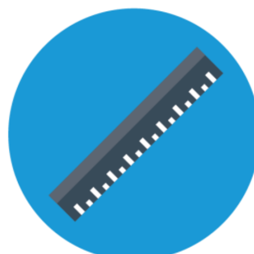
FIRST PERSON
CONSULTING

Evaluation of the Referral Decision Aid

Prepared for the

HealthWest Partnership and the Pathways for Children with Developmental Delays Alliance



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Executive Summary

Findings from the Australian Early Development Census (AEDC) demonstrated that the proportion of children identified as being developmentally vulnerable in Melbourne's west is increasing, in contrast to Victoria as a whole, which has seen a decrease in the proportion of developmentally vulnerable children in the same five year period (2009 to 2015). The Pathways for Children with Developmental Delays (PCDD) project was created to address this increasing need. The project was funded by the Department of Health and Human Services (DHHS) with the following objectives:

1. To have clarity about eligibility and pathways for public services for children with developmental delays in Melbourne's West
2. To have a set of recommendations for public service providers and funding bodies aimed at improving service coordination across the region.

During Phase 1 of the PCDD project, HealthWest led a process of in-depth consultation with local service providers, referrers and other stakeholders to identify system challenges and draft a set of recommendations in addressing these. As such, the PCDD Alliance[1] was established with the role of being responsible for progressing these recommendations. The key recommendations emerging from the aforementioned process of consultation were:

- Community health and hospitals align definitions of severity and 'areas' to domains used in the Australian Early Development Census (AEDC) and apply consistently.
- Community health and hospitals align eligibility criteria to ensure there are no gaps:
    - Community health align criteria to be mild delays in up to two areas, moderate delays in one area (except cognition), moderate delays in one area plus a secondary area of mild delay, and severe delays in communication skills only.
    - Hospitals align criteria to include moderate to severe delays in two or more areas.
- Development and dissemination of a tool or resource that would communicate alignment of eligibility criteria and improve referrals.

In actioning these recommendations, the Referral Decision Aid was developed by the PCDD Alliance. HealthWest led and facilitated this process by employing a Project Officer to coordinate the process. The Referral Decision Aid was launched **online** November 2017 and was initially **disseminated** via the HealthWest website resource page, the HealthWest monthly enewsletter, a stakeholder email list put together by the PCDD Alliance, dissemination within Alliance organisations including presentations to staff, emails to expanded stakeholder email lists based on initial responses and enquiries, and additional invited presentations and events.

Evaluation of the Referral Decision Aid

An evaluation of the Referral Decision Aid was undertaken by First Person Consulting (FPC) in July-August 2018 which focused on the **reach**, **usability, effectiveness and outcomes** of the Referral Decision Aid. In this evaluation, the evaluators:

[1] Alliance member organisations include HealthWest Partnership, Western Health, Djerriwarrh Health Service, cohealth, IPC Health, Royal Children's Hospital, Early Childhood Intervention Service (ECIS) intake, Department of Health and Human Services (Western Region)

- Explored the steps taken to develop the tool and what worked and did not work about this process
- Established a sense of the reach of the Referral Decision Aid and finding out what factors influenced its uptake
- Identified the short term outcomes and developing a narrative around what these short term outcomes might indicate in terms of ongoing impact and benefit of the Referral Decision Aid.

Data collection included:

- Collation of survey responses to an initial feedback survey that was designed and distributed by HealthWest in November 2017 (n=5)
- An evaluation survey designed by FPC and sent to referrers in the region (n=29)
- Interviews with referrers to explore the usability of the tool, their personal-professional experiences of using the tool, and the outcomes of using the tool including: Preschool Field Officers (n=2); Early Childhood Educators (n=2); and Maternal and Child Health Nurse (n=1)
- Interviews with a sample of clinicians providing services to children in the region (n=3)
- Interviews with a sample of representatives from the PCDD Alliance (n=4)

Key Findings

Process and partnership

The process of developing the Referral Decision Aid was described as collaborative and cooperative. Those who had been a part of the process particularly appreciated the willingness from Alliance members to be open about professional opinions and organisational referral processes with the rest of the group. Most participants who were employed by Alliance organisations were satisfied with the process and with the outcome. The two main aspects of the development and dissemination of the Referral Decision Aid that were identified as areas for improvement were the dissemination of the resource and the involvement of referrers and clinicians in the processes of both development and dissemination. The majority of participants believed that the Referral Decision Aid has a role in supporting referrers to make appropriate referrals and that the tool itself could be replicated for other regions or for other service pathways. The key to achieving this would be to follow a similar process ensuring that clinicians in all key service provider organisations are consulted during the development phase.

Reach, uptake and usability

The data indicated that the Referral Decision Aid is still unknown to a large proportion of referrers in the region. There is sufficient evidence to indicate that there are referrers in the region who are currently using the Referral Decision Aid and/or would be interested in and potentially use the tool if they were made aware of it, particularly Early Childhood Educators and Preschool Field Officers. There was also some indication that certain groups of referrers, in particular some Maternal and Child Health Nurses, had not responded to the Referral Decision Aid as something they would use at this time, largely due to already having a decision-assisting tool internal to their organisation. Others however had used the tool. It should also be noted that the majority of Maternal and Child Health Nurses still saw value in disseminating the Referral Decision Aid as a tool to support other

groups of referrers. For example, 80% of survey respondents said that they had either shared the Referral Decision Aid with others or intended to do so and three quarters of survey respondents said the Referral Decision Aid was relevant to them in their role.

These findings should be interpreted in light of the relatively brief amount of time that the Referral Decision Aid has been available (eight months at the time when this evaluation commenced) and the complexity of current referral pathways, evidence of practitioner concerns about inappropriate referrals, and the widely shared concerns about excessive waiting times for services.

On the whole, the data indicated that the Referral Decision Aid was seen as a clear and easy to use tool that is fit-for-purpose for referrers working with children with developmental delay that may contribute to a reduction in inappropriate referrals. The feature that respondents most commonly appreciated was the clear, step-by-step flowchart format. A number of improvements were suggested and these are reported in the main evaluation report.

Outcomes and impact

Just over half the survey respondents who had seen the Referral Decision Aid prior to completing the survey said they had used it to assist them with making referrals. These included Early Childhood Educators, Maternal and Child Health Nurses, Preschool Field Officers, and Clinicians. These referrers reported that the Referral Decision Aid had increased their knowledge of appropriate referral pathways.

Early Childhood Educators, Maternal and Child Health Nurses and Service Coordinators reported feeling more confident in referring children to the correct service with the Referral Decision Aid than without it (40% of survey respondents). Survey respondents who felt equally confident in referring children **with and without** the Referral Decision Aid (no difference) included a Paediatrician, Preschool Field Officers, and Maternal and Child Health Nurses (52% of survey respondents).

Only 36% of survey respondents felt more confident that children will receive the service they need quickly and easily with the Referral Decision Aid than without it. A total of 64% of survey respondents reported that the Referral Decision Aid did not make a significant impact on their confidence that children with receive the service they need quickly and easily **because waiting times for all services are excessively long**. These issues were identified by participants as being beyond the scope of the Referral Decision Aid.

Unintended and unexpected outcomes

A number of unexpected ways of using the Referral Decision Aid emerged in the evaluation including evidence of clinicians and referrers using the Referral Decision Aid with families to explain why they are being referred to Early Childhood Intervention Services (ECIS). In doing so, clinicians have reported that families find this extremely useful in understanding what to expect from the referral process and the role of ECIS and the new Early Childhood Early Intervention (ECEI) services under the NDIS.

The process of developing the Referral Decision Aid depended upon the Alliance members being willing to compare referral pathways and service eligibility criteria, highlighting inconsistencies and attempting to identify ways to address these as an Alliance. The identification of potential gaps in service provision and inconsistencies between existing referral pathways have been further

strengthened through the dissemination of, and feedback on, the Referral Decision Aid. This has added to the knowledge of the referral networks that the PCDD Alliance can respond to moving forward.

Implications for the Referral Decision Aid in the context of the NDIS

A number of participants commented on the importance and relevance of the Referral Decision Aid and its potential helpfulness in clarifying referral pathways that will change as the transition to the National Disability Insurance Scheme (NDIS) begins in the region. The data indicated that referrers and service providers are still in the process of discovering what the NDIS service system will mean for the eligibility of children with developmental delays for various services and there is a high degree of confusion among practitioners. However, potentially 'minor' revisions that can be made to the Referral Decision Aid mean that it can continue to have a role in providing referral information in the interim period as the NDIS rolls out. Making minor or major changes to the Referral Decision Aid will require ongoing funding support.

