



# Ability Links NSW Final Evaluation Report 2016

Prepared for the NSW Department of Family and Community Services

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## Acronyms

ACFC	Aboriginal Child and Family Centres
ADHC	Ageing, Disability and Home Care
ALNSW	Ability Links NSW
CALD	Culturally and Linguistically Diverse
DHS	Department of Human Services, Australian Government
ELNSW	Early Links NSW
FACS	Department of Family and Community Services
ILC	Information, Linkages and Capacity Building
LAC	Local Area Coordinator
LALC	Local Aboriginal Land Council
LGA	Local Government Area
MOU	Memorandum of Understanding
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NSW	New South Wales
PHaMs	Personal Helpers and Mentors
PIR	Partners in Recovery
SPSS	Statistical Package for the Social Sciences

## Acknowledgement

Urbis would like to sincerely thank all the people who have contributed to this evaluation report. This includes people with disability who have had contact with Ability Links NSW and/or Early Links NSW, their family members and carers, and management and staff of the contracted providers. It also includes agencies and organisations that have been linked to the program in various ways. We greatly appreciate the time, thought and insight that has been provided through consultations and interviews.

# Executive Summary

## INTRODUCTION

- Funded by NSW Ageing, Disability and Home Care (ADHC), Ability Links NSW (ALNSW) is a new approach to supporting people with disability aged 9 to 64 years, their families and carers. Together with Early Links NSW (ELNSW) which supports the parents of children with disability from birth to 8 years, it provides a whole of life approach through supporting people to overcome practical, emotional and/or cultural barriers to participation in all aspects of community life. It also supports services, businesses and the broader community to be more inclusive of people with disability.
- Key features of the ALNSW model is that:
  - It is a facilitator of change at an individual and community level: it is not a service provider in the traditional sense.
  - It aims to empower people with disability to determine their own goals, make their own decisions and work towards achieving what is important for them.
  - It is staffed by Linkers who work alongside a person with disability or a carer to help them plan for the future and link them to whatever community organisations, services or businesses in their local community will assist them achieve their goals.
  - It includes a community engagement component involving networking, partnerships and community development activities – to support organisations and communities to become more welcoming and inclusive of people with disability.
- ALNSW aims to offer aspirational, person-centred and flexible support to the people it works with. There are no formal eligibility criteria (other than the person identifying they have a disability and being aged between 9 to 64 years), no formal assessments at program entry, and no limits on the number of times a person may seek support from their Linker. It aims to have a 'light touch' on the people it has contact with, with the locus of control lying firmly with the person with disability.
- ALNSW was piloted in the Hunter Region from July 2013 to coincide with the launch of the National Disability Insurance Scheme (NDIS) and was subsequently rolled out across the state from July 2014. In late 2014, a process was initiated to align ELNSW (a program that had been operating as Early Start Diagnosis Support Program since 2009) with ALNSW. There are now 28 providers operating in the state, staffed by 347 Linkers, of which 74 are Aboriginal-specific positions located within Aboriginal community controlled organisations.

## THE EVALUATION

- Urbis was commissioned to undertake an independent process and outcomes evaluation of the first three years of ALNSW from 2013 to 2016. The evaluation incorporates an evaluation of ELNSW in 2015/16 and the progress of the program alignment.
- The last round of evaluation activity took place in March to May 2016. In all, 475 people were consulted via in-depth interviews, discussion groups and surveys. This included ALNSW and ELNSW management and staff, people with disability, their families and carers as well as Linked agencies – services, businesses and community organisations that have had contact with the program over the last 12 months. Analysis of program data was also undertaken.
- This report is the Final Evaluation Report of the three year evaluation.

## In its first two full years of operation, ALNSW and ELNSW have been very successful in achieving outcomes for individuals and families

- It is estimated<sup>1</sup> that over 43,500 people are being supported by Ability Links NSW and Early Links NSW each year. Of these, 29,410 have been provided with information only, and 10,376 have been provided with facilitated support and have achieved one or more outcomes. A further 3,747 people have been provided with facilitated support and are working towards an outcome.
- It is estimated<sup>1</sup> over 18,850 outcomes are being achieved by individuals and families each year through the programs. These include service engagement (44%), social, community and civic participation (39%), education and training (11%), and employment outcomes, which include volunteering and work experience (7%).
- In line with the objectives of ALNSW and ELNSW, the majority of the outcomes achieved by individuals and families relate to connection to community organisations and groups, and to mainstream, rather than to disability services.
- People are being supported to navigate the service system, to set their own goals, and to build their confidence, skills, motivation and self-worth through community participation. The result for many individuals and families supported by ALNSW and ELNSW, is an improved quality of life. Feedback from people with disability and their families about their experience with the program is overwhelmingly positive – in significant contrast to many prior experiences with the service system.
- In-depth interviews with people with disability, their families and carers, Linkers and Linked agencies have shown that:
  - **Significant change for people can occur through small steps**, albeit that these small steps may initially require a degree of courage or risk-taking due to many people lacking self-confidence or a sense of self-worth.
  - **Linking to community and services can have a profound effect on the quality of people's lives** resulting, for example, in people feeling more optimistic and hopeful about the future; feeling safer, healthier, happier and more in control of their lives; and feeling better able to independently seek information or support for themselves and make better and more-informed decisions about their or their child's future.
  - **Linking to community can be just as important and, at times, is the most important catalyst for change.** Individuals report that, through the program, they have more people they can go to ask for support or share experiences and challenges with; more opportunities for social connection to do the things they really enjoy; and most importantly, more opportunities to participate in mainstream community. Breaking down social isolation is what many people value most highly as it opens doors to a new way of living.
  - **Participation in ALNSW and ELNSW leads to contribution to community.** Through contact with the program, many individuals and parents are now actively contributing to community, for example, running peer support groups, organising community events, seeking funding for community projects, advising community groups or businesses on how to be more inclusive, or taking on key roles in local community groups.

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<sup>1</sup> Annual estimate is based on six months program data (January to June 2016)

## A good level of engagement with Aboriginal and CALD communities

- ALNSW and ELNSW have been very successful in reaching Aboriginal and Torres Strait Islander people with disability. This is partly due to the way the program has been funded and structured, and partly due to the program model. Critical to this success is that funding has been provided for Aboriginal-specific positions within local Aboriginal community-controlled organisations. The ALNSW / ELNSW model has strongly resonated with Aboriginal people and communities, as it encompasses an informal, flexible, non-bureaucratic, and whole-of-family approach. Many Aboriginal funded organisations have provided cultural awareness training and support to generalist providers which has increased accessibility and provided greater choices for Aboriginal people with disability.
- There has been reasonably good engagement of people with disability, their families and carers from culturally and linguistically diverse (CALD) backgrounds. However, more needs to be done to increase awareness of ALNSW and ELNSW in CALD communities. The evidence suggests that, once they become aware of the program, people from CALD communities have responded very positively to the program's flexible, person-centred approach.

## Community outcomes are beginning to emerge from Linker and individual/family activity

- Community outcomes from ALNSW and ELNSW are based on relationship-building, a strategic approach and persistence. It takes time to achieve systemic change. However, there are a growing number of examples where ALNSW and ELNSW activities are beginning to have an impact at an organisational and community level. These illustrate the considerable potential of the program to have a stronger and wider community impact over time.
- The aims of ALNSW and ELNSW go beyond supporting individuals and families, and include working with the community to support them to be more inclusive of people with disability. The programs do this in various ways, including through:
  - raising awareness and understanding of disability within community organisations, mainstream services and businesses
  - partnering with individual organisations to assist them to become more inclusive
  - building the capacity of individual organisations to become more inclusive on an ongoing basis
  - engaging in larger community development projects designed to have a broader social impact.
- Since the last evaluation report in 2015, there has been a noticeable improvement in the community engagement aspects of ALNSW. There is more activity than there was previously, reflecting a shift in focus from raising awareness of ALNSW to building relationships and partnerships with organisations to increase accessibility and inclusion. ALNSW and ELNSW are achieving more than 2,000 community outcomes each year<sup>2</sup>, including leadership, education and awareness, improvements in business practices and improved accessibility.
- The key learnings from the evaluation are that small, practical steps can lead to significant change, but that larger, community development projects are also important. To date, most community outcomes relate to increased awareness of disability and the adoption of more inclusive organisational practices and policies. One in four Linked agencies surveyed have made changes or taken active steps to introduce more inclusionary policies, practices or systems. These are promising results, which are to the credit of both the Linkers and to the organisations involved.

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<sup>2</sup> Annual estimate is based on six months program data (January to June 2016).

- Individual outcomes and community outcomes can be inter-related. Some of the most positive stories from the consultations involve individuals and family members who have become engaged in activities that have added to the social capital and the achievement of social inclusion objectives.
- There are also examples where community members have become advocates for inclusion within their own organisations. This can involve as simple a step as organising transport for a person with disability to attend a group or event or providing work experience for a young person, and the ripple effects that flow from that. Examples in this report demonstrate the potential of ALNSW and ELNSW to achieve broader community outcomes. However, more time will be required to test this further, through feedback from a larger number of Linked agencies and a deeper analysis of the organisational and community impacts over a longer time period.
- Despite the progress that has been made, many providers would benefit from adopting a more planned and strategic approach to community engagement, rather than the somewhat ad hoc or individualised approach that exists at present. Meanwhile, there is a need to continually educate and inform the community to overcome persistent attitudinal and systemic barriers to inclusion.

### The key aspects of the ALNSW model underpinning its success are emerging

- The key aspects of the ALNSW model that strongly resonate with people with disability, their families and carers include:
  - the **soft entry** point into the program
  - the **non-bureaucratic, flexible approach** to support people in a myriad of ways, depending upon their individual needs and goals
  - the focus on **individual empowerment**
  - the **strengths-based approach** which focuses on people's interests, aspirations, and abilities as the key to change
  - the **community-driven and embedded** nature of the program
  - the **independence** from government and from the disability services sector
  - the **dual aspects** whereby linking people with disability, their families and carers to the community, and linking community to people with disability is resulting in mutual benefits and outcomes
  - the **culturally-appropriate** program design, funding and delivery mechanisms
  - the **continuum of support**, whereby individuals and families can easily re-engage with the program if they so desire.
- The key aspects of the model that are proving effective with engaging community organisations include:
  - the non-threatening, **soft entry approach**, starting with small practical steps
  - the **strategic alignment** of ALNSW/ELNSW with community organisation or business objectives
  - the ability to **tap into and harness considerable goodwill** in the community
  - **persistence** and **creativity** in finding solutions to barriers.

- Critical to the success of ALNSW and ELNSW is the individual or family's relationship with their Linker. The Linker is the face of the program, and individual experiences with ALNSW or ELNSW are largely based on the quality of that relationship. As such, ALNSW and ELNSW is experienced by individuals and families as a personalised service: when they talk about the program, they talk about their Linker. The skills and attributes of individual Linkers are therefore at the heart of the success of ALNSW and ELNSW.
- The aspects of the Linker's approach that people value particularly highly include being open and personable, person-centred, collaborative, flexible, reliable, persistent and creative. People also value Linkers giving them time to make their own decisions, responding quickly to requests for information, and most importantly, doing what they say they will do. When these things happen, people experience the service as truly person-centred and feel Linkers genuinely care about them. This is in marked contrast to many other programs where people said they often feel "just like a number".

### Implementation of the new program over the last three years has been relatively smooth

- The state-wide roll out of ALNSW and ELNSW has gone relatively well. Much was learned from the evaluation of the pilot phase in 2013, which informed the subsequent expansion of the program across the state.
- Program delivery occurs through a reasonably complex funding and delivery structure comprising a mixture of large, medium and very small size local community-based providers; a combination of stand-alone and formal partnerships/consortium arrangements; and diverse partnership arrangements whereby partners are either the sole providers of ALNSW or ELNSW in a particular region or they share responsibility across regions. Furthermore, the service delivery mix includes organisations that provide ALNSW only, ELNSW only, or provide both ALNSW and ELNSW. It also includes providers that have been operating ELNSW (or its predecessor) for many years and those that only commenced operations in the last year.
- This relatively new and complex funding and service-delivery landscape makes it somewhat challenging to assess the extent to which ALNSW and ELNSW are being implemented effectively across the state. That said, a number of broad patterns are emerging.
  - **Formal partnership arrangements are improving.** They are working most effectively where there is strong leadership, a culture of collaboration and respect, a shared vision of ALNSW and ELNSW, and aligned priorities and practices. Partnerships offer people choice, access to a wider range of skills and resources, and a broader platform for ALNSW/ELNSW practice and program development. However, partnerships take significant effort to establish and maintain, and in one or two cases, the arrangements are not operating as envisaged, resulting in a degree of confusion on the ground and limited collaboration at an organisational level.
  - **Informal partnerships between providers are variable.** There are generally good relationships between generalist and Aboriginal providers operating in the same region, and many examples of good collaboration in relation to referrals, capacity-building, training, promotional activities and community engagement. This is not the case everywhere however: in some areas, there is little if any contact between generalist and Aboriginal providers.
  - **Implementation has been more challenging for some Aboriginal providers.** Providers that have a very small number of Linkers (two or three only), no Team Leader, limited organisational infrastructure, and a large region to cover have sometimes struggled to implement the program effectively. A number of these providers have recently restructured to include a Team Leader position, and are working in close collaboration with the local generalist provider to overcome some of these challenges. Nevertheless, some small Aboriginal providers continue to struggle to meet demand in their region, given travel time, limited resources and the high level of need in the community.

- **Recruiting or retaining suitable staff has been an issue for some providers.** At the time of consultation, some providers were struggling to fill vacant Linker positions. Some of this has been due to poor recruitment decisions. Over time, however, the attributes and skills that make an effective Linker have become apparent, and providers are now clearer about what they are looking for and how they can test that when recruiting. This has reportedly led to better and more targeted recruitment than before. More recently, providers have lost skilled staff to the NDIS as the scheme is rolled out across the State.
- Ongoing implementation challenges in the next year or so relate to strengthening some of the formal partnerships; clarifying the role of individual Linkers in relation to different forms of community engagement; adopting a more strategic approach to community engagement and encouragement; and recruiting and retaining staff at a time when other, potentially better remunerated and secure positions are emerging in the sector.

### **The alignment of ALNSW and ELNSW is a work in progress**

- There is broad support in the sector for the alignment of ALNSW and ELNSW. However, it is still early days in terms of implementation.
- The expanded workforce of Linkers is very enthused and excited about what can be achieved for individuals and families through providing support from birth through to 64 years. In practice, however, the alignment has varied considerably across providers depending upon the funding and program delivery arrangements.
- Few, if any, providers have achieved full alignment, although some are making good progress. Aboriginal providers and providers funded to deliver both ALNSW and ELNSW are making most progress. Where funding for ALNSW and ELNSW is split across providers and/or localities, less progress has been made due to cultural, professional or historical barriers.
- There remains much to be done for the vision of a fully aligned program to be realised. Barriers include the funding and service structure arrangements whereby ALNSW and ELNSW are delivered by different providers or in different locations; a degree of confusion amongst some providers about the alignment and what is expected of them; a lack of leadership amongst some providers to drive change; and anxieties and concerns about the implications of the alignment for Linker roles, particularly those of Early Linkers.

### **ALNSW and ELNSW are developing important practice learnings that could have broader application**

- There is interaction and communication between ALNSW, ELNSW and the NDIS at the ground level – basically relating to information provision and cross-referrals. Linkers are increasingly being asked to provide information about the NDIS, and are supporting people to become ‘NDIS-ready’.
- Importantly, valuable lessons are emerging from ALNSW and ELNSW that could inform other program models, systems and supports, both in the NDIS and elsewhere. The ALNSW model and approach is very similar to that of Partners In Recovery (PIR), the Federally-funded program targeting people with severe and persistent mental health issues. There may be value in bringing together the learnings from these programs to inform NDIS transitional arrangements and service sector reform.

## Issues for consideration

The report concludes with 28 actions for consideration addressing the following areas:

- Alignment of ALNSW and ELNSW
- Linker role and activities
- Linker training and development
- Community engagement
- Practice development
- Program and brokerage funding
- ALNSW, ELNSW and the NDIS
- Evaluation and monitoring.

# 1 Introduction and methodology

## 1.1 INTRODUCTION

In 2013, Urbis was engaged by Ageing, Disability and Home Care (ADHC), part of the NSW Department of Family and Community Services (the Department), to conduct a three year evaluation of Ability Links NSW (ALNSW) which now incorporates Early Links NSW (ELNSW). The evaluation aims to provide the Department with an evidence base to assess the effectiveness of these two key programs in delivering outcomes for people with disability, their families, carers and the broader community. A Cost Benefit Analysis and Social Return on Investment of the programs is also being conducted by Urbis, and will be submitted in a separate report.

The evaluation of ALNSW is based on the first three years of implementation, from July 2013 to June 2016. There are two core objectives for the evaluation:

- the first is the concept of 'learning as we go', which was realised through a formative evaluation of the 2013/14 program pilot in the Central Coast and Hunter New England Districts. Findings of this evaluation helped to inform the state-wide implementation of the program in 2014/15; subsequent evaluation activities have informed the ongoing strengthening of the program
- the second is to undertake an evaluation of the processes involved in the state-wide implementation of the program; an assessment of the outcomes achieved for people with disability, their families and carers; and the outcomes achieved at the broader community level.

The evaluation of the ELNSW component of ALNSW seeks to:

- measure the impact of ELNSW on outcomes for children with disability and their families
- test and demonstrate the benefit of aligning ALNSW and ELNSW to provide a continuum of supports for people with disability, their families and carers across the lifespan, from 0 to 64 years.

In consultation with ADHC and key stakeholders, Urbis developed a Program Logic and an Evaluation Framework to guide the evaluation of ALNSW. The Program Logic is attached at Appendix A.

## 1.2 ALNSW

ALNSW was established as the NSW approach to local area coordination for people with disability, their families and carers. It is a critical component of the NSW transition to person-centred and individualised funding arrangements. The program is part of the NSW contribution to the National Disability Insurance Scheme (NDIS) and aligns with the early intervention aspects of the NDIS. The introduction of ALNSW represents an original investment of \$75.4 million (2013-14 dollars) over three years, with \$30.8 million allocated annually for 2014-15 and 2015-16 (2013-14 dollars).

ALNSW was officially launched in the Central Coast and Hunter New England Districts on 1 July 2013. Following the state-wide implementation of ALNSW a year later, there are now 16 ALNSW providers across NSW, eight of which involve partnership arrangements (see Appendix B). The 16 providers are comprised of four large ALNSW (generalist) providers and 12 smaller ALNSW (Aboriginal) providers. There are 268 Ability Linker positions across the State, of which 47 are Aboriginal-identified.

The target group for ALNSW is people with disability aged 9 to 64 years who do not currently access specialist disability support services and whose needs can be met by taking part in activities in their local community or through accessing mainstream services. ALNSW is staffed by Linkers who have three main roles:

- to work with people with disability, their families and carers to plan for their future
- to help people with disability become more confident, build on their strengths and skills and support them to achieve their goals by building new networks and accessing support and services in their community

- to work alongside communities and mainstream services (Linked agencies), supporting them to become more welcoming and inclusive of people with disability.

The fundamental aim of ALNSW is to assist people with disability to develop networks in their own communities so they can do what they want with their lives outside of the traditional disability service system.

### 1.3 ELNSW

The ELNSW program is a key part of NSW's approach to local area coordination and decision supports for families of children aged 0 to 8 years with disability around the time of diagnosis. ELNSW was launched in 2009 and was formerly known as the Early Start Diagnosis Support Program. ELNSW has similar components and objectives to ALNSW; in particular, both programs focus on local area coordination to improve outcomes for young children with disability, their families and carers.

ELNSW funds Early Linkers who provide time-limited, individually-tailored support to families of children with disability or development delay during the time of, or while awaiting, diagnosis. Early Linkers provide families with person-centred and family-centred support, information and assistance to access services and supports to meet the family's goals within their local communities. The Linkers play a key role in improving access to mainstream options and linking families to services.

Currently there are 20 ELNSW providers across NSW, of which seven are generalist and 13 are Aboriginal providers (See Appendix B). There are 79 Early Linker positions, of which 27 are Aboriginal-identified.

### 1.4 PROGRAM ALIGNMENT

In September 2013, steps were taken to align the ALNSW and ELNSW programs. Four of the ALNSW providers received additional funding for Early Linker positions. These four providers joined a number of early intervention support organisations that had previously been funded to deliver ELNSW as a standalone service. The broad aims of the alignment were to provide seamless support to people with disability aged 0 to 64 years, to ease transition between ELNSW and ALNSW, and to embed the philosophy and aims underpinning the ALNSW model regarding mainstream services and community within the ELNSW model.

In July 2015, ELNSW was further expanded. An additional six ALNSW providers received funding for new Early Linker positions to enable these providers to support individuals and families across the life span from 0 to 64 years.

### 1.5 THIS REPORT

This Final Evaluation Report is the fifth report prepared since 2013 and documents findings from extensive consultations undertaken between March and May 2016. It also builds upon data collected over the three years of the ALNSW evaluation as documented in previous Interim Evaluation Reports.

The first Interim Evaluation Report in 2014 focussed on the implementation and early outcomes in the ALNSW pilot site. Following the state-wide implementation of ALNSW in July 2014, Urbis undertook the first state-wide evaluation of ALNSW, with a relatively limited focus on ELNSW, restricted to the small number of ALNSW providers that had also received ELNSW funding.

This Final Evaluation Report is the second state-wide evaluation of ALNSW and the first opportunity to report on all ELNSW providers, now fully integrated within the ALNSW framework. It focuses on:

- the experiences of people with disability, their families and carers with ALNSW and the outcomes being achieved
- the experiences of parents of children receiving support from ELNSW across the state and the outcomes being achieved

- the experiences of Linked agencies and the community outcomes that are being generated through the program
- organisational and implementation issues
- the progress made in aligning ALNSW and ELNSW.

The report also identifies issues for consideration relating to program alignment, implementation and development.

## 1.6 EVALUATION METHODOLOGY

### 1.6.1 OVERVIEW

Table 1 provides a summary of the key evaluation activities undertaken by Urbis over the last three years.

TABLE 1 – SUMMARY OF EVALUATION METHODOLOGY 2013 - 2016

STAGE	TIMEFRAME	KEY EVALUATION ACTIVITIES
<b>Interim Report 1 on the Evaluation Pilot Program</b>	November – December 2013	<ul style="list-style-type: none"> <li>▪ Discussion groups with generalist and Aboriginal provider management and Linkers in the Hunter Region</li> <li>▪ Interviews with Linked agencies</li> <li>▪ Interviews with key stakeholders</li> <li>▪ Site visit</li> </ul>
<b>Interim Evaluation Report 2</b>	January – May 2014	<ul style="list-style-type: none"> <li>▪ Interviews with people with disability, parents and carers</li> <li>▪ Online survey of Linkers</li> <li>▪ Discussion groups/interviews with generalist and Aboriginal provider management and Linkers</li> <li>▪ Interviews with Linked agencies</li> <li>▪ Site visits</li> </ul>
<b>Interim Evaluation Report 3 and Social Cost Benefit Analysis</b>	June – December 2014	<ul style="list-style-type: none"> <li>▪ Thematic analysis of qualitative outcome data for people with disability collected by providers</li> <li>▪ Cost Benefit Analysis / Social Return on Investment report on ALNSW</li> </ul>
<b>Interim Report 4</b>	March – June 2015	<ul style="list-style-type: none"> <li>▪ Interviews and surveys with people with disability, parents and carers</li> <li>▪ Online survey of Linkers</li> <li>▪ Discussion groups/interviews with generalist and Aboriginal provider management and Linkers</li> <li>▪ Interviews with Linked agencies</li> <li>▪ Site visits</li> </ul>
<b>Final Evaluation Report and Social Cost Benefit Analysis</b>	March – June 2016	<ul style="list-style-type: none"> <li>▪ Participant satisfaction survey</li> <li>▪ Interviews and surveys with people with disability, parents and carers</li> <li>▪ Online survey of Linkers</li> <li>▪ Discussion groups/interviews with generalist and Aboriginal provider management and Linkers</li> <li>▪ Interviews with Linked agencies</li> <li>▪ Online survey of Linked agencies</li> <li>▪ Site visits</li> <li>▪ ALNSW/ELNSW program data analysis</li> <li>▪ Cost Benefit Analysis / Social Return on Investment analysis of both ALNSW and ELNSW</li> </ul>

## 1.6.2 FIELDWORK FOR FINAL EVALUATION REPORT

The final stage of the evaluation was conducted between March and May 2016. The methodology for this stage of the evaluation was both qualitative and quantitative. It involved consultations with all ALNSW and ELNSW providers including 23 site visits and 14 telephone consultations. Consultations included in-depth interviews with provider management, Linkers, people with disability, their families and carers, and Linked agencies. It also included online surveys of Linkers, Linked agencies and parents. In all, some **475** people were consulted for the final phase of the evaluation (see Table 2).

TABLE 2 – SUMMARY OF FIELDWORK FOR FINAL EVALUATION REPORT

METHODOLOGY	ALNSW	ELNSW	TOTAL
<b>Consultations:</b>			
Interviews and discussion groups with provider management and Linkers	12 site visits	11 site visits	23 site visits
Interviews and discussion groups with provider Area Coordinators / Team Leaders	14 telephone consultations		-
Discussion groups with Linkers			
Face-to-face and telephone interviews with people with disability, their families and carers	54 interviews	28 interviews	82 interviews
Face-to-face and telephone interviews with Linked agencies	53 interviews	33 interviews	86 interviews
<b>Online surveys:</b>			
People with disability, their families and carers	34	40	74
Linkers	123 Ability Linkers	38 Early Linkers	161 Linkers
Linked agencies (ALNSW only)	60	-	60

### PROVIDERS

ADHC advised ALNSW and ELNSW providers that the evaluation was taking place and Urbis contacted each provider to confirm their willingness to participate in the evaluation and to establish a time for the consultations.

### LINKED AGENCIES

ALNSW and ELNSW providers gave Urbis the contact details of participating Linked agencies. A sample of Linked agencies for interviews was then selected by Urbis from this list to capture a wide range of organisations across a range of geographic locations. The majority of consultations with Linked agencies took place by telephone to enable a broad cross section of Linked agencies across New South Wales. Linked agencies were also invited to provide feedback via an email or an online survey.

### PEOPLE WITH DISABILITY, THEIR FAMILIES AND CARERS

In March 2014, Urbis obtained ethics approval to undertake evaluation activities with people with disability, their families and carers receiving ALNSW support. Urbis offered multiple entry points into the evaluation, including face-to-face interviews, telephone interviews and an online survey. Individuals were advised by Linkers about the evaluation and were provided with an information flyer prepared by Urbis which explained how they could contribute to the evaluation. Individuals expressing a desire to participate in the evaluation signed a consent form which enabled the Linker to provide Urbis with their contact details. Urbis then selected people to interview to achieve a spread in terms of provider, region, age, program and cultural diversity. A number of people from culturally and linguistically diverse (CALD) backgrounds requested an interview in their own language, and this was arranged. All interviews were voluntary, anonymous and confidential.

## SITE VISITS

Face-to-face discussions with provider management and staff, Linked agencies, people with disability, their families and carers were scheduled over a one to two day visit to each site by members of the Urbis team. As some providers are operating as a partnership, additional site visits were conducted to enable as many staff as possible to take part in face-to-face consultations. Additional site visits were also conducted with the largest ELNSW provider operating across a large number of Sydney metro and regional locations in Northern NSW (see Appendix C for more detail).

### 1.6.3 DATA COLLECTION AND ANALYSIS

Interviews and discussion groups with provider management and staff, Linked agencies, people with disability, their families and carers were recorded with permission and were transcribed for analysis. Where individuals did not provide consent to audio record the interview, researchers took detailed notes. Interviews were analysed using NVivo software and a thematic analysis approach was taken with transcripts and notes read iteratively to identify common themes and to develop a structure of perspectives from different groups. A qualitative research approach does not allow for the number of participants holding a particular view on individual issues to be quantified. This approach therefore provides an analysis of themes and reactions among research participants rather than exact proportions of participants who hold a particular perspective. Quotes have been provided throughout the report to support and illustrate the key findings under discussion.

The quantitative survey data was collected via online survey software and analysed using the Statistical Package for the Social Sciences (SPSS) and Microsoft Excel programs. Percentages presented in the report are based on the total number of valid responses made to the question being reported. In most cases, results reflect those respondents who had a view and for whom the questions were applicable. Percentage results throughout the report may not sum to 100% due to rounding or due to the acceptance of multiple responses for some questions.

