals and disability services in regards to LGBTQ+ community', particularly in regional and rural areas (p. 61). Issues of discrimination were also discussed, with people reporting 'additional barriers to being included and feeling a sense of belonging' (p. 61).

Suggestions for improvement included increasing 'understanding of people with disability who identify as LGBTQ+ to inform design of programs' and the importance of 'new policies and actions' being 'co-designed with people who are LGBTQ+, as well as other specific groups, to make sure policies protect and support people' (The Social Deck, 2019, p. 61).

#### **5. Children and young people with disability**

Children with disability experience a range of heightened barriers and challenges related to safety, education, empowerment and rights. Analysis of the 2016 ABS Personal Safety Survey shows that one quarter of young people with a disability report experiencing violence in the last 12 months (Centre of Research Excellence in Disability and Health, 2021, p. 13). The Royal Commission notes ongoing issues of discrimination and exclusion across the education system (Royal Commission, 2019b), including the use of restrictive practices (Royal Commission, 2021b), as well as the presence of 'gatekeeping', where students with disability are denied access or informally discouraged from attending their choice of school (Royal Commission, 2019b, p. 3). Advocacy Tasmania have raised concerns about how difficult it is 'for children with disability to realise their rights if their wishes contradict those of their parents or guardians' (Royal Commission, 2021c, p. 12). The United Nations Committee on the Rights of Persons with Disability have expressed concern at the lack of 'disability and age appropriate assistance to enable them [children and young people] to express their views' (Royal Commission & McCallum, 2020, p. 29).

Stage 2 of the consultation on the NDS captured a range of ideas for improving early supports for children and their families. These included the need for a 'centralised source of reliable information'; for collaboration to 'reduce silos of service provision'; and 'for an approach that places parents and their children with disability at the centre' (The Social Deck, 2021, pp. 28-29). Responses to the Royal Commission's Education and Learning Issues Paper (Royal Commission,



2020c) call for increased knowledge and training for staff (p. 6) and the involvement of students in the design of inclusive learning (p. 7).

### ***6. Women with disability***

Women with disability experience extremely high levels of violence, harassment and abuse. A report from the Centre of Research Excellence in Disability and Health (2021a) analyses data available from the Australian Bureau of Statistics 2016 Personal Safety Survey, noting that 'one in two women (334,076 women) with psychological and/or cognitive impairment have experienced sexual violence in their lifetime' (p. 14), and that 'women with disability are twice as likely to report sexual violence over their lifetime than women without disability' (p. 10). Women with disability are also more likely to experience sexual harassment at work than those without disability, with 52% of women with disability reporting experiences of sexual harassment at work in the last 5 years (Women with Disabilities Australia, 2021). In their response to the Royal Commission's Issues Paper on the Criminal Justice System (RC, 2020b), ANROWS notes the issue of 'dependence on perpetrators for care, or dependence on a partner or caregiver to lodge complaints' whilst Domestic Violence Victoria discussed challenges with family violence, in particular, 'identifying the perpetrator of violence, difficulties in having reports believed and the justice system's "one-size fits all" approach' (RC, 2020b, p. 10).

Responses collected during consultations for the next National Disability Strategy noted 'the importance of ensuring disability is reflected within existing women's, and women's safety, policies and agreements across all levels of government' (Social Deck, 2019, p. 60). Women With Disabilities Australia (WWDA) argue that "'Safety from Violence and Abuse" should be a new, stand-alone Outcome Area of the new NDS' (Women with Disabilities Australia, 2020, p. 25). Moreover, they argue that women with disability require more information about reporting harassment and abuse, and free legal and advocacy services (Women with Disabilities Australia, 2021).

### ***7. People with disability who experience other intersectional disadvantage***

The Centre of Research Excellence in Disability and Health (2021a) note the intersection of disability and socioeconomic hardship with 34% of people with disability living in financial hardship (compared to 14% of people without disability). People living in financial hardship are more likely to experience violence, and people with disability in financial hardship are three times more likely to experience violence than those without disability and financial hardship (p. 15).