Key lessons learned

- A collaborative 'Alliance' approach is an effective means for bringing key players together to address system-level complexity but can be strengthened by ensuring that all parties feel represented in the process
- As referrers are the key end-users of the Referral Decision Aid, their involvement in planning the dissemination of the tool is essential
- Targeted dissemination requires process and may require increased dissemination capacity in order to ensure that the Referral Decision Aid reaches the more isolated referrers who appeared to consider the tool to be very valuable
- In the short term, the reach and uptake of the Referral Decision Aid may be difficult to track but in the longer term there will be a range of benefits of tracking of the impact of the Referral Decision Aid

Recommendations

In light of the key findings discussed in this evaluation report, the following Recommendations are offered:

1. The PCDD Alliance should continue to invest time and resources into improving referral outcomes for children with developmental delays
2. The PCDD Alliance should continue efforts to build relationships with a range of referrers and find out more about how to reach Early Childhood Educators and investigate their current obstacles and challenges in making referrals
3. The PCDD Alliance should invest in planning for ongoing strategic dissemination of the Referral Decision Aid **after** the Alliance has considered the most appropriate next steps in light of the NDIS transition and any necessary changes to the Referral Decision Aid
4. A second version of the Referral Decision Aid should be developed in collaboration with the NDIS ECEI Partner, incorporating changes to referral pathways implied by the NDIS transition to ensure referral pathways remain as smooth as possible during transition

5. The PCDD and NDIS ECEI Partner should identify referral pathways for children who will not be eligible for support through the NDIS, such as those who are ineligible on the grounds of residency status
6. The PCDD Alliance should advocate for funding and support to review the role of, and capacity for, early childhood educators to create referrals
7. Targeted dissemination efforts should include and focus on networking events for Early Childhood Educators, such as those organised by Early Childhood peak bodies
8. The PCDD Alliance should review mechanisms for incorporating feedback from a range of clinicians within Alliance organisations into the processes of revising and agreeing on the content of the Referral Decision Aid
9. The PCDD Alliance should review mechanisms for communicating changes in the Referral Decision Aid and agreed domains and definitions back to clinicians and child health teams at Alliance organisations as referrers and clinicians will need clear information and support during the transition to the NDIS
10. The PCDD Alliance should advocate for funding and support to identify next steps in addressing system weaknesses such as excessive waiting times and the increasing need in the region for timely early intervention services for preschool children
11. The PCDD Alliance should present these findings to the Department of Health and Human Services and seek clear guidance about State-wide strategies to address regional system gaps such as children being referred to the wrong services and compounding impacts on excessive waiting times

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Acronyms

AECD Australian Early Development Census

DHHS Department of Health and Human Services

ECEI Early Childhood Early Intervention

ECIS Early Childhood Intervention Services

FPC First Person Consulting

LGA local government area

MCHN Maternal and Child Health Nurse

NDIS National Disability Insurance Scheme

PSFO Preschool Field Officer

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1 Background

1.1 The Pathways for Children with Developmental Delays project

Findings from the Australian Early Development Census (AEDC) have demonstrated that the proportion of children identified as being developmentally vulnerable in Melbourne's west is increasing. This is in contrast to Victoria as a whole, which has seen a decrease in the proportion of developmentally vulnerable children in the same five year period (2009 to 2015).

Illustrating this, the percentage of children identified as being developmentally vulnerable on one or more domain of development[2] decreased by 0.4% across Victoria as a whole, and Australia as a whole saw a decrease of 1.6%. However, while the proportion across the whole of Melbourne's west only increased by 0.1% during the same five year period, the proportion of children in this category **increased by 3.9% in Brimbank, 1.4% in Melton, and 2.5% in Wyndham[3]**.

Similarly, the proportion of children identified as being developmentally vulnerable on two or more domains decreased across Victoria (0.1% decrease) and Australia as a whole (0.7% decrease), while two of the five local government areas (LGAs) in Melbourne's west have seen significant increases. **In particular, the proportion of children in the Brimbank LGA identified as developmentally vulnerable on two or more domains increased by 4.9% during this period, while the increase in Melton was 1.9%[4].**

The Pathways for Children with Developmental Delays (PCDD) project grew out of the realisation among key service providers that these findings reflect a rapid increase in the prevalence of children with developmental delays in key parts of Melbourne's west. Preschool children in the region that have been identified as having developmental delay are typically referred to community health services, hospital based services, and Early Childhood Intervention Services (ECIS).

From October 1 2018, the National Disability Insurance Scheme (NDIS) will become available in the Melbourne's west. This will mark the commencement of a transition that will affect all of the aforementioned service providers and referral pathways for children with developmental delay in the region. As the NDIS partner for early childhood early intervention services (ECEI), the Brotherhood of St Laurence (BSL) will become the key ECEI service provider for children aged 0-6 with a disability or developmental delay in the region. The PCDD Alliance identified the need to build communication and alignment between services in order to help prepare for and respond to changes as required by NDIS, and ensure a smoother implementation for the regional ECEI provider (BSL).

The Department of Health and Human Services (DHHS) provided funding towards the PCDD project with the aim of developing a clearer and more streamlined service system that better prepares for meeting the growing demand for services for children with developmental delays in the region.

[2] AEDC domains of development are: Physical health and well-being; Social competence; Emotional maturity; Language and cognitive skills; Communication skills and general knowledge.

[3] Based on data provided by the Australian Early Development Index (www.australianaedi.org.au)

[4] Based on data provided by the Australian Early Development Index (www.australianaedi.org.au)

The key objectives of the PCDD project were:

1. To have clarity about eligibility and pathways for public services for children with developmental delays in Melbourne's West
2. To have a set of recommendations for public service providers and funding bodies aimed at improving service coordination across the region.

During Phase 1 of the PCDD project, HealthWest led a process of in-depth consultation with local service providers, referrers and other stakeholders to identify system challenges and draft a set of recommendations for next steps in addressing these. The main challenges identified through this process related to inconsistencies in eligibility criteria, variability in referral and intake processes, and a number of factors stemming from high levels of vulnerability, disadvantage and cultural and linguistic diversity in the region.

As such, an advisory committee was established during Phase 1 of the project as a collaborative of practitioners working for key service providers in the region with the role of progressing recommendations from the PCDD project. The PCDD Alliance was born from this advisory group with an expanded role in developing a joined-up service response to concerns about the increasing demand for services for children with developmental delay in the region. The overall aim of the PCDD Alliance is to develop a more equitable and responsive service system that better meets the growing and changing demand for services for children (aged 0 to school entry) with developmental delays in Melbourne's west.

1.2 The Referral Decision Aid

The key recommendations emerging from the aforementioned process of consultation were:

- Community health and hospitals align definitions of severity and 'areas' to domains used in the AEDC and apply consistently.
- Community health and hospitals align eligibility criteria to ensure there are no gaps:
  - Community health align criteria to be mild delays in up to two areas, moderate delays in one area (except cognition), moderate delays in one area plus a secondary area of mild delay, and severe delays in communication skills only.
  - Hospitals align criteria to include moderate to severe delays in two or more areas.
- Development and dissemination of a tool or resource that would communicate alignment of eligibility criteria and improve referrals.

In actioning these recommendations, the Referral Decision Aid (Figure 1 & Figure 2) was developed by the PCDD Alliance. HealthWest led and facilitated this process by employing a Project Officer to coordinate the process[5]. This process commenced in January 2017 and the PCDD Alliance met regularly over a period of nine months until agreement was reached on consistent domains and definitions that could be used across the region. The domains that were agreed upon align with the AEDC domains but are presented in the Referral Decision Aid as three domains rather than five. The developmental domains that were agreed upon are:

[5] Three people were employed in the Project Officer role during this period and the role was sometimes vacant for brief periods. The role was a 0.4 FTE position.

1. Physical health and wellbeing
2. Communication skills and cognition
3. Social competence and emotional maturity

Definitions of severity were drawn from AEDC definitions as well as definitions commonly in use among services in the region. The resulting definitions used in the Referral Decision Aid focused on functional impacts of delays in order to align with NDIS access guidelines.

Once the PCDD Alliance had reached agreement on the domains and definitions of severity, the team began mapping current referral pathways and identifying existing service provision across the Alliance organisations. This led to the identification of inconsistencies and gaps between services and between referral pathways and intake processes. As a result, the PCDD Alliance was then able to consider a range of options for ways to reduce inconsistencies and address gaps in referrals and barriers to children and families accessing appropriate services in a timely manner.

Gradually a set of referral pathways were consolidated into a two page tool that could provide a visual decision aid for referrers. As each draft of the tool was produced, it was then circulated among the Alliance organisations for comment and extensive feedback. This included two feedback surveys which were sent to referrers (Survey A) and clinicians (Survey B) in May 2017. Feedback was received via these surveys from ten clinicians and three referrers.

In September 2017, after a process of drafting and revising the tool, the PCDD Alliance arrived at a two page version of the Referral Decision Aid that all parties signed off on. A six week process of creating a suitable graphic design for the Referral Decision Aid then followed and during this six week period the PCDD Alliance developed plans for dissemination of the tool to the key audiences. The final version of the Referral Decision Aid is shown in Figure 1 and Figure 2. The PCDD Alliance disseminated the Referral Decision Aid as a tool that would be current until October 2018 when the transition to the NDIS would commence.

The Referral Decision Aid was launched **online** November 2017 and was initially **disseminated** via the following channels:

- The HealthWest website resource page
- The HealthWest monthly enewsletter (Dec 2017 and Apr 2018)
- Emailed to a stakeholder email list put together by the PCDD Alliance (Mailchimp email campaign) including recipients in the following categories:
    - Maternal and Child Health teams
    - Early Years teams at all councils in the region
    - Victorian Department of Health and Human Services
    - Victorian Department of Education and Training
    - PCDD Alliance organisations
    - Child FIRST and family services teams
    - Any other existing contacts or interested stakeholders
- Dissemination within Alliance organisations including presentations to staff
- Emailed to recipients on expanded stakeholder email lists based on initial responses and enquiries
- Shared on:

  - North West Melbourne Primary Health Network (PHN) Health Pathways site
  - Brimbank Children and Families newsletter (Dec 2017)
  - Western Melbourne Children and Youth Area Partnership newsletter (Dec 2017)
- Presentations including:
  - **Referral Decision Aid launch celebration event** (Dec 2017)
  - Additional scheduled presentations at various reference group, committee meetings, forums, and group meeting events across the region (between Nov 2017 and May 2018)

The Project Officer has continued to respond to various opportunities and requests for ongoing dissemination and will continue to do so until the findings of this evaluation have been considered in light of the commencement of the transition to the NDIS in October 2018.

REFERRAL DECISION AID

For children with developmental delays in Melbourne's west
(zero to school-aged)

This guide will help referrers understand referral pathways for services.
Valid until implementation of the National Disability Insurance Scheme (NDIS).
Implementation in Melbourne's west is planned to commence October 2018.