### 1.6.4 LIMITATIONS OF THE DATA

Urbis relied on the support of ALNSW and ELNSW providers to access management, senior staff and Linkers for in-depth interviews and also to distribute the Linker survey to all Linkers. All provider management and staff therefore had the opportunity to participate in the evaluation.

Providers also submitted to Urbis the details of people with disability, their family or carers and Linked agencies who had formally consented to take part in the evaluation. While Urbis is extremely grateful for this considerable support, it should be noted that a reliance on providers to approach people with disability, their family members and Linked agencies to take part in the evaluation may have a selection bias to favourable responses to the program. Urbis attempted to minimise selection bias by requesting providers to approach a broad range of people and agencies to participate in the evaluation, and provide a list of consenting participants, from which Urbis selected people to interview. In addition, to minimise any potential for bias, data from all available sources was triangulated to test the veracity of themes and opinions presented. We found a high level of congruence between the findings of the extensive quantitative and the qualitative research activities undertaken for the evaluation.

When the ALNSW pilot commenced in the Hunter on 1 July 2013, an initial reporting template was put in place to enable providers to report data during the early establishment phase of the program. ALNSW providers continued to use this reporting template in the first year of the state-wide rollout which commenced a year later. This initial reporting template captured data from providers at an aggregate level and focused on throughput of 'new' individuals accessing the program, either for 'information only' or 'facilitated support'. The reporting format did not allow for any detailed analysis of individual outcomes or demographics such as ethnicity, age or type of disability. However, qualitative case studies submitted by providers served to describe the range of individual and community outcomes being achieved through the program.

As part of the partnership approach and co-design process that has underpinned the implementation of ALNSW, FACS worked with providers to design a more comprehensive online data and reporting system, which became operational January 2016. Accordingly, it has only been possible to report on program data for the first six months of 2016, with extrapolations made to estimate annual figures. As with any new data collection system, there is a possibility of some variability in reporting and/or coding practices across providers. However, the Department has undertaken a number of quality checks to test the reliability of the data, and are confident that the number and trends are reasonably accurate in describing program utilisation and outcomes.

## 2 People with disability, their families and carers: experiences and outcomes

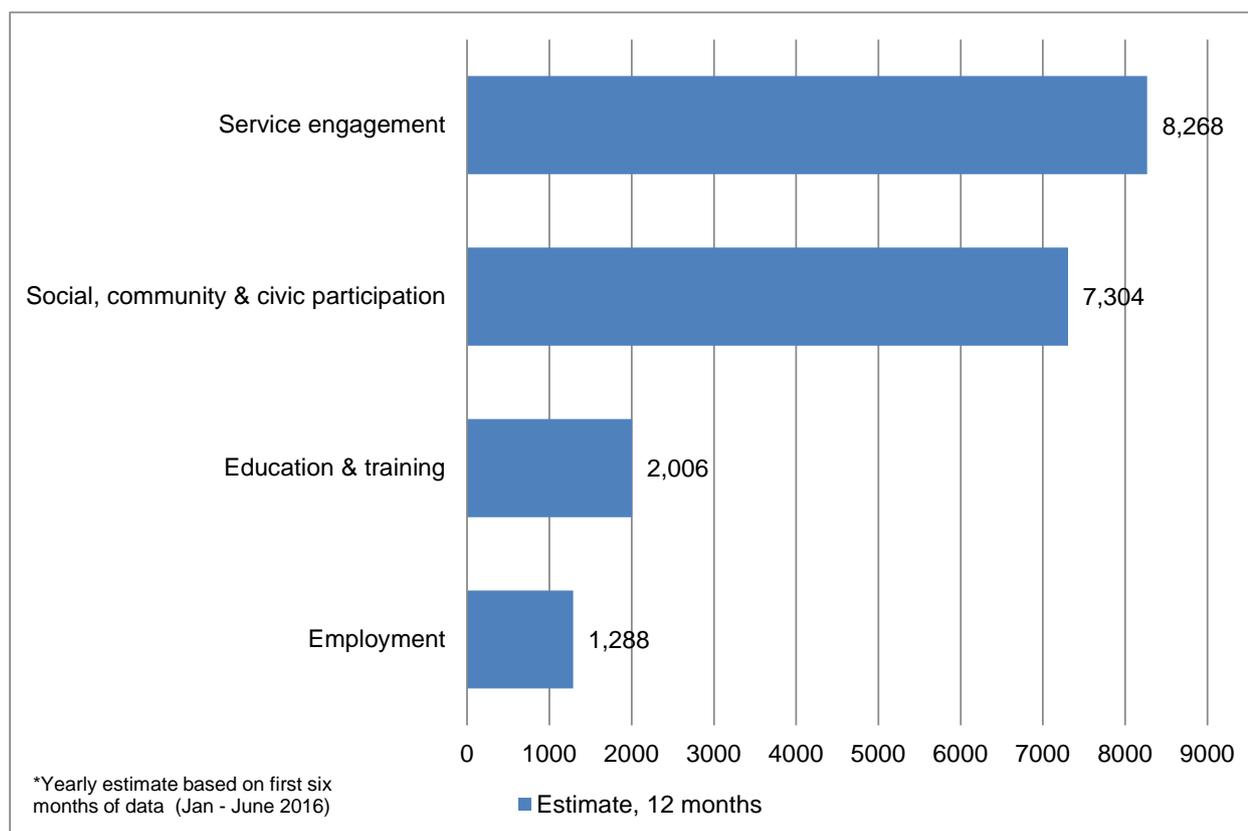
### 2.1 INTRODUCTION

This chapter reports on the experiences and outcomes for people with disability, their families and carers. It draws on a survey of over 70 individuals and in-depth interviews with some 80 people as well as feedback from Linkers and Linked agencies.

### 2.2 PROGRAM PARTICIPATION AND OUTCOMES

Over the last three years, an increasing amount of program data has been collected from providers. In 2015, a decision was made to move to a common platform via a data set to expand the scope and quality of the program data. This new platform commenced in January 2016. However, it should be noted that due to the ALNSW model not having any eligibility or assessment criteria, participant demographic data is collected on a voluntary basis and is reliant on participants disclosing personal information, for example information about their ethnicity.

FIGURE 1 – NUMBER OF OUTCOMES ACHIEVED BY INDIVIDUALS AND FAMILIES ANNUALLY



Extrapolating from these first six months figures, it has estimated that each year ALNSW and ELNSW assists approximately **43,533 people**, of which some 29,410 have been provided with information, 3,747 with **facilitated support and are working towards an outcome** and **10,376 have been provided with facilitated support and have achieved some 18,866 outcomes.**<sup>3</sup>

Most commonly, people with disability, their families and carers are achieving **service engagement** outcomes (44%) which include access to mainstream or specialist disability support. The second largest

<sup>3</sup> Annual estimate is based on six months program data (January to June 2016).

source of individual and family outcomes relate to **social, community and civic participation** (39%) which includes connections with friends, peers, family support, recreational or social events and cultural networks. Just over one in ten (11%) individual outcomes are **education and training** related which includes assistance in identifying or connecting with schools, TAFE, universities or other training options. Fewer **employment outcomes** are being achieved (7%), nevertheless one in 20 individuals have been successful in commencing volunteering, work experience, connection to disability employment services or employers, and receiving support with starting up their own business (see Table 3).

TABLE 3 – PEOPLE WITH DISABILITY, THEIR FAMILIES AND CARER OUTCOMES

	ALNSW	ELNSW	Total
<b>Social, community &amp; civic participation outcomes</b>			
Connection with friends/peers	13%	13%	13%
Informal family support activities	10%	34%	20%
Connection with a community or interest group	27%	12%	21%
Recreational activity linked to passions	19%	7%	14%
Community or social events	7%	7%	7%
Connection with services specifically focused on increasing community connections	18%	24%	20%
Cultural connection	6%	3%	5%
<b>Social, community &amp; civic participation (% of total outcomes)</b>	<b>39%</b>	<b>38%</b>	<b>39%</b>
<b>Service engagement outcomes</b>			
Access mainstream services	57%	45%	52%
Access specialist disability support	43%	55%	48%
<b>Service engagement (% of total outcomes)</b>	<b>40%</b>	<b>49%</b>	<b>44%</b>
<b>Employment outcomes</b>			
Small business/entrepreneurial advice/grants information	5%	1%	5%
Skills development support	25%	41%	27%
Assistance negotiating/liasing with employers to secure employment	17%	13%	16%
Connecting with disability employment services	21%	30%	22%
Work experience	9%	5%	8%
Volunteering	24%	10%	22%
<b>Employment (% of total outcomes)</b>	<b>10%</b>	<b>2%</b>	<b>7%</b>
<b>Education &amp; training outcomes</b>			
Assistance identifying/connecting to TAFE or University courses	39%	2%	23%
Training activities related to employment	23%	7%	16%
Support accessing or liaising with schools	38%	91%	61%
<b>Education &amp; training (% of total outcomes)</b>	<b>10%</b>	<b>11%</b>	<b>11%</b>

Note: Proportional split based on outcomes from January to June 2016. Individual outcomes classified as "other" have been excluded from this analysis.

Table 3 highlights the different outcomes being achieved reflecting the differing needs of people with disability, their families and carers. ELNSW has a stronger focus on disability service engagement outcomes, while ALNSW has a stronger focus on facilitating access to mainstream services. Nevertheless, in terms of the broad patterns of outcomes being achieved, there is considerable similarity between ALNSW and ELNSW which suggest program outcomes are being realised.

Within the service engagement outcomes, the majority of people accessing ALNSW were connected to mainstream rather than to disability supports, in line with the program objectives. However, a substantial minority (43%) were linked to specialist disability supports. Although the original model of ALNSW was to link people to community and mainstream services, there is clearly a need to link people into disability-specific services as and when required. This may be due to a range of reasons, including where the person:

- *does not think of themselves as having a disability*, and is not aware of what assistance they are entitled to
- *has not been able to access the disability service they need or they require assistance with making an application to the NDIS*
- *wants to connect with others in the same situation* so they can share ideas, information and support (e.g. carers of adult children with disability)
- *experiences difficulties in accessing supports due to language barriers or because they are recently arrived in Australia.*

By contrast, over half of the parents accessing ELNSW were linked to specialist disability supports, in line with their specific needs around the time of the diagnosis of their child's disability.

The program data also indicate that ALNSW and ELNSW **have been very successful in reaching Aboriginal and/or Torres Strait Islander people**. As many as 27% of individuals and families who have achieved an outcome identify as Aboriginal and/or Torres Strait Islander. The very high level of Indigenous participation in the program is due to a number of factors including:

- the decision of ADHC to fund Aboriginal-specific Linker positions through a range of locally-based Aboriginal controlled organisations
- the service model resonating strongly with Aboriginal families and communities
- the higher incidence of disability within the Aboriginal population.

ALNSW and ELNSW have been reasonably successful in reaching people from diverse backgrounds – with 18% of people achieving outcomes identifying as CALD. One large ALNSW provider that works in partnership with two large generalist providers specialises in supporting communities from CALD backgrounds. This partnership has undoubtedly been successful in reaching and supporting people from CALD communities.

Nevertheless, other generalist providers are of the view more needs to be done to reach CALD communities in areas which are not covered by this specialist service, and also in CALD communities which traditionally have been more difficult to reach. One or two generalist providers have decided to create designated project positions to devise and drive strategies to increase CALD engagement in ALNSW and ELNSW.

## 2.3 SATISFACTION WITH THE QUALITY OF SERVICE

A total of 74 individuals and families completed a survey to provide feedback on their satisfaction with ALNSW and ELNSW. The survey revealed a very high level of satisfaction (satisfied or very satisfied) with the quality of service provided by ALNSW and ELNSW.

In descending order of satisfaction, individuals and parents were most highly satisfied with:

- their Linker's availability to talk to them when they need them (92% net satisfaction)
- their relationship with their Linker (90%)
- the ability of their Linker to understand their needs and any challenges they faced (89%)
- the knowledge that their Linker has of services and groups in the local community (89%)
- the timeliness of the advice and information provided by the Linker (88%)
- the way the Linker communicated with them (86%)
- the amount of support they received from their Linker (83%)
- the ability of the Linker to link them to appropriate community support and services (83%).

When individuals and families surveyed and interviewed were asked to identify what it was about the contact with the Linker that they found most helpful they echoed the findings of research conducted last year with Linkers being *open and personable, person-centred, collaborative, flexible, persistent, creative, reliable* and *genuinely caring*. It is these Linker qualities and approaches that assist people to achieve the 'soft outcomes' of increased confidence (see Table 4).

TABLE 4 – LINKER ATTRIBUTES VALUED BY PEOPLE WITH DISABILITY, THEIR FAMILIES AND CARERS

LINKER QUALITY	BENEFITS
Open and personable	<ul style="list-style-type: none"> <li>▪ People feel comfortable conveying their 'story', including any previous (positive and negative) experiences of the service sector</li> <li>▪ People feel comfortable expressing their needs, even when they are personal and do not relate to the provision of traditional services (e.g. social isolation)</li> <li>▪ People trust that the Linker is 'on their side', promoting continual honest communication</li> </ul>
Person-centred	<ul style="list-style-type: none"> <li>▪ People feel respected, and in control of their own life</li> <li>▪ Linker understands what each person accessing the program wants and needs to live their own, personally defined, 'good life'</li> <li>▪ Linker tailors links and other activities to each individual or family</li> <li>▪ A person's confidence and self-worth grows through the Linker understanding and relating to them as a unique individual</li> </ul>
Collaborative working style	<ul style="list-style-type: none"> <li>▪ People feel respected, and in control of their own life</li> <li>▪ A person's confidence grows</li> <li>▪ Upskilling of people with disability so that they can eventually meet their needs alone (or with minimal assistance)</li> <li>▪ People are more likely to continue engagement with the program due to a sense of ownership and self-determination</li> <li>▪ Encourages people to take a risk</li> </ul>
Flexible, unpressured contact-style	<ul style="list-style-type: none"> <li>▪ People feel like the Linker (and other ALNSW staff members) has respect for their unique situation</li> <li>▪ People located in regional or remote areas are able to engage with the program on a continual basis</li> <li>▪ Program access does not feel pressured or burdensome, resulting in ongoing engagement</li> </ul>
Reliable	<ul style="list-style-type: none"> <li>▪ Strengthening of trust in Linker by individuals and families</li> <li>▪ People are more likely to continue engagement with the program</li> <li>▪ People feel valued and respected</li> </ul>
Timely, practical support	<ul style="list-style-type: none"> <li>▪ Person accessing the program quickly experiences tangible outcomes</li> <li>▪ People more likely to continue engagement with the program</li> </ul>
Persistent and creative	<ul style="list-style-type: none"> <li>▪ Strengthening of the Linker-individual/family relationship, with people increasingly feeling that the Linker is genuinely interested in providing assistance</li> <li>▪ People are motivated by their Linkers ideas and energy</li> </ul>
Genuinely caring	<ul style="list-style-type: none"> <li>▪ People feel they are being treated as a person not a number</li> <li>▪ Encourages people to take a risk/try something new</li> </ul>

The case study on the next page – **Navigating the service system** – provides a good example of how Linker attributes are applied to support the individual and family to achieve a positive outcome.

## Navigating the service system

Jia\* is in her 50s. She arrived in Australia almost four years ago to join her son. A string of marital issues and a damaged relationship with her son resulted in a mental breakdown. Jai has lacked support from family and friends and experienced difficulty in getting through life on a day-to-day basis. She is in the process of rebuilding her life, but poor emotional and mental health makes this a struggle. Recently, she found herself homeless.

She approached a Family Service Centre where she says she was referred to a number of organisations. Through this initial contact, she contacted ALNSW and was paired with her Linker. Jia sought support from the program to help her navigate through life on a day-to-day basis, manage daily challenges in conjunction with her mental health, and improve her emotional well-being.

Jia was put in contact with her Linker almost five months ago. Initially her expectations of the program was like any other service, minimal contact and not much direction. However, her expectations have been exceeded.

*[Linker] helped me at my lowest point. He encouraged me to get back into society and showed me step by step how to do that.*

She says she has developed a close relationship with her Linker. They meet once a week and keep in touch by phone. Her immediate concern has been upskilling and securing employment.

*We are in contact by phone and meet maybe once a week... [Linker] contacts me via phone, and he responds to my calls in odd hours.*

Through the program, Jia has sought assistance with being upskilled for employment and ultimately being independent. The major barrier she faces have been her language skills.

*In China, I was a good business woman. But here it's difficult for me because my English is not very good.*

To help alleviate the language barrier, Jia has sought assistance in seeking out English classes through her Linker. Currently she is enrolled in English classes at TAFE. Jia hopes that in addition to increasing her work prospects, she can grow her social circles if she becomes fluent in English.

*I want a good job like I had before, and I want to be able to meet more people and communicate with them.*

The Linker has also sought out low-cost accommodation for Jia, as well as work recruitment options through Centrelink. Jia is expanding her social circle at the Church she visits. Her Linker introduced her to the chaplain there.

*I feel like [Linker] rescued me. He's helped me to have a second chance with everything.*

For Jia, life has taken a dramatic change for the better. She has a greater sense of direction, belonging and purpose.

*He gave me a second chance to live. He is truly my angel.*

Through the program, Jia has been encouraged to become fully independent and successful in life. She has developed self-confidence and optimism for the future, and attributes a lot of this to her Linker. Her new challenge is to acquire a full-time job.

*[Linker] trained me how to answer questions in a job interview...Australia is a different culture to China, so it's really good to get this advice from him...Slowly, I'm more confident, and excited about opportunities.*

Jia is exceptionally satisfied with ALNSW. She has a new lease on life and is increasingly excited about the future. She attributes a lot of this to her Linker.

Her English skills are developing as a result of being enrolled in the program.

*I'm starting to develop my English, I'm happy about this.*

She says she is less anxious in life and is no longer afraid about the future. Her Linker has reportedly helped her find a direction. Compared with other programs, Jia expressed an appreciation for the attention to detail her Linker has shown and the personal approach. He has helped her with 'everything'.

\* Name has been changed

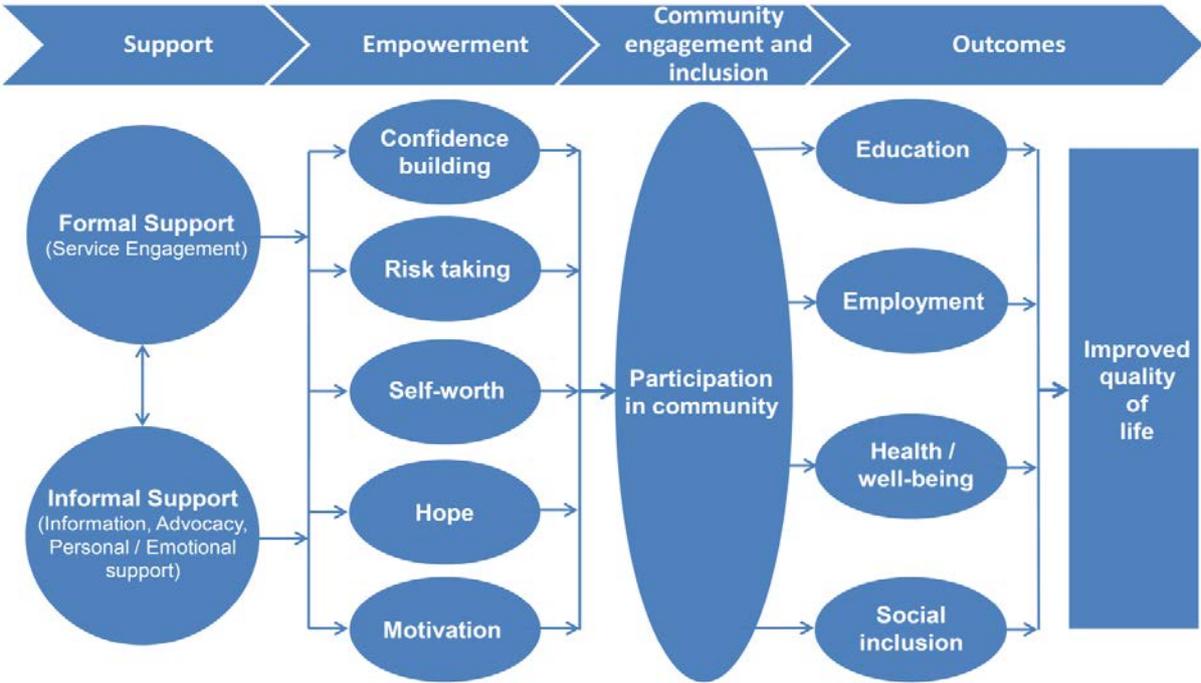
## 2.4 INDIVIDUAL OUTCOMES: A PROCESS OF ACHIEVING

### 2.4.1 OVERVIEW

Four types of outcomes for individuals have been identified. These outcomes are achieved as a continuum of individual empowerment, through to community engagement and participation, resulting in an improved quality of life.

The process of engagement within ALNSW and ELNSW can be seen as a journey whereby individuals and families access facilitated support information (formal and informal supports), which leads to various forms of empowerment, which in turn leads to increased community engagement, which results in improved health, education and employment outcomes for the individual. The journey is not necessarily linear; it can be iterative and staged. Thus, risk taking can result in participation in community, which in turn can lead to improved confidence, which then leads to further community engagement, and so on.

FIGURE 2 – OVERVIEW OF OUTCOMES FOR INDIVIDUALS AND FAMILIES



**Formal support** from ALNSW and ELSNW takes the form of linkages to the service system, mainstream or disability-specific depending on the needs of people with disability, their families and carers.

**Informal support** is relationship-based and involves the provision of personal support from the Linker. This involves gaining the confidence and trust of the individual or family so that they can have open communication. It involves exploring their strengths, passions and interests, identifying ways of working alongside the individual/family to increase their confidence, encourage them to take a risk, helping build their self-worth and hope for the future, and to set some goals and directions that they can work towards – whether it be more social connections, participation in education or employment, or improved health and wellbeing.

The case study **Finding a way back to employment and independence** on the page 13 illustrates how contact with a Linker has provided the strength and hope to find a new pathway in life, for someone who had become physically incapacitated through a work injury several years ago.

## Finding a way back to employment and independence

Jing\* migrated to Australia from overseas over thirty years ago. He suffered a stroke eight years ago, and this affected his overall physical mobility. As a result of the stroke, disruption was brought to his professional life and he's since experienced economic and social downward mobility. He is 46 years of age, married with no children. His wife is the primary income earner.

Over the years, Jing has improved physically and now has 20 per cent physical disability – a great improvement on previous years. Despite this improvement, Jing's emotional and mental well-being and confidence have depreciated substantially. A family friend took the initiative to enrol Jing into ALNSW and he has now been in contact with his Linker for about three to four months. He had no expectations coming into ALNSW, particularly given that the process was initiated for him. His primary interest is to re-engage professionally, update his skills to enable him to go back into the work force, and become more independent and optimistic about his future.

Prior to his stroke, Jing worked as an IT professional, but the industry has changed a lot since his full-time employment, and this has impacted on his confidence.

*Before, I was very good at my work. Now a lot of time has gone and there is a lot to learn again.*

Despite his initial reluctance to get help, he is now keen to reconnect with community and to secure voluntary work to transition back into full-time employment.

The primary areas where Jing has received support are education (to upskill) and volunteer work (to transition back into employment). Through the assistance of his Linker, Jing was enrolled into a local TAFE to update his IT skills. He also secured volunteer work at his Local Council, once a week. The support of the Linker has increased his confidence and he has started to feel good about himself again. He has occasional contact with his Linker to update her on his progress in work and study.

The nature of his volunteer work at the council is to assist people having technical problems with their computers. Assisting others has motivated him to help himself through developing self-confidence and avoiding early retirement.

*I'm only 46 years old. I'm too young to retire... I have to work on getting better.*

The main change for Jing as a result of coming into contact with Ability Links is the long-term goal he's set for himself. He has plans to move into part-time paid employment, then eventually into full-time.

Reconnecting with community through study and work has contributed to Jing feeling like a valuable member of society again.

*When I got sick, I stopped seeing people and going out... now I'm beginning to feel normal, like I can help society again.*

Prior to being in contact with the program, Jing had little to no connection with community. He is now attending regular classes and work, and overcoming his avoidance of people.

*[Linker] has really helped me have plans for the future. Learning how to look forward has been a big deal.*

The support of the Linker has also helped Jing become less isolated. His willingness to put himself 'out there' has been a big step. The program has also helped Jing test his boundaries. Ability Links has been an emotional achievement for him as much as it has been a social and professional one. He has not been as involved in programs previously, so he is unable to draw a comparison except to feel reassured that he has direction. As he says:

*This program has been a massive change for me... now I am part of the community again.*

Jing's main feedback is that there be greater promotion of the program, because he would like others in a similar situation to benefit as much as he has.

\* Name has been changed

## 2.4.2 FEEDBACK FROM ALNSW PEOPLE AND FAMILIES

A total of 54 people with disability and carers who had accessed ALNSW were interviewed face to face or via the telephone and an additional 34 completed an online survey questionnaire. Although the number of individuals that completed the survey was relatively low (34), the results strongly correlate with the qualitative data obtained from the in-depth interviews.

The majority of individuals reported since contacting ALNSW, they had experienced various quality of life improvements including the following:

- they felt *more optimistic about the future*
- they felt *safer, healthier and happier*
- they felt *more socially connected*
- their *self-esteem had increased*
- there had been an *improvement in their family relationships*.

The majority of people with disability, their families and carers supported by ALNSW also reported some or a lot of improvement in relation to:

- their *ability to find information and support* in the local community
- the number of *people they could ask for help* if they needed it
- the *amount of control they have over how they live their life*
- *opportunities to go out with friends* to attend social occasions
- *opportunities to do the things they really enjoy doing*
- the *number of people in the community they can trust*
- the *opportunity to learn new things*
- the *opportunity to do things in the community that they feel are important*
- their *hopes and aspirations* for the future
- confidence in making decisions about the future.

This feedback is highly consistent with feedback obtained from more than 100 individuals and families interviewed in the previous year, and also with feedback from ALNSW Linkers.

The strong focus on achieving positive outcomes through overcoming social isolation is well-illustrated in the case study on page 14, **From Isolation to Contribution**.

## From isolation to contribution

Sarah\* was spending a lot of time at home and had started to feel like she was becoming very isolated from the community. She first came across an ALNSW information stall in her local shopping centre where she spoke with a Linker, and then later reconnected with ALNSW through her church.

Sarah started to receive support from ALNSW. The Linker listened to what she wanted to do in order to help her work out the support she needed to achieve her goals. In the process of working with Sarah, the Linker found out that the local church was looking for someone to teach an art therapy class for people with mental health needs. Based on Sarah's skills and experience, the Linker connected her to the church and encouraged her to take on the voluntary teaching position as a way of getting out of the house and reconnecting with the community. She was perfect for the job and she has now been teaching the weekly art therapy class for more than six months. As Sarah explained:

*Ability Links were very hands on. The Linker helped me help myself. She kept pushing things at me. She listened to what I needed and wanted and then told me where to go, here and there. I'm now teaching other people who suffer from mental health issues and isolation. So I've gone from being the isolated one to helping others not being isolated.*

The Linker has also supported Sarah by linking her to local community services and groups that provide support for her children. Sarah has been able to pass on the knowledge provided to her by the Linker to tell other families how they can get in contact with community activities in the local area.

The relationship Sarah has had with her Linker makes her feel comfortable about asking for support and advice. For example, the Linker has provided Sarah with advice about the Department of Housing and pointed her in the right direction of where she can get help by herself.

Ability Links has had a noticeable impact on Sarah's connectedness with community life, and this has renewed her confidence. She has now commenced study at university in visual design, which she hopes to use to find a job in the future. As she commented:

*I feel like I have a connection now with the community. I feel like I've gone from just sitting at home, to getting out of my house. Doing the art class has basically changed all my life. It has improved my mental health. It has improved me and I must admit, if it wasn't for Ability Links, I probably would still be at home staring at the TV.*

\* Name has been changed

A further case study on the following page – **Learning to connect and be independent in a new community** – provides the perspective of a carer of an adult child with disability who is new to Australia and illustrates a very positive experience with ALNSW.

## Learning to connect and be independent in a new community

Bana\* is in her mid 50s. She migrated to Australia almost a year ago from war-torn Syria. She is a full-time carer to her adult daughter, Amira\*, who is paralysed and has cognitive delay from complications in childbirth. Bana resides with her husband and daughter. She is accommodating to life in Australia, and is keen to become more independent. Despite settlement challenges, she is grateful for being in a safe country and for having the required social services to help her be a better support to her daughter.