An evaluation, conducted by the University of New South Wales, of an ILC funded project targeting 'hard to reach' people with disability, such as those who are or at risk of becoming homeless, those living in institutions, and/or people with psychosocial disability, identified the complexity of providing information to this cohort and of connecting them to mainstream services such as emergency accommodation, health and mental health services (Gendera et al., 2020). Gendera et al. (2020) suggest that information provision and connection to mainstream services hinges on the (lengthy) development of relationships and networks between support workers and individuals, noting the value of Disabled People's Organisations as those trusted by this cohort, in the context of high distrust of government information sources.

### ***Provision of supports to wider cohort of people with disability than those eligible for NDIS, and for families and carers***

As discussed previously, an intention of the Tier 2 design was that it would provide benefit to all people with disability in Australia, tied to increasing the sustainability of the NDIS. The original Productivity Commission design of Tier 2 recognised that while mainstream services were, in

theory, available to all Australians, 'these services were often fragmented and difficult to access and navigate, particularly for those with limited informal supports, resources or capacity' (Productivity Commission, 2011 cited in Brotherhood of St Laurence and Mission Australia, 2020, p. 10).

The ILC Policy (NDIA, 2015) reinforces the focus on all people with disability, stating that the 'ILC will also ensure the NDIS establishes and facilitates capacity building supports for people with disability, their families, and carers that are not directly tied to a person through an individually funded package' (NDIA, 2015, p. 1). The ILC Commissioning framework further underscores this focus, stating the ILC:

*also has an important role to play in supporting people who do not have an NDIS plan. By providing appropriate support in the community, it will help those who are not NDIS participants to have access to the things that keep them strong, independent and connected in their community, and therefore reduce the need for funded supports (NDIA, 2016, p. 7).*

While many funded ILC projects are seen as likely to have benefits for all people with disability, such as via increasing the inclusivity of community activities, the Commissioning framework identifies that the individual capacity building program 'will **prioritise people with disability who do not have an NDIS plan** ... [and] organisations will need to make clear in their applications how they are meeting the needs of this group' (NDIA, 2016, p. 20, emphasis in original). However, this intent may not have been fully operationalised, as evidenced by ILC grant application forms and project descriptions of recipients.

The submissions of representative bodies to various consultations and inquiries echo the focus on all people with disability, not just those in receipt of NDIS funding, as they advocate for the needs of their respective cohorts. However, as identified elsewhere in this report, it is difficult to easily identify, quantify and prioritise the needs of people with disability in Australia. To this end, the Brotherhood of St Laurence and Mission Australia (2020) recommend that

*the Productivity Commission... conduct and publish a gap analysis of services available to people with disability who do not meet access to the NDIS - in line with Recommendation 3.5 from the Commission's review of the NDA - to identify the supports and services available in each state and territory since the NDIS transition and expose any issues prior to the new NDS and/or the NDA revision (p. 5).*

### **2.2.2 Building the capacity of user-led organisations**

The *ILC Commissioning Framework* (NDIA, 2016) identified a focus of the ILC on 'delivery by people with disability, for people with disability' via 'supporting organisations that are run and controlled by people with disability' (p. 18). This focus is reinforced in the 2018 ILC investment strategy (NDIA, 2018) which identifies that the ILC program will be 'refocused' on a range of key elements including 'planned investment in systemic support to build the maturity' of peer support organisations, and a 'sharpened focus on organisations run by and for people with disability' (p. 5). This is consistent with advocacy from a range of representative groups. For example, the First Peoples Disability Network (2021) calls for support to build the Aboriginal and Torres Strait Islander community controlled sector of disability services, while others highlight the importance of co-production



activities with their cohorts of people with disability (e.g. Valued Lives, 2021). Commentators identify the importance of this investment to disability-led and peer support groups who may not survive without this funding (given withdrawal of other funding sources), leading to a loss of lived-experience knowledge capital (Ramcharan et al., 2020). This focus on the capacity building role of the ILC was recently underscored by the Independent Advisory Council (IAC) (2021) noting that there had been 'insufficient and inadequately directed investment in Tier 2 to enable a well-funded ILC and a strong network of Disabled Persons Organisations and Family Organisations' (p. 4). The IAC further identified the primary function of the Tier 2 of the NDIS, as:

*the development of a living, breathing organism of Disabled Persons' Organisations, Peer Support networks and true Local Area Coordination through engagement with local community organisations and local businesses. The function of this network is to act at the gateway to Tier 3 of the NDIS (Independent Advisory Council, 2021, p. 18).*

Walsh (2021) agrees that a key focus of Tier 2 funding is the development of 'skilled and dedicated Disability Support Organisations to provide independent capacity building, support coordination, and assistance in decision making' to support people with disability needing extra support to access the NDIS and mainstream services (p. 8).