STEP 1 IDENTIFY THE DEVELOPMENTAL DOMAINS WHERE DELAYS ARE PRESENT

DOMAIN 1 PHYSICAL HEALTH AND WELLBEING	DOMAIN 2 COMMUNICATION SKILLS AND COGNITION	DOMAIN 3 SOCIAL COMPETENCE AND EMOTIONAL MATURITY
– Fine motor – Gross motor – Coordination – Self care – Dressing – Toileting – Sensory – Eating, drinking and swallowing	– Understanding – Using words and language – Speaking clearly – Voice, fluency (including stuttering) – Thinking, ideas and learning skills – Problem solving – Play skills	– Social and emotional regulation (e.g. tantrums, impulsivity) – Self confidence – Social relationships – Behaviour – Separation – Attention

STEP 2 IDENTIFY THE SEVERITY OF THE DELAY IN **EACH DOMAIN** [✓]

Domain 1			Domain 2			Domain 3		
☐ MILD	☐ MODERATE	☐ SEVERE	☐ MILD	☐ MODERATE	☐ SEVERE	☐ MILD	☐ MODERATE	☐ SEVERE

MILD
- Skills/function a little less advanced or show a minor difference to the child's peers, AND/OR
- Child needs occasional support from adults to participate in activities.

MODERATE
- Skills/function noticeably less advanced or different to child's peers, AND/OR
- Child needs regular support from adults to participate in activities.

SEVERE
- Child has disability or substantial functional limitations that prevent them from participating in activities in the same way as their peers.

STEP 3 IDENTIFY THE MOST APPROPRIATE LOCAL SERVICE FOR REFERRAL

DOES THE CHILD HAVE:	DOMAIN OF DELAY:	RECOMMENDED REFERRAL:
Severe delay/s (YES)	In **2 or more** domains	Hospital Allied Health and ECIS and Paediatrician
Severe delay/s (YES)	In **1 domain**, with moderate or mild delay/s in other domains	Hospital Allied Health and ECIS and Paediatrician
Severe delay/s (YES)	In **1 domain** only (excl. stutter*)	Paediatrician → Child is unlikely to have 1 severe delay only, refer to paediatrician for assessment
Severe delay/s (YES)	*Stutter only	Community Health
Severe delay/s: NO → Moderate delay/s (YES)	In **2 or more** domains	Hospital Allied Health and ECIS
Moderate delay/s (YES)	In **1 domain**, with or without mild delay/s in other domains	Community Health
Moderate delay/s: NO → Mild delay/s only (YES)		Community Health

There may be rare exceptions to this process. In these instances please contact the relevant service before referring.

Figure 1. Referral Decision Aid (front page)

STEP 4 COMPLETE APPROPRIATE REFERRAL PROCESS FOR THE SELECTED SERVICE

CONCURRENT REFERRALS:

- Children referred to a **hospital-based allied health service** should also be referred to the **Early Childhood Intervention Service (ECIS)** intake service. This will ensure they are included in the transition process to the NDIS agreed by Victoria and the Commonwealth.
- Children referred to a **hospital-based allied health service with severe delay/s** must also be referred to a **Paediatrician** for a paediatric assessment. This will ensure they receive the most appropriate services.

PAEDIATRICIAN

If the child does not currently have a Paediatrician, they will need to see their GP for a referral.

This applies to both public and private Paediatricians.

COMMUNITY HEALTH SERVICES

cohealth
LGAs Maribyrnong, Moonee Valley, Melbourne and parts of Brimbank (when cohealth is the closest service)
Phone (03) 9448 5521
Fax 7000 1827
Email serviceaccess@cohealth.org.au
www.cohealth.org.au

Djerriwarrh Health Service
Melton Community Health Centre and Caroline Springs Community Health Centre
LGA Melton
Phone (03) 9747 7609
www.djhs.org.au

IPC Health
LGAs Brimbank, Hobsons Bay and Wyndham
Sunshine (03) 9296 1200
Hobsons Bay (03) 8368 3000
Hoppers Crossing (03) 8734 1400
www.ipchealth.com.au

Contact organisations for additional information about services and referral process.

PLEASE NOTE

Wait lists can apply for public providers, families may prefer to see a private provider.

Some private providers are listed on the National Health Services Directory website: https://about.healthdirect.gov.au/nhsd

HOSPITAL-BASED ALLIED HEALTH SERVICES

Djerriwarrh Health Service (Melton Health)
LGA Melton
Phone (03) 9747 7603
www.djhs.org.au

Western Health (Sunshine Hospital) Children's Allied Health Service (CAHS)
LGAs Brimbank, Hobsons Bay, Maribyrnong and Wyndham
Phone (03) 8345 1430
www.westernhealth.org.au/services/cahs

Royal Children's Hospital (RCH)
LGAs Moonee Valley and Melbourne
Phone (03) 9345 5522
www.rch.org.au/outpatient/referrals/
To access RCH allied health services, a paediatric assessment is usually required before a referral can be made.

Refer to websites or contact organisations for additional information about services and referral process.

EARLY CHILDHOOD INTERVENTION SERVICE (ECIS)

Department of Education and Training
LGAs Brimbank, Melbourne, Hobsons Bay, Maribyrnong, Melton, Moonee Valley and Wyndham
Phone (03) 8397 0263 (Duty Line)
Email ecis.intake.swvr@edumail.vic.gov.au
Mail P.O. Box 2141, Footscray, 3011
Referral forms available at **www.education.vic.gov.au/childhood/parents/needs/Pages/ecis.aspx**
Referral forms to be emailed or mailed as above.

Produced October 2017 by HealthWest Partnership and project partners. For more information visit **www.healthwest.org.au**

Figure 2. Referral Decision Aid (back page)

2 Evaluation of the Referral Decision Aid

2.1 Scope of the evaluation

The scope of this evaluation was to undertake an evaluation that encompasses the development and dissemination of the Referral Decision Aid from its inception until the present day. The evaluation focused on the **reach**, **usability, effectiveness and outcomes** of the Referral Decision Aid, and on the process by which it was developed.

This was a **process and impact evaluation, focusing on evidence of short and medium term outcomes.** In this evaluation, the evaluators:

- Explored the steps taken to develop the tool and what worked and did not work about this process
- Established a sense of the reach of the Referral Decision Aid and finding out what factors influenced its uptake
- Identified the short term outcomes and developing a narrative around what these short term outcomes might indicate in terms of ongoing impact and benefit of the Referral Decision Aid.

The evaluation framework is provided in Section 2.3.

2.2 Overview of evaluation methodology

The evaluation was carried out during July and August 2018. An evaluation plan was developed in consultation with the Project Officer and some members of the PCDD Alliance and the methodology included the following key steps. The evaluation methodology is outlined in detail in Appendix 1. The key stages of the evaluation were:

- An **inception meeting** to get to know each other and familiarise the team with the background and context of the Referral Decision Aid, and finalising project management processes.
- A high level **review of key documents** related to the Referral Decision Aid and its history and context, as well as any existing data.
- A **brief targeted process of stakeholder consultation**, in which we spoke with four key members of the PCDD Alliance, including the Project Officer, and were able to identify and further clarify the particular areas of interest that should guide the evaluation.
- At this point we synthesised what we have heard and read in order to develop and **present the evaluation plan**.
- **Data collection** included:
    - A follow up survey sent to referrers who may be aware of the Referral Decision Aid (referred to as the evaluation survey)
        - A total of 29 people responded to this survey
    - Collation of survey responses to a ‘first impressions’ survey that was designed and distributed by HealthWest in November 2017 (referred to as the HealthWest survey)
        - A total of five people responded to this survey
    - Interviews with referrers to explore the usability of the tool, their personal-professional experiences of using the tool, and the outcomes of using the tool

    - A total of five referrers were interviewed including Preschool Field Officers (n=2), Early Childhood Educators (n=2), and Maternal and Child Health Nurse (n=1)
  - Interviews with a sample of clinicians who were willing to comment on the Referral Decision Aid and its impact and reach, as well as any comments on the process by which it was designed
    - A total of three clinicians were interviewed
  - Interviews with a sample of representatives from the PCDD Alliance to find out a) whether they have noticed any changes in the referrals they have received and b) their reflections on the process used to develop the Referral Decision Aid and what worked and what did not work in this process
    - A total of three Alliance members plus the Project Officer were involved in the initial consultations at the evaluation planning stage, and a further two Alliance members plus the Project Officer were interviewed during the data collection period
- **Data analysis** involved **descriptive statistical analysis and thematic analysis of qualitative data**.
- We then presented the preliminary findings to the Project Officer and Executive Officer of HealthWest and used these as prompts for a discussion to inform the direction and structure of the final evaluation report.
- Integrating feedback from the presentation of preliminary findings, we developed a **comprehensive draft evaluation report** and polished this to become **a final draft**.

2.3 Evaluation Framework

An overview of the key evaluation questions and sources of data that will be used as evidence is outlined in Table 1.

Table 1. Evaluation Framework

Areas of interest	Key evaluation questions	Sub-questions	Evidence & Data sources
Process and partnership	1. What worked and did not work in the steps taken to develop the Referral Decision Aid?	a) What were the steps of the process that were most essential to the development and dissemination of the Referral Decision Aid? b) To what extent could these steps be replicated? c) How easy would it be to adapt the Referral Decision Aid so that it could be implemented in other regions? d) What are the key lessons learned at this stage of the implementation of the Referral Decision Aid?	Review of meeting minutes Review of project report Mapping process of development and identifying implications and considerations of scaling Interview with the Project Officer and representatives from Alliance organisations
Reach and uptake	2. What is the extent of the reach of the Referral Decision Aid within the target region(s)?	a) To what extent has the uptake of the Referral Decision Aid met expectations? b) What were the factors influencing uptake?	Mailchimp analytics Follow up survey to referrers Interviews with referrers Interviews with key service providers (members from Alliance organisations)
Usability	3. How usable is the Referral Decision Aid from the perspective of a range of key stakeholders?	a) What do referrers and other key stakeholders like most about the Referral Decision Aid? b) Is there anything that could be changed to improve the usability of the Referral Decision Aid and make it more useful to referrers?	Follow up survey to referrers Interviews with referrers
Outcomes and impact	4. What are the short and medium term outcomes associated with the Referral Decision Aid? 5. What have been the ongoing impacts and value of the Referral Decision Aid?	a) What are the implication for the long term usefulness of the Referral Decision Aid in light of the changing environment and the findings of this evaluation?	All data

2.4 Limitations of the evaluation

It was identified in the planning stage of this evaluation that the key participant groups for this evaluation were:

- Referrers who may or may not have used the Referral Decision Aid including:
  - Preschool Field Officers (PSFOs)
  - Maternal and Child Health Nurses (MCHNs)
  - Early Childhood Educators (educators)
- Clinicians working for organisations that provide services for children with developmental delay within Melbourne's west
- Members of the PCDD Alliance

A key limitation of this evaluation is that it was challenging to recruit participants to be interviewed within the evaluation period. The final number of participants for each of these key informant groups is shown in Table 2.