Bana first came into contact with ALNSW via an organisation she was referred to upon arrival to Australia almost a year ago. A worker introduced her to ALNSW, to assist with her responsibilities as a full-time carer. She had no specific expectations of the program, only that her Linker could serve as a contact to point her in the direction to get support for her daughter.

*I didn't know exactly what Ability Links is and what to expect, I remember thinking any help is good.*

Through the Linker, Bana has been able to enrol her daughter into a support group to engage with other people with physical and intellectual disabilities, and in swimming lessons. Subsidised dentistry, physiotherapy and a taxi service have also been accessed through Linker activity.

Both Bana and her daughter's confidence have increased as a result of contact with ALNSW. With Amira now being more connected to community, pressure has been alleviated for both mother and daughter. They are now both more engaged with community and happy for it.

*My daughter has really changed; the services have been good for her...I've been happier also because my daughter is involved in doing things. She spends time with people so that makes her feel a lot better.*

The contact Bana has made with services through ALNSW has encouraged her to be more independent and optimistic about the future.

*I'm learning what is out there. It's good for me too because I'm new to the country and I want to be able to learn and do more by myself.*

Being new to the country, Bana still contends with general settlement issues – ease of access to places, familiarity with roads, services, identifying opportunities for development. There is still a lot to learn, but she is confident she will get there.

*Me and my husband rely on our other daughter who has lived here...it's a lot of pressure on her, but it takes time. Seeing different people and learning about different places through Ability Links has been good for everyone.*

Bana attributes some of her optimism for the future to the contact she has had with her Linker.

*Talking with the Linker makes me feel I can ask questions and get advice without feeling like I'm troubling my other daughter, and makes me feel better about myself.*

ALNSW has been a positive vehicle for change in the life of Bana and her daughter, supporting her to source support services with greater ease.

*I have more confidence in getting assistance, learning to help myself, and finding my way around town. It's good.*

ALNSW has also afforded Bana a greater ability to manage her time and engage in programs for herself, which has translated into improved health and well-being of her family.

*Like for me as well, I have more time to think about myself. I've been going to groups with women who have lived in war. This is really emotionally very good for me. Ability Links was really for my daughter, but it's really helped me too.*

Bana put forward suggestions for improvement with great reluctance. However, she mentioned a desire for more regular contact with services and a broader range of services for carers.

*I would like more services and programs for carers.*

But her main request is to be supported in becoming more independent.

*I want to learn this land, and this country... I want to know how everything works... this is a necessity.*

\* Names have been changed

## 2.4.3 ALNSW LINKER ACTIVITIES AND POSITIVE OUTCOMES FOR INDIVIDUALS AND FAMILIES

TABLE 5 – ALNSW LINKER ACTIVITIES LEADING TO OUTCOMES FOR INDIVIDUALS AND FAMILIES

ABILITY LINKER ACTIVITIES	INDIVIDUAL/FAMILY OUTCOMES	EXAMPLES
<b>Providing information to people with disability and their families</b>	<ul style="list-style-type: none"> <li>People are informed about the range of services and supports available</li> </ul>	<p><i>The Linkers keep us in the loop with new information about the NDIS and other assistance available for our family.</i></p>
<b>Navigating a complex service system</b>	<ul style="list-style-type: none"> <li>People with disability, their families and carers learn how to access community services and supports</li> <li>Building individual and family knowledge of what is available</li> <li>Building an individual's confidence to seek information and supports independently</li> </ul>	<p><i>I've had to be in contact with ALNSW again because I needed help with housing. I was having an issue and they helped point me in the right direction for where to get help for that.</i></p> <p><i>I have more confidence in getting assistance, learning to help myself, and finding my way around town, it's good.</i></p> <p><i>The Linker has helped me get into the hearing clinic, helped with the Housing Commission and is now helping me to get the support I need to get my driver's licence.</i></p>
<b>Provide emotional support for individuals</b>	<ul style="list-style-type: none"> <li>People with disability, their families and carers better manage periods of mental and emotional distress</li> </ul>	<p><i>I started to get really badly depressed in the middle of last year. I just went downhill really badly, and one day the Linker approached me and took me to one side and said: 'What is going on? I've noticed you go downhill and I'm really quite concerned'. She had a cuppa with me and linked me into counselling and a support group which is bloody amazing. So I needed help and she noticed it and actually took action.</i></p> <p><i>The Linker has a beautiful personality. She really understands me, understands where I'm coming from. She can see that I've been going through some hard times recently.</i></p>
<b>Identifying interests and building confidence</b>	<ul style="list-style-type: none"> <li>Builds rapport and trust that the Linker is on their side</li> <li>Builds momentum for individuals and families through incremental outcomes to achieve further goals</li> <li>Builds self-confidence and hope for the future</li> </ul>	<p><i>They make you feel comfortable and like I'm important. They take the time to make enquiries about what it is that's bothering me and where nobody else could.</i></p> <p><i>The Linker was listening to my wishes and she understood me.</i></p> <p><i>ALNSW has given me something to look forward to.</i></p> <p><i>My mental health has definitely improved. I go to TAFE at the moment, so I'm skilling up, or new skilling, and just generally feeling better.</i></p>
<b>Advocating / supporting people with initial entry point into service system</b>	<ul style="list-style-type: none"> <li>Helps to gain access to social services and disability support services</li> <li>Better understanding of services and processes</li> <li>People are able to fill out forms, collect relevant documents to fulfil criteria of support services</li> <li>Builds confidence in being able to access the services they need</li> </ul>	<p><i>They helped us with the government, and helped us to complete forms for packages and get them back to them.</i></p> <p><i>Without ALNSW, there's no-one to be an advocate for you, no-one to introduce you to services or to work with you with a service if you're struggling. None of us have the money to suddenly hire a solicitor to come to our aid.</i></p> <p><i>The Linker went into Centrelink with me and he had interviews with the manager there and the social worker to try and find a solution for me.</i></p>

TABLE 5 – ALNSW LINKER ACTIVITIES LEADING TO OUTCOMES FOR INDIVIDUALS AND FAMILIES (CONT'D)

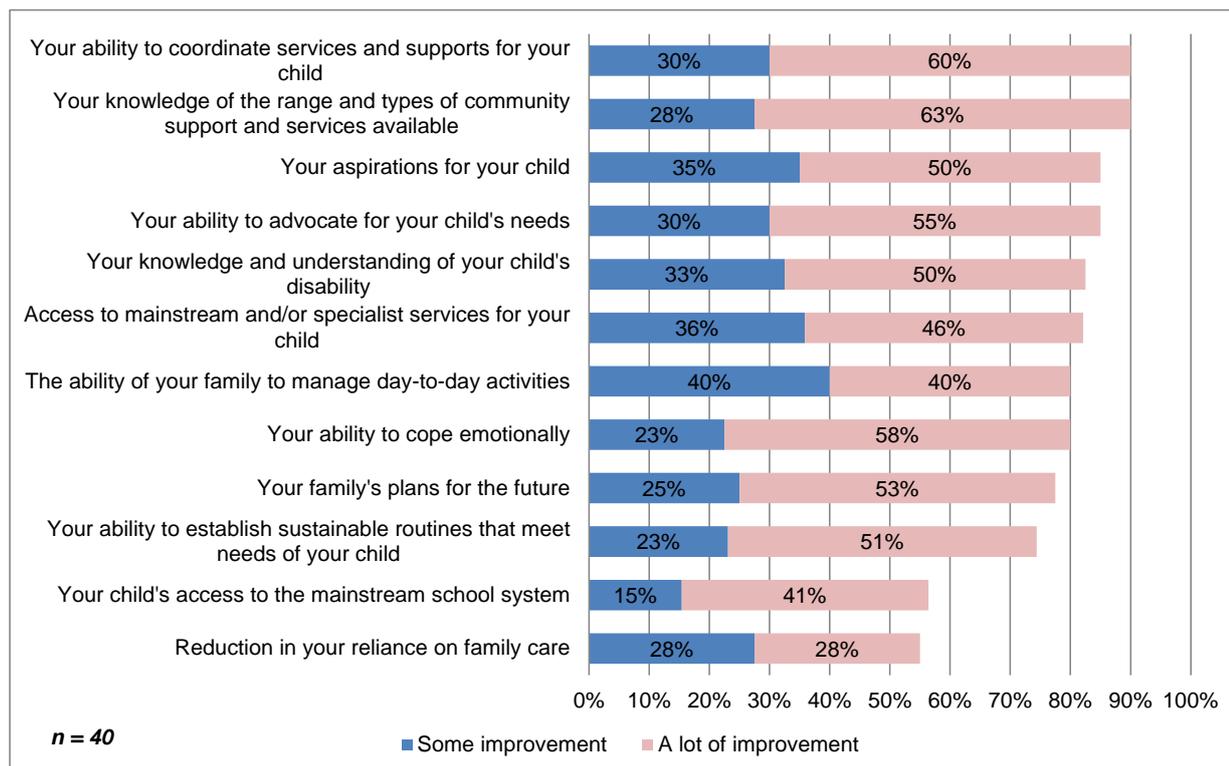
ABILITY LINKER ACTIVITIES	INDIVIDUAL/FAMILY OUTCOMES	EXAMPLES
<b>Building personal capacity and skills</b>	<ul style="list-style-type: none"> <li>▪ Develops individual's skills and knowledge based on their needs, interests and passions</li> <li>▪ Increase individual's skills to assist in transitioning to employment or volunteering</li> <li>▪ Builds confidence, knowledge, and self-reliance</li> </ul>	<p><i>I go out a lot now. I wasn't quite sure how to do things, but ALNSW gave me the opportunity to go out. They helped to show me how to catch a bus, and now I've got more freedom than before.</i></p> <p><i>I'd like to get a job, and the Linker has linked me to a computer course to help me upgrade my skills.</i></p> <p><i>My son's goal is to get his driver's licence, and the Linker is helping to do this. This will give him a lot more independence.</i></p>
<b>Linking to employment opportunities</b>	<ul style="list-style-type: none"> <li>▪ People with disability gain confidence and a sense of purpose through work experience and volunteering</li> <li>▪ Builds social and community connections</li> <li>▪ Potentially creates pathways to employment for people with disability</li> </ul>	<p><i>The Linker helped me to get a week of work experience...I got to know a lot of people at the store and they let me stay on...I'm now I'm hoping to get full-time work once I finish school.</i></p>
<b>Linking to community groups</b>	<ul style="list-style-type: none"> <li>▪ People with disability, their families and carers engage in social and community groups</li> <li>▪ People are able to pursue their interests</li> <li>▪ Builds individual's confidence</li> <li>▪ People with disability have an opportunity to contribute to community</li> </ul>	<p><i>The Linkers help in bringing us together and making us more confident, so you get more confidence out of helping other people.</i></p> <p><i>The Linker introduced me to a lady with the local garden club because I was doing so much in my garden and pretty isolated and she said 'I reckon you will get along well with this lady'. She linked me to her so that I had someone to share my garden stuff with.</i></p> <p><i>The Linker introduced me to the local historical society. They have a big exhibition on there and I'm going to have a look at that myself and to hear a talk about the exhibition. The Linker is also trying to find me a group that is interested in a type of music that I like.</i></p>
<b>Initiating community activities</b>	<ul style="list-style-type: none"> <li>▪ People with disability, their families and carers can build their aspirations and passions</li> <li>▪ Individuals create community value through participation</li> <li>▪ Individuals have a greater sense of self-worth</li> </ul>	<p><i>The creative arts program that the Linker started is inspirational. It's got longevity and it makes you feel worthwhile.</i></p>

## 2.5 OUTCOMES FOR ELNSW FAMILIES

### 2.5.1 PARENTS' SURVEY RESULTS

A total of 40 ELNSW parents completed a survey, providing feedback on their experiences with ELNSW. Their responses, which aligned with feedback from interviews with a further 28 parents, were overall extremely positive, with the majority of parents reporting improvements (some improvements or a lot of improvements) on all 12 outcome indicators (see Figure 3). The greatest improvements related to parents' *ability to coordinate services and supports for their child* (90%) and *their knowledge of the range and types of community supports and services available* (91%). The great majority of parents also reported improvement in *their aspirations for their child* (85%), *their ability to advocate for their child's needs* (85%), and *their knowledge and understanding of their child's disability* (83%).

FIGURE 3 – OUTCOMES FOR ELNSW FAMILIES



The case study – **Linking: a family-centred approach** – illustrates the wide range of activities that Early Linkers engage in to support families with a young child with disability.

## Linking: a family-centred approach

Sam\* is a seven year old Aboriginal boy. He was removed from the care of his biological parents at six weeks of age. The Department of Family and Community Services placed Sam in the care of a family member through a kinship placement.

His conditions at the time were multidimensional and included attention deficit hyperactivity disorder and behavioural issues. He also had difficulties with his sleeping routines and maintaining positive relationships with people around him.

Leonie\*, who is Sam's primary carer, has a diagnosed intellectual disability. She had become very stressed and depressed due to Sam's ongoing behavioural issues and sleep patterns. Sam was referred to the ELNSW program by his school who expressed concern about his behaviour at school.

The support that the Aboriginal Early Linker who worked with Sam provided was multi-faceted, reflecting the complex needs of many families who come to ELNSW. These included links to paediatric, diagnostic and medical services as well as informal support to help Leonie and her mother to manage Sam's behaviours and sleep concerns. The Linker provided the following support:

- referral to a paediatrician for a medication review
- linking with the local optometrist for optometric assessment
- linking with the local Community Health Dental Clinic for oral health assessment
- linking with Community Health for audiometric assessment
- referral to the region's Aboriginal Medical Service
- liaising with school teacher and Aboriginal Education Support officer in relation to supporting for behaviour and medication management
- supporting Leonie and her mother to develop a routine chart to address Sam's behaviour and sleep concern
- registering Sam for community based swimming lessons and other community based school holiday activities.

As a result the Linker advocating for a medication review, Sam is now sleeping better, which has reduced both Leonie's and her mother's stress.

As a result of the Linker's discussion of medication management with Leonie, her mother and the school, it was discovered that Sam was only taking his medication sporadically when at home. His medication routine was then adjusted to allow for medication to be given at school. As a result, there is now more regular medication dosage which in turn, has resulted in Sam's improved behaviours at school and at home.

As a result of the Linker linking Sam to the Aboriginal Medical Service to undertake a comprehensive health review, issues were identified with Sam's hearing, eyesight and oral health. His family was supported to engage with appropriate health professionals to manage, and where possible, resolve ongoing health concerns.

Sam is also soon to start swimming lessons at the local swimming pool.

Leonie is now attending TAFE three days a week to learn painting, sculpting and computer skills. She is happy, and has a good relationship with her mother.

*Sam is still a handful, but much better now. He sleeps more regularly and so do I. School does not call as often as they used to. He actually turns up to classes regularly and enjoys it. I go to TAFE because I enjoy it and meet new friends. I am more confident. There is still a long way to go, but I feel we are getting there.*

\* Names have been changed

## 2.5.2 ELNSW LINKER ACTIVITIES AND OUTCOMES FOR FAMILIES

Early Linkers engage in a wide range of activities to support the specific needs of young children with disability and their families around diagnosis. Table 6 sets out some of the key activities of Early Linkers, the outcomes that are being achieved and examples from parents supported by ELNSW.

TABLE 6 – ELNSW LINKER KEY ACTIVITIES LEADING TO OUTCOMES FOR FAMILIES

EARLY LINKER KEY ACTIVITIES	OUTCOMES	EXAMPLES
<p><b>Providing information to families</b></p>	<ul style="list-style-type: none"> <li>▪ Parents are informed about the range of services and supports available for their child and their family</li> <li>▪ Parents gain a better understanding of their child's diagnosis or condition</li> </ul>	<p><i>I didn't know that I can put [child] into a mainstream school. I didn't know that there are special programs that are run before [child] goes to kindy. I didn't know that there are some government funded places that I can take [child] to instead of using all your money. The Early Linker also worked out how not to go into debt with my funding and also they have supported me in occupational therapy and speech, which is what I really needed in the beginning for [child]. Also they've brought me a lot of information about mental health, where I can go to places and chat.</i></p> <p><i>It's mainly referrals. So I've been referred onto other services and showing me things like other learning disabilities that they may have and finding other disabilities that I didn't realise that the kids had.</i></p>
<p><b>Assisting parents obtain a diagnosis</b></p>	<ul style="list-style-type: none"> <li>▪ Relieves the uncertainty about what they are dealing with</li> <li>▪ Facilitates entry to diagnosis and support</li> </ul>	<p><i>We are more positive now. It's been a positive change because now we know what is wrong and why their behaviours are that way.</i></p>
<p><b>Navigating a complex service system at a time of stress</b></p>	<ul style="list-style-type: none"> <li>▪ Relieves anxiety and a sense of being overwhelmed</li> <li>▪ Builds parent knowledge of what is available</li> <li>▪ Assists families to access funding relating to the child's diagnosis</li> <li>▪ Assists parents to make informed decisions about service options</li> </ul>	<p><i>She came with me to my appointments with the NDIA to get funding for my son. She supported me into organising all of that and to organising to get him into different activities to help him along.</i></p> <p><i>Well you feel less insecure and you feel like you're being helped. You're being supported that there is help out there and that help makes me less anxious with what I'm going to expect.</i></p>
<p><b>Providing personal and emotional support</b></p>	<ul style="list-style-type: none"> <li>▪ Alleviates parents' isolation and distress</li> <li>▪ Assists families deal with grief, stress and anxiety of the diagnosis</li> <li>▪ Provides parents with emotional coping strategies</li> </ul>	<p><i>Being able to blow off steam and have somebody to talk to that understood me means that I was able to be a better mother which was positive for the family.</i></p> <p><i>It just removed that feeling of isolation that we had and feeling lost. I mean we didn't know the sort of things to ask for or we didn't really know the sort of questions that we had. We got a lot of value out of having somebody just to come and listen to us, someone who understands what we were going through and help us have a bit of hope.</i></p> <p><i>Just having someone to support us, having someone to ring and ask questions, just to have someone that we could contact and say 'have you heard of this' and someone to say 'I don't know I'll have a look for you', I think that was the most important thing.</i></p>

TABLE 6 – ELNSW LINKER KEY ACTIVITIES LEADING TO OUTCOMES FOR FAMILIES (CONT'D)

EARLY LINKER KEY ACTIVITIES	OUTCOMES	EXAMPLES
<p><b>Advocating / supporting parents with initial entry point into service system</b></p>	<ul style="list-style-type: none"> <li>▪ Reduces fear and anxiety</li> <li>▪ Assists with interpreting and explaining technical / medical terms</li> <li>▪ Helps build confidence over time, as parents take control</li> </ul>	<p><i>When you get that diagnosis, a whole lot of information comes at you and it can feel like an overload and you don't necessarily take it all in. So [Linker] was there to translate for me to a certain extent, even though I was asking the questions. So she was able to nurse me through a little bit to make sure I understood exactly what was being said to me and what was happening.</i></p> <p><i>There were certain questions I could answer straight away but back then it was too much and I didn't understand them fully and I didn't want to answer incorrectly. [Linker] was able to translate it for me so I could put the correct answer down for our situation and now that we have the Carer's Allowance and the Carer's Pension and that's a weight off my back.</i></p>
<p><b>Establishing or linking parents to peer support groups</b></p>	<ul style="list-style-type: none"> <li>▪ Provides a forum for families facing the same challenges to share information, ideas, and provide mutual support</li> <li>▪ Provides a mechanism that parents control and shape to their changing needs</li> <li>▪ Parents more aware of the importance of self-care and coping strategies</li> <li>▪ Reduces parents' anxiety and fears</li> </ul>	<p><i>Well you can listen to other people's stories of how they came through, how they've gone past all these stages of treatment and things like that. What's the experience going to be like. It's nice to hear. They tell you it's going to be okay, things are going to be progressed. It's very reassuring to hear from other parents that have kids with autism.</i></p> <p><i>The support was pretty much it for us. Just basically connecting to the people we needed and then we sort of took it over ourselves. The social group is now run completely on our own. We now do a gymnastics program. We've adapted the program so we're kind of self-sufficient now.</i></p>
<p><b>Assisting parents to set goals and see a future for their family and their child</b></p>	<ul style="list-style-type: none"> <li>▪ Builds parents' hope and aspirations for their child</li> <li>▪ Helps establish a plan of action that parents can work towards – so they feel more in control</li> <li>▪ Help transition from Early Linkers to Ability Linkers</li> </ul>	<p><i>Early Links has made a huge difference. Basically, it felt like there was someone in our corner, someone who was giving us information, someone who was there to support us. I definitely feel that, going through, I would never had known that the Trans program existed. I would never have heard of Ability Links. I would never have heard of anything had I not done the Early Links first and not been connected. It's just a big stepping stone when you finish with early intervention to realise that there are other services available to you that weren't privatised and that didn't cost you a million dollars.</i></p>

TABLE 6 – ELNSW LINKER KEY ACTIVITIES LEADING TO OUTCOMES FOR FAMILIES (CONT'D)

EARLY LINKER KEY ACTIVITIES	OUTCOMES	EXAMPLES
<p><b>Providing parents with training, tools and resources to advocate and support their child</b></p>	<ul style="list-style-type: none"> <li>▪ Parents provided with a resource that helps them talk about their child in a positive way at day care, school etc.</li> <li>▪ Enables parents to draw out the strengths in their child and focus on encouragement and practical skills</li> </ul>	<p><i>Now that I know, I understand. I think I'm more patient with him. I'm able to employ tactics to help him and help us. I've learnt some things that give him a choice, simple choices to break down what I need him to do into simple phrases.</i></p> <p><i>[Child] is a much happier and brighter girl which makes me happy to see her that way. Before, she was upset. I didn't know what she needed. I didn't know what she wanted. Now I understand her more and I get to her needs more and that makes her happy.</i></p>
<p><b>Linking parents and children to community groups</b></p>	<ul style="list-style-type: none"> <li>▪ Builds parents' confidence, morale and community support base</li> <li>▪ Builds family's connection to community</li> <li>▪ Builds community understanding of what they can do to support children with disability</li> </ul>	<p><i>She basically connected. It was the biggest thing she would do. She would send information about things that were happening in town. She would go okay, have you tried doing this? Did you know that this was available? That kind of stuff was invaluable – connecting me to services that were available around town.</i></p>
<p><b>Accessing schools and school support services</b></p>	<ul style="list-style-type: none"> <li>▪ Provides access to mainstream playgroups, family fun days, sports clubs etc.</li> <li>▪ Builds connection between parents and school before transition</li> <li>▪ Parents more aware of the range of supports and assistance available at schools</li> <li>▪ Parents and children now school ready</li> <li>▪ Parents supported though homework clubs, early ready, writing and literacy challenges</li> </ul>	

The case study on the following page – **A family's journey with ELNSW** – illustrates the impact that ELNSW has had on one family who were searching for solutions.

## A family's journey with ELNSW

When June\* first came to ELNSW, she was, as she described 'at a desperation point, a total state of shock and grief' about her daughter's conditions. Her journey with an Early Linker has changed her family's life.

June's daughter, Violet\*, has a very rare medical condition. She does not qualify for any funding because the condition is not known in Australia and thus does not fit into any registered type of disability. She can only access early intervention services and has been refused public health services. June was told that it was the 'family's battle to fight'.

For the next two and a half years, June tried desperately to find out more about Violet's condition and services that might support her. She was unsuccessful time and time again. Violet's paediatrician had no further answers or suggestions. Eventually, June stopped going to early intervention as she felt there was nothing available there for her daughter through this service. Again, she was told that there was nothing the public health system could do to assist her because Violet's condition was too complex.

Even though June was a strong woman and had support from her husband, the weight of the responsibility and thought of a continuing battle to find help for her daughter with no light at the end of the tunnel made her very depressed. Indeed, the whole family was affected emotionally and relationships were strained. The family began to lose friends. They did not have any family living close by. They felt alone, not knowing what the future might hold for them and their daughter. Then, June met her Early Linker.

*Our life changed the moment I met [the Linker]. I felt for the very first time that someone actually understood my daughter, and was there for us. We talked and her knowledge and ideas were so comforting and exciting. Before I had even left her office, she had applied for the Brilliant Life funding for a series of occupational therapy sessions, and helped me to see a whole new direction in life, and new ways to encourage Violet.*

Six months later, June and her family's life have improved significantly. She now regularly attends a social gathering that the Linker introduced her to. June, Violet and her family also attended a function organised by the Linker to promote inclusivity at the local recreational park, and they regularly get involved in other community group events.

June and her husband have recently had their first evening out (as a result of the Linker organising respite support), where she met other parents who are in the same situation.

*What I really love about [the Linker] is that she listens, really listens, to us. She constantly asks us what we want for ourselves and our children. It's so refreshing to have people in your life who really want to help, investigate and deliver excellent information, and invite us to events. I always look forward to our get together as I always learn something, meet someone really cool, and have amazing honest conversations with wonderful and interesting people.*

With the support of her Linker and the ELNSW team, June has gained confidence to explore new options for with her daughter and find the answers she needs. She shared all the information she learnt with her Linker. With that knowledge, the Linker was able to find out many things to help June access the resources, training and treatments necessary for Violet. Meanwhile, Violet has thrived and is now starting to talk and do things June and her husband did not think were possible.

*I am totally confident now. It is much easier for me to go forward. [The Linker's] experience and forward-thinking attitudes make it easy for us and for all her other families. She has pulled us back together as a family unit and has provided us with support, helped us with respite, funding, and courses that have really changed our life. So now we can focus on being strong, fabulous parents instead of depressed, anxious people who fluff around without any direction and support.*

\* Names have been changed

## 2.6 SUCCESS FACTORS TO ACHIEVING POSITIVE OUTCOMES FOR INDIVIDUALS AND FAMILIES

### BREAKING DOWN THE FEAR

Ability Linkers and Early Linkers support individuals and families by being 'present', having conversations, providing information about services, attending appointments initially if necessary, or providing assurance that alleviates fear and anxiety. This suggests that the Linker's informal support is a fundamental aspect of ALNSW and ELNSW. It is an essential part of the continuing process of achieving outcomes – enabling individuals and families to empower themselves and pursue their goals independently.

### TAPPING INTO GOODWILL

A key factor that enables people with disability and families to participate in community is a community's openness to inclusion. There are numerous examples from people with disability, Linkers and Linked agencies where community organisations, and services to a lesser extent, have responded very positively to approaches by ALNSW and ELNSW. Tapping into goodwill within the community is proving to be very effective.

### COLLABORATION BETWEEN SERVICE PROVIDERS AND COMMUNITY GROUPS

At the service level, particularly in the disability or early intervention space, collaboration between services is important to facilitate referrals, and ensure all parties are working towards the needs of the individual and family.

## 2.7 BARRIERS TO ACHIEVING POSITIVE INDIVIDUAL AND FAMILY OUTCOMES

### ATTITUDINAL AND SYSTEMIC BARRIERS

A barrier to achieving positive outcomes is resistance or reluctance by some services and community groups to engage with people with disability or their families. For example, Early Linkers talked about difficulties in getting access to some child care centres which argue they lack resources to accommodate children with a disability or have a concern that accepting them will affect the commercial aspects of their businesses. Similarly, ALNSW Linkers reported commonly experiencing resistance from community groups due to their fear or lack of knowledge about people with disability and of how to appropriately support them.

Some agencies in the service system do not understand the ALNSW/ELNSW model, have a different view about disability that is more clinical, and/or are protective of their clientele as they form the basis of their business revenue. Other challenges are experienced by Ability Linkers in assisting people with disability to access employment. Some employers are unwilling to make reasonable adjustments, or say they lack the resources to do so. The tightening of the labour market in areas where there is high unemployment is also challenging.

TAFE is also difficult for some Linkers to effectively link individuals to, for various reasons. There is reportedly a view expressed by some TAFE staff that individuals should not be 'set up to fail'. Linkers report that TAFE can at times be reluctant to enrol people in a course who they think may not be able to participate effectively or complete their training within the expected timeframes.

### LIMITED COMMUNITY SUPPORTS OR FINANCIAL MEANS

A significant challenge encountered by some individuals and families is a lack of services or community supports in their area. This issue is particularly prevalent in regional and remote areas. For ELNSW, some of the services that are lacking in their region include behavioural psychologists, speech therapists, physiotherapists, occupational therapists, psychologists, psychiatrists and paediatricians. There is also reportedly an acute shortage of Aboriginal specialists who have the cultural background to work with Aboriginal families. These shortages result in long waiting lists, which can last up to 18 months.

A lack of Aboriginal-specific services is a further barrier for Aboriginal people with disability who need to navigate mainstream services. Lack of effective engagement with mainstream services in the past can be self-perpetuating with negative experiences leading to long term low self-esteem and scepticism of mainstream services.