### **2.2.3 Cultivating a healthy market of disability service providers to deliver ILC outcomes**

While, a market development focus is a not clearly articulated in ILC Policy, Commissioning or Strategy, except in the case of a focus to strengthen user-led organisations, Argyrous, Hassall and Rahman, (2017) in their evaluation of the early rounds of ILC grants funding, argue that a purpose of the ILC grants is to cultivate a healthy market of disability service providers to deliver the ILC outcomes. Considering this purpose, they conclude that the ILC grants program, as it was framed in 2016-17, is insufficiently oriented to this. They argue that a focus on unsuccessful applicants is needed in order to build their capacity to both remain in the market and build their ILC capacity, as ILC outcomes cannot be meaningful achieved without contribution of the total market.

Use of the ILC grants for market development has been documented in Aboriginal and Torres Strait Islander contexts, for example alongside Northern Territory government investment in market innovation to 'enhance the ability of support providers to deliver supports, collaborate and come up with new methods for providing supports' (Ferdinand et al. 2019, p. 44). This is in the context of significant market gaps and barriers in the delivery of services to remote and rural areas. However, Ferdinand et al. (2019) note that limited direct business support was provided to Aboriginal community controlled organisations in this respect. Ongoing attention in this area has involved the Northern Territory government's State Indigenous Affairs Department, Indigenous Business Australia, Aboriginal Community Controlled organisations, and NDIA among others (Ferdinand et al. 2019).

Walsh (2021) argues that there has been insufficient market stewardship resulting in 'persistence of outdated service models and reluctance to embrace innovation' or consumer empowerment, among service providers (p. 2). His commentary remains unclear about whether the tier 2 funding should be used to support innovation and encourage new service models.

## Conclusion

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The ILC has been broadly framed to address multiple needs across multiple cohorts and inevitably therefore intersects with various other government-funded activities (across all jurisdictions). The consultations in relation to the NDS confirm that the major needs facing people with disability in Australia remain, largely, unchanged with heightened attention brought to bear via other inquiries and strategy development. Perhaps what has changed is the embedding of the NDIS and, with it, a change (and loss of) funded services and, arguably, some entrenching of out-dated market practices. Finally, there has been a failure to see substantial change in the inclusive capacity of mainstream services. Some groups of people with disability continue to remain particularly marginalised.

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## Appendix 1- Detailed review of intersectional cohorts

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### *Place-based disadvantage and people with disability living in rural and remote areas*

In addition to investment in multi regional activities (i.e. 'activities that would be inefficient if delivered separately in different local areas – for example, advice or information that is not based on location and could be relevant anywhere' (NDIA, 2016, p. 18), ILC Policy identifies an interest in place-based approaches (NDIA, 2015). ILC Policy argues that 'A place-based approach to ILC supports should be undertaken, in response to local and community need' (p. 17). States and Territories consulted by DSS in 2020 about the ILC (Commonwealth of Australia, 2020) identified the need to support 'local organisations ... (to) deliver solutions to meet local needs at a point in time' (p. 29), preferably as identified by each jurisdiction. The need for locally led activity, in response to local need, is also affirmed by First Peoples Disability Network (2021) as an appropriate mechanism for Aboriginal and Torres Strait Islanders with disability.

The 2019 report on the consultation for the next NDS (The Social Deck, 2019) identified that people in rural and remote areas have different experiences to those in urban areas. In particular, people with disability in rural and remote areas experience much higher rates of lack of access to accessible transport, as well as lack of access to sports, arts, recreation and leisure, specialist and health care. This suggests that priorities for rural and remote regions are likely to be very different from those in urban centres.