Table 2. Participant numbers

	Survey respondents	Interviewed
Maternal and Child Health Nurses	5	1
Preschool Field Officers	2	2
Early Childhood Educators	4	2
Clinicians (identified under 'Other' plus manual entry of job role in comments box)	9	3
Other job roles identified on survey[6]	9	n/a
Members of the PCDD Alliance	n/a	3 x initial consultations during evaluation planning 3 x interviews during data collection

Interestingly, the majority of participants (n=18) who did respond to the survey identified their current role as 'Other', indicating that they were not MCHNs, PSFOs, or early childhood educators. This finding will be discussed further in Section 3 as it may be indicative of a number of factors that are of relevance to the effectiveness and reach of the Referral Decision Aid. Please note, the *clinicians* identified in Table 2 identified themselves under the 'Other' category in the survey but entered their current job role in the comments box. The total number of survey responses was 29.

[6] Cited job roles included: Project Officer, Pathways Worker, Coordinator, Manager/Management, Receptionist, Key Worker, Case Manager

3 Key findings

3.1 Process and partnership

The process of developing the Referral Decision Aid was described as collaborative and cooperative. Those who had been a part of the process particularly appreciated the willingness from Alliance members involved in the process to be open about professional opinions and organisational referral processes with the rest of the group. This was seen as essential to achieving a good outcome because the group needed to collaborate to develop a tool that gave an accurate picture of the referral pathways for children with developmental delay in the region.

> *"[It was an] incredibly cooperative group, no doubt driven by the fact that everybody really has children's needs at heart" (Alliance member)*
>
> *"Everybody putting cards on the table about what they dealt with and then refining it" (Alliance member)*
>
> *"The willingness of everybody to be open about the situation" (Alliance member)*

Most Alliance members who were interviewed were satisfied with the process and with the outcome and it was stressed that there was an emphasis on reaching consensus which took a long time and a lot of communication between members of the PCDD Alliance, as well as cycles of revisions of the Referral Decision Aid.

> *"It really does help define what are appropriate referrals" (Alliance member)*
>
> *"It was a tightly scoped approach … we put pretty definite boundaries around the project … lots of other services we could have brought in but we wanted to keep it simple to get something done even if its small … if its useful let's build on in it in the future" (Alliance member)*

The process of circulating drafts of the Referral Decision Aid for ongoing expert feedback was mostly seen as a positive process by those who were directly involved.

> *"A colleague brought back many draft versions … [there was a] long consultation period for many stakeholders to have lots of input … sounds like a really positive process [with a] good range of people involved … all the right players" (Alliance member)*
>
> *"We changed our referral forms to match the Referral Decision Aid … that was a really good learning we hadn't thought about earlier … being exposed to new ways of thinking was a real positive" (Clinician)*

However, several participants employed by one of the Alliance organisations did not feel that their team had been adequately involved in the process.

> *"… not a lot of opportunity to be involved, emails got lost … [I feel] our voice would should have been heard" (Clinician)*
>
> *"Sometimes surveys came through and sometimes they didn't … this prevented senior therapist involvement" (Alliance member)*

The two main aspects of the development and dissemination of the Referral Decision Aid that were identified as areas for improvement were the dissemination of the resource and the involvement of referrers and clinicians in the processes of both development and dissemination. As previously stated, response rates to the surveys used to gather feedback from referrers and clinicians were during the development of the Referral Decision Aid were lower than hoped (referrers = three; clinicians = ten). There were however clinicians among the PCDD Alliance members and several of the referrers who were interviewed in this evaluation stated that they had provided feedback during the development process.

> *"It's hard to know how the individual referrers are responding to it … Maybe we needed to have consultation with the referrers who were actually going to be using the tool which could have been much more complicated" (Alliance member)*
>
> *"Referrers were part of the initial consultation but they weren't include beyond that" (Alliance member)*
>
> *"The Aid hasn't been distributed widely from the beginning … [this] had a huge impact on the use of it" (Alliance member)*

There was evidence of strategic targeted dissemination of the Referral Decision Aid through known channels, led by the Project Officer and members of the Alliance. The challenge to more extensive dissemination appeared to be partly due to gaps in knowledge around how to reach sub-groups of referrers such as staff working in childcare centres. Several participants made comments concerning the need to target dissemination efforts and identify ways to reach these more isolated referrers, such as Kindergarten teachers. This is something that can be a priority moving forward with the ongoing dissemination of the tool.

> *"… trying to find streams where we can filter down … train the top person to disseminate down" (Clinician)*
>
> *"The hole in the system is childcare centres and childcare workers because I don't know who is the over-arching … I wouldn't know where to start … I still don't know who to contact to say look here's a referral decision aid, it's really important … wouldn't know how to get this out to all the childcare centres" (Clinician)*

In light of what worked well and the areas for improvement, the **most essential steps in the process** of developing a Referral Decision Aid appeared to be:

- Making sure that there was buy-in and commitment from all Alliance organisations at a senior level
- Setting parameters for the project and establishing the boundaries to the scope and purpose of the project
- Making sure that there was a Project Officer to drive the process but who remained neutral and open to suggestions from all parties
- Committing to and sticking to a process of talking through each component of the Referral Decision Aid one step at a time and investing time in addressing any discrepancies between the different professionals or organisations represented

- Making the most of the expert input of those that were part of the process and sending out multiple versions of the Referral Decision Aid for comment
- Adhering to the commitment to reaching consensus as the ultimate foundation of the approach taken to the develop the Referral Decision Aid

The majority of participants believed that the Referral Decision Aid could be replicated in other regions or for other service pathways. The key to achieving this would be to follow a similar collaborative process incorporating the essential steps identified above, and in doing so, the differences between service providers would come to light if the PCDD Alliance were open enough and felt their opinion was welcomed and heard.

> *"I think it should work well anywhere except that the wording ECIS needs to be changed to ECEI NDIS" (Alliance member)*

> *"I think it could definitely work in other regions … The only thing is where there are services that have multiple streams within them … other services in other regions might do both … they are going to make their own decisions" (Alliance member)*

3.2 Reach and uptake

Having mapped referral pathways across the region, the PCDD Alliance also identified the groups of referrers and other key stakeholders who might have use for the Referral Decision Aid. This led to the targeted dissemination processes outlined on page 6.

Mailchimp[7] analytics from the initial Mailchimp email campaign created and initiated by HealthWest (Table 3) indicated that a proportion of the 81 original recipients forwarded the email on, leading to an additional **1641 opens of the email**. Of the 1679 total email opens across this campaign, there were **247 clicks on a link within the email**.

Table 3. Reach of initial Mailchimp dissemination campaign (collated by HealthWest)

Method	Original Mailchimp email campaign	Further email mail-outs from Alliance members	Total
Email campaign recipients	81	Not applicable	Not applicable
Opens	38	1641	1679
Click-throughs (clicking on a link within the email)	24	223	247

Several participants commented that recent interactions with other practitioners in the region indicated that people had come across the Referral Decision Aid and expressed an interest in it. This indicates that there has been additional dissemination and passing on the tool across the region that the PCDD Alliance is at this stage unaware of.

[7] Mailchimp is a marketing automation platform

"When I run into people at meetings and networks … [I have been] chatting to people who I don't know and people say 'I've seen [the Referral Decision Aid] … we think it's a great tool and we've sent it on' … a really good sign that it is being passed on" (Alliance Member)

"Lots of kinders and early childhood centres are taking the tool to use … the tool has been sent around to kinders and other centres" (Alliance member)

"Melton Council asked for 80 copies to send out to all centres" (Alliance member)

Conversely, several Alliance members commented that they have had interactions with practitioners who are potential referrers who had not yet seen the tool. As such, several participants commented on the challenge of mapping the **actual** reach of the tool and to the target audience in particular.

"I have shown it to referrers when I've been to their meetings … it was like they had seen it for the first time … More disseminating to the people that need it [is needed]" (Alliance member)

"Really really difficult to say [whether the Referral Decision Aid has reached the target audience]" (Alliance member)

The response rates to the evaluation survey are an indication of the dissemination pathways that are currently being used to distribute information about the Referral Decision Aid across existing networks within the region with Alliance organisations being the point of origin for these communications. Likewise, the responses to the evaluation survey may indicate a number of things including which groups of practitioners are interested in the tool and engaged enough to provide their feedback[8]. Table 4 shows the distribution of survey respondents across the professional roles listed as survey responses options.

Table 4. Evaluation survey respondents' current role

	Maternal & Child Health Nurse	Preschool Field Officer	Early Childhood Educator	Other
Number of responses	5	2	4	18

The high proportion of evaluation survey respondents selecting the 'Other' category may be an indication of categories of practitioners that are interested enough in the Referral Decision Aid to complete the survey. Below is a complete list of the job roles that were recorded by those who selected the 'Other' category:

- Physiotherapist
- Allied Health Manager
- General Practitioner
- ECIS Key Worker
- Coordinator, Disability Service / Aged & Disability Services

[8] We also acknowledge that there are a range of other reasons why participants may complete the survey.

- Receptionist
- Management/Manager
- Speech pathologist
- Occupational Therapist
- Pathways Worker
- Paediatrician
- Project Officer
- Paediatric Occupational Therapist
- Paediatric trainee
- Family Services Case Manager

Of the 29 evaluation survey respondents, 16 (55%) had seen the Referral Decision Aid prior to completing the evaluation survey. Those that had seen the Referral Decision Aid prior, said that they were made aware of it via:

- Emails from colleagues or managers
- Direct communication from HealthWest, the Referral Decision Aid Project Officer, or the PCDD Alliance
- Team meetings

Additional comments in interviews with referrers described the processes by which resources like the Referral Decision Aid are disseminated to referrers such as early childhood educators.