A lack of financial means is an additional challenge for some people. Many people do not have the financial means to physically access health services, attend community groups, enrol in training courses, or travel due to the lack of transport or high transport costs.

## INDIVIDUALS AND FAMILIES WITH COMPLEX NEEDS

Another challenge to achieving positive outcomes occurs when individuals and families have complex needs, for example, when more than one family member has a disability, there are behavioural issues, and/or the parent or carer has an intellectual disability. Poverty, lack of financial means to access medical services and homelessness are other factors. The primary presenting needs of these individuals and families tend to be for basic social services rather than broader community participation. Furthermore, Ability Linkers report working with many individuals with mental health issues. The range and complexity of needs of some individuals means that more urgent, presenting issues need to be dealt with first, before social inclusion goals can be addressed.

## BEYOND THE 'LIGHT TOUCH' APPROACH TO SUPPORT

A challenge to achieve outcomes for some individuals and families is the need for an approach to providing support that extends beyond the 'light touch' of the program. There are a number of individuals and families with multiple or complex needs that can find it a challenge to progress with goals and interests where a 'light touch' to personal development and service engagement is insufficient. Some Linkers feel that they have to engage in some level of case coordination or to address the complex needs within a family before social inclusion aspects can be undertaken.

Furthermore, individuals or children may have a form of disability that has not been diagnosed which means they are not eligible for disability support or diagnosis services or other funding. The Linker may need to spend more time to investigate potential sources of support for these individuals and families.

## 3 Outcomes for organisations and communities

### 3.1 INTRODUCTION

A key aim of ALNSW and ELNSW is to influence community attitudes towards people with disability. This chapter reports on the outcomes that are being generated by ALNSW and ELNSW at the organisational and community level.

ALNSW and ELNSW aim to achieve a number of community outcomes. The longer term community outcomes are to undertake activities that will lead to local services and communities becoming advocates for change in relation to the engagement of and support for people with disability.

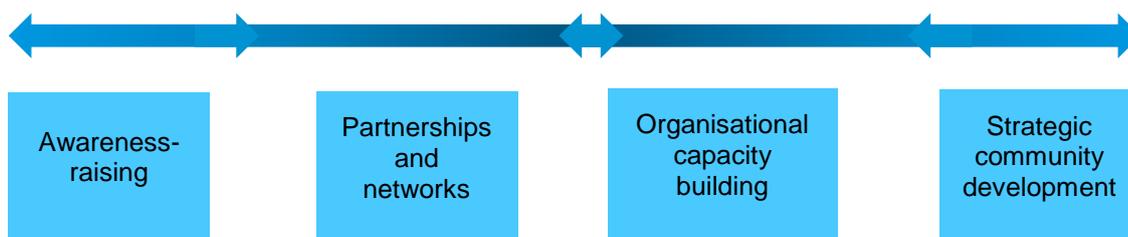
In the short to medium term, ALNSW and ELNSW aim to encourage Linked agencies to rethink their response to disability, and to be more inclusive of people with disability.

Community engagement is thus a key component of the ALNSW program. Not only do Linkers work with individuals to help them identify and achieve their individual goals, they also work with local communities to help them become more welcoming and inclusive of people with disability. Part of the community engagement activity is linking people with disability to Linked agencies, such as community groups, sporting associations and services to help them meet their needs and goals. The linking process also involves linking agencies together to provide support for people with disability as well as initiating community development projects. There is a continuum of community-related activities which includes:

- initial community engagement and awareness-raising of ALNSW and ELNSW including how to access it
- the development of relationships and partnerships with Linked agencies to improve access for people with disability
- working with Linked agencies to build their capacity to be more inclusive of people with disability
- strategic community development activities with a broader aim and impact.

This is illustrated in Figure 4 below.

FIGURE 4 – COMMUNITY ENGAGEMENT CONTINUUM



The level and type of community engagement undertaken by providers varies. In the first year, most ALNSW providers were focussed on community awareness-raising and promotional activities. Many have now gone further and begun establishing partnerships with other services and community organisations, while a few have commenced community development projects.

The extent to which ALNSW providers have progressed along the continuum of community engagement towards strategic community development is dependent on a number of factors, including:

- the length of time they have been operating
- the geographical area they cover – for example, how large it is and how remote

- the number of existing partnerships/community connections of the auspicing organisation or partnership
- the skills, knowledge and connections of the Linkers
- provider leadership and strategic capacity.

## 3.2 RAISING AWARENESS

### ORGANISATION LEVEL

Linkers are working to assist the service sector to change their attitudes and rethink the pathways to inclusion. This is being achieved primarily by raising awareness of disability inclusion and highlighting practical ways that Linked agencies can be more welcoming to people with disability.

A number of Linkers describe the approach to rethinking pathways to inclusion as aiming for the *lightbulb moment*, being the point at which Linked agencies reach an understanding of the power of inclusion. This is particularly true for Linked agencies that believe they already have inclusive practices in place but have a relatively limited understanding of inclusion and may be unaware that some of their practices are, in fact, exclusionary.

*If you talk to a lot of organisations they'll say 'Yes I'm inclusive' but nobody, like a person with a disability walks through their door, and they don't understand why. It's those conversations that we have with that organisation to say have you thought of this, or you only need to do that. A really soft entry actually does make the difference. It puts the lightbulb on I suppose, for some shopkeepers or whoever it might be.(Management)*

Linkers emphasise practical and achievable approaches to incremental community change and describe how successful approaches to attitude change often involves a small action that can, over time, have a large impact on accessibility and inclusion in the broader community. The following example is from a Linker.

*A participant wanted to do an online course about parenting, and noticed that there was no captioning on the website. The Linker who happens to have a hearing impairment got in touch with the organisation and said have you ever thought about captioning your training courses? They had never thought about that and so we worked with them and now all their online training courses have captioning Australia-wide. So to me, they're little tiny things.*

### COMMUNITY LEVEL

Linkers are also working within local communities to raise awareness of ALNSW and ELNSW and to demonstrate the range of supports they can offer to individuals and Linked agencies. While community engagement serves a number of purposes, establishing credibility, networks and respect in the community are the foundations of successful community development activities.

A broader aim of raising awareness through community engagement is to influence community attitudes towards people with disability over the medium and long term. While community change takes time, a number of Linkers spoke of *planting the seeds* in the community by raising the profile of disability inclusion. Linkers are working to change attitudes by encouraging Linked agencies to rethink their perceptions of the capacities of people with disability and to reframe the pathways to inclusion.

Linkers and management commented that raising awareness is an ongoing activity and priority particularly in the absence of a program level communication campaigns to drive awareness of the program and disability inclusion more broadly. Linkers and management also noted that a strong community presence is necessary to build networks with Linked agencies and to generate quality referrals to the program.

During the early stages of implementation, most ALNSW providers spent a considerable amount of effort on community awareness-raising and promotional activities to establish the service and to raise the profile of disability inclusion broadly. Promotion and awareness-raising activity has included:

- attending and participating in a wide range of local community events
- attending community groups
- distributing flyers and posters
- attending expos and information stalls in community centres, shopping centres, sports days etc.
- networking with Linked agencies including mainstream and disability service providers, community groups, sporting clubs, schools, businesses, and Local Councils.

Early Linkers report not having the promotional materials or branding to be able to promote specific support services aimed at the 0 to eight age group. Some providers have developed their own promotional material, including logos and brochures to establish a presence in the community. There is a desire in the sector to better promote Early Links through separate branding or as a core component of ALNSW.

### 3.3 PARTNERSHIPS AND NETWORKS

A key activity aimed at achieving community outcomes has been the development of partnerships with a wide range of Linked agencies.

Establishing and maintaining networks and partnerships with Linked agencies is important for Linkers to emphasise the role and value of ALNSW to the community. This also improves the referral pathways in and out of ALNSW, enables the sharing of knowledge, experiences and skills between organisations, and supports the development of innovative capacity-building initiatives. Partnerships and networks have also assisted some Linkers to position themselves as thought leaders on social and disability inclusion.

The amount of contact and collaboration between ALNSW and Linked agencies varies widely depending on the needs of individuals and the community. It is also dependent on the needs, capability and motivation of a Linked agency to work with ALNSW and ELNSW on broader community initiatives. Some Linked agency relationships may involve relatively straightforward referral pathways, through to intensive and collaborative engagement to address an identified gap in the community.

Linked agencies that ALNSW and ELNSW have created partnerships and networks with include the following:

- community and social services
- education and training providers, including schools and TAFE
- Aboriginal Land Councils
- Aboriginal Medical Services
- employment agencies
- disability services
- child care and playgroup services
- Local Councils
- interagency networks
- local media
- community organisations and groups.

The example below illustrates how an Early Linker has sought to promote inclusivity through an organised network of parents and services. In this instance, the Early Linker incorporated both a family support service (for disability) and a community health service in a playgroup session for families to meet other parents and also receive support services from the two organisations.

*I have a playgroup which is being run right this minute by parents. It's a joint playgroup so the family support program and I have come together to make it inclusive. Before, I was running a playgroup individually and I wasn't getting the numbers and we had parents say 'I'd love to have a group where I could bring my child with a disability and bring my child without a disability where they could play together and learn that'. So we have Area Health on board and they come every week with a different focus, a nutritionist, a health nurse, a dietician, a dental program, and others. Community health come out and they speak with the parents about how the children are walking or how they're going with their crawling or how they're eating, are they able to swallow? All those questions are answered and then they work from there. (Linker)*

Many Linkers are well-embedded in their local communities and are developing opportunities to collaborate with partners on community initiatives. The following are examples of how Linkers are working in partnership with Linked agencies to achieve community outcomes:

- **Advice on Disability Inclusion Action Planning** – Linkers are finding benefits of building strong relationships particularly with Local Councils. They are increasingly being asked to participate in a range of strategic activities such as Disability Inclusion Action Planning and conducting audits of public spaces.
- **Participation in interagency committees and networks** – Linkers are improving referrals, pathways, finding 'hard to reach' people with disability in the community, and facilitating referrals into existing services.
- **A catalyst for community stakeholders to collaborate on projects** – Linkers are working to bring stakeholders together to work on new community projects. For example, one Linker supported a young person with disability to engage with TAFE, a youth centre and a local arts organisation in to start a youth council and organise events that engage the whole community.
- **Developing partnerships that highlight and celebrate the outcomes of individuals and families** – Linkers are working with local media to promote and celebrate the achievements of individuals and families. These partnerships have the potential to improve an individual's social and community connectedness as well as raising disability awareness in the broader community.

### 3.4 COMMUNITY LEVEL OUTCOMES

Based on figures for the first six months of 2016, ALNSW and ELNSW is achieving 2,132 community outcomes annually<sup>4</sup> relating to:

- 806 leadership in social inclusion and education awareness outcomes
- 872 business practice and service improvement outcomes
- 452 outcomes of improved physical and environmental accessibility.

Further details of these outcomes and the percentage breakdown for ALNSW and ELNSW is presented in Table 7.

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<sup>4</sup> Annual estimate is based on six months program data (January to June 2016). 1,260 community outcomes categorised as "other" have been excluded from this analysis.

TABLE 7 – COMMUNITY LEVEL OUTCOMES

	ALNSW	ELNSW	Total
<b>Improved physical and environmental accessibility outcomes</b>			
Improved accessibility of physical access for those with mobility issues	51%	37%	46%
Improved accessibility of sensory environment	30%	37%	32%
Improved signage and other communication methods	19%	27%	22%
<b>Improved physical and environmental accessibility (% of total outcomes)</b>	<b>23%</b>	<b>19%</b>	<b>21%</b>
<b>Business practice / service improvement outcomes</b>			
Changed internal policy documents to build in inclusive practices	6%	7%	6%
Delivered staff training on disability inclusion and awareness	12%	11%	12%
Improved employment/recruitment process	1%	4%	3%
Promotes their organisation as being actively inclusive of people with disability	81%	78%	80%
<b>Business practice / Service improvement (% of total outcomes)</b>	<b>42%</b>	<b>40%</b>	<b>41%</b>
<b>Business / organisation leadership in social inclusion and education and awareness outcomes</b>			
Organised/hosted education or awareness raising activities	50%	45%	48%
Implemented formal partnership arrangements	50%	55%	52%
<b>Business / organisation leadership in social inclusion and education and awareness (% of total outcomes)</b>	<b>36%</b>	<b>41%</b>	<b>38%</b>

Note: Proportional split based on outcomes from January to June 2016. Community outcomes classified as “other” have been excluded from this analysis.

### 3.5 ORGANISATIONAL CAPACITY-BUILDING

Through awareness raising, partnerships and linking, ALNSW is increasingly working with organisations to increase their capacity to be inclusive. Examples include:

- **training in disability awareness** – for services, businesses, and schools
- **developing policy and practice guides to enable organisations to be more inclusive of people with disability**
- **assisting Linked agencies identify and fill gaps in service delivery** – for example, an Early Linker assisted an Early Learning Centre to identify they needed a support worker to assist children with disability. This has resulted in staff receiving additional disability support training which has reportedly had a positive impact on families attending the centre
- **advising businesses and employers on how to be more inclusive** – for example, providing practical advice to businesses on how to employ a person with disability. This includes providing information to employers about people with disability that highlights their capabilities, interests and their goals as well as advice on practical supports to help businesses become more inclusive workplaces
- **assisting community groups to hold accessible events** – Linkers are working with community groups and organisations to educate them about accessibility and supports. Linkers are also supporting arts organisations to develop inclusive audience strategies and to support professional artists
- **conducting accessibility audits of public spaces, businesses and community infrastructure that is being used for accessibility planning** – these initiatives are being used to improve awareness of accessibility and to open the dialogue with Local Councils and other managers of public space about how they can be more inclusive of people with disability (for example, shopping centres, public toilets, swimming pools, theatres, gyms and community centres)
- **educating community groups and sporting clubs about inclusion** – for example, providing education and advice about how sporting clubs can develop all-inclusive activities

- **initiating events with Linked agencies to build the capacity of the community** – for example Linkers are working with Linked agencies to develop carers' forums, workshops and social groups for people with disability
- **providing cultural advice and materials to mainstream service providers to build their capacity to be more welcoming of Aboriginal people with disability.**

The following case study – **Increasing accessibility through capacity-building** – provides one example of how Linkers are working with a sports facility to be more inclusive.

### **Increasing accessibility through capacity-building**

In one regional town, Linkers have been working to build community capacity to support people with disability. In the process of working with the Local Council to develop an outdoor gym, a partnership with the local community gym was developed. The Linker and the manager of the local gym identified an opportunity to use the gym's facilities and to run a pilot program for a group of people with disability supported by ALNSW. The gym manager explains:

*We developed a gym program with a personal trainer to work with a group of six people with disability for one hour a week. It was supported financially by the ALNSW host organisation to cover the fees of a personal trainer, gym membership fees for participants and operational costs for a three month trial.*

Before the project started, a Linker who uses a wheelchair undertook an accessibility assessment of the gym. Following this, staff moved equipment around to improve movement within the gym. They also bought a piece of additional equipment that could be used by people with disability.

The aim of the trial program was to increase participant engagement in the community, reduce their social isolation and increase their confidence to independently engage with a general gym session. After a three month period, half of the project participants had subsequently engaged in general gym sessions.

One gym participant explained how important programs like the gym have been to her life:

*Having things like the gym gives you a routine and it pulls you back in because otherwise you're at home day after day, it's just a shade of grey. All of a sudden, those few days you're looking forward to it. You become a butterfly, you blossom.*

A couple of the participants have made their own arrangements with other gym members who have agreed to support them in participating in a regular gym session. The personal trainer involved in the pilot also decided to offer two free spots to ALNSW participants through her practice.

A challenge for the program is to make it sustainable. Although the program continued beyond the three month trial, the gym has to ensure the program can be financially sustainable in order to benefit more people with disability. A broader goal is for the gym participants to be able to pay for their own gym membership, which would allow for that money to be reinvested in the project for new people who take part.

Key success factors of the partnership have been the collaborative relationship between the Linker and Linked agency, and the Linkers having a strong reputation in the local community. As the gym manager elaborated:

*I've got the Linker's number in my phone. I can ring her and say help! I've got this idea, what do you reckon? And she says, what funding is out there? What can we apply for? We've got a really good working relationship and I know that they've got credibility in the community.*

In the months since conducting the first interview, the all-abilities weekly gym program has continued to run, and the ALNSW provider continues to work with the gym to find longer-term funding sources. Several of the program participants have since purchased annual gym memberships and attend regular gym sessions along with the rest of the community. One of the participants now volunteers several times of the week, helping other community members to exercise effectively and ensuring the gym runs well.

## 3.6 COMMUNITY DEVELOPMENT

As ALNSW has become established, a number of the larger providers have begun to work on activities that aim to achieve change at a systemic level. These system-level activities are typically extensions to the work Linkers are undertaking with Linked agencies at the organisational level, but aim to drive social inclusion outcomes at a broader level to achieve wider impacts. These are referred to as community development projects.

The ability to identify and undertake community development activities is primarily dependent on the needs of the community, strategic leadership, Linker skills and the time and resources available to work on community and system-level outcomes. The significant time, effort and expertise involved in driving system-level outcomes means they are sometimes beyond the scope of some providers. This is particularly the case for ELNSW and smaller ALNSW providers where the needs of individuals and families typically take precedence, as caseloads have grown.

Examples of community development projects that have the potential to generate broader community impacts include the following:

- **Accessible beaches** – Linkers have identified gaps for wheelchair users who want to access beaches. An enquiry on behalf of a person who uses a wheelchair and who wanted to access the beach found that all beaches in the area had all-terrain wheelchairs available for use, but public awareness of the equipment was low and lifeguards were not trained in how to use them. Linkers raised this issue with relevant authorities, and as a result, a training package is being developed for the Australian Lifeguard Services NSW which will be available to all lifeguards across the country.
- **Local accessibility map and business audit tool** – one provider has developed an accessibility map for the local city precinct with funding from Surf Lifesaving NSW. Linkers also undertook an access assessment of local businesses and developed a hard copy map for distribution. This has been well-received, with businesses now approaching the provider to have their business included on the map. A business audit tool in app format is being considered for development.
- **Local accessibility training** – one provider is working to support the Macarthur Access Group for Inclusive Communities which promotes accessible businesses in the local area through a website and app. Linkers have developed a training package including a PowerPoint presentation and fact sheets for businesses on a range of topics, including pathways to employ people with disability and information about how to be an inclusive employer and business.
- **Hearing loops** – a Linker with a hearing impairment advocated for a hearing loop to be installed at the local regional airport so that members of the public with a hearing impairment would be able to hear flight announcements. This has led to an invitation to the Linker to speak to managers of all regional airports across NSW and the potential to install hearing loops in all regional airports.
- **Accessible wheelchairs in National Parks** – in the process of linking a person who uses a wheelchair who wanted to get back into bushwalking, Linkers discovered that all National Parks have an all-terrain wheelchair that are often not used as few people are aware of their existence and staff did not know how to use them. This person is now working with National Parks and Wildlife NSW to help them test out the wheelchair in various settings and to install signage to increase public knowledge about their availability.
- **Liberty swings** – ALNSW is working to install a liberty swing at a zoo in Western NSW. In the process, they have identified an unused swing in another city and are investigating the opportunity to install another one in a different town. The next steps are to identify other liberty swings and opportunities, with a plan to develop an accessibility map for the public.
- **Improving the accessibility of Opal card readers** – a person with a vision impairment raised an accessibility issue with a Linker regarding the Opal card system at his local train station. A lack of tactile indicators has resulted in the person being unable to tap off on occasions, and being over-charged when he could not find the reader. It was subsequently discovered there are no tactile indicators on Opal readers at any train station in the region. The Linker arranged meetings with Transport NSW to discuss the issue and to assist them to find a solution.

### 3.7 LINKED AGENCY EXPERIENCES

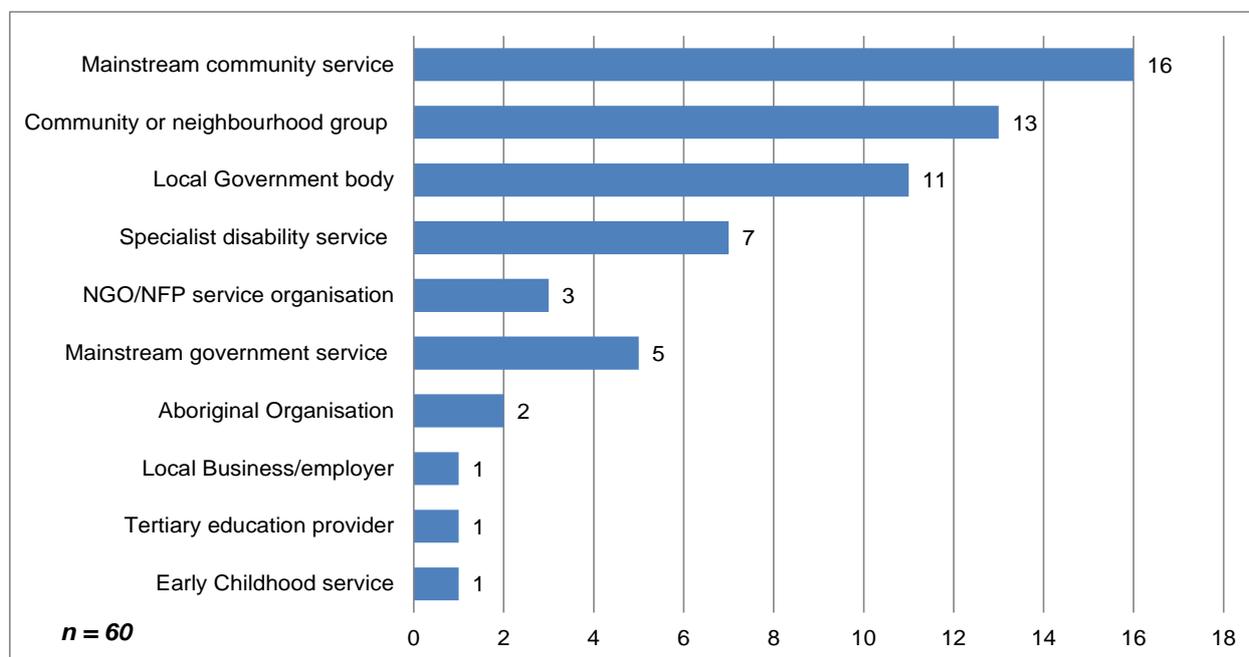
A total of 86 in-depth interviews were undertaken with Linked agencies that had contact with ALNSW and ELNSW. In addition, a further 60 ALNSW Linked agencies responded to an online survey. ALNSW providers were requested to provide a list of Linked agencies they had contact with to Urbis who then selected some of these to participate in telephone interview. Urbis distributed the online survey to all Linked agencies with email addresses.

A broad cross section of Linked agencies responded to the survey and the data has been triangulated with the in-depth interview data. The relatively small sample, however, may not be representative of the total population of Linked agencies.

#### 3.7.1 TYPE AND NATURE OF CONTACT WITH LINKED AGENCIES

Consultations and survey data identified a range of relationships between ALNSW and ELNSW and Linked agencies. Strong relationships with Linked agencies are a key component of a functioning and successful ALNSW program, and are strongly related to the Linker’s ability to create rapport, credibility and trusting relationships with community stakeholders. The profile of the 60 Linked agencies that responded to the online survey is detailed at Figure 5. (NB only ALNSW Linked agencies were surveyed).

FIGURE 5 – LINKED AGENCY PROFILE (ALNSW ONLY)



Mainstream community services, community or neighbourhood groups and Local Government bodies were the three main types of Linked agencies that responded to the survey. Only a small number of responses were received from local businesses/employees or tertiary education providers.

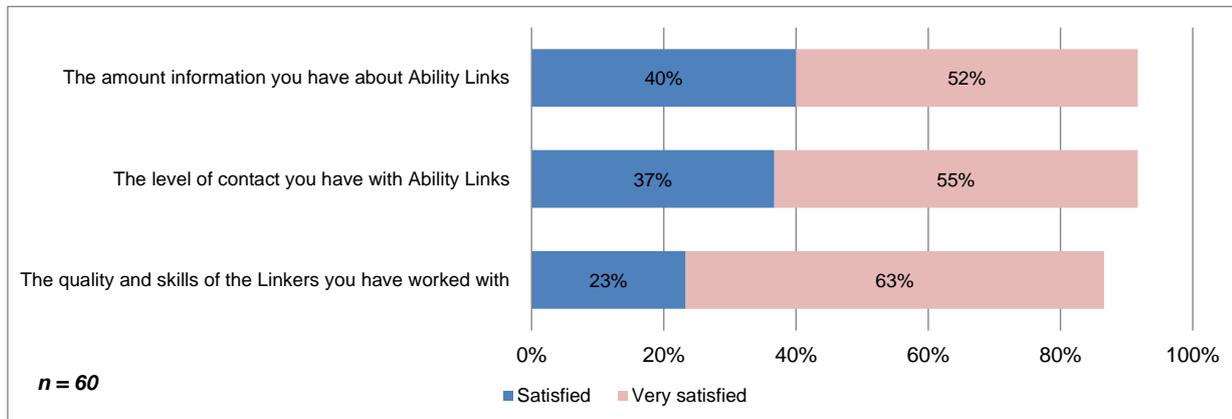
The majority of Linked agencies (69%) had been in contact with ALNSW for more than 12 months, and most had referred people to ALNSW (86%) and two-thirds had received referrals from ALNSW. Linked agencies had also worked with ALNSW through interagency committees and networking events. They had also collaborated in organising events, expos, info stalls, presentations, workshops and information sessions, as well as providing complementary services to support individuals.

In line with the specific needs of families engaged with ELNSW, Linked agencies that predominantly work with Early Linkers are much more likely to have a health, family and early childhood focus (such as health professionals, allied health workers, early diagnosis and intensive family support services), and providers of early childhood learning and social supports such as playgroups and schools.

### 3.7.2 LINKED AGENCY SATISFACTION WITH ALNSW

The great majority of Linked agencies surveyed were satisfied with the *amount of information they have about ALNSW* (92% net satisfaction), the level of *contact with Linkers* (92% net satisfaction) and the *quality and skills of Linkers they have worked with* (87% net satisfaction) (see Figure 6). The great majority 88% of Linked agencies also indicated that they were *planning to work with ALNSW in the future* and more than 90% were likely to *recommend ALNSW to other organisations*.

FIGURE 6 – LINKED AGENCY SATISFACTION WITH ALNSW

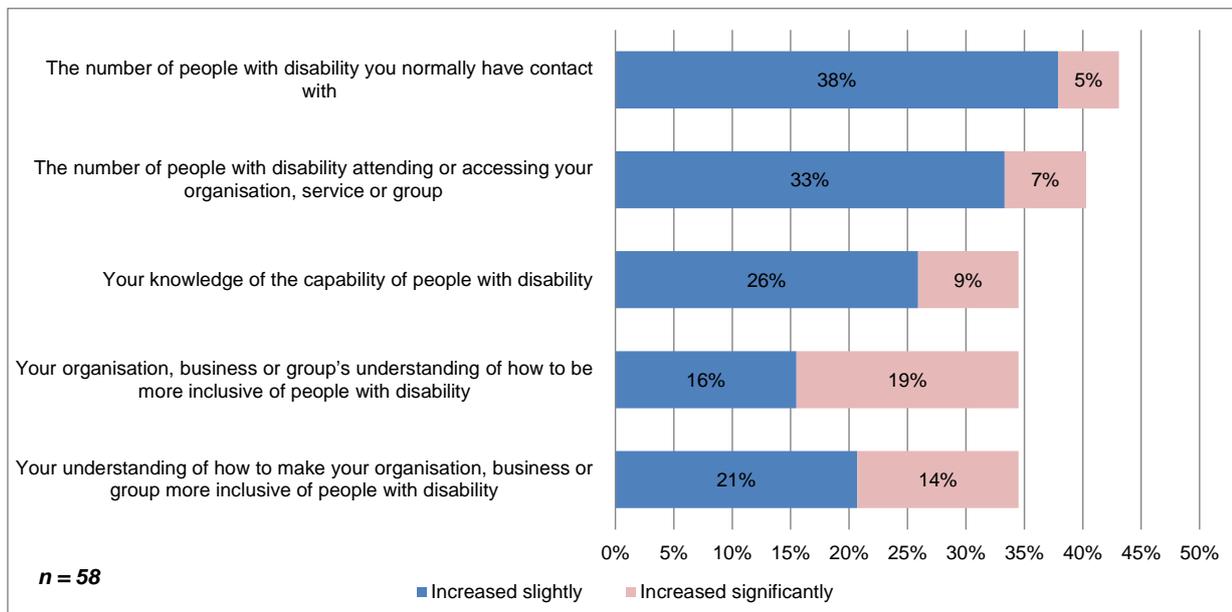


The positive survey responses were supported by the 86 in-depth interviews. Linked agencies are generally of the view that ALNSW is having a positive impact in the community. However, some identified factors that might weaken their relationships with ALNSW or ELNSW including that the strength of the relationship may be based on an individual, rather than on the organisation, and that there is some lack of clarity regarding the Linker role.