The 2021 consultation for the NDS also identified issues in relation to early support for children and families and, notably, a 'need to address compounding challenges for families in regional and remote areas' (The Social Deck, 2021, p. 29). Issues raised included lack of appropriate training in inclusive services, limited availability of disability services leading to delayed diagnosis and access to support ultimately resulting in higher levels of undiagnosed children in remote and rural areas. Families identified higher needs for support to navigate and access services.

### *Aboriginal and Torres Strait Islander people with disability*

A range of evidence highlights the increased prevalence of disability among Aboriginal and Torres Strait Islander peoples and poor access to mainstream services (Ferdinand et al., 2019). While the ABS concludes that Aboriginal and Torres Strait Islander people are 1.8 times more likely to be living with disability, the First Peoples Disability Network suggests this proportion is likely to be much higher given rates of non-diagnosis and different attitudes towards and understanding of disability in Indigenous communities (Ferdinand et al., 2019). Culturally, family members of Aboriginal and Torres Strait Islanders with disability bear a kinship responsibility for the care and support of their family members, resulting in significant burden on families. This is coupled with cultural as well as geographic and logistical barriers to accessing services, along with key infrastructure limitations in some areas such as inadequate housing, lack of accessible and public transport, and lack of suitable assistive technology relevant to living contexts of many Aboriginal and Torres Strait Islander people. Gordon et al. (2019) cite evidence to suggest that the Aboriginal and Torres Strait Islander people's negative experience of services is likely to be magnified under the NDIS 'which does not specifically incentivise culturally safe or rural and remote care' (p. 226). In this context, First Nations people desire a holistic response to needs e.g. housing, health, education and employment via culturally appropriate community-controlled services (Ferdinand et al., 2019).

The 2019 report on the consultation to shape the next NDS (The Social Deck, 2019) identifies that First Nations people with disability face significant systemic issues such as intersectional racism and discrimination, poverty, lack of and overburdened community services. This is matched by the need for culturally appropriate responses, including trauma informed interventions and those not based on the medical model of disability. Similarly, the First Peoples Disability Network Australia (2021), identifies a need for wider screening for disability (especially related to children and young people) and greater equity in NDIS funding allocations for Aboriginal and Torres Strait Islanders who receive comparatively less funding for supports to 'learn new things' and participate in education, training and skill development. Further support is needed to build community controlled and led disability services and workforce, with locally led programs, staffed and run by Aboriginal and Torres Strait Islander people.

Gordon et al. (2019) review Aboriginal responses to NDIS government consultations over a 10 years period and argue that government conceptualising of Aboriginal and Torres Strait Islander experience of disability is overly framed on this cohort living in rural and remote areas whereas Aboriginal submissions suggest this focus is overstated, and misses key issues faced by urban dwelling Aboriginal and Torres Strait Islander people with disability, including thin markets of culturally appropriate service providers. In this context, a focus on geographical barriers obscures other issues such as historical disenfranchisement leading to mistrust of government (Gordon et al., 2019).

Intersectional disadvantage is emphasised in submissions and research about Aboriginal and Torres Strait Islander people with disabilities. Gordon et al. (2019) identify a range of Indigenous commentary that explains the overlaying of factors to marginalise this cohort from the NDIS and services. Capacity building, as understood by Indigenous commentators, is framed in the context of self-determination and overcoming historical and systemic disempowerment (Gordon et al., 2019). Overall, First Peoples Disability Network Australia, (2021) argues that an intersectional lens needs to be embedded into all policy, accompanied by the funding of specialist intersectional discrimination advocacy support/advice.

The First Peoples Disability Network (2021) argues that strategies and activities need to align with the National Agreement on Closing the Gap to maximise impact, and in recognition of the fundamentally unique position occupied by Aboriginal and Torres Strait Islander people resulting from their historical context (Gordon et al., 2019). In this context, Gordon et al. (2019) present that argument of Indigenous commentators that responses to Indigenous needs regarding disability and NDIS should not position Aboriginal and Torres Strait Islanders with disability as simply one of many 'different' groups, but as requiring unique understandings and responses.