> *"Usually things do trickle down to me, the hierarchy within council … this would go to PSFOs who would send it through to our team leaders … I'm third in line to get this" (Early Childhood Educator)*

> *"We heavily promote it and encourage educators particularly to use it … We have emailed it extensively to educators and stakeholders … We include it with all our PSFO documentation … We have a guide to professional support and it's in that" (Preschool Field Officer)*

> *"We did distribute it to all the staff as an adjunct to the one we were using … scanned it in and emailed it around" (Maternal and Child Health Nurse)*

Of those completing the survey, 22 out of 29 survey respondents (76%) reported that the Referral Decision Aid was relevant to them in their role, and a further 5 (17%) reported that they were unsure whether it was relevant or not.

Of the 17 participants who had seen the Referral Decision Aid prior to completing the survey, a total of 9 participants reported that they had used the Referral Decision Aid to assist them with making referrals, as shown in Figure 3. This finding should be interpreted in light of the fact that not all survey respondents were referrers.

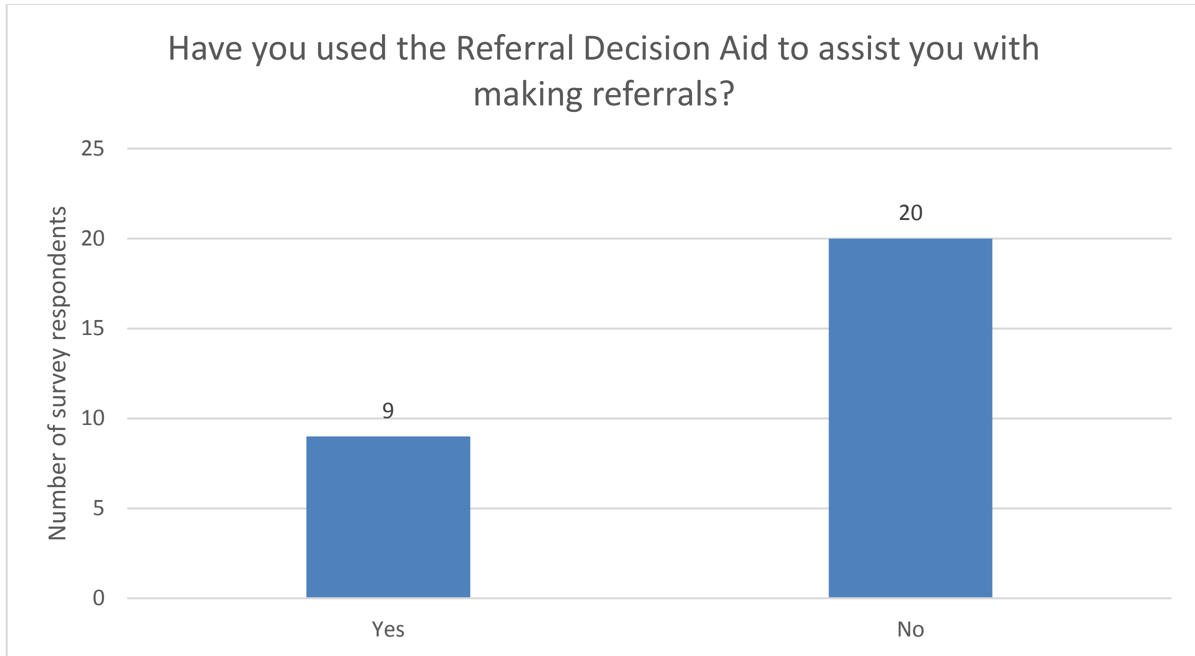

Figure 3. Have you used the Referral Decision Aid to assist you with making referrals? (Evaluation survey responses)

While use of the Referral Decision Aid to assist with referrals was low among the survey respondent population, there is sufficient evidence to indicate that there are referrers in the region who are currently using it and/or would be interested in and potentially use the tool if they were made aware of it.

> *"Community Health teams are using it to actually consider what they're doing … [we have received] reports that its being used and they've been thinking about how it could be used" (Alliance Member)*

> *"[After the Referral Decision Aid was launched] I decided not to use the PSFO flowchart, just to use the Referral Decision Aid and disseminate as widely as possible" (Preschool Field Officer)*

> *"[I had] no awareness [of the Referral Decision Aid] before this at all … I think it is fantastic" (Clinician)*

Though there was also some indication that certain groups of referrers had not responded to the Referral Decision Aid as something they would use because they already felt sufficiently informed about referral processes and/or had an alternative tool to use.

> *"Staff felt they know how to refer … not much buy in" (Alliance member)*

> *"We haven't used it personally" (Maternal and Child Health Nurse)*

These findings are also interpreted in light of the relatively brief amount of time that the Referral Decision Aid has been available (eight months at the time when this evaluation commenced) and the extent of the problem and complexity of current referral pathways.

> *"[There may have been] naïve expectations of reach and impact and outcomes" (Alliance member)*

> *"Referrers had no idea which services are provided out there" (Alliance member)*

"Maternal and Child Health Nurses were referring everywhere, Preschool Field Officers were referring nowhere" (Alliance member)

In terms of further dissemination of the Referral Decision Aid to increase its reach moving forwards, while only 7 of evaluation survey respondents (28% of those who responded to this question) had shared the Referral Decision Aid prior to completing the evaluation survey, 13 (52% of those who responded to this question) indicated that they had not yet shared it but intended to do so (Figure 4).

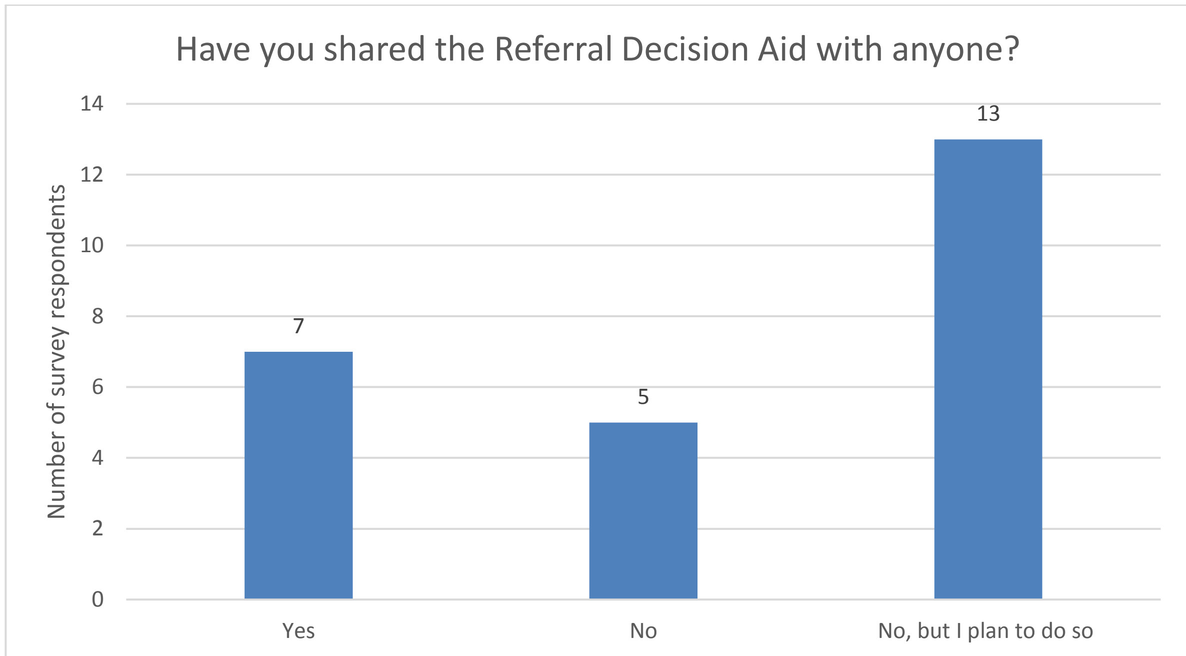

Figure 4. Have you shared the Referral Decision Aid with anyone? (Evaluation survey responses)

A selection of evaluation survey respondents who said that they had either shared the Referral Decision Aid already or intended to do so cited the following as those that they had/were intending to share the tool with:

- Teachers and educators
- MCHNs
- Child health team at community health centre
- The whole team at a kindergarten
- All clinics in the western region

"Now I can direct plenty of audiences to same document [the Referral Decision Aid]" (Preschool Field Officer)

3.3 Usability

Of the nine participants who reported that they had used the Referral Decision Aid to assist them with making referrals, eight responded to the survey question asking how easy it was to use. All eight rated the tool as either Fairly Easy (n=4) or Very easy (n=4) to use (Figure 5).