### 3.7.3 LINKED AGENCY OUTCOMES

Linked agencies were also surveyed to gauge the impact of ALNSW on their organisation (see Figure 7).

FIGURE 7 – AS A RESULT OF YOUR ORGANISATION'S CONTACT WITH ALNSW, TO WHAT EXTENT HAVE THE FOLLOWING INCREASED?



Linked agencies surveyed reported that ALNSW is having a tangible impact on their organisation:

- 43% of Linked agencies reported that *the number of people with disability they have contact with* has increased slightly or significantly
- 40% of Linked agencies reported that *the number of people with disability attending or accessing their organisation, service or group* has increased
- 35% of Linked agencies reported that *their organisation’s understanding of how to be more inclusive of people with disability* has increased.

Furthermore, 35% of Linked agencies reported that contact with ALNSW had *increased their knowledge of the capability of people with disability, and their understanding of how to make their organisation more inclusive of people with disability.*

Across the five indicators, approximately half (between 45% to 60%) of respondents indicated that there had been *no change to their organisation*. Many Linked agencies are already working in the disability and community services sector, where disability awareness and support is already high. This finding may also be an indication that organisational change is a long-term process and that many organisations may only be at the beginning of that journey.

The case study on the following page – **Mutual benefits and discoveries: an employer’s experience** – provides an example of a Linked agency (a business), where the manager and employees now have a better appreciation of the capabilities of people with disability and of the benefits that can flow to their business from being more inclusive.

The online survey of the Linked agencies also found that 45% of respondents reported that their organisation is *developing a culture of inclusiveness and respect for people with disability* as a result of contact with ALNSW (see Table 8). This highlights the impact Linkers are having in assisting agencies to rethink their attitudes/organisational approaches to supporting people with disability.

One in four Linked agencies reported they had *taken active steps to be more physically accessible, or changed practices and processes to be more inclusive of people with disability*. This is consistent with feedback from interviews. Linked agencies and Linkers perceived change at the practice and processes level. Community outcomes are a continual process of working towards a long term change which takes time.

In consultations, Linked agencies further commented that contact with ALNSW has given them confidence to provide more effective support to the people with disability and strategies to better connect with their local community.

TABLE 8 – LINKED AGENCY VIEWS ON ORGANISATIONAL IMPACTS

HAS YOUR ORGANISATION OR GROUP WORKED WITH ALNSW IN THE FOLLOWING WAYS?	YES	NO	NO, BUT CONSIDERING	NOT SURE
Developing a culture of inclusiveness and respect for people with disability	45%	39%	2%	14%
Taken active steps to be more physically accessible for people with disability	25%	40%	19%	16%
Changed or developed policies, procedures or practices to be inclusive of people with disability	25%	46%	14%	14%

## Mutual benefits and discoveries: an employer's experience

A regional manager of an IT support company invited a Linker to speak to a networking group of about 30 local business people that meets monthly. In her presentation, the Linker gave an introduction to ALNSW, what Linkers are trying to achieve and how businesses could work together to provide opportunities for people with disability. One of the most memorable parts of the presentation was a story the Linker told about a successful work placement at a local bookstore, where both the bookstore and the person with disability got a lot of benefit out of the placement.

The manager who had invited the Linker to speak decided to provide a volunteer work-placement opportunity for a young person with disability for two hours a week after school. The manager describes his initial thoughts:

*His name is Jake\* and going into this, we thought we were going to need a fair bit of help. But we found that the guy's biggest challenge was his social skills. He was quite able in every other way. It was a real eye opener for me. All the stuff that we take for granted that these guys don't have because they don't have a place in the community. They're often hidden away.*

*Regardless of how much work they get through while they're here, they have a place here. In the case of Jake, his biggest thing is he wants to get a real job. So everything we do is about trying to help him progress and if one day he leaves us and goes and gets a real job, that's cool because we've helped him on his way.*

This experience has helped the manager and his team think differently about the capabilities and capacity of people with disability. Staff expressed surprise that Jake had more capability than many of the high school work experience students they had had in the past. As the manager commented:

*It's kind of ironic that the guy who's been singled out by the system as needing additional help is more capable than these other guys. School wasn't for me, and I don't think school is for Jake necessarily. The way you get measured at school, he's not going to look great academically, but it doesn't mean you can't be great, have a great future.*

The manager also commented that he had seen a change in Jake's family's perception of their son. Jake's mother had thought that he wouldn't have many opportunities to work, but as a result of the work placement, she can see that he is capable of getting a job.

A key to the success of the Linker and Linked agency relationship has been the way that the Linker supported Jake in line with his needs, interests and abilities. Jake loves computers and found a lot of the staff at the IT support company had similar interests. He got along well with the staff, and the business was keen to provide him with work experience that would help him reach his ultimate goal of a full-time job.

Another success factor is the way that the Linker demonstrated the benefits for the business in taking Jake on, in a language that they understand. As the manager explained:

*The Linker – she's passionate and it's not like rubbish with her. It's really direct. This is how it works. This is the benefit. There's a productivity benefit for us there as our trained technicians don't have time to do the stuff that Jake does.*

In the months since conducting the first interview, the manager reports that he is now looking for a new ALNSW participant to fill Jake's position. Jake has moved on to a paid after-school job at a local supermarket, and is one step closer to his goal of full-time employment once he finishes school.

\* Name has been changed

## 3.8 CRITICAL SUCCESS FACTORS

Consultations identified a number of critical success factors for achieving positive community outcomes. At the heart of successful community outcomes is the Linker, and success in delivering community outcomes is related to their individual knowledge, attributes, skills and experience in community development. Achieving positive community outcomes also requires support and strong leadership from the management team.

### 3.8.1 PROVIDING A SOFT PATHWAY TO INCLUSIVE PRACTICES

Community outcomes are being achieved by Linkers where they are able to **provide a soft entry to social inclusion**. When Linkers can understand the challenges of the Linked agency in becoming inclusive and can think creatively about how inclusion can be incrementally achieved, they are more likely to have success in achieving community outcomes. A number of Linkers referred to practicing **soft advocacy** when engaging with Linked agencies. Soft advocacy involves being an advocate for social inclusion through finding common ground and highlighting existing inclusive practices or procedures.

*Linkers are now going into businesses and having conversations about accessibility, but not coming in as an expert knocking down the doors saying you're doing it wrong. One of the Linkers tells the story about having a conversation one day with a café owner and saying 'It's great you've got pictures on your menu'. The Linker realised the café had never thought of it like that, which led to further conversations about accessibility. Since then, the café has installed a ramp and all these other things because of this continual engagement and the relationship. (Management)*

Some Linkers described the soft entry approach as **planting the seed** of inclusion to engage Linked agencies.

*You've just got to ask a small question and plant that seed because if you try and advocate too strongly or too quickly, you can get people off side and that can be just as damaging. It's a double edged sword, and it's a very fine balancing act for Linkers to find that balance.*

Linkers are also finding success in adopting the soft advocacy approach by *pitching change as broader community inclusion rather than just an issue of disability access.*

*Understanding what we do actually benefits everybody. For example, we worked with the Council to get a grant to put automatic doors into all areas of the pool. My reasoning was coming from not only a disability point of view, but also as a parent with a pram and children and aged people as it benefits everybody. It's not just a disability program, it's more an inclusion program.*

Another successful approach for driving community outcomes has been the confidence and traction Linkers have gained by demonstrating the tangible benefits and using successes to open new doors.

*We decided to highlight to Council how captions on the outdoor movies weren't being shown and that automatically excludes a lot of people within the community. It was a bit of a light bulb moment for them. Suddenly they saw something tangible about Ability Links. That we had come up with something that we could actually do for them. They then asked if I could link them to somebody with hearing impairment because they wanted to talk to them and see how they could make future events more accessible.*

### 3.8.2 IDENTIFYING A STRATEGIC ALIGNMENT BETWEEN LINKED AGENCY AND ALNSW

Another success factor is having a **clear strategic alignment and mutual understanding** between Linkers and a Linked agency. Linked agency partnerships with ALNSW appear to be stronger where there is an understanding of the value of social inclusion to their organisation and partners can clearly see ALNSW and ELNSW as important.

A strong partnership is more likely where ALNSW and Linked agencies find mutual benefits in the relationship, which can be leveraged for greater community outcomes. This success factor is also dependent on management and staff having a clear and effective approach to communicating the benefits of a partnership, and where added value is clearly articulated in a language that Linked agencies understand. It is therefore extremely important to be able to 'speak the language' of business, the arts sector or the mental health sector etc. to ensure that they understand how and where the meaningful points of collaboration exist.

### 3.8.3 BUILDING ON EXISTING INITIATIVES IN THE COMMUNITY

Linkers have more success with achieving community outcomes when they are **able to tap into existing momentum and networks** within a community rather than establish initiatives from scratch. By encouraging collaboration and being supportive of available resources in the community, community outcomes are more likely and sustainable. Linkers with strong links to, and knowledge of, their community often have more success in achieving community outcomes, particularly in smaller rural communities.

*I honestly believe you have to have people that live in that area to work in that area. Simply because there's so many dynamics and so many different issues in those towns relating to drought and suicide etc. You come in and you don't understand a lot of it, so you're on the back foot to start with. It's taking me ages to get to that community because they're so close and so guarded. I think, having people working in their local communities, I think is vital in that sort of area. (Linker)*

## 3.9 CHALLENGES AND BARRIERS TO COMMUNITY OUTCOMES

### 3.9.1 UNDERSTANDING COMMUNITY ENGAGEMENT WITHIN THE LINKER ROLE

A key challenge identified by many managers and Linkers is the view that not all Linkers have the competency or the motivation to engage in broader community development activities. There is a perception that community development work requires specific skills and attributes that differ from the skills of a Linker who works with individuals. There is the perception that some Linkers are more suited to community development work than others, which can impact on their ability to achieve outcomes.

Despite most Linkers receiving some training in community engagement and community development, there appears to be a lack of common understanding about the range of community activities, what a successful outcome looks like and what a Linker's responsibility is to achieve outcomes at a community and system level.

A number of Linkers commented that some of their colleagues feel overwhelmed by the larger community development projects. Moreover, some are anxious these would be pursued, at the expense of smaller incremental steps that can make a difference and have an impact.

*I was concerned early on that Ability Links was trying to achieve those big goals and getting those done and not taking into consideration the knock on effect of achieving some of the smaller goals. It's amazing the small things can be. It's not necessarily about the big ones. (Linker)*

*We've worked with a local swimming pool to make sure that a person with disability and a guide dog is able to have access, which was not allowed before. The community awareness and that education is having that ripple effect and I think Linkers are being put off by, or probably scared because when they see examples of community development, they see this big thing that has happened. They think I can't achieve that. But really big change can come from small things. They've been doing that, but they're not identifying it as community development. (Linker)*

Most providers appear to be balancing the responsibility for community work across the team by allowing those that have skills and expertise in community development to reduce their participant load. There are still uncertainties around the intensity of the role of a Linker in community development, which comes at the expense of time with individuals. For example, an ALNSW manager commented that a Linker should instigate and support the development of activities, but not be the 'event manager'.

### 3.9.2 RISK AVERSE COMMUNITIES

Linkers also find it a challenge to achieve community outcomes without the support of the community. As ALNSW has become better known in the community services sector, the resistance to collaboration from some organisations has decreased, as has the perception of ALNSW as a threat to other services. However, many organisations are risk averse. They may have tried something inclusive once in the past and failed and they are reluctant to try again. As one Linker explained:

*Some are just worried whether they can cater to the person's disability. They're also worried about insurance and things. With the volunteering, they're often worried about insurance. The lack of understanding at times about people with disability is absolutely ludicrous. But it is simply a lack of understanding and education in the community.*

### 3.9.3 BALANCING RESOURCES

Balancing Linker resources between working with individuals and families and working towards broader community outcomes is another challenge for the program. It takes time to cultivate, build and maintain strong relationships and partnerships. As caseloads grow, and more demands are placed upon Linkers to work with individuals, finding that balance between this work and relationship building and community development work can be challenging.

*One of our biggest jobs is getting out and meeting the community and getting into organisations and spreading the word around. If you don't go there after a certain time, then they're going to forget about you. (Linker)*

*A lot of community groups, if you don't break it down, and keep going back to break it down, they're very cliquy. (Linker)*

The challenge of maintaining partnerships is considered to be more difficult due to a perceived lack of promotion and marketing support at program level.

## 4 Program implementation and alignment

This chapter provides an organisational profile of ALNSW and ELNSW providers and discusses various implementation issues, including the recent alignment of the two programs.

### 4.1 ORGANISATIONAL PROFILE AND MANAGEMENT STRUCTURES OF PROVIDERS

Program providers fall into three categories:

- providers that support **people with disability aged 9 to 64 years** and their families (ALNSW only)
- providers that support **people with disability aged 0 to 64 years** and their families (ALNSW and ELNSW)
- providers that support families with **children with disability aged 0 to 8 years** (ELNSW only).

Within the three structures, there are both generalist organisations and Aboriginal community controlled organisations with Aboriginal-identified Linker positions. The funded organisations include a mixture of very large and very small, locally-based providers (see Appendix B for a list of all providers and Linker positions).

All providers are funded on a per Linker basis. The 2015/16 funding per Linker was \$122,994, of which \$5,749 was for brokerage funding.

There are four large ALNSW generalist providers that employ between 35 and 67 Linkers. With one exception, the local ALNSW Aboriginal providers are relatively small, and typically employ three or four staff.

Most ALNSW generalist providers have the following program management structure:

- a Program Manager
- an Operations Manager or Intake Officer
- three to four Area Coordinators or Team Leaders
- Linkers working within a local team.

The smaller ALNSW Aboriginal providers typically operate with a part-time manager, a small number of Linkers (often two or three) and, in some cases, a Team Leader. Over time, some Aboriginal providers have appointed a Senior Linker to a Team Leader role. This has improved management and supervision and enabled the provider to focus on strategic objectives.

Providers that deliver ELNSW only have relatively small teams compared with ALNSW providers due to the smaller number of funded Early Linker positions. However, in most cases, the host organisation delivering ELNSW offers a range of complementary family, child support and disability-specific services within the same location. A number of Aboriginal ELNSW providers operate out of, or in partnership with, Aboriginal Child and Family Centres (ACFCs) which provide a range of culturally appropriate services to families in the local area.

All providers that receive both ALNSW and ELNSW funding to support the full 0 to 64 age range are in the early stages of integrating Ability Linkers and Early Linkers within one team, and moving to a single line of reporting and supervision.

## 4.2 PARTNERSHIPS

### 4.2.1 FORMAL PARTNERSHIPS

Three of the four generalist providers operate in a formal partnership as does one of the Aboriginal providers. Two of the generalist partnerships involve a partnership between a mainstream and a culturally and linguistically diverse (CALD) service.

There are three types of formal partnership delivery models across the state:

- partners in the consortium **take responsibility for delivering services in different areas within the funded region**
- partners in the consortium **jointly provide services in all areas within the funded region**
- partners in the consortium **jointly manage services to the funded region.**

The partnership structure has also been designed to ensure that the service response is appropriate to the needs of a range of people with disability with higher access needs such as CALD and Aboriginal communities.

The formal partnership arrangements are still a work in progress, but there are signs of improvement compared with last year. Program managers within partnerships identified a number of benefits and challenges to partnership arrangements, most of which are consistent with what was reported in the 2015 Interim Evaluation Report (see Table 9).

TABLE 9 – BENEFITS AND CHALLENGES OF FORMAL PARTNERSHIPS

BENEFITS	CHALLENGES
Access to a broader knowledge base to share practice learnings and experiences	Different approaches to staffing, supervision and organisational structures
Access to a broader diversity of experience and knowledge	Different understandings and expectations of the program
Access to resources and specific skill sets, e.g. in-language CALD linking support	Culture of competitiveness between partner organisations can affect collaboration and knowledge sharing
Collaboration on policies and processes	Inconsistent practices can create tensions between partners and confusion for people and the broader community
	Inconsistent approaches to community engagement, communications and branding

Program managers reported one of the key strengths of partnerships and alliances was the ability to draw upon a diversity of experiences and skills to develop best practice approaches to program delivery. Effective partnerships hold regular meetings to discuss strategy and practice and benefit from the experiences of Linkers operating in different contexts. Program managers have also found that a culture of openness and knowledge sharing also provides an additional source of support and the opportunity to discuss implementation issues.

There are a number of common organisational factors associated with the more successful partnerships:

- strong leadership and coordination of consortium members
- culture of openness, collaboration, sharing and respect
- collegial atmosphere free of competition between partners
- agreement on the alignment in organisational priorities
- shared vision and focus for practice development
- consistent approaches to branding and promotional activities
- strategic meetings at management level and practice meetings for Linkers.

The 2015 Interim Evaluation Report identified some partnerships that were experiencing challenges in working effectively together. A year later, these partnerships are reported to be improving and it is apparent that a substantial amount of work has been undertaken at all levels of the organisations to effectively work together. This work has included:

- ensuring Linkers from partnership agencies engage with community as a unified team, and collaborate in the development of unified promotional materials including brochures, banners and T-shirts
- regular meetings at the program manager and coordinator level to discuss vision, strategy and operational issues
- regular meetings of Linkers to discuss local issues, share calendars for events and identify opportunities to collaborate
- encouraging Linker to Linker relationships to improve the consistency of on-the-ground service delivery.

Despite an improvement in partnership operations, providers agree that maintaining a partnership requires ongoing effort. Resources dedicated to partnership maintenance have sometimes had a negative impact on the resources available for strategic planning at the provider level. The challenges of maintaining a workable partnership have also placed additional demands upon Linkers who have sometimes needed to negotiate operational challenges between organisations on-the-ground. Linkers also have to navigate differing organisational expectations regarding the resources to be dedicated to community development work.

There are a number of reported advantages and disadvantages of different partnership models. Partners that have distinct geographic areas to service commented there was a level of autonomy and a reduction in operational bureaucracy. However management noted that this model can have a negative impact on collaboration and resources across the funded region. The relative advantages and disadvantages of partnership implementation models are set out in Table 10.

TABLE 10 – ADVANTAGES AND DISADVANTAGES OF PARTNERSHIP MODELS

PARTNERSHIP IMPLEMENTATION MODEL	ADVANTAGES	DISADVANTAGES
Partners providing ALNSW to separate areas within the region	<ul style="list-style-type: none"> <li>▪ Clear understanding of geographic boundaries to service delivery</li> <li>▪ Ability to learn from the experiences of partner organisations operating in different regions</li> <li>▪ Ability to access the diversity of skills and knowledge within the partnership to collaborate on processes, policies and staff training.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Geographic distance can restrict ability to undertake face-to-face meetings and create a greater reliance on technology</li> <li>▪ Less ability for team work and collaboration at the Linker level.</li> </ul>
Partners jointly providing ALNSW within the same region	<ul style="list-style-type: none"> <li>▪ Improved choice for people as to which provider they would like to be supported by</li> <li>▪ More capacity to meet the needs and preferences of people such as in-language linking for CALD people with disability</li> <li>▪ Resource advantage to target specific communities or populations</li> <li>▪ More opportunity for cross-referrals between Linkers.</li> </ul>	<ul style="list-style-type: none"> <li>▪ A higher need for consistency across service delivery</li> <li>▪ Can cause confusion for the community if there are inconsistencies in community engagement activities</li> <li>▪ Increased pressure and strain on managerial systems at the provider level to deal with operational challenges between Linker teams, e.g. differing expectations of staff hours and working on weekends.</li> </ul>
Partners with segmented Linker teams servicing the region	<ul style="list-style-type: none"> <li>▪ Clear understanding of service responsibilities</li> <li>▪ Streamlined Linker to Linker activities and relationships, clear reporting lines for staff.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Less opportunity for cross-referrals in locations with only one Linker team</li> <li>▪ Less ability to leverage partner resources for targeted on-the-ground activity or to meet needs of individuals not aligned with partner resources</li> <li>▪ Challenge to communicate where the organisation provides ALNSW support, particularly where awareness of a partner organisation extends beyond the allocated regions.</li> </ul>

#### 4.2.2 GENERALIST AND ABORIGINAL PROVIDER PARTNERSHIPS

Generalist and Aboriginal Linkers operate in overlapping regions and are working together to support people with disability in the community. There is only one formal partnership between generalist and Aboriginal Linkers; most involve informal partnerships and connections between providers and Linkers operating in the same region.

Overall, generalist and Aboriginal providers are working well together, and there is evidence of collaborative approaches, knowledge-sharing and joint capacity-building initiatives. While the level of collaboration between generalist and Aboriginal providers is positive overall, there are some regions where there is limited contact between providers.

Some examples of the ways that generalist and Aboriginal providers are working together include:

- cross-referrals between generalist and Aboriginal Linkers i.e. generalist providers offering Aboriginal individuals and families the choice to work with an Aboriginal Linker, and vice versa
- regular meetings of Linkers and management to reflect on practice, share ideas and ensure consistency in service delivery to minimise confusion in the community
- providers working together to enhance the support and linkages provided to Aboriginal people with disability, their families and carers, e.g. generalist Linkers working to assist an Aboriginal Linker secure brokerage funding for an Aboriginal person with disability; generalist and Aboriginal Linkers sharing caseloads in some instances
- Linkers sharing event calendars and inviting other providers in the area to jointly participate in community events and engagement activities
- Aboriginal Linkers providing advice to generalist Linkers regarding culturally appropriate and culturally sensitive practice when engaging with Aboriginal communities and people with disability
- generalist Linkers providing administrative assistance or professional development opportunities to smaller Aboriginal providers where appropriate
- joint participation in program-wide activities such as the Linker gatherings and provider forums.

One partnership involving Aboriginal and generalist providers is reported to have a very positive and strong working relationship. Key factors supporting the success of this relationship include strong leadership, mutual trust and respect, a culture of openness, and a willingness to collaborate.

Despite the high level of collaboration between many generalist and Aboriginal providers, several areas for improvement were identified particularly in areas where there is limited contact between generalist and Aboriginal providers.

- In some areas, Linkers have identified **inconsistencies in the service approach** between generalist and Aboriginal Linkers working in the same region. Linkers noted that this can cause confusion in the community and create tension between Linkers. For example, providers in one region have adopted a different approach to the use of brokerage funds and the level of support they will provide an individual or family.
- In other areas, Aboriginal Linkers suggested that **more work is required to ensure that generalist Linkers provide culturally sensitive and appropriate support to Aboriginal families**. The lack of cultural competence is reported to be a source of tension between Aboriginal and generalist Linkers in some regions.
- Aboriginal Linkers commented on the need to continue to **improve referral processes** between providers. In some cases, referrals are reportedly being made to the Aboriginal provider because the individual or family is Aboriginal, rather than because they specifically sought an Aboriginal Linker.
- Most Aboriginal providers have very small Linker teams who cover large geographic areas. They may be located in regions some distance from generalist providers. The **time taken to travel and limited resourcing can restrict the ability of Aboriginal Linkers to collaborate** with, and participate in, meetings and activities with generalist Linkers in their region.
- In some instances, there is **little or no communication between generalist and Aboriginal providers**, although attempts have been made. It is uncertain why this is the case and what underlies the limited communication.

## 4.3 PROGRAM ALIGNMENT

### 4.3.1 STRUCTURAL CONTEXT

The alignment of ALNSW and ELNSW is still a work in progress given the short-timeframe that some of the services have been operating ELNSW, and the fact that the alignment has only really been a strong focus over the last year or so. However, there are clear differences across organisations regarding the extent to which ALNSW and ELNSW Linkers are communicating, engaging and working together.

The structure of funding allocated to provide Linker positions in generalist community organisations, Aboriginal community controlled organisations and specialist child and family service organisations has resulted in at least six variations in service-delivery settings.

ABILITY LINKS AND ELNSW 0 TO 64 YEARS	ELNSW ONLY 0 TO 8 YEARS	ALNSW ONLY 9 TO 64 YEARS
Generalist	Generalist	Generalist
Aboriginal	Aboriginal	Aboriginal

The different types of service delivery settings have implications for the degree of alignment between ALNSW and ELNSW.

#### **Generalist ALNSW and ELNSW 0 to 64 years**

There are two generalist providers funded to provide both ALNSW and ELNSW. These providers have had funding for ELNSW since the alignment of the programs in September 2013, and until recently delivered ALNSW and ELNSW as two teams with separate lines of reporting. In the last six months, both providers have restructured their ALNSW and ELNSW teams and reporting lines to become one integrated team of Linkers supporting people with disability 0 to 64 years. Overall, where ALNSW and ELNSW are delivered by the one generalist provider, there appears to be a greater level of understanding of the vision of a 0 to 64 Linker role in the generalist context and a greater level of collaboration between Ability Linkers and Early Linkers.

#### **Aboriginal ALNSW and Aboriginal ELNSW 0 to 64 years**

There are seven Aboriginal providers that deliver both ALNSW and ELNSW support to the 0 to 64 age range. Two of these providers have had funding for Ability Linkers and Early Linkers since program alignment in 2013, and five received funding for Early Linkers in 2015/16. The 0 to 64 approach to linking is seen as being a relevant and culturally appropriate model for working with Aboriginal communities. It also is where the vision for Linkers working across the whole community is finding most success. While Aboriginal providers have recruited Early Linkers with specific early childhood and family experience and skills, a team of Linkers is usually working across the 0 to 64 age range to provide whole-of-family support to Aboriginal communities.

#### **Generalist ALNSW and ELNSW provided by separate organisations**

In the majority of regions across the state, there are typically two providers funded separately to deliver ALNSW or ELNSW. In these areas, there are varying levels of cooperation, collaboration and contact between funded organisations. There is also varying understanding of the vision of ALNSW and ELNSW to be working closely together to provide support across the 0 to 64 age range.

#### **Aboriginal ALNSW and Aboriginal ELNSW provided by separate organisations**

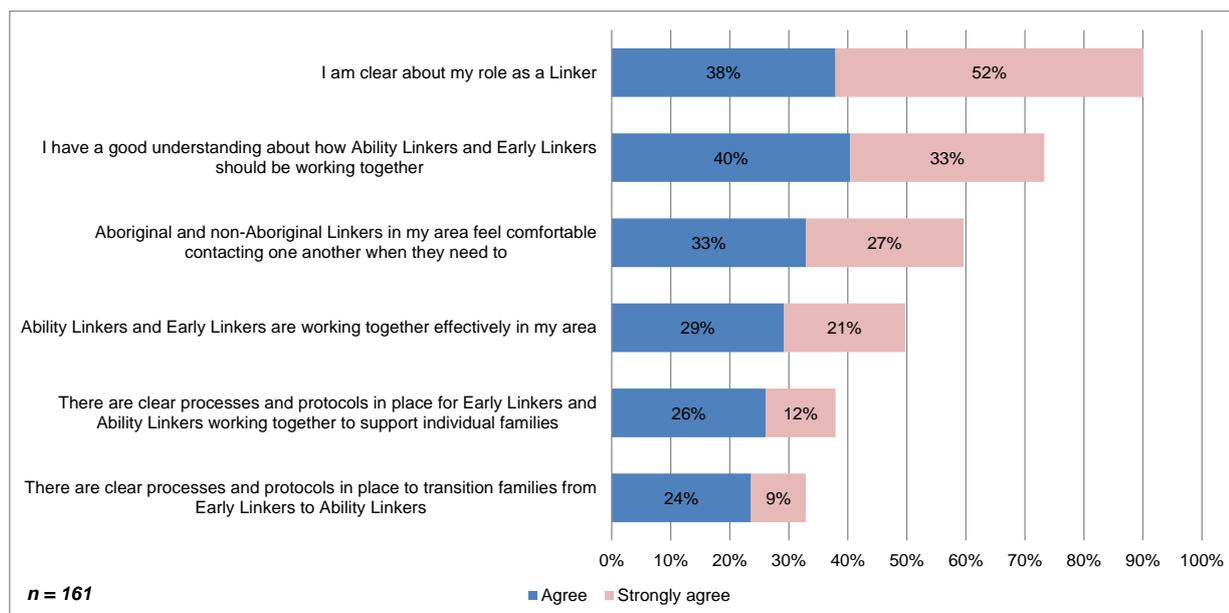
In regions where the programs are being delivered by separate Aboriginal organisations, there is generally a moderate amount of contact and collaboration between providers. In regional areas, the capacity of Aboriginal ELNSW and Aboriginal ALNSW providers to work closely within a specific locality is limited by available Linker resources and the time taken to travel from one location to another. Typically, Aboriginal ALNSW and ELNSW providers work in separate towns or cities within a FACS District which limits their ability to collaborate on family support and community-capacity building initiatives. Nevertheless, Aboriginal-funded services adopt a whole-of-family approach, regardless of the age of the person with disability. Providers will often be working with the whole family, and may not see the need to refer to other providers on the basis of the age of the person with disability.