### ***People with disability from culturally and linguistically diverse (CALD) backgrounds***

Culturally and linguistically diverse people with disability experience a range of additional barriers in regards to service access and social inclusion (The Social Deck, 2019; Royal Commission, 2021d). Language barriers and a lack of interpreters have made it difficult for CALD people with disability to access key programs and support, including the NDIS (Royal Commission, 2021d). A lack of culturally appropriate services has also been identified, with participants involved in the second round of consultations on the next National Disability Strategy suggesting that cultural training for the disability workforce be included in the next Strategy (The Social Deck, 2021). Some people with



disability with CALD backgrounds, particularly newly arrived refugees, have experienced significant violence and trauma, and as a result are reluctant to share their stories or engage with government agencies (Royal Commission 2020d). In some cases, people with disability from CALD backgrounds are stigmatised and isolated in their own communities, a problem which can be compounded by broader attitudes 'towards disability and cultural and linguistic diversity' (Royal Commission, 2021d, p. 4).

### ***Lesbian, gay, bisexual, transgender and intersex (LGBTQIA+) people with disability***

People with disability who identify as LGBTQIA+ experience a range of compounding challenges and barriers. In their response to the Royal Commission's Criminal Justice Issues Paper (RC, 2020b), ANROWS note that LGBTQIA+ women are one of the groups who 'are particularly disadvantaged when it comes to accessing supports and services' (p. 11). Responses to the RC's Rights and Attitudes Issues Paper (RC, 2021c) highlighted how LGBTQIA+ people, as well as other intersectional identities, experience 'greater degrees of rights deprivation and attitudinal barriers' (p. 11).

Consultations conducted as part of the development of the next National Disability Strategy (The Social Deck, 2019) highlighted concerns around the 'lack of understanding among health professionals and disability services in regards to LGBTQIA+ community', particularly in regional and rural areas (p. 61). Issues of discrimination were also discussed, with people reporting 'additional barriers to being included and feeling a sense of belonging' (p. 61). Suggestions for improvement included increasing 'understanding of people with disability who identify as LGBTQIA+ to inform design of programs' and the importance of 'new policies and actions' being 'co-designed with people who are LGBTQIA+, as well as other specific groups, to make sure policies protect and support people' (p. 61).

### ***Children and young people with disability***

Children with disability experience a range of barriers and challenges. Analysis of the ABS Personal Safety Survey by the Centre of Research Excellence in Disability and Health (2021a) shows that young people with disability experience high levels of violence:

- '25% of young people with disability (165,835 young people) reported experiencing violence in the last 12 months, compared to 20% of those aged 30-44 and 11% of those aged 45-65 with disability'
- 'Young women with disability (18-29 years) are twice as likely to report experiencing sexual violence over their lifetime than young women without disability'
- 'Young people with disability were three times more likely to report being stalked in the last 12 months compared to young people without disability' (p. 13).

Other key areas of concern were related to education, empowerment and rights. The RC (2019b) notes that 'some early childhood settings discriminate against children with disability and seem to readily exclude them' (p. 3). Moreover, it notes 'significant levels of gatekeeping across Australia' (p. 3) where students with disability are denied access or informally discouraged from attending their choice of school. Furthermore, 'the segregation of children with disability in special education units/classes or 'special' schools has increased' (p. 3). Experiences of segregation and restraint were also reported in Children and Young People with Disability Australia's 2019 National

Education Survey which reports one third of students with disability had experienced restraint or seclusion in the previous year (RC, 2021b, p. 7).

In their response to the RC Rights and Attitudes Issues Paper, Advocacy Tasmania noted a reluctance on behalf of some parents to seek support or pursue cases of discrimination against their child. This reluctance was explained to be the result of previous experiences with a disrespectful and disregarding system (RC, 2021c, p. 12). Advocacy Tasmania, with reference to the NDIS, also raised concerns about how difficult it is 'for children with disability to realise their rights if their wishes contradict those of their parents or guardians' (RC, 2021c, p. 12).