"Seeing the format of the tool itself … such a user-friendly type of form compared to other things that get sent around" (Alliance member)

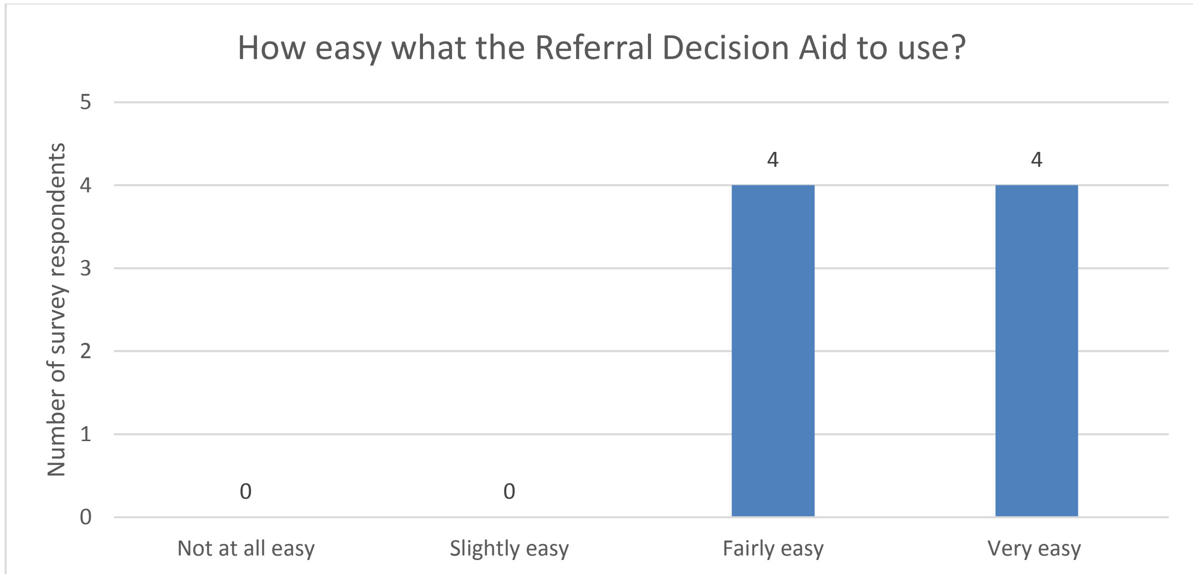

Figure 5. How easy was the Referral Decision Aid to use? (Evaluation survey responses)

The features of the Referral Decision Aid that survey respondents and interview participants liked the most fell under the following categories:

- Clarity of information provided and simple language used
- Visually easy to follow
- Stepped process that is laid out in flow chart format
- Clear definitions of mild, moderate and severe
- Handy reference and helpful tool to clarify referral eligibility
- Having all the services and contact details in one place

"I think it's quite clear and easy to follow … Most of my team feel the same way that I do, that it's easy to follow" (Preschool Field Officer)

"I did like the columns and the domains … a little bit different to ours … the Referral Decision Aid has more detail … Nothing that was contradictory" (Maternal and Child Health Nurse)

"I really like having it on website and being able to print often is useful" (Clinician)

A total of nine evaluation survey respondents said that they would suggest improvements to the Referral Decision Aid and these included:

- Updating and including information relevant to the transition of the NDIS
- Adding maps of the referral process for each service listed on the Referral Decision Aid
- Adding contact details for paediatricians in the region

- Adding private service providers for children with developmental delay in the region
- Amending the information provided for children with severe communication disorder indicating that they are eligible to be seen by community health service providers
- Amending the information provided so that children with two or more moderate delays should be seen by a paediatrician
- Separating the domains of 'cognition' and 'communication' into two categories
- Better alignment between the Referral Decision Aid and clinical decision making aids internal to Alliance organisations or vice versa
- Having one or more sections of the Referral Decision Aid available in other languages so that referrers can talk non-English speaking families through the information easily
- Simplifying language and avoiding jargon
- Providing easy-access to the forms that would need to be filled in when making a referral as mapped on the Referral Decision Aid such as the forms attached to or part of the Referral Decision Aid or a link provided to each form or template
- Including referral to a Preschool Field Officer for additional support as an option for early childhood educators to make use of

"It would be great to alert early childhood educators to the support PSFOs can offer" (Preschool Field Office]

3.4 Outcomes and impact

Since the Referral Decision Aid was only launched in November 2017 (eight months ago), we have attempted to identify evidence of short-term outcomes in this evaluation. The first obvious short-term outcome is the achievement of reaching agreement, at least partially, on the content and format of the first version of a tool that maps pathways for referrals in the region that is now being used for its intended purpose. The evidence suggests that consensus was reached among those who were part of the PCDD Alliance developing the tool but has also identified that there are service providers within the Alliance organisations who feel as yet unheard and who are not completely comfortable with the pathways mapped out on the tool.

This being said, there is clear evidence that this project initiated and facilitated a process of bringing key stakeholders together and scaffolding conversations that led to a degree of consensus that made it possible to develop the first version of this tool from scratch.

"The services were uncertain and inconsistent internally … [the process] got the services together to create the pathways" (Alliance member)

"There must have been reasonable consensus because the way that [the Referral Decision Aid is] set out (flow chart) looks like a standardised method for discerning eligibility" (Alliance member)

The short-term outcomes therefore include:

- The formation of a collaborative PCDD Alliance

- Progression with the process of mapping referral pathways in the region
- Production of a Referral Decision Aid tool

Just over half of the survey respondents who had seen the Referral Decision Aid prior to completing the survey said they had used it to assist them with making referrals. If this figure were to be indicative of the proportion of referrers who become aware of the Referral Decision Aid and then go on to use it, this would indicate that the Referral Decision Aid could be considered useful by just over half of the referrers who are made aware of it. This is speculative but was supported by survey responses and comments made in interviews in which referrers stated that they had not previously been aware of the Referral Decision Aid but now that they are, they would make use of it.

> *"From now I would use [the Referral Decision Aid] … that would be the first place I would go … If [the Referral Decision Aid] was with me last year, this would have made a huge difference" (Early Childhood Educator)*

> *"Rather than me saying what I think … I'm directing [early childhood educators] to use the Referral Decision Aid and come to a conclusion themselves about where the child should go" (Preschool Field Officer)*

As stated, nine survey respondents said that they had used the Referral Decision Aid to assist them with making referrals. Of these, eight respondents also rated the extent to which the Referral Decision Aid **assisted them with making an appropriate referral** (Figure 6). Unfortunately we have not yet been able to quantify how many referrals this actually refers to and do not yet know the outcomes of these referrals for the referrer, service providers, families and children.

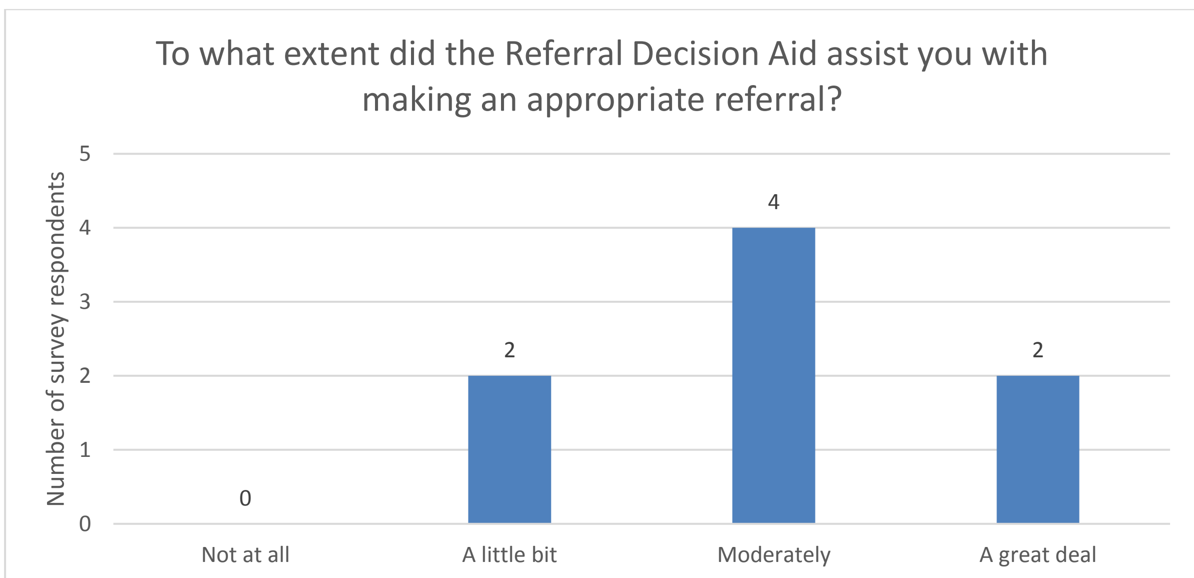

Figure 6. To what extent did the Referral Decision Aid assist you with making an appropriate referral? (Evaluation survey responses)

The extent to which the Referral Decision Aid had an impact on user's knowledge of appropriate referral pathways varied from 'not at all' (n=1) to 'a great deal' (n=2) (Figure 7).

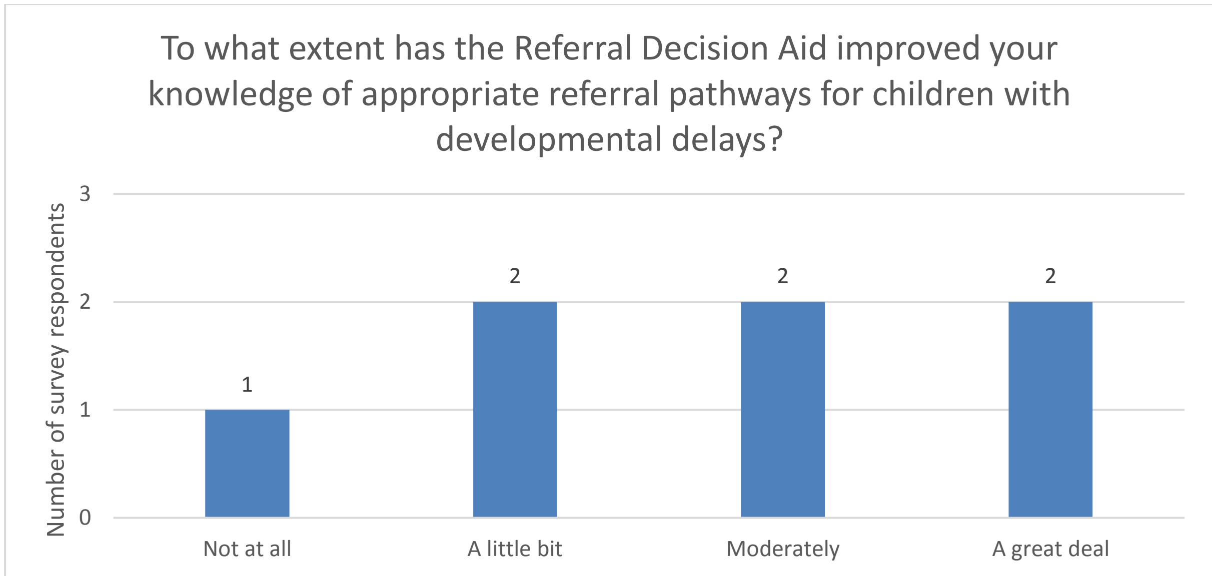

Figure 7. To what extent has the Referral Decision Aid improved your knowledge of appropriate referral pathways for children with development delays? (Evaluation survey responses)

Figure 8 shows the differences in confidence in referring a child with developmental delays to the correct service provider between 'without the Referral Decision Aid' and 'with the Referral Decision Aid' reported by survey respondents in **aggregated form**. Figure 8 indicates that overall fewer survey respondents felt 'not at all confident', 'not so confident' or 'somewhat confident' with the Referral Decision Aid than without it. And similarly, more survey respondents indicated that they felt 'very confident' with the Referral Decision Aid than without it.