### 4.3.2 LINKER AND MANAGEMENT VIEWS ON PROGRAM ALIGNMENT

An important measure of alignment and partnership is the extent to which providers and Linkers understand their roles, and assess how effectively they are working together. All Linkers were asked to participate in an online survey to test some of these indicators. The results reveal that there is still some way to go in aligning ALNSW and ELNSW (see Figure 8).

On the positive side, the majority of Linkers (73%) said they had a *good understanding about how Ability Linkers and Early Linkers should be working together*. However, while this is a good result overall, it indicates that more than one in four Linkers either disagree, are not sure, or neither agree nor disagree with this statement, which is problematic.

FIGURE 8 – LINKER VIEWS ON ALNSW AND ELNSW WORKING TOGETHER



Furthermore, only half of the Linkers agreed or strongly agreed that *Ability Linkers and Early Linkers are working together effectively in my area* (with only 21% strongly agreeing). This correlates with feedback from the consultations which found that while most Linkers reported having some contact with the corresponding Linkers in their region, this contact ranged from little or no contact outside of formal Linker conferences, through to ALNSW and ELNSW Linkers working in partnership to support families across the age continuum. Some Linkers and providers reported having made attempts to contact providers in their region, but have had few successful experiences to date.

The Linker survey also identified a lack of understanding of policies and procedures of how ELNSW and ALNSW should be working together in practice. Only 38% of Linkers agreed *there are clear processes and protocols in place for Early Linkers and Ability Linkers working together to support individual families*. Furthermore, only 33% agreed that *there are clear processes and protocols in place to transition families from Early Linkers to Ability Linkers*. One of the reasons for this is a degree of confusion about the relationship between ALNSW and ELNSW at a management level amongst some of the providers, as the following quote illustrates.

*Out of the Linker conference, I don't think there were conversations about how do you work together and collaborate. I think amongst people, the atmosphere and the feeling was positive. I think people get it, but I don't think people necessarily get it that it's the same thing. Clearly different groups of people are involved but I think there's still a distinction between Ability Links and Early Links.*

The survey also revealed there is more to do regarding relationships between Aboriginal and non-Aboriginal providers. Although a majority (60%) of Linkers agreed that *Aboriginal and non-Aboriginal workers in my area feel comfortable contacting one another when they need to*, 40% either did not agree, were not sure or neither agreed nor disagreed. This implies a need for further improvement.

Consultations with Linkers and program managers identified some perceived differences between the roles and approaches of Ability Linkers and Early Linkers:

- **ALNSW and ELNSW are seen to support individuals and families with different needs** – the priority needs of families with young children are a range of often intensive supports and information provision around diagnosis and support into early intervention services. This is in contrast with ALNSW that primarily aims to support young adults and adults through a 'light touch' to connect with mainstream services and community.
- **ALNSW and ELNSW Linker skills and background are seen to vary** – many Ability Linkers have been recruited on the basis of their knowledge of, and connection to, the community. Community knowledge and capacity-building are also important skills for an Early Linker, however the type and level of support families need from Early Linkers generally requires a level of knowledge and experience in early childhood development. Many Linkers perceive Early Linkers to have more of a case coordination role (at least initially), in contrast to the ALNSW light touch model.

Clearly there are a range of perceptions amongst provider management and Linkers regarding the relevant skills, orientation, role and the degree of alignment between ALNSW and ELNSW. While the aim is to formally align the two programs, a range of cultural, professional and organisational factors are impacting upon the extent to which the sector is embracing the change and implementing it effectively. Many in the sector seem to be looking for some acknowledgement that, although there is common ground between ALNSW and ELNSW, there are also some distinctions that need to be made between the two programs in terms of role and some of the activities.

#### 4.3.3 HOW ABILITY LINKERS AND EARLY LINKERS ARE WORKING TOGETHER

As noted above, many providers felt that the alignment of ALNSW and ELNSW is still in the early stages and is a work in progress. However, many strongly support the integration of the two programs, but say there is a critical need to develop effective strategies to provide supports to families in a coordinated way across the life span.

Where good alignment has commenced, Linkers have worked together in the following ways:

##### **In regions with multiple or separate ALNSW and ELNSW providers:**

- referrals between ALNSW and ELNSW providers to request additional support for a family or parent
- joint community engagement activities involving Ability Linkers and Early Linkers attending the same events and forums and staffing information stalls
- networking and knowledge sharing between Ability Linkers and Early Linkers to ensure that people with disability, their families and carers are aware of the available supports
- combined ALNSW and ELNSW Linker team meetings, ranging from occasional invitations to build networks through to regular meetings to discuss and share practices and engagement activities
- sharing of knowledge about Aboriginal culture and practice with generalist providers across ALNSW and ELNSW providers.

##### **Within providers that offer both ALNSW and ELNSW:**

- collaboration to provide a whole-of-family approach to support families with ALNSW and ELNSW needs: this is taking various forms, such as Ability Linkers and Early Linkers attending appointments together, working with families jointly (adults, older children and children under nine years), transitioning from an Early Linker to an Ability Linker. Early Linkers and Ability Linkers are also supporting each other 'behind the scenes', particularly in situations where introducing a new Linker could be stressful for a family
- joint capacity-building and community development initiatives
- joint team meetings, supervision and training that provide opportunities for ALNSW and ELNSW Linkers to learn from each other through reflective practice.

Providers offering both ALNSW and ELNSW are finding a number of benefits to being able to offer support from 0 to 64 years. These include: **the capacity to use Ability Linkers or Early Linkers as an interchangeable resource** which is helping providers to better manage caseloads. There is also **knowledge-sharing across teams which is building the overall capacity of Linkers**: some managers commented that Ability Linkers are developing knowledge of early childhood development and the diagnosis process, while Early Linkers are gaining knowledge in community engagement and community development from Ability Linkers. These are important developments which are beginning to realise the benefits to providers and people with disability, their families and carers of program alignment. An increased diversity of Linker skills is **improving the capacity of providers to respond to a diversity of individual and family needs**. For example, one provider with two male Ability Linkers recruited two female Early Linkers to enhance their capacity to meet preferences of individuals and families.

Significantly, Aboriginal providers offering both ALNSW and ELNSW see the 0 to 64 years approach as a culturally appropriate way of supporting Aboriginal communities through working with the whole family. One ALNSW manager commented that they were providing ELNSW before they received funding because they *wouldn't discriminate inside a family*. As an Aboriginal Linker explained further:

*I was originally employed as an Early Linker but I found that when you went into a home you are working with the family group. You might be working with little Susie that's seven years old, but you're working with mum first before you even get to Susie. So I need to work with the elders first. So it works out, because we take a whole family approach.*

#### 4.3.4 CHALLENGES TO SUCCESSFUL PROGRAM ALIGNMENT

The challenges to developing a fully aligned program are detailed in Table 11. A key factor underlying the challenge is a need for a clear understanding of how the 0 to 64 support continuum should be implemented that takes into account the diversity of organisational and service settings.

TABLE 11 – CHALLENGES TO SUCCESSFUL ALNSW AND ELNSW ALIGNMENT

CHALLENGES	IMPACTS	EXAMPLE
<b>Program leadership regarding program vision and how alignment should occur</b>	<ul style="list-style-type: none"> <li>A perceived lack of program leadership is causing some confusion at a provider level as to the proposed vision for the alignment of ALNSW and ELNSW</li> <li>This confusion is strongest where ALNSW and ELNSW funding has been split across organisations in the one area.</li> </ul>	<p><i>I've mentioned numerous times - - - to articulate to all providers where Ability Links and Early Links sit...Is it one program or is it two? And what does it look like?</i></p> <p>(Management)</p>
<b>Lack of leadership at provider level</b>	<ul style="list-style-type: none"> <li>Communication and collaboration between ALNSW and ELNSW providers is very limited in some regions</li> <li>Many Linkers have a limited understanding of how Ability Linkers and Early Linkers are meant to be working together, or the processes or protocols for doing so</li> <li>Lack of protocols or procedures for cross-referrals or joint working.</li> </ul>	
<b>Lack of alignment program communication and material</b>	<ul style="list-style-type: none"> <li>Limited materials that communicate the combined approach</li> <li>Confusion or lack of knowledge from the perspective of the individual/family and community as to how Ability Links and Early Links work together</li> <li>Ability Links appears to be better known in the community than Early Links.</li> </ul>	<p><i>A generic brochure that looked after both Early Links and Ability Links so that people understand the journey of how ADHC is perceiving that it is looking like in community. Understanding Early Links is very different, but stepping out into the Ability Links world by having a simple brochure that everyone can read.</i> (Linker)</p>

CHALLENGES	IMPACTS	EXAMPLE
<b>Conflicts or competition between funded providers</b>	<ul style="list-style-type: none"> <li>Where the program is split across multiple providers in the one area, this can limit provider collaboration due to perceived competition between organisations (particularly where ELNSW is offered by a disability service provider).</li> </ul>	<i>I think ADHC need to be mindful that we're different providers in the same patch and expected to be working together.</i> (Management)
<b>ELNSW resources limit outreach, especially in regional areas</b>	<ul style="list-style-type: none"> <li>Challenge to effectively undertake a coordinated outreach support within a designated region, when the support required to ELNSW parents is typically more intensive.</li> </ul>	<i>They [Early Linkers] are definitely funded to go down to [town] but there's little capacity.</i> (Linker)
<b>Role of alignment of program in regards to other related programs</b>	<ul style="list-style-type: none"> <li>Understanding how the aligned program should operate in relation to early intervention support programs and network development programs.</li> </ul>	<i>There are the Early Linkers, who we met just recently and they came to the conference at the end of last year. We also have a Network Development Officer who we have a lot to do with. Often we'll be talking to the parents and she'll be dealing with the kids and even now she works up to 15 years so she'll work with older kids as well.</i> (ALNSW Management)
<b>Confusion about the expected balance between working with families and community development</b>	<ul style="list-style-type: none"> <li>Challenge for providers to meet the different needs of ELNSW and ALNSW individuals and families within the same Linker team</li> <li>ELNSW support requires expertise and understanding of early childhood development and disability diagnosis processes, whereas the community development component of the role requires different skills. This raises the question of whether all skills are expected to reside within a person (the program model) or within a team.</li> </ul>	<i>If you've got a family who has just had a new born and they've had a diagnosis of a disability. They're working through early specific targeted early intervention, and it could be many years before that child is getting the support they need. So we do really need to focus in on very specific early support diagnosis and early intervention and it needs to be quite heavily done at that time.</i> (Management)

## 4.4 IMPLEMENTATION ISSUES

### 4.4.1 BROKERAGE

The ALNSW and ELNSW model includes a small amount of brokerage funding as a proportion of the per Linker unit amount. Brokerage funding is provided by ADHC to enable providers to support community connections and inclusion, including by meeting one-off and emergency needs (examples include providing transport to an activity, purchase of small equipment, minor modifications to enable access, or funding of an all-inclusive community activity). Program guidelines restrict providers from using brokerage in certain situations (for example, where funding could be met through other avenues) to encourage providers to think creatively and effectively use brokerage to build sustainable community partnerships or develop community capacity.

Brokerage has been used in various ways across providers to meet the needs of individuals and families, and where it has been determined that the funding will provide the greatest benefit to the broader community. Examples of how brokerage has been used by providers include:

- the purchase of a custom-made tandem bike in partnership with a local cycling club for the use of people with disability in the community
- the funding of a small piece of gym equipment and a program for a group of people with disability that aimed to encourage participation into the general gym community
- the funding of a hoist for a local swimming pool that was purchased through a combination of brokerage funding and fundraising in the local community

- funding of a pair of special glasses that allowed a person with a vision impairment to participate in a number of community activities and social groups
- emergency transport costs for families in rural and remote locations.

There are inconsistencies in the use of brokerage funds across providers. This appears to be related to how the brokerage guidelines have been interpreted and applied by providers. Linkers say this is causing confusion in the community, particularly where there are inconsistent practices within the same region.

Linkers have said they would like a clearer and consistent approach to funding community development projects as well as more flexibility to provide very moderate financial support to individuals in the form of brokerage funding to facilitate their pathway to participation in the community.

#### 4.4.2 ALLOCATION OF LINKERS – REGIONAL

ALNSW and ELNSW providers have been funded an allocated number of Linkers relative to population size. While this is an apparently equitable approach and has resulted in all providers across NSW being funded on a consistent model, it does not take into account the geographic issues that may affect the increased cost and delivery of service and support in regional and remote locations.

Given smaller and more dispersed populations in many non-metropolitan areas in NSW, Linkers have found it difficult to undertake linking across their region. They also face the challenge of very limited availability of services or supports to link people to, which may require the Linker to take on additional work. The following two Linker quotes highlight the challenges of servicing rural areas.

*We can't provide services in remote communities or towns if they're not available. Community capacity-building in these regions takes a huge amount of time and resources which our organisation seems to be reluctant to fund. (Early Linker)*

*Referral pathways are very scarce in remote areas, particularly for case management which most people need. A blanket approach often isolates remote communities simply because they don't fit the criteria / boundaries which have been set down by the program. Transport, lack of choice and accessibility are constant issues that can't be resolved by throwing more money at it. Organisations that are based outside our area but receive funding to cover our area and have one worker attend once a month is not good enough. Being told to just go to a town, three and a half hour's drive away, is isolating and disheartening. (Ability Linker)*

#### 4.4.3 MARKETING AND PROMOTION

Linkers undertake a range of promotional activities in order to raise awareness of the existence of the program in their local communities. This is being undertaken with a minimal amount of program level marketing and communication materials and is heavily reliant on the Linkers as the face of the program. While a need for Linkers to be present and visible in the community is very important for developing trust, rapport and effective community partnerships, many Linkers commented that further marketing and promotions activity at the program level could enhance and support the grassroots approach they have taken to date. As a Linker commented.

*Active promotion would improve the program. We have had to basically door knock to get people, and I am sure many people don't know we exist.*

Linkers commented that program-level communications activity could fast-track understanding of the work of the Linker, and showcase the outcomes that ALNSW and ELNSW are generating for individuals and communities.

*A short media campaign where ALNSW was promoted potentially on TV. I feel that the message of how Ability Linkers can support people, carers and families living with disability will reach more people and encourage them to make the step to contact a Linker and get the wider community more aware as well. I have promoted and continue to promote ALNSW extensively, however I still find that there are people out there who have not heard of us.*

Linkers also commented that marketing and promotions should be developed in order to better communicate how ALNSW and ELNSW should be working together. One Linker also commented that the ALNSW and ELNSW program could be better promoted and aligned with the NDIS via communications activity, to provide individuals or families with pathways into the Scheme.

## 4.5 SUMMARY

There are 28 providers funded to deliver ALNSW and ELNSW within the 16 NSW FACS Districts. There are currently six ways that providers are funded to offer support: for the 9 to 64 age range, for the 0 to 64 age range, and for the 0 to 8 age range. Providers are generally working reasonably well in informal and formal partnerships to deliver support to people with disability and their families across the state. However the level of contact between providers and the depth of partnership and collaboration varies considerably across regions.

Formal partnerships have generally strengthened over the last year and considerable efforts have been made to consolidate and enhance the partnership arrangements. A number of ongoing challenges remain for partners to manage, including the need to ensure a unified and consistent service delivery approach to avoid partners having differing views on implementation, and staffing and program expectations. There are also improvements that could be made to address some challenges partner organisations face servicing the same geographic area.

Across generalist and Aboriginal providers, there has been overall a good level of collaboration and cooperation which has facilitated the development of culturally appropriate referral processes that provide people with disability a provider of choice.

Factors associated within successful partnerships include a culture of openness, collaboration and respect, strong governance, a shared vision of the priorities for program delivery, and regular contact to share learnings and knowledge.

The alignment of ELNSW and ALNSW is still in early stages. There are varying levels of contact and integration across providers. Providers offering both ALNSW and ELNSW support are the early adopters of the integrated Linker model. Aboriginal providers see the adoption of a whole-of-family approach as critical to working with Aboriginal people with disability, and draw less of a distinction between Early Linkers and Ability Linkers. To achieve more effective alignment of ALNSW and ELNSW, there is a need for more organisational leadership and communication regarding not only the vision of an integrated approach, but practical ways that can be achieved. This is particularly important for providers who employ only Ability Linkers or Early Linkers, and for whom there are historical, organisational and cultural barriers to integration and alignment.

While these barriers exist, there is seen to be considerable potential in aligning ALNSW and ELNSW. Despite some reservations in the sector, there is considerable enthusiasm for the move amongst many providers and individual Linkers (which was palpable at the National Linker Gathering in 2015). Many in the sector are calling for more clarity on the alignment, the rationale, the implications for the Early Linker role and the activities they have traditionally undertaken, and more guidance on how the ALNSW and ELNSW providers and Linkers can effectively work together. At the same time, amongst some providers, there appears to be a lack of leadership in instituting the reform processes, particularly where funding is split across providers.

## 5 Linker workforce and development

### 5.1 INTRODUCTION

This chapter discusses developing learning about the skills and attributes of an effective Linker workforce, and their professional development needs.

### 5.2 LINKER ATTRIBUTES AND SKILLS

Over the last three years, as the Linker role has developed and evolved, a picture is developing of what is required to be an effective Linker. It has become apparent that **it is just as much about personal attributes as it is about skills** which partly explains the broad diversity of the Linker workforce. Linkers (particularly Ability Linkers) have very varied backgrounds – including people who have worked in government, community organisations and the private sector. They include former tradies, soldiers, retail workers, community workers, hairdressers and disability support workers. Early Linkers, in contrast, tend to have qualifications in early childhood development.

Over time, the wide range of requisite Linker skills and aptitudes is emerging, which are summarised in Figure 9. While across ALNSW and ELNSW, there are many skills and aptitudes in common activities, some differentiation in skills and aptitudes are needed to effectively conduct the full range of activities that are currently embedded in the Linker's role.

When ALNSW first commenced, the model was that all Linkers would undertake linking work with individuals **and** networking and engaging with community to effect organisational or community change. While there are some individuals who do possess an expansive range of expertise across these two broad types of activities, more commonly Linkers will have strengths that may lean them more towards one aspect of this role than the other.

Increasingly, some providers are forming the view that it is unrealistic to expect all Linkers to fulfil all aspects of the role equally effectively. Accordingly, some providers are adopting an approach whereby they **recruit a team that together encompasses the range of skills**. A few providers have allocated a certain amount of time within a Linker's role to conduct community development activities in recognition of the fact that some Linkers have a particular aptitude for that work. One of the larger providers has taken an even bolder step by appointing a manager with specific responsibility to support the development of strategic community projects at a whole-of-provider level.

This is not to say that individual Linkers relinquish responsibility for undertaking community engagement, but that it is undertaken in a more coordinated and planned way than it has in the past and the balance of that work may vary within a team.

With ELNSW coming into the ALNSW frame, there have been expectations that Early Linkers will be required to undertake more activities that involve linking children under nine and their parents into the community, and to work with community and other organisations to effect attitudinal and organisational change.

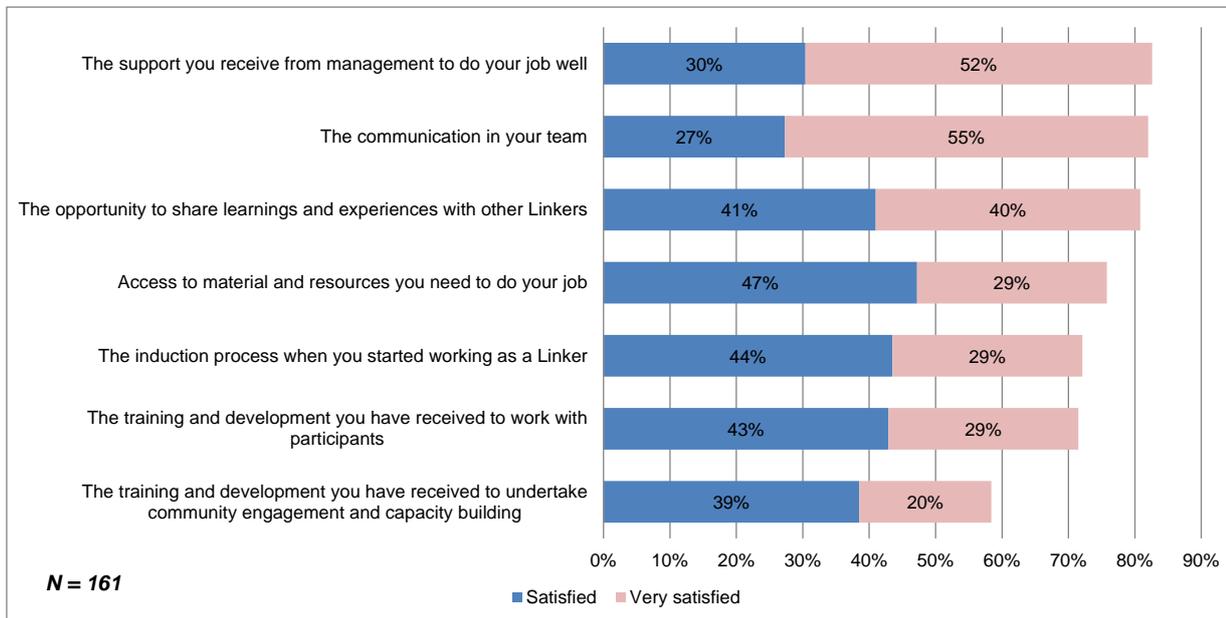
At the same time, it has become apparent through this evaluation, that Early Linkers require certain **specific skills and knowledge** relating to the intense work they need to undertake when supporting families before, during and after the diagnosis. They also need to have some level of **case coordination skills**, as they typically play a more active role than Ability Linkers, particularly in the early phase of contact with parents of young children with disability.

As Ability Linkers and Early Linkers increasingly interact and work jointly with families, skills and knowledge will extend across the team of Linkers. Nevertheless, a prevailing theme from consultations was that many Early Linkers who have specialist expertise in early childhood development currently feel ill-equipped to undertake broader community development reform. They say they are often time poor given that so much of their time is spent providing intensive support to parents around the time of diagnosis.



- access to materials and resources they need to do their job (76%)
- training and development they have received to work with individuals and families (72%)
- training and development they have received to undertake community engagement and capacity building (59%).

FIGURE 10 – LINKERS’ SATISFACTION WITH TRAINING AND SUPPORT



It is apparent that the **lowest level of satisfaction relates to community engagement and capacity-building**: over one in five Linkers (22%) said they were either dissatisfied or very dissatisfied with this aspect of their training and support. An additional one in five Linkers (19%) were dissatisfied with their induction process and one in seven Linkers (16%) dissatisfied with the training and development they had received to work with individuals and families.

There were some differences in the responses of Ability Linkers and Early Linkers. Generally, Early Linkers were somewhat less satisfied than Ability Linkers. Nevertheless, in all but one aspect, more than half of the Early Linkers expressed satisfaction with the training and support received. The one exception was **training in community engagement and capacity-building** where one in three (32%) were either dissatisfied or very dissatisfied (see Table 12).

TABLE 12 – SATISFACTION WITH TRAINING AND SUPPORT: COMPARISON BETWEEN ABILITY LINKERS AND EARLY LINKERS

	NET SATISFACTION ABILITY LINKERS N= 123	NET SATISFACTION EARLY LINKERS N= 38
The opportunity to share learnings and experiences with other Linkers	81%	82%
The support you receive from management to do your job well	84%	79%
The communication in your team	84%	76%
The induction process when you started working as a Linker	72%	71%
The training and development you have received to work with individuals and families	72%	68%
Access to material and resources you need to do your job	79%	66%
The training and development you have received to undertake community engagement and capacity building	62%	47%

### 5.3.2 TRAINING

The Linkers undertake various courses and training during induction and ongoing training depending on the provider and their identified training needs. Early Linkers typically have received training in disability, as well as mental health, accidental counsellor, child protection, person-centred training, how to conduct workshops, and learning how to use the reporting system.

Ability Linkers in larger providers have typically accessed a range of non-disability training such as community development, media training, trauma informed care and other professional development offered by their organisation. Some Linkers commented that they would like to receive more mental health and counsellor training, but this is not always offered or available.

Most Early Linkers think that the induction package developed by ADHC is a very useful document in addition to their organisation's own induction processes to help Linkers understand the program, its goals and the processes that are expected. Some organisations develop an induction pack regarding particular issues relevant to Linkers' cohort they support, for example mental health vulnerability. The objective is to train Linkers to work with their induction pack and roll it out as part of a broader training to improve their skills and knowledge.

Some Linkers expressed a desire for more training and information around disability, particularly in a rapidly changing policy and program environment, to assist them provide information to families. The shift from the Early Start Diagnosis Program (which involved a lot of specialist training) to ELNSW has left some Early Linkers frustrated because they see their role as providing intensive support which requires specialist training.

Other Linkers commented on the need for more training on community capacity-building and community development to assist them to prioritise and engage effectively in this aspect of their role.

### 5.3.3 SUPPORT

As we have seen, most Linkers are satisfied with the level of support from their organisations and their teams. However, *promoting self-care* is becoming an increasing priority for providers, reflecting the toll the Linker role can have on staff well-being.

*For the first time, last week the family's situation makes me cry. There were three of them in the family, all with alcohol and drug problems, and also intellectual disability. When I ran around to talk to them, it just broke my heart. It's the first time in this role I've felt really on the verge of crying because you could see this family is really struggling. So I went straight to my boss and she offered me support, like counselling and she said it's there if you want it. I had a good talk to her and I said in all the years I've been doing this, it's the first time it's really hit me. So she wants me to go and have counselling. (Early Linker)*

Linkers also receive support from their peers. As many Linkers are spread geographically they support each other through informal contact. Such support can also be structured, for example through a buddy system, where each Linker is linked with another Linker who may work in another office. The aim is to ensure that Linkers have time to debrief and talk amongst themselves, in addition to the support from their managers, to make sure that they remain safe and well.

### 5.3.4 NETWORKING BETWEEN LINKERS

Linkers see networking with Linkers from other organisations as a very helpful way to support each other as well as collective problem-solving. These networks are initiated by the Linkers themselves through Skype sessions or phone calls. Linkers report that sharing successes as well as challenges provides support and motivation in the context of a challenging job.

Networking between Aboriginal and generalist Linkers is a powerful way for both Linkers and organisations to leverage each other's skills and cultural knowledge.

Linkers see networking events beneficial for professional development and peer support. They would like future conferences to focus on this more, and to have a good balance of Early Linker and Ability Linker participation.

Early Linkers also implemented a network of early diagnosis support workers to get together on a regular basis to talk about referrals, waiting lists and common challenges. They also use these networks to discuss the model of service delivery. As different teams are delivering ELNSW in different ways, there is a need to explore ideas that they can incorporate into their own practices to improve the quality and consistency of support. There is also potential to network around community capacity-building initiatives.

## 5.4 WORKFORCE ISSUES

### 5.4.1 EARLY LINKERS: BALANCING A LIGHT TOUCH WITH THE NEED FOR INTENSIVE SUPPORT

Addressing the specific needs and support requirements of families with children in the 0 to 8 age group within the model of ALNSW is a challenge for Early Linkers.

The below quote illustrates the need for case coordination from a parent's perspective.

*I can't imagine how other mothers would be getting through this process without that kind of support. It's a very challenging time if you don't know what to do and you have to become a caseworker basically. You have to go to so many appointments and learn all of this. All the protocols and all the different programs and all the different names and things because you don't know the right names for things and you can't access them because you don't ask for the right thing. It's all very challenging and very time-consuming and very emotionally draining.*

Linked agencies also perceive that there is a continuing need for intensive support from Early Linkers in the diagnosis stage.

### 5.4.2 INDIVIDUALS AND FAMILIES WITH COMPLEX NEEDS

Ability Linkers often find it challenging to achieve successful linkages for people with complex social needs. Such individuals may not be ready for linking into social groups or the community, and there are some individuals who are accessing ALNSW without a diagnosis who are thus not deemed eligible for certain social services. Where services do exist, Linkers are able to help individuals and families address their essential needs through a form of case coordination before they can be engaged to set goals and participate in community activities. However, a number of Linkers are finding that as a result of disability sector reforms, there are fewer case management services available to address complex needs, particularly in regional areas.