The Australian Human Rights Commission and the United Nations Committee on the Rights of Persons with Disability have expressed concern at the lack of 'disability and age appropriate assistance to enable them [children and young people] to express their views' (Royal Commission & McCallum, 2020, p. 29). Both recommend that concrete steps be taken in this regard.

Stage 2 of consultation on the NDS captured a range of ideas for improving early supports for children and their families. These included the need for a 'centralised source of reliable information'; for collaboration to 'reduce silos of service provision'; and 'for an approach that places parents and their children with disability at the centre' (The Social Deck, 2021, pp. 28-29). Responses to the Royal Commission's Education and Learning Issues Paper (Royal Commission, 2020c) call for increased knowledge and training for staff (p. 6) and the involvement of students in the design of inclusive learning (p. 7).

### ***Women with disability***

Women with disability experience extremely high levels of violence, harassment and abuse. A report from the Centre of Research Excellence in Disability and Health (2021a) analyses data available from the Australian Bureau of Statistics 2016 Personal Safety Survey. It notes:

- one in two women with psychological and/or cognitive impairment have experienced sexual violence in their lifetime (p. 14).
- all women are at higher risk of sexual violence than men, and women with disability are twice as likely to report sexual violence over their lifetime than women without disability (33% women with disability vs 16% of women without disability) (p. 10).
- Women with disability aged 15 and over are more likely to report experiencing violence by an intimate partner and emotional abuse by a current or previous partner compared to women without disability (36% vs 21%, and 37% vs 20%) (pp. 11-12).

Respondents to the Royal Commission's Issues Paper on the criminal justice system (RC, 2020b) highlighted a number of key concerns for women with disability. ANROWS' submission notes the issue of 'dependence on perpetrators for care, or dependence on a partner or caregiver to lodge complaints' whilst Domestic Violence Victoria discussed challenges with family violence, in particular, 'identifying the perpetrator of violence, difficulties in having reports believed and the justice system's 'one-size fits all' approach (RC, 2020b, p. 10).

Responses collected during consultations for the next National Disability Strategy noted "the importance of ensuring disability is reflected within existing women's, and women's safety, policies and agreements across all levels of government" (Social Deck, 2019, p. 60) Women With Disabilities

Australia (WWDA) argue that ‘Safety from Violence and Abuse’ should be a new, stand-alone Outcome Area of the new NDS’ (Women with Disabilities Australia, 2020, p. 25).

Women with disability’s experience of safety in the workplace is also a negative one as they are more likely to experience sexual harassment at work than those without disability, with 52% of women with disability reporting experiences of sexual harassment at work in the last 5 years (Women with Disabilities Australia, 2021). As discussed above, women with disabilities are more likely to be excluded from the workplace than men with disability (Women with Disabilities Australia, 2021). Overall, they require more information about reporting harassment and abuse, and free legal and advocacy services (Women with Disabilities Australia, 2021).

These dimensions of exclusion, marginalisation and abuse point to the additional layers of exclusion experienced as a result of intersectional identities. Women with Disabilities Australia (2021) argues that ‘intersectional discrimination acknowledges that people with disability do not experience discrimination in the same way as a homogenous group’ (p. 11).

### ***People with disability who experience other intersectional disadvantage***

The Centre of Research Excellence in Disability and Health (2021a) note the intersection of disability and socioeconomic hardship with 34% of people with disability living in financial hardship (compared to 14% of people without disability). People living in financial hardship are more likely to experience violence, and people with disability in financial hardship are three times more likely to experience violence than those without disability and financial hardship (p. 15).

An evaluation, conducted by the University of New South Wales, of an ILC funded project targeting ‘hard to reach’ people with disability, such as those who are or at risk of becoming homeless, those living in institutions and people with psychosocial disability identified the complexity of providing information to this cohort and of connecting them to mainstream services such as emergency accommodation, health and mental health services (Gendera et al., 2020). Gendera et al. (2020) suggest that information provision and connection to mainstream services hinges on the (lengthy) development of relationships and networks between support workers and individuals, noting the value of Disabled People’s Organisations as those trusted by this cohort, in the context of high distrust of government information sources.