> *"I would feel a lot more confident [with the Referral Decision Aid] because it's the unknown … the visual guide in front of you would definitely make it easier" (Early Childhood Educator)*
>
> *"The flowchart is really helpful and this will stop a lot of the wrong referrals" (Clinician)*
>
> *"It gives me the confidence to say we are refusing this referral and go back to the referrer to suggest where we might go in the community … And if I'm on leave it helps my junior staff to redirect more confidently … Because we know that all services should be aware of the Referral Decision Aid." (Clinician)*

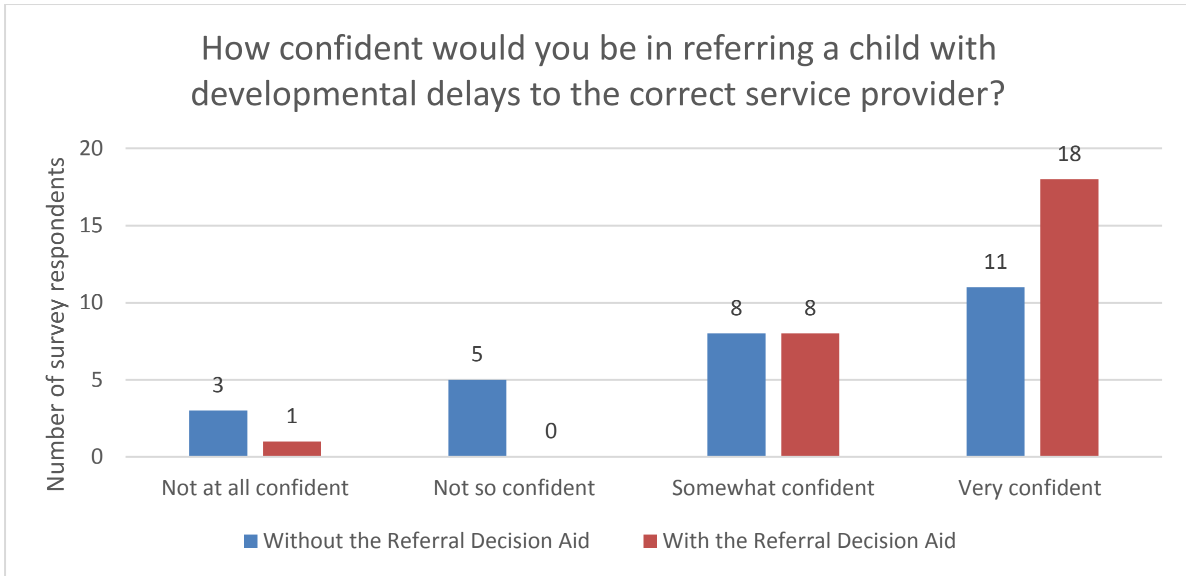

Figure 8. How confident would you be in referring a child with developmental delays to the correct service provider? (Evaluation survey responses)

Figure 9 shows the difference in confidence in referring a child with developmental delays to the correct service provider between 'without the Referral Decision Aid' and 'with the Referral Decision Aid' **for each participant** who answered this question on the evaluation survey. Bars above the x axis indicate that the participant indicated greater confidence with the Referral Decision Aid than without and the bars below the x axis indicate the opposite.

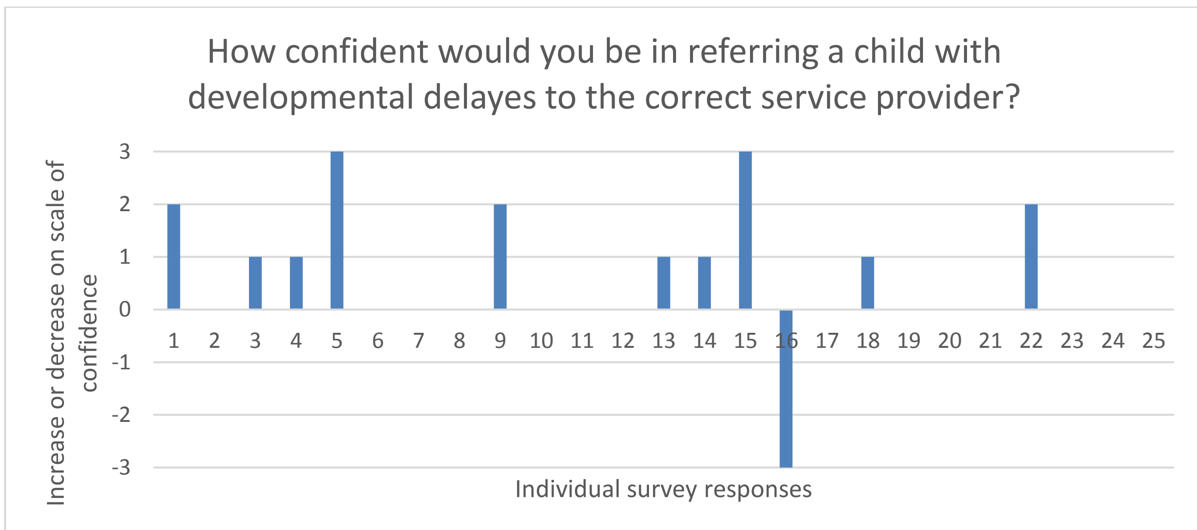

Figure 9. Confidence in referring a child with developmental delays to the correct service provider with and without the Referral Decision Aid (Individual survey responses)

A total of 14 of those who responded to this question indicated that the Referral Decision Aid had no impact on their confidence in referring a child with developmental delays to the correct service provider. A total of five of those who responded to this question indicated that their confidence in

referring a child with developmental delays to the correct service provider increased by two or three points on the scale with the Referral Decision Aid. A further five indicated that their confidence was one point higher on the scale with the Referral Decision Aid, and one participant indicated that their confidence was three points lower with the Referral Decision Aid.

The survey respondents who indicated the biggest increase between their confidence with and without the Referral Decision Aid were:

- One Family Services Case Manager
- One Maternal and Child Health Nurse
- One Occupational Therapist
- One Service Coordinator
- One Early Childhood Educator
- One person who identified their role as Clinic Management
- One Physiotherapist

The survey respondent who felt significantly less confident in referring a child with developmental delays to the correct service provider with the Referral Decision Aid, compared to without it, explained their answer in relation to the exclusion of children with severe communication delay from being eligible for community health service provision on the referral pathways mapped on the current version of the Referral Decision Aid. This was something that the PCDD Alliance had discussed at length and decided on. These comments therefore indicate that there may still be a lack of agreement on definitions of severity and referral pathways among clinicians.

Figure 10 shows the differences in confidence that children will get the services they need quickly and easily 'without the Referral Decision Aid' and 'with the Referral Decision Aid' reported by survey respondents in **aggregated form**. Figure 10 indicates that overall fewer survey respondents felt 'not at all confident' or 'not so confident' with the Referral Decision Aid than without it. Figure 10 also shows that more survey respondents indicated that they felt 'somewhat confident' with the Referral Decision Aid than without it. However, very few participants recorded 'very confident' either with (n=2) the Referral Decision Aid and no survey respondents recorded 'very confident' without it.

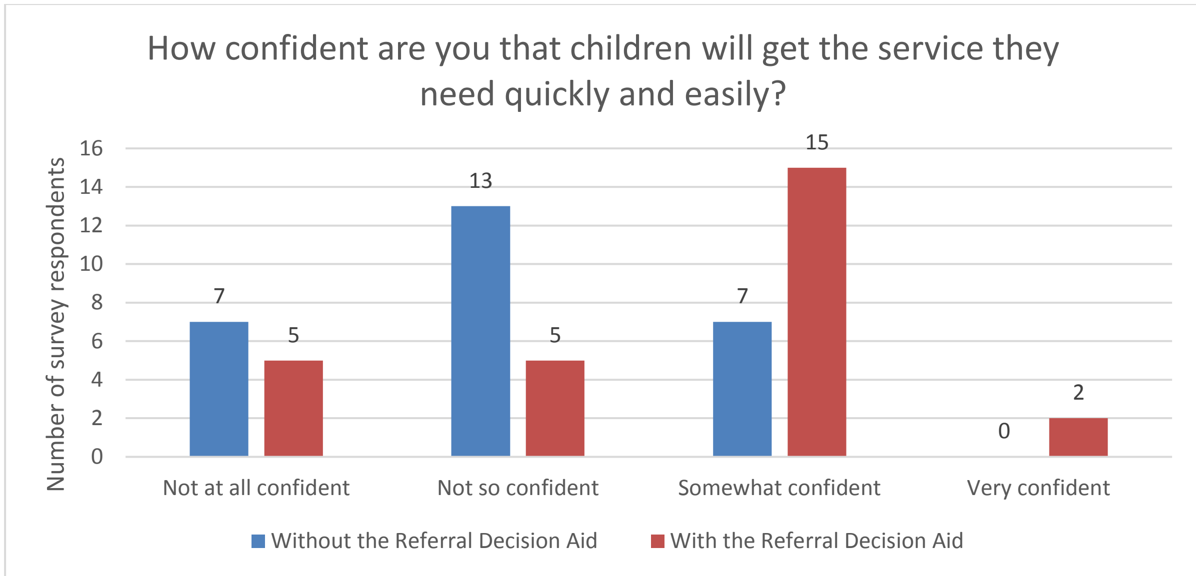

Figure 10. How confident are you that children with get the service they need quickly and easily? (Evaluation survey responses)

Figure 11 shows the difference in survey respondents' confidence that children will get the service they need quickly and easily 'without the Referral Decision Aid' and 'with the Referral Decision Aid' **for each participant** who answered this question on the evaluation survey. A total of three survey respondents expressed that their confidence would increase by two points on the four point scale with the Referral Decision Aid and seven indicated that their confidence would increase by one point on the four point scale.