Ability Linkers have also identified difficulties supporting people with considerable mental health needs, without having specific expertise in this area. Linkers commented that it can be difficult to support people whose interests and goals may frequently change or which would take significant time to realise.

Similarly, Early Linkers experience the challenge of coming to grips with families' complex needs. They feel it is critical to understand the family context and their broader needs. Housing, for example, is one of the bigger issues affecting a family's stability that needs to be resolved before they can be supported towards other goals.

### 5.4.3 OVERLAPPING BETWEEN THE LINKERS' ROLE AND OTHER SERVICES

#### OVERLAPPING BETWEEN EARLY LINKERS' INTENSIVE SUPPORT AND EARLY INTERVENTION SERVICES

The Early Linkers spend the majority of their time working with families. Linkers who work in organisations that provide disability services, tend to refer or transfer families to the early intervention team; for other organisations, there are some overlaps between the perceived work of the Early Linker and other services within the organisation.

The lack of clarity about the Linkers' role and what Linkers can provide for families sometimes leads to a lack of cooperation between organisations, particularly early intervention services. In addition, these services may not support Linkers to recommend other early intervention services, which limits the Linker's

ability to provide independent information and advice to parents. This issue is a challenge for Linkers to do their job effectively within a sector that has a traditional view and approach to securing and maintaining their client base. This may be increasingly problematic as the services move toward NDIS.

## PERCEIVED OVERLAPPING BETWEEN ABILITY LINKERS' ROLE AND OTHER PROGRAMS

One aspect of the Ability Linker role is to understand how the program best interacts with other similar person-centred programs available to support people with disability to connect with community. For example, there are a number of programs such as Partners in Recovery (PIR) and Personal Helpers and Mentors (PHaMs) funded through the Federal government that specifically work within a recovery framework to assist people with severe and persistent mental health needs.

Linkers overall have been collaborating well, referring and networking with PIR and PHaMs workers to support people with mental health issues in the community. While overall the relationship between Linkers and these support workers are positive, there are perceived issues of overlap and lack of clarity as to how ALNSW and these programs can and should be effectively working together.

### 5.4.4 LIMITED UNDERSTANDING ABOUT EARLY LINKS

Early Linkers do not appear to be well-known in the community. Linked agencies and many parents interviewed are of the view that many services and the broader community do not understand the Early Linkers' role. Some services mistakenly believe Linkers are part of the NDIS (perhaps because they spend lot time giving information about the NDIS). Other services (particularly early intervention services) think that Early Linkers undertake early intervention work that overlaps with their role. Many parents say they had never heard of Early Links before, even though some had been struggling with a child with disability for some time.

The linking concept is new to the disability services sector especially in the early childhood field. It is neither well-understood nor embedded in services or in the community. The quote below illustrates this further. It also shows that there is a perception that ALNSW and ELNSW are two different programs, with the former having a clearer purpose and being better understood by the community.

*I know a couple of my friends who just can't seem to get connected. I get the impression that no-one really knows what they're meant to be connecting them to. There needs to be more continuity around what people are getting, what the service is, and what the support is. There needs to be more continuity. I did feel that with Ability Links, their objective is to get my older son connected so I felt the objective was clear but I don't think Early Links really make their objective clear and that's maybe because it's flexible. (Parent)*

This parent also raised the issue of branding of ELNSW and ALNSW, saying that rebranding of ELNSW to ALNSW hinders Early Linkers' work because families are confused about the two services. A number of Linked agencies similarly expressed some confusion about the role of ELNSW and the relationship to ALNSW.

### 5.4.5 TIME MANAGEMENT

As the Linker workload has increased, it can become difficult to find an appropriate balance between linking individuals and working at a community level. Linkers say they need excellent time management skills to juggle those two aspects of their work.

### 5.4.6 GEOGRAPHICAL COVERAGE

Linkers in regional areas and Aboriginal Linkers typically find it difficult to cover the areas they have been allocated. The large regions they have responsibility for makes it difficult to reach some families or engage effectively with the community. The problem is compounded when services and local community groups are not located in the same area as families. This means that individuals and families are often not able to attend services or community groups. The thin spread of Linker resources and services combined with transport difficulties compounds access difficulties in rural and regional locations, resulting in poorer access to programs for individuals and families residing outside metropolitan areas.

### 5.4.7 LACK OF SERVICES

Another challenge for some Linkers is the lack of services and community groups to link individuals to, particularly in regional and remote areas. Individuals and families may not be able to afford the travel costs to attend services or community groups. Linkers work creatively to find support through brokerage funds and related support services such as community transport, especially for the smaller communities to attend the medical or other specialist services. However, the availability of transport options is often limited and can be a barrier.

## 5.5 SUMMARY

The Linkers' activities are broadly categorised into:

- providing information to individuals and families
- providing personal support to individuals and families
- building relationships with individuals and families
- working with individuals and parents to develop goals, and match goals to their needs, and relevant community groups and services
- providing tools and developing individuals' skills to participate in employment, education and community activities
- providing tools for parents to manage their children's behavioural issues and medical conditions
- assisting individuals and parents to access services
- networking with the community groups and services to promote and link individuals and families
- organising and facilitating community group activities to provide support.

The Linkers' personal attributes and skills are critical factors to enable them to perform these activities successfully. These skills and attributes work interdependently to enable the Linkers to form positive and trusting relationship with individuals, families and community.

While Linkers receive some professional development through the various courses they attend, most Linkers feel that they need more, especially specialist training to help them understand complex needs of individuals and families to be able to assist them appropriately. There is an expressed need for further training on community development and on mental health.

Linkers are generally satisfied with the level of support they receive from their managers. Most Linkers refer to networking with other Linkers as the most helpful way for them to share their experiences, cope with the demands of their work, and learn new and different ways to work with individuals, families and community.

## 6 The NDIS, ALNSW and ELNSW

This section discusses how ALNSW is currently working with the National Disability Insurance Agency (NDIA) and some of the emerging issues concerning the potential alignment between ALNSW, ELNSW and the NDIS.

### 6.1 HOW ALNSW AND ELNSW ARE SUPPORTING THE NDIS IMPLEMENTATION

The NDIS is transforming the disability landscape in Australia. At the time of the 2016 consultations, the NDIS was in the final months of the Scheme's trial phase and the NDIS was available in the Hunter and in the Nepean Blue Mountains areas (for children and young people). At this time, a significant proportion of Metropolitan Sydney, Southern NSW, Central Coast and New England regions were preparing to commence full transition to the NDIS on 1 July 2016<sup>5</sup>. By 2018, it is expected that the NDIS transition will be complete.

Linkers are providing a range of information and referral activities to individuals and families as the NDIS implementation progresses across the state. This includes:

**Providing information to individuals and families** – The progress of the NDIS rollout across NSW has led to an increased level of demand for information about the NDIS from people in the community, and high expectations of Linkers to be able to provide accurate detailed information. Most Linkers feel comfortable with providing basic information about the Scheme and refer interested people to the NDIS website for the most up-to-date information.

**Collaborating on forums and community engagement activities** – The increased demand for information has also resulted in a number of ALNSW and ELNSW providers running successful NDIS readiness forums both independently and in conjunction with the NDIA. Early Linkers in NDIS implementation sites are also inviting NDIA staff to present at peer support group programs.

While ALNSW and ELNSW have a critical role to play in providing information about the NDIS, there was concern from a few providers that the high demand for information has seen some disability service providers making a sales pitch for their service rather than providing independent advice.

**Preparing individuals and families for NDIS** – Linkers working in NDIS implementation sites have been providing advocacy and capacity-building to individuals and families. Activities have included ensuring individuals and families have a plan of action before interviews with NDIS Planners and providing independent general advice to individuals and families about working with service providers that manage NDIS plans.

### 6.2 THE ROAD TO THE NDIS

Two key aspects of the transformation have a particular impact on ALNSW and ELNSW: the transfer of responsibility for disability support from the States to the Commonwealth; and the perceived overlap between the role of ALNSW/ELNSW and the NDIS.

#### 6.2.1 TRANSFER OF RESPONSIBILITY TO THE COMMONWEALTH

A key aspect of the NDIS legislation and the bilateral agreements between the Commonwealth and the State and Territory governments that form the basis for the establishment of the NDIS is the transfer of responsibility for disability support from the States and Territories to the Commonwealth. That responsibility will be managed on behalf of the Commonwealth by the NDIA.

From the perspective of the New South Wales government, this transfer of responsibility will ultimately result in the closure of ADHC. However, some aspects of the transfer are still to be resolved, for example, the transfer of government-owned disability housing.

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<sup>5</sup> Visit the NDIS website for details: [www.ndis.gov.au](http://www.ndis.gov.au)

At a time of unprecedented change, it is not surprising that those working with people with disability have concerns about exactly how the transition will work and what impact it will have on the people they support. Consequently, some Linkers have questions relating to the degree to which the NDIS will replace, match or enhance the existing disability system, particularly for individuals and families who may not satisfy eligibility requirements in order to receive a full individualised support package. Notwithstanding communication from the NDIA and FACS that the number of people with disability in NSW supported under the NDIS and the available supports will actually increase, many Linkers are either not aware, or not convinced, this will actually happen.

In addition, a number of Linkers reported that some aspects of the transition to the NDIS are having a negative impact on their practice. They said they are experiencing an increase in referrals for people with high support needs, due to an apparent reduction in the availability of case management and other services.

Linkers in the pilot site reported that some disability service providers have reduced the availability of services in order to re-align their business model in preparation for the transition from block funding to individualised funding.

Management and Linkers also commented on the impact of the transition on Linker recruitment. As the NDIA ramps up to resource implementation, new roles are being offered through the NDIA and through funded NGOs, including the Local Area Coordinator (LAC) role for the transition period. The LAC role is being perceived by many in the sector to be similar to the Linker role; it is reportedly better remunerated and seen to offer a more stable career path compared with ALNSW. As one program manager explained:

*We've just had four resignations this week to the NDIA. So there's more money being paid for what is seen to be the same job. It's not the same job, but it does seem to be the same job.*

### 6.2.2 THE FUTURE OF ALNSW AND ELNSW

The success of ALNSW and ELNSW combined with a sense of uncertainty about the future of the program, point to the need for early and considered planning to determine how the important role of the Linker can be continued beyond 2018 to support people with disability.

A number of providers raised questions about the future of ALNSW and ELNSW once the NDIS is fully implemented across the State. Several ALNSW providers and Linked agencies expressed concerns about how people with disability currently supported through ALNSW will be integrated into the NDIS. Some providers and Linked agencies are of the view that ALNSW has the potential to help identify and address the gaps in the service system and expressed interest in allowing ALNSW and ELNSW to continue to provide this support. A number of providers and Linkers have attended information sessions about the NDIS in preparation for changes and some providers are focusing on preparing people with disability for the reforms by talking to them about individualised funding arrangements.

In December 2015, the NDIA released a consultation draft of the Information, Linkages and Capacity Building (ILC) Commissioning Framework<sup>6</sup>. The ILC, previously referred to as Tier 2 of the NDIS, is focused on a set of activities that will benefit people with disability, their families and carers, regardless of their eligibility to receive a full individualised funding package under the Scheme. The document outlines five activity streams of the ILC which are:

- information, linkages and referrals
- local area coordination
- capacity-building for mainstream services
- community awareness and capacity-building
- individual capacity-building.

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<sup>6</sup> *Information, Linkages and Capacity Building Commissioning Framework – Consultation Draft*, National Disability Insurance Agency, December 2015. Available on the NDIS website: <https://myplace.ndis.gov.au/ndisstorefront/news/ilc-commissioning-framework-released.html>

In the transition phase of the NDIS, a number of the ILC activity streams are being delivered by Linkers under ALNSW and ELNSW. At the time of consultations, the future roles and responsibilities of Linkers and LACs under the full Scheme were uncertain. Linkers reported concern that under the full Scheme, the LAC will replace the role of the Linker. The role of the LAC is proposed to help people plan and access supports in the community, with an emphasis on connecting people with mainstream supports and services. It is proposed they will work to positively influence community attitudes and address some of the systemic barriers to participation.

The phasing into the Scheme by cohorts of participants means that LACs and NDIS Planners prioritise the successful transition of people with disability that should automatically receive a package under the Scheme. This process has led to some Linkers raising concerns that the role of the LAC under the full Scheme will not provide individuals and families with the same level of support that ALNSW has provided. These concerns may diminish once the Scheme is fully implemented, however it highlights the importance of communicating the roles and responsibilities of LACs and the substantial framework of ILC support that will become available over time.

The concerns voiced in consultations about the ability of the Scheme to support individuals and families appear to be largely based on the experiences of being a Linker in the community. A number of providers commented that the NDIA should not underestimate the substantial and ongoing staffing and resource investment required to engage communities as a Linker. There are concerns that without understanding the lessons of the ALNSW and ELNSW model in developing the ILC service model, the LACs and NDIA may face difficulties in engaging meaningfully with individuals and communities in a way that builds trust, rapport and acceptance. One manager commented:

*The problem I see with the LACs is they are going to pop up overnight and the trust that you need, especially with people in rural community, you've got to be born in a town before they trust you. So in [town] which is only a 40 minute drive from here, we've been going religiously once a week for 18 months and we still are not accepted. So for the LACs to pop up overnight and they're going to give all this information on NDIS and develop a plan, I wish them well, I wish them a lot of luck.*

Many Aboriginal ALNSW providers commented that to date the current transition model to fund LAC positions in NSW has only included mainstream NGOs, unlike ALNSW and ELNSW which prioritised funding for Aboriginal community controlled organisations to reach Aboriginal people with disability. There is a concern that if the current LAC funding model remains over the longer term, it has a potential to reduce the effectiveness of the NDIA in reaching and supporting Aboriginal communities. One program manager commented that, in regional areas, LACs are asking Aboriginal Linkers to facilitate access to Aboriginal communities, without appearing to understand culturally appropriate practice or the level of engagement required to achieve effective outcomes. This approach is seen to be counterproductive and risks damaging the Linker's relationship with the community. Another Aboriginal program manager commented that some LAC positions sit within religious organisations that may have had a negative relationship with Aboriginal communities in the past. Without providing a choice for participants to receive support from Aboriginal organisations or LACs, Aboriginal people with disability may experience barriers to engage with the NDIS.

### 6.3 ROLE OF LINKERS IN THE NDIS

Many providers and Linked agencies could see value in ALNSW and ELNSW continuing alongside the NDIS. In the long term, the support currently being provided by Linkers will come under the ILC framework that will allow all people with disability, their families and carers access the supports they need. The continued success of the Linker role under ALNSW and ELNSW highlights the importance for the NDIA to develop similar approaches to support individuals and families in implementation of the ILC framework. There are a number of specific elements of the ALNSW and ELNSW model that are beneficial to support people with disability, their families and carers within the NDIS. These include:

**Independence** – ALNSW and ELNSW providers are seen as an independent voice for people with disability outside of the perceived 'big government' of the NDIS. A number of Linkers commented that people had raised concerns that the NDIS might be administered through the Federal Department of Human Services (DHS) shopfronts, in contrast to the informal support provided by Linkers out in the community. For many, the DHS has negative connotations with welfare and Centrelink. A few Ability Linkers also highlighted the value of being independent from disability service providers, given the perceived conflict of interest in providing advice to individuals in preparing their plans.

**Navigating pathways into the NDIS** – the number of people eligible for a full individualised package under the NDIS will be much smaller than the number of people with disability who will require some level of access to community supports. The ALNSW model has highlighted the importance of creative, flexible and person-centred approaches to meet the needs of these individuals and families. Over time, the ILC framework should work to support the large population of people with disability, their families and carers not eligible for individualised funding packages. However, in the short to medium term, there will remain a demand for Linkers to work closely with the NDIS transition to ensure that the primary target group for ALNSW/ELNSW support do not fall through any gaps in the system.

**Intensive support will still be required** – the experience of ALNSW and ELNSW demonstrates that people with disability, their families and carers will still require a level of intensive support to connect with community and to achieve their aspirations and goals, particularly those who will not receive an individualised funding package under the NDIS with no financial means to pay for services. Furthermore, for children and families awaiting diagnosis, there will be an ongoing need for Early Linkers to provide intensive support to guide families through the diagnosis process, which is often beyond the capacity of health professionals.

**Balancing individual/family support with strategic community development** – the ability to manage the dual roles of providing support to people with disability and families with community and systemic capacity-building initiatives is likely to be a challenge for LACs or other funded services under the ILC framework. The Linker model has a role to play in demonstrating how NDIS participants are provided with information, advice and appropriate supports, while simultaneously building social inclusion within the community.

## 7 Conclusions and issues for consideration

### 7.1 CONCLUSIONS

#### 7.1.1 ABILITY LINKS NSW: A NEW APPROACH

ALNSW was established by ADHC in 2013 as the NSW Government's approach to local area coordination for people with disability, their families and carers. The program is part of the NSW contribution to the NDIS and aligns with the early intervention aspects of the NDIS.

ALNSW heralded a new approach to supporting people with disability, their families and carers. Fundamentally, it takes a 'whole-of-life' approach to assist people with disability to address the challenges they face through:

- supporting them to overcome practical, emotional and/or cultural barriers to participation in all aspects of community life
- supporting services, businesses and the broader community to be more accessible and welcoming to people with disability.

Key features of the ALNSW model is that:

- It is a facilitator of change at an individual and community level, it is not a service provider in the traditional sense.
- It aims to empower people with disability to determine their own goals, make their own decisions and work towards achieving what is important for them.
- It is staffed by Linkers who work alongside a person with disability or a carer to help them plan for the future and link them to whatever community organisations, services or businesses in their local community will assist them achieve their goals.
- It includes a community engagement component involving networking, partnerships and community development activities – to support organisations and communities to become more welcoming and inclusive of people with disability.

ALNSW aims to offer aspirational, person-centred and flexible support to the people it works with. There are no formal eligibility criteria (other than the person identifying they have a disability and being aged between 9 to 64 years), no formal assessments at program entry, and no limits on the number of times a person may seek support from their Linker. It aims to have a 'light touch' on the people it has contact with, with the locus of control lying firmly with the person with disability.

After a year-long pilot of ALNSW in the Hunter Region, to coincide with the launch of the NDIS in the Hunter from 1 July 2013, the program was rolled out across NSW from July 2014. ALNSW now operates across the state, with 16 providers, 268 Linkers (47 of whom are Aboriginal-identified) and management support. It comprises four large generalist providers and 12 Aboriginal-specific providers.

Each provider covers a defined geographic area, and each area is supported by a large generalist ALNSW provider and one or more smaller Aboriginal ALNSW providers. Half of the providers are sole operators of the program, and half are operated through a formal partnership or consortium arrangement. There is considerable variation in the size of ALNSW and ALNSW (Aboriginal) auspicing agencies and the size of the program (varying from 1 to 67 Linkers across the provider agencies) and the type of regions they cover.

### 7.1.2 EARLY LINKS NSW: IN TRANSITION

ELNSW is a key part of the NSW Government's approach to local coordination and decision-support around diagnosis for families of children with disability from birth to eight years.

Key features of ELNSW are that:

- It provides families with individual tailored support before, during, and after their child's diagnosis.
- Similar to ALNSW, it aims to empower parents to determine their own goals, make their decisions and provide them with information and resources to enable them to support their child.
- It is staffed by Linkers who work alongside parents to help them obtain a diagnosis, navigate a complex service system and link them to services and community supports.
- It includes a community engagement component to assist the service system and community groups to be more inclusive of young children with disability.

Formerly the Early Start Diagnosis Support Program (launched in 2009), the program was renamed ELNSW and has been brought into alignment with ALNSW over the last two years.

The program is now operated by a mixture of former providers of the Early Start Diagnosis Program and new providers, some of them ALNSW providers. There are now 20 ELNSW providers across the state (13 Aboriginal-specific) employing 79 Early Linkers, of which 27 are Aboriginal-identified positions.

The vision behind aligning ELNSW and ALNSW is that, together, these two programs will support individuals with disabilities and families across the 0 to 64 year age span. This would require ELNSW to explicitly incorporate aspects of the ALNSW model, in particular linking to community, community engagement and capacity-building. The Department's vision is that ALNSW and ELNSW form one program and that all staff be referred to as Linkers, rather than Ability Linkers or Early Linkers. Nevertheless, at this stage, most providers and staff still describe themselves as operating under either ALNSW or ELNSW.

### 7.1.3 PROGRAM UTILISATION AND ACCESS

ALNSW and ELNSW are now **supporting over 43,500 people with disability, their families or carers each year**<sup>7</sup>. The program is reaching a wide range of people in terms of disability, age and gender. **The program has been particularly successful in reaching large numbers of Aboriginal people with disability.** Just over a quarter (27%) of people who achieved an outcome identify as Aboriginal and/or Torres Strait Islander. This is a major achievement and is likely to reflect:

- the funding arrangements (a large number of locally-based Aboriginal organisations funded for Aboriginal-specific Linker positions)
- the high level of need in Aboriginal communities for disability support
- that the informal, flexible, non-bureaucratic ALNSW/ELNSW model and approach resonates strongly with Aboriginal families
- that Aboriginal people have a choice as to whether they can access an Aboriginal or generalist provider

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<sup>7</sup> Annual estimate is based on six months program data (January to June 2016).

- Aboriginal ALNSW providers have been effective in providing generalist providers with cultural awareness training.

In its first three years, the program has **been reasonably successful in reaching diverse communities** with 18% of all individuals who achieved an outcome identifying as CALD. Two of the large providers partnered with a large CALD organisation operating in metropolitan Sydney, which has been a factor in engaging effectively with people from CALD backgrounds, despite the stigma or shame that is often associated with disability in these communities. Other providers have been less successful in reaching CALD members of the community and recognise they need to do more. One or two providers already have plans to employ a CALD Community Engagement Manager to devise and implement a strategy to address this gap. Similar to Aboriginal communities, the ALNSW model seems to resonate with the needs and preferences of diverse communities, albeit some of these families may require additional support due to language, cultural or system barriers.

Other people who might benefit from, but are not utilising ALNSW or ELNSW to the same extent (or until a later stage) include people who do not see themselves as disabled (e.g. they have a psychiatric disability, or have acquired disability through accident or injury) or who do not recognise that they or their child have a disability.

#### 7.1.4 OUTCOMES FOR INDIVIDUALS AND THEIR FAMILIES

Annually, it is projected that ALNSW and ELNSW are assisting over 43,500 people with disability and their families<sup>8</sup>. This includes 10,376 people who have been provided with facilitated support and have achieved over 18,850 outcomes relating to:

- social and community inclusion
- engagement with mainstream, disability or other services
- employment
- education and training.

These outcomes are in line with program objectives and highlight that linkages to services, and outcomes relating to community and civic participation are what the majority of people with disability, their families and carers are seeking.

Over 160 individuals receiving facilitated support have been surveyed or interviewed in-depth for the evaluation over the last two years. Their feedback about ALNSW and ELNSW has been overwhelmingly positive. It is acknowledged there may be some selection bias at play here as, for privacy reasons, people were approached to participate in the evaluation through providers. However, in the experience of the evaluator, it is unusual for there to be such a consistently high level of client satisfaction in a new program, and for feedback to be so glowing. The evaluation identified many cases where ALNSW and ELNSW has had a very major impact on the lives of people with disability and their families.

Critical to the success of ALNSW and ELNSW is the individual or family's relationship with their Linker. The Linker is the face of the program, and individual experiences with ALNSW or ELNSW are largely based on the quality of that relationship. As such, ALNSW and ELNSW is experienced by individuals and families as a personalised service: when they talk about the program, they talk about their Linkers. The skills and attributes of individual Linkers are therefore at the heart of the success of ALNSW and ELNSW.

The aspects of the Linker's approach that people value particularly highly include that they are open and personable, person-centred, collaborative, flexible, reliable, persistent and creative. People also value that Linkers give them time to make their own decisions, respond quickly to requests for information, and most importantly, do what they say they will do. When these things occur, people experience the service as truly person-centred and feel Linkers genuinely care about them. This is in contrast to other programs where people sometimes said they feel 'just like a number'.

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<sup>8</sup> Annual estimate is based on six months program data (January to June 2016).

The great majority (80%) of people surveyed and interviewed for the evaluation were satisfied or very satisfied with their **relationship** with their Linker; their Linker's **availability** and ability to **understand their needs and challenges**; and the way the Linker **communicated** with them. Individuals were also highly satisfied with the **timeliness** of the support received, the **knowledge** their Linker had of local services and community groups, their **ability to link** them appropriately, and the **amount** of support received.

The statistics on the outcomes fail to convey the full impact that ALNSW and ELNSW have had on some people's lives. In-depth interviews with people with disability, their families and carers, Linkers and Linked agencies have shown that:

- **Significant change for people can occur through small steps**, albeit that these small steps may initially require a degree of courage or even risk-taking due to many people lacking self-confidence or a sense of self-worth.
- **Linking can have a profound effect on the quality of people's lives** resulting for example, in people feeling more optimistic and hopeful about the future; feeling safer, healthier, happier and more in control of their lives; feeling able to independently seek information or support for themselves; and able to make better and more-informed decisions about their or their child's future.
- **Linking to community can be just as important, and at times is *the most important* catalyst for change**. Individuals report having more people they can go to ask for support, or share experiences and challenges with; more opportunities for social connection to do the things they really enjoy; and most importantly, more opportunities to participate in mainstream community.
- **Participation in ALNSW and ELNSW leads to contribution to community**. Consultations revealed many instances where individuals and parents were contributing to community in various ways, for example through independently running peer support groups or community events, advising community groups or businesses on how to be more inclusive, taking on a key role in local community groups.

It is through community connection, participation and contribution that self-confidence, self-worth aspiration motivation and skills develop.

While the greatest success that ALNSW and ELNSW have achieved for individuals and families to date has been in relation to service and community linkages, there is still some way to go to achieving employment outcomes. Consultations with Linkers and management suggest that gaining work experience, volunteering, or employment for people with disability can be challenging. This is principally due to community attitudes and systemic barriers, whereby groups or businesses express concerns about insurance, or potential negative impacts on their business or employees. These are also barriers for some parents wishing to put their young child with disability into a day care centre.

### 7.1.5 SUCCESS FACTORS AND CHALLENGES

Critical success factors for achieving positive outcomes for individuals and families include:

- **tapping into an individual's passions and interests** to encourage and motivate them
- **encouraging the locus of control** to lie with the individual and family not the program nor any service they are referred to
- **encouraging people to take a risk** to try new things and overcome their fears and anxieties
- **harnessing and building on the considerable goodwill in the community** to become more inclusive of people with disability
- **partnering** with other services and groups to fill gaps in the service system.

There are a range of systemic and individual challenges or barriers for individuals seeking positive outcomes. These include:

- **low levels of awareness or understanding of disability** in services, business or community groups coupled with a resistance to be 'open' to inclusion
- **lack of knowledge** about the importance or potential benefits of inclusion, coupled with a lack of desire to make it a priority
- **fear** that becoming 'inclusive' requires considerable effort, resources and time and potentially could lead to insurance difficulties or litigation
- **shortage of local services or community groups** that people may be linked to particularly in some rural and remote locations
- **the complexity or urgency of an individual or family's needs** meaning that they may require considerable emotional, practical or specialist support that goes beyond linking into care coordination
- **difficulties people may experience to travel to or participate in training, education or community events** due to lack of transport (no car or public transport) or lack of finances.

## 7.2 COMMUNITY OUTCOMES

The aims of ALNSW and ELNSW go beyond supporting individuals and families, and include working with community in various ways to support them to be more inclusive of people with disability.

The programs do this in various way, including through:

- raising awareness and understanding of disability within community organisations, mainstream services and businesses
- partnering with individual organisations to assist them to become more inclusive
- building the capacity of individual organisations to become more inclusive on an ongoing basis
- engaging in broader, more strategic community development projects designed to have a broader social impact.

It is estimated that ALNSW and ELNSW are achieving some 2,132<sup>9</sup> community outcomes each year, including leadership, education and awareness, improvements in business practices and improved accessibility. Feedback from some 60 Linked agencies has revealed many and different ways that these improvements have come about. Since the last evaluation report in 2015, there has been a noticeable improvement in the community engagement aspects of ALNSW. There is more activity than there was previously, reflecting a shift in focus from raising awareness of ALNSW to building relationships and partnerships with organisations to increase accessibility and inclusion. It takes considerable time to gain the trust and confidence of partners or organisation and make an impact at an organisational level. One in four Linked agencies surveyed for the evaluation reported they have made changes or taken active steps to introduce more inclusionary policies, practices or systems. These are promising results, which are to the credit of both the Linkers and to the organisations involved.

However, the impact of ALNSW and ELNSW on some Linked agencies is yet to be realised. Determining the reasons for this will require more investigation in the future. It may be the agencies are at an early stage working with ALNSW or ELNSW; that the Linkers or the staff members lack the skills or the authority to implement change; or that there are limited resources or competing demands that impact on the time that Linkers can devote to developing partnerships or community capacity-building initiatives.

Critical success factors in achieving positive community outcomes include:

- the ability of the Linker to make a **soft entry** into a business or organisation, for example, starting with small practical steps; finding common ground with the Linked agency; highlighting and building upon any inclusive practice or initiatives; pitching the broader community and business benefits of inclusion

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<sup>9</sup> Annual estimate is based on six months program data (January to June 2016).

- Linkers having the **requisite skills, aptitudes and motivation**
- seeking to **align** an initiative with a Linked agency's strategic objectives.

Barriers or challenges in achieving positive community outcomes include:

- the factors previously described in relation to achieving outcomes for individual and families: lack of knowledge or awareness of disability, and a concern that any organisational change will require time and resources that the agency does not have or is not willing to prioritise
- some Linkers having insufficient confidence, motivation, skills or time to undertake community engagement (this is a particular issue for some Early Linkers)
- failure by some providers to strategically target and prioritise community engagement activity.

Individual outcomes and community outcomes are often inter-related. Some of the most positive and inspiring stories to emerge from consultations have occurred when **individuals and family members have become involved in activities that have added to the social capital and the achievement of social inclusion objectives**. Some people supported by ALNSW and ELNSW have become advocates and drivers of change through setting up or establishing peer support groups, taking on a key role in community organisations, or becoming involved in community capacity-building and community development projects through providing advice based on their lived experience.

There are also examples where **community members have become advocates for inclusion** within their own organisations. This can involve as simple a step as organising transport for the person with disability to attend a group or event. There is considerable potential therefore, for this to have a 'ripple' effect through their organisation. Examples provided in this report demonstrate the potential of ALNSW and ELNSW to achieve these broader community outcomes. However, more time will be required to test this further both through a larger sample and a deeper analysis of the organisational and community impacts.

### 7.3 IMPLEMENTATION

Piloted in 2013/14, ALNSW has been operating state-wide for two years only and was formally aligned with a rebranded and revised model of ELNSW relatively recently. Moreover, many providers are providing Early Links support for the first time, through the expansion in funding in 2015/16. For many providers, it still very early days in terms of implementing a new service, let alone a new service model and a newly aligned program structure.

Program delivery occurs through a reasonably complex funding and delivery structure comprising a mixture of large, medium and very small size local community-based providers; a combination of stand-alone and formal partnerships/consortium arrangements; and diverse arrangements whereby partners are the sole providers of ALNSW or ELNSW in a particular region, or they share responsibility in a given region. Furthermore, the service delivery mix includes organisations that provide ALNSW only, ELNSW only, or provide both ALNSW and ELNSW. It also includes providers that have been operating ELNSW (or its predecessor) for many years and those who have just commenced operations in the last year.

This relatively new and complex funding and service-delivery landscape makes it somewhat challenging at this stage to assess the extent to which ALNSW and ELNSW are being implemented effectively across the state. That said, a number of broad patterns seem to be emerging.

**Formal partnership arrangements are generally improving.** They are working best where there is strong leadership, a culture of collaboration and respect, a shared vision of ALNSW and ELNSW, and agreement, aligned priorities and practices. This offers choice to people as well as access to a broader range of skills and resources, and a broader platform for ALNSW/ELNSW practice and program development. However, partnerships take significant effort to establish and maintain, and in one or two cases, the arrangements are not operating as envisaged, potentially leading to confusion on the ground and limited collaboration at a strategic level.

**Informal partnerships between providers is variable.** However, overall there are reasonably good relationships between generalist and Aboriginal providers of ALNSW operating in the same region, and

many examples of good collaboration around cross-referrals, capacity-building, training, promotional activities and community engagement. This is not the case everywhere however, and in some areas, there is limited if any contact between generalist and Aboriginal providers due possibly to cultural, logistical or resourcing issues.

Across providers, state-wide implementation of ALNSW has gone reasonably well in the first two years. Learnings from the pilot were identified and informed the state-wide roll out. The Department has expended considerable resources on bringing together managers and Linkers on an annual basis to facilitate a common vision for the program and to support the development of a new workforce. Most providers have forged ahead to implement the program in line with its objectives, with only one or two smaller providers struggling to establish momentum. Providers have established networks and mechanisms around data and practice learnings which also assisted in the early implementation phase.

Implementation has been more challenging for some of the Aboriginal ALNSW providers that have a very small number of Linkers (two or three), no Team Leader, limited organisational infrastructure, and a large region to cover. A number of these providers have recently restructured to include a Team Leader position, and worked in close collaboration with the local generalist provider to overcome some of these challenges. Nevertheless, some small Aboriginal providers continue to struggle to work effectively across their region, given travel time and other logistics, limited resources and the high level of need in the community.

**Recruiting or retaining suitable staff has been an issue for some providers that has impacted on implementation.** At the time of consultation, there were a number of vacant Linker positions. Some of this has been due to poor recruitment decisions. Over time, however, the attributes and skills that make an effective Linker have become apparent, and providers are now clearer about what they are looking for and how they can test that when recruiting. This has reportedly led to better and more targeted recruitment than before. Providers have also lost some skilled staff to the NDIS, as the scheme is rolled out across the State. Another issue may relate to providers trying to find Linkers who encompass the broad range of skills and capacities in line with the Linker role, which may be in short supply.

## 7.4 ALIGNMENT OF ALNSW AND ELNSW

The alignment of ALNSW and ELNSW is still a work in progress. The Department's vision of a seamless, single program approach supporting people from birth through to 64 years working with all family members as required, has yet to be fully realised.

There are varying responses to the alignment of ALNSW and ELNSW across the sector. A few providers are truly embracing the vision and have commenced action to put this in place. Others are making attempts to integrate the two, but are struggling with various aspects of implementation. Others (in particular ELNSW) are effectively operating as a stand-alone program – where ALNSW is seen as a point of referral, rather than a program partner.

On the positive side, **Aboriginal Linkers have strongly embraced the new program alignment.** Aboriginal Linkers work with families and communities rather than individuals, and combining ALNSW and ELNSW aligns well with cultural practice. Furthermore, there are many Aboriginal families where both a parent or carer and one or more children have a disability. In these circumstances, it makes eminent sense to take a whole-of-family approach. On site visits, there were many examples of Ability Linkers and Early Linkers working closely together, in some cases, inter-changeably as needed.

Alignment of ALNSW and ELNSW has also gone **reasonably well in providers that receive funding for both programs**, particularly if they are co-located. In some cases, the nomenclature of Ability Linkers or Early Linkers has been removed, and they are now all referred to as Linkers. Linkers have been brought under a common management and reporting framework. These Linkers work closely to transition individuals from one stage to the next, and to work with two or more family members on their own or jointly, depending on skills and experiences.

Alignment of ALNSW and ELNSW has **progressed more slowly or been more problematic in regions where generalist ALNSW and ELNSW is provided by different providers.** Organisational, historical, locational and other factors have made alignment more challenging in these circumstances. There appears to be a lack of leadership and strategy in some provider organisations to address these barriers or to lead the change. Even amongst Aboriginal providers, alignment can be challenging where ALNSW

and ELNSW are provided by different organisations in a particular region, due to resource constraints and/or being located in different parts of the region.

Acknowledging that the alignment has only been in place for a relatively short time, there are a number of barriers. Some managers and Linkers are **confused about the alignment**, and are unclear about whether ALNSW and ELNSW are two programs operating under one banner, or two programs working alongside each other. Others are frustrated that there seems to be a **lack of acknowledgement that Early Linkers require specific skills** beyond the linking skills of ALNSW Linkers given the differing focus and timing of the engagement with families, and the intensity of their needs around diagnosis. Many ELNSW Management and Linkers have **expressed concerns about the community engagement aspects of the Linker role** – due to perceived lack of time or resources as priority is seen to line with meeting the needs of families around diagnosis. Others are **questioning the extent to which community engagement should be a key aspect of their role**. In some cases, they lack confidence or skills to undertake such work.

While some of the above may reflect a lack of leadership and a reluctance to embrace change and the new model, it would seem important for the Department to have a dialogue with providers about these concerns and perceptions, in order to provide more leadership, guidance and support around alignment goals and implementation. During this dialogue, it would also be important to unpack definitions of community engagement and case coordination/case management and the expectations of Linkers to undertake this work.

## 7.5 WORKFORCE DEVELOPMENT AND SKILLS

The majority of ALNSW and ELNSW Linkers feel well-supported in their roles by management and reasonably well catered to in terms of induction and ongoing professional development. However, Early Linkers are somewhat less satisfied than Ability Linkers in the orientation and training provided to them to assist them perform their role. Feedback through interviews and surveys suggest a need for additional training on:

- community engagement, particularly for Early Linkers
- mental health, given the large numbers of people presenting with mental health issues.

ALNSW and ELNSW has a strong team focus, and Linkers develop a lot of valuable learning ‘on the job’, and through close and regular contact with their peers. State-wide gatherings and conferences have also been useful networking events.

What makes an effective Linker is becoming clearer: **it is as much about personal attributes as it is about skills and experience**. Having a good knowledge of the local community and the services and supports available is critical. There is a high level of agreement regarding the requisite qualities and skills, and how these are critical to families and communities achieving positive outcomes.

The original model of the ALNSW and ELNSW Linker role may, nevertheless, require some refinement. It was based on a model where all Linkers would undertake all aspects of the Linker’s role – balancing work with individuals and with community engagement activities. In reality, it can be difficult to find people who hold this broad range of skills. Linkers have different skills, strengths and interests. Some have a strong leaning towards working with individuals, and others a preference for engaging in broader community engagement. Increasingly, providers are recognising this and seeking to achieve a balance in required skills and aptitudes **across the team** rather than embedded within an individual. This is not to say that Linkers focus on one activity or the other, but rather that the balance of the activity might vary amongst individuals within a Linker team.

Further guidance on the definitions of community engagement could provide a framework for determining the types of community engagement that all Linkers are required to undertake, and those (towards the community development end of the continuum) which they may do, but which other Linkers on the team have a stronger focus. An alternative framework, being implemented by at least one provider, is to restructure program resources to establish a position to prioritise, coordinate and implement strategic community development across the organisation.

## 7.6 ALNSW AND ELNSW AND THE NDIS

As the NDIS is progressively rolled out, Linkers are increasingly being asked by people to provide information about the Scheme. This is being done on a one-on-one basis and in information forums, some of them jointly run with the NDIA. ALNSW and ELNSW are meeting with LACs and cross referrals are occurring.

The proposed role for the LAC under the full NDIS may potentially overlap with the current role of the Linker. It is unknown at this stage the level of resources that will be allocated by the NDIA to undertake the LAC program of work, how resources will address the balance between individual and system capacity-building roles, and the scope of community engagement activities. As ALNSW and ELNSW have developed and evolved over the last two years, much is being learned about effective engagement with people with disability and with the broader community that would be important to share for transitional arrangements.

The final phase of the evaluation was conducted in a period of some uncertainty as the sector prepared to transition to the full Scheme by 2018. Within this period of some uncertainty, Linkers reported concern about the coordination and scope of support for individuals and families currently being assisted by ALNSW and ELNSW. These concerns largely relate to the potential for gaps in the disability system, and a lack of clarity regarding the supports available for people not eligible for a full individualised plan under the Scheme.

## 7.7 THE ALNSW MODEL

The ALNSW model has a number of key strengths that allow Linkers to support people with disability, carers and families across the 0 to 64 age spectrum. The great majority of staff, individuals, families and Linked agencies consulted believe it is highly appropriate and extremely effective model.

The key strengths of the ALNSW model are:

**Soft entry point for individuals and families** – There are no eligibility criteria to access ALNSW and ELNSW and this is a major strength of the program. Individuals and families can access support without paperwork or a diagnosis and do not have to tell their story of disability unlike other support services. This provides a soft entry for individuals or families, particularly those that might not engage due to past experiences or a lack of confidence. ALNSW and ELNSW offer an effective pathway for individuals and families who may have fallen through the gap due to lack of disability, diagnosis or early intervention. This is particularly important for supporting a range of people outside of the traditional disability system, such as people with undiagnosed conditions.

**Flexibility to support individuals, families and their needs** – Linkers have the flexibility and freedom to support individuals and families in a myriad of ways. Some Linkers refer to this freedom as having a *licence* to listen and address an individual's or family's needs rather than fitting them into a pre-determined structure. Linkers adjust their approach depending on the individual's or family's needs whether they require information and referrals, or are non-bureaucratic linking style approach, or coordinated support.

**Shift from service dependence to individual empowerment** – ALNSW and ELNSW shift individuals and families from being service dependent to being empowered to set and achieve their own life goals. This shift represents a truly person-centred view focussing on the individual/family's needs.

**A continuum of support** – Linkers offer a continuum of support that engages people in relevant activities, develops their confidence and aspirations as they undertake successful participation in their community. The Linkers are part of the individual's journey. They are advocates for them when they need to be, and provide them with confidence and encouragement as they develop their goals.

**Strength-based approach** – With the support of the Linker, individuals and families have the opportunity to access relevant services that meet their needs and participate in community life. These experiences provide an opportunity to see themselves differently, to identify their strengths and raise their aspirations for the future.

**Community driven** – Linkers are embedded in the community which is a key strength of the program. They are the voice of social inclusion and work to break down barriers by directly connecting people with disability to the community, and working with the community to promote accessibility and support for people with disability. The mutual process of individuals participating in community and community opening pathways to include people with disability has the potential to empower individuals, families and the broader community.

**Independent** – A key strength of ALNSW and ELNSW is independence from government and the disability sector. Independence builds a rapport and trust with people and allows Linkers to provide advice that is not dictated by the available service model. Detaching support from a service provider encourages Linkers to listen to people and to seek creative approaches to connect with community based on needs and interests, rather than a set list of available programs and services. This is an enduring strength, with some Linkers commenting that people are hesitant to engage with what they regard as bureaucratic, government agencies.

**Aboriginal Linkers enable culturally appropriate pathways to engage and support Aboriginal individuals and families** – Aboriginal Linkers based in Aboriginal controlled organisations can support Aboriginal people with disability and families effectively because they have the cultural knowledge and community contacts. Aboriginal Linkers also work to build the knowledge of mainstream services, community groups and generalist Linkers to deliver cultural appropriate and sensitive support to Aboriginal communities. Aboriginal Linkers are able to build bridges for the community with service sectors, and to support them in ways that reduce the fear and distrust of engaging with disability and social services.

**The dual aspect of the model** – Linking individuals to community, and linking community to individuals is showing considerable potential. There is considerable goodwill in the community which can be tapped into relatively quickly and easily which is beginning to open the door to greater social inclusion and the building of social capital.

## 7.8 ACTIONS FOR CONSIDERATION

The following issues for consideration have been based on the evaluation findings and implications that can be drawn from these.

TABLE 13 – ISSUES FOR CONSIDERATION

ISSUE	RATIONALE	ACTION FOR CONSIDERATION
<b>Alignment of ALNSW and ELNSW</b>	<ul style="list-style-type: none"> <li>Alignment still a work in progress</li> <li>Needs strengthening at program management, provider leadership and Linker levels</li> </ul>	<ul style="list-style-type: none"> <li>The Department communicates to providers the rationale, structure, processes and expectations of the alignment, possibly linked to KPIs</li> <li>Providers held accountable through being required to report on alignment strategies and outcomes</li> <li>Mechanism established to share experiences and learnings from providers on how ALNSW and ELNSW effectively work together in different service structures and settings</li> <li>Program communication materials revised to better articulate the range of supports across the 0 to 64 years age range, acknowledging the additional support provided by Early Linkers</li> </ul>
<b>Linker role and activities</b>	<ul style="list-style-type: none"> <li>Requires clarification</li> </ul>	<ul style="list-style-type: none"> <li>The Department to clarify the range and scope of ALNSW and ELNSW Linker activities, acknowledging the specific needs of families around diagnosis</li> <li>The Department to clarify the roles and expectations of individual Linkers in relation to strategic community development projects</li> <li>Acknowledge the need for some case coordination in rural or remote areas where there are limited services and supports</li> </ul>
<b>Training and Development</b>	<ul style="list-style-type: none"> <li>Gaps in Linker training and knowledge</li> </ul>	<ul style="list-style-type: none"> <li>Additional Linker training and development in areas such as mental health and community engagement</li> <li>Consider training activities on how Ability Linkers and Early Linkers can effectively work together</li> </ul>

ISSUE	RATIONALE	ACTION FOR CONSIDERATION
<b>Community engagement</b>	<ul style="list-style-type: none"> <li>▪ Diverse definitions and understandings of community engagement leading to confusion and misunderstandings about role expectations</li> </ul>	<ul style="list-style-type: none"> <li>▪ The Department to clarify the range and types of activities that constitute community engagement</li> <li>▪ Providers be given the flexibility to restructure their workforce to more effectively implement their individual/family linking and community engagement activities</li> <li>▪ Consider defining minimum scope of work required of an individual Linker in relation to community engagement to ensure program integrity (e.g. awareness-raising, partnership development and organisation capacity-building)</li> <li>▪ Regional provider and participant forums to be conducted to share examples and learnings of effective community development aspects of community engagement and to identify opportunities for providers to come together to work on strategic cross-regional projects</li> <li>▪ Providers to support government departments and Local Councils in the development of their Disability Inclusion Action Plans</li> </ul>
<b>Practice development</b>	<ul style="list-style-type: none"> <li>▪ Need to capture ongoing learnings regarding program and practice development for wider distribution</li> </ul>	<ul style="list-style-type: none"> <li>▪ Regional forums/road shows to focus on practice learnings including the alignment of ALNSW and ELNSW in different contexts, and effective approaches to implementing community engagement</li> <li>▪ Capture emerging lessons on how to effectively engage with businesses</li> <li>▪ Consider developing a Practice Manual</li> </ul>
<b>Program funding</b>	<ul style="list-style-type: none"> <li>▪ Rural, remote and smaller providers challenged to effectively implement the program</li> </ul>	<ul style="list-style-type: none"> <li>▪ Consider the level of funding to smaller and regional providers to take account of high travel costs and limited resources to operate across large regional areas, and the need to take on a case coordination role in some instances due to a lack of services</li> </ul>
<b>Brokerage funding</b>	<ul style="list-style-type: none"> <li>▪ Inconsistent practices across providers</li> </ul>	<ul style="list-style-type: none"> <li>▪ The Department provide further guidance on the appropriate use of brokerage</li> </ul>
<b>ALNSW and ELNSW and NDIS</b>	<ul style="list-style-type: none"> <li>▪ Value in ALNSW and ELNSW communicating learnings relevant to NDIS</li> <li>▪ Explore effective ways for NDIS and ALNSW/ELNSW to work together</li> </ul>	<ul style="list-style-type: none"> <li>▪ Dialogue between Department and NDIS about practice learnings and effective engagement with individuals and community</li> <li>▪ Explore ways for Linkers to effectively work with NDIS in the transition phase of implementation</li> <li>▪ Explore value in bringing together learnings from ALNSW and Partners in Recovery (PIR) to obtain a broader perspective and evidence platform for reform</li> </ul>
<b>Evaluation and monitoring</b>	<ul style="list-style-type: none"> <li>▪ Need to continually monitor program access, utilisation and outcomes</li> <li>▪ Need to better understand and track community outcomes</li> </ul>	<ul style="list-style-type: none"> <li>▪ New data set be used to monitor program access and outcomes annually</li> <li>▪ Consider implementing a confidential program-wide participant feedback mechanism (e.g. consent to participate in an evaluation, completing a client satisfaction form)</li> <li>▪ Consider implementing a confidential program-wide Linked agency feedback mechanism</li> <li>▪ Consider commissioning a meta-analysis of the findings of all ALNSW and ELNSW evaluation activities</li> <li>▪ Utilise the evaluation findings as a focus of discussion in regional workshops/forums</li> <li>▪ Any future program-wide evaluation activity prioritises accessing community outcomes in more detail</li> </ul>

## Disclaimer

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## Appendix A

## Program Logic

# Ability Links NSW Program Logic

## Ultimate outcome

*People with disability achieve their goals and are valued and equal members of the community*

### Longer term outcomes

- People with disability determine and achieve their goals using an appropriate mix of specialist disability and mainstream services, businesses and community groups/options
- People with disability actively engage with community groups and in community activities
- People with disability can access employment in line with specific goals
- People with disability, their families and carers have an improved quality of life
- Local services (disability specific and mainstream) and communities become advocates for change in relation to engagement and support for people with disability

### Intermediate outcomes

- People with disability have greater confidence and skills to plan for their future, make their own decisions and access support
- People with disability, their families and carers value and are satisfied with the support received from Ability Links
- Mainstream services, businesses and community groups are more inclusive of, and engage more effectively with, people with disability
- Specialist disability services connect more effectively with mainstream services and community groups to meet the needs of people with disability
- Culturally appropriate and respectful responses to the needs of Aboriginal people and CALD communities are developed

### Immediate outcomes

- People with disability, their families and carers are aware of and access Ability Links
- Effective relationships are established between participants and Linkers
- Specialist disability services, mainstream services, businesses and community groups rethink their response and approach to disability
- Ability Links, the NDIS and other services (specialist disability and mainstream) work together more effectively and efficiently to support the needs of people with disability

### Inputs and process outcomes

- Suitable service providers are selected and funded to establish Ability Links across NSW
- Appropriately skilled and experienced staff are recruited
- An effective learning and development strategy is developed to support future operations and program rollout
- Effective community and service system communications, promotion and relationship-building are commenced
- Good program management, monitoring, reporting and evaluation mechanisms are put in place

### Needs

- Community members who have disability support needs require a range of support and linkages to achieve their individual goals
- Specialist disability support services may not be best placed to provide this assistance
- The broader service system and community often lack the knowledge or awareness to effectively engage with and support people with disability

## Appendix B

## Summary of Providers

## ALNSW AND ELNSW PROVIDERS

Table 14 provides a summary of all ALNSW 9 to 64, ALNSW 0 to 64 and ELNSW 0 to 8 providers across the State as at June 2016.

TABLE 14 – ALNSW AND ELNSW PROVIDERS

ALNSW Provider	Type	Total Number of Linkers	Number of Early Linkers	FACS District
<b>Ability Links Providers 9 – 64 years</b>				
St Vincent de Paul Society in partnership with Settlement Services International	Generalist	35		South Western Sydney South Eastern Sydney Sydney
Uniting in partnership with Settlement Services International	Generalist	67		Northern Sydney Nepean Blue Mountains Western Sydney Illawarra Shoalhaven Southern NSW
North West Alliance (a partnership including Northern Rivers Social Development Council, Mid Coast Communities, Intereach, Pathfinders, and CareWest)	Generalist	64		Hunter New England Mid North Coast Northern NSW Murrumbidgee Western NSW Far West NSW
Kinchela Boys Home Aboriginal Corporation in partnership with Annecto - The People Network	Aboriginal	2		South Western Sydney Sydney
Ngurralla Aboriginal Corporation	Aboriginal	2		Mid North Coast
Illawarra Aboriginal Corporation	Aboriginal	2		Illawarra Shoalhaven
National Aboriginal and Torres Strait Islander Corporation, Community Transport Network	Aboriginal	5		Northern NSW
Booroongen Djugun Limited	Aboriginal	3		Mid North Coast Hunter New England
<b>Ability Links Providers 0 – 64 years</b>				
St Vincent de Paul Society	Generalist	44	9	Hunter New England Central Coast
CareWest Incorporated (North West Alliance)	Generalist	19	6	Western NSW Far West NSW
Jaanimili (Unitingcare Children, Young People & Families)	Aboriginal	10	7	South Western Sydney Western Sydney
Western Alliance Group (a partnership including Deniliquin Local Aboriginal Land Council (LALC), Orange LALC, Broken Hill LALC and Intereach)	Aboriginal	14	3	Western NSW Far West NSW Murrumbidgee
South Coast Medical Service Aboriginal Corporation	Aboriginal	3	1	Illawarra Shoalhaven Southern NSW
Sydney Region Aboriginal Corporation	Aboriginal	3	1	Nepean Blue Mountains Western Sydney Northern Sydney
Barkuma Neighbourhood Centre	Aboriginal	6	2	Central Coast Hunter New England
Kurrannya Aboriginal Corporation	Aboriginal	4	2	South Eastern Sydney Sydney
Winanga-Li Aboriginal Corporation	Aboriginal	6	1	Hunter New England

Cont'd

ALNSW Provider	Type	Total Number of Linkers	Number of Early Linkers	FACS District
<b>ELNSW Providers 0 – 8 years</b>				
Northcott	<b>Generalist</b>	<b>21</b>	<b>21</b>	Western Sydney Nepean Blue Mountains Northern Sydney Mid North Coast Northern NSW Hunter New England
Lifestart Cooperative Ltd	<b>Generalist</b>	<b>10</b>	<b>10</b>	South Eastern Sydney South Western Sydney
Koorana Child & Family Services	<b>Generalist</b>	<b>1</b>	<b>1</b>	Sydney
Mission Australia (Sydney City Mission)	<b>Generalist</b>	<b>3</b>	<b>3</b>	Illawarra Shoalhaven
Plumtree Pathways for Children and Families	<b>Generalist</b>	<b>3</b>	<b>3</b>	South Eastern Sydney Sydney
Ngambaga Bindarry Girrwa Community Services	<b>Aboriginal</b>	<b>1</b>	<b>1</b>	Mid North Coast
Muloobinba Aboriginal Corporation	<b>Aboriginal</b>	<b>1</b>	<b>1</b>	Nikinpa ACFC
Relationships Australia (NSW) Cullunghutti ACFC	<b>Aboriginal</b>	<b>1</b>	<b>1</b>	Cullunghutti ACFC
Centacare	<b>Aboriginal</b>	<b>1</b>	<b>1</b>	Mid North Coast
Bunjum Aboriginal Cooperative	<b>Aboriginal</b>	<b>1</b>	<b>1</b>	Northern NSW Ballina ACFC
Brewarrina Business Cooperative Ltd	<b>Aboriginal</b>	<b>2</b>	<b>2</b>	Brewarrina and Lightning Ridge

# Appendix C

# Site Visits

## SUMMARY OF SITE VISITS FOR 2016 EVALUATION

Table 15 provides a summary of the 23 site visits conducted to ALNSW and ELNSW locations between April and May 2016. For sites listed twice under ALNSW and ELNSW, Urbis conducted separate consultations with Ability Linkers, Early Linkers and management staff with a focus on both program types.

TABLE 15 – LOCATION OF 2016 SITE VISITS

<b>Providers</b>	<b>Location of Site Visit</b>	
<b>ALNSW site visits</b>		
Settlement Services International in partnership with St Vincent de Paul	1.) Woolloomooloo (SVDP) 2.) Ashfield (SSI)	
Uniting in partnership with Settlement Services International	3.) North Parramatta (Uniting)	
St Vincent de Paul Society	4.) Newcastle	Also an ELNSW provider
North West Alliance (a partnership including Northern Rivers Social Development Council, Mid Coast Communities, Intereach, Pathfinders, and CareWest)	5.) Lismore (Northern Rivers Social Development Council) 6.) Wagga Wagga (Intereach) 7.) Dubbo (CareWest)	CareWest is also an ELNSW provider
South Coast Medical Service Aboriginal Corporation	8.) Nowra	Also an ELNSW provider
Jaanimili (Uniting)	9.) Minto	Also an ELNSW provider
Sydney Region Aboriginal Corporation	10.) Harris Park	Also an ELNSW provider
Western Alliance Group (a partnership including Deniliquin Local Aboriginal Land Council (LALC), Orange LALC, Broken Hill LALC and Intereach)	11.) Deniliquin	Also an ELNSW provider
Barkuma Neighbourhood Centre	12.) Kurri Kurri	Also an ELNSW provider
<b>ELNSW site visits</b>		
St Vincent de Paul Society	13.) Newcastle	Also an ALNSW provider
CareWest Incorporated	14.) Dubbo	Also an ALNSW provider
South Coast Medical Service Aboriginal Corporation	15.) Nowra	Also an ALNSW provider
Jaanimili (Uniting)	16.) Minto	Also an ALNSW provider
Northcott	17.) Parramatta 18.) Coffs Harbour 19.) Ballina	
Lifestart Co-operative	20.) Miranda	
Mission Australia	21.) Shoalhaven	
CentaCare	22.) Port Macquarie	
Bunjum Aboriginal Co-op Ltd	23.) Ballina	



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