A total of sixteen survey respondents reported that they felt no more or less confident that children will get the service they need quickly and easily with the Referral Decision Aid. Many survey respondents wrote comments in support of their answers to this question. The vast majority of those who commented identified long waiting lists as a serious problem that impacts on children getting the service they need quickly and easily. A number of survey respondents mentioned other confounding factors such as:

- The complexity of the referral process
- Denial among families and/or practitioners that there is a developmental delay that warrants attention
- High demand for services for children with developmental delay (need)

"The waiting lists have been a huge problem for a long time in this region … unfortunately I don't see them improving for a while even when NDIS rolls-out, I think that's going to cause more issues and create more of a waiting list for community health … We constantly emphasise [to referrers] the need to refer even though there are long waiting lists" (Preschool Field Officer)

"We get frustrated because we don't have the resources to refer to … Accessing private services is prohibitive … people don't have the resources … so they just don't go … they don't have the money" (Maternal and Child Health Nurse)

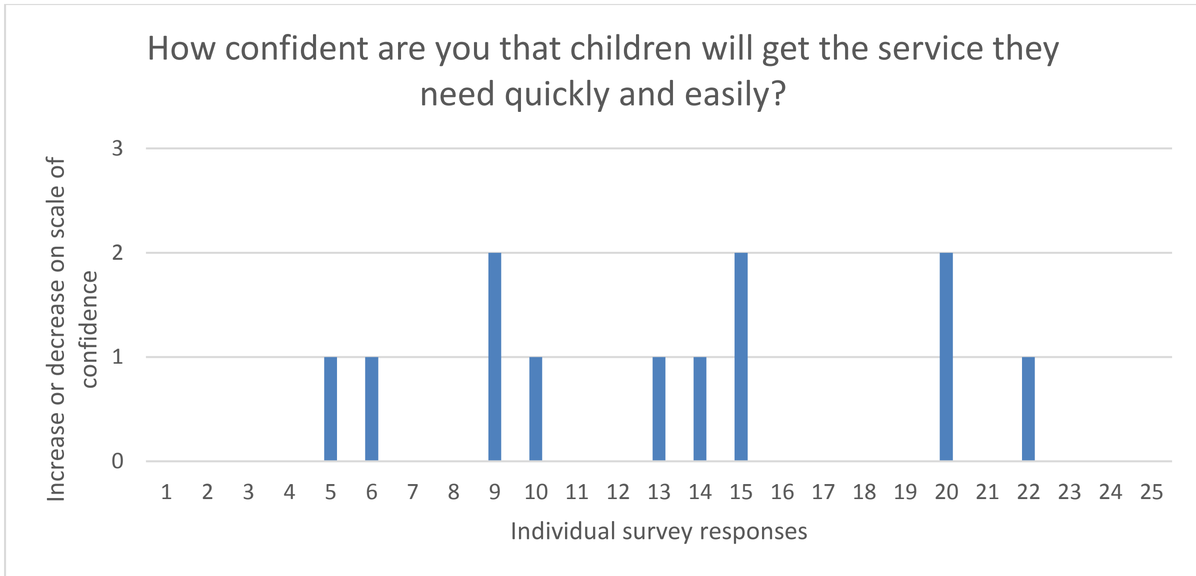

Figure 11. Confidence that children will get the service they need quickly and easily with and without the Referral Decision Aid (Individual survey responses)

A number of participants commented that it was too soon to be able to identify clear impact on the number of inappropriate referrals that are being received by service providers in the region. However several participants did suspect that there had been a decrease in 'scattergun' referrals and possibly decreased waiting times but it is unclear whether this was solely attributable to the Referral Decision Aid.

> *"The situation [within a community health service provider] remains relatively unchanged but this doesn't mean the tool doesn't have a utility" (Alliance member)*
>
> *"[The] scattergun approach has reduced … this has been observed by staff" (Alliance member)*
>
> *"… wait lists are very slightly shorter" (Alliance member)*

These participants did not interpret the lack of evidence of direct impact on inappropriate referrals to be a sign that it was not effective in achieving its aims, but rather that the dissemination of the tool is ongoing and there will be a lag before the use of the Referral Decision Aid in making referrals will lead to changes in the way referrers make referrals in a way that can be obviously linked back to the Referral Decision Aid.

> *"[We] can see that it has potential to have an impact if it continues to be promulgated" (Alliance member)*
>
> *"I would maybe like to see it in GP clinics and paediatrician offices on the wall … available for the public to make note of as well. The more people talking about it, the more likely it is to be used." (Preschool Field Officer)*
>
> *"If a referrer has this piece of paper handy while referring I reckon that will solve a lot of the problems" (Clinician)*

In the longer term, Alliance members will be looking for evidence of appropriate referrals evident in the needs of the children that are arriving in their waiting room having reached the top of the waiting list.

> *"The Referral Decision Aid would be used by referrers to make a decision to come to us and we would see whether that was correct or not … the hope would be that the Referral Decision Aid would mean that children aren't coming to community health if the need is more complicated" (Alliance member)*

3.5 Unintended and unexpected outcomes

A number of participants cited ways in which the Referral Decision Aid is being used that may be slightly different to the ways in which the PCDD Alliance pictured it being used initially.

> *"[We have received] positive reports that it is being used within organisations in different but consistent ways … not necessarily the way we thought it would be" (Alliance member)*

One of these observations is that there has been evidence of clinicians using the Referral Decision Aid with families to explain why they are being referred to the ECIS. In doing so, clinicians have reported that families find this extremely useful in understanding what to expect from the referral process and the role of ECIS.

> *"Clinicians might use the Referral Decision Aid to show a family what's happening" (Alliance member)*

Similarly, Preschool Field Officers reported encouraging early childhood educators to use the Referral Decision Aid and walking them through the process of making decisions about a referral.

> *"I encouraged [the early childhood educator] to get the Referral Decision Aid out in front of her … then I went through it with her over the phone" (Preschool Field Officer)*

This finding also extends to Early Childhood Educators who have also reported using the Referral Decision Aid as a tool to show families how the referral process works and what the possible pathways for children with development delays might be. Interestingly, one educator commented that having the Referral Decision Aid may help families to trust her when she is communicating with a family about a referral that she wants to initiate.

> *"The domains are very clear so you could say 'this is a tool that we use and these are the areas that we have concerns in and from this tool its identifying this delay'" (Early Childhood Educator)*

> *"… having [families] trust an educator with things that are health professional issues … unless you have the written document to back you up its really hard and especially in a really small unit" (Early Childhood Educator)*

> *"The domains are a great way of checking if a child has achieved … not just what they can't do … for all children, are they OK in all those areas" (Early Childhood Educator)*

Similarly, service providers have received referrals with the Referral Decision Aid attached presumably as a way of providing evidence for decision-making at the referrer end of the referral chain.

> *"[I have heard] people saying they are printing forms and attaching them [referrals are still faxed] … people are faxing [the Referral Decision Aid] off … It wasn't intended as a form" (Alliance member)*

There has been some additional feedback from Alliance members around the role of the Referral Decision Aid in supporting Intake teams to interpret referrals which will then lead to important decisions about whether a child is seen by that service provider or not.

> *"[The] feedback from clinicians is that it works really well … [it] gave clarity to intake to either accept or reject a referral and validated any decision-making that went on" (Alliance member)*

> *"I showed it to all of my staff but they are the receivers of the referrals rather than the referrers, though I said to them if you're reading a referral read step 3 to see whether they think they need to be referred elsewhere and use it to make a referral" (Alliance member)*

Further to participants' comments about the benefits of having a process in which key players were open in communicating their professional and organisational perspective, several participants highlighted that through this process potential gaps in service can also be pinpointed.

> *"Some of the community health services did and still do have an idea that two areas mild or severe should be sent to ECIS … It does mean there is a gap in service … two areas of mild delay … Some would refer on while others would take that child on" (Alliance member)*

> *"That service gap is happening all over the place and this sort of thing would help identify that for all the different services … who the funding body is and what they do without it is another thing … [the process of developing the Referral Decision Aid] does at least allow for that to become evident so that people can talk about it" (Alliance member)*

In combination with the participant comments about the inconsistencies between the Referral Decision Aid and the clinician perspective on the intake of children with severe communication delay, the identification of these gaps and inconsistencies means that the PCDD Alliance can be aware of these moving forward. The development of the Referral Decision Aid and this evaluation also gave referrers, clinicians, and Alliance members an opportunity to voice their concerns about problems in the service system for children with developmental delay and raise awareness of system gaps.

> *"We wouldn't know how to do it [make referrals] … We have never been taught how to do that … [we are just] waiting for that referral process to happen … This is just the way that we've always done it … you get the PSFO in and they do the referral" (Early Childhood Educator)*

> *"Early Intervention is a bit of bullshit … in the meantime you have lost the opportunity to have a meaningful impact on their early development" (Maternal and Child Health Nurse)*

> *"You can waste so much time referring children to wrong service" (Preschool Field Officer)*

3.7 Implications for the Referral Decision Aid in the context of the NDIS

The implementation of the NDIS in Melbourne's west later in 2018 was identified by a range of participants as a significant contextual factor that will have considerable implications for the content and relevance of the Referral Decision Aid.

> *"The NDIS is over-shadowing and changing the scope of practice" (Alliance member)*
>
> *"We're really worried about what's going to happen … we're so confused" (Early Childhood Educator)*

Comments on this topic emphasised the need to change and update the pathways listed on the Referral Decision Aid in line with the new service pathways that will develop under the NDIS. In this context, a number of participants commented on the importance and relevance of a tool like the Referral Decision Aid and its potential helpfulness in clarifying referral pathways that may have changed.

> *"Wouldn't it be amazing is there was a central intake point and this tool was there as part of the online process and you would log in and this process would be there … electronic version that says 'oh that means you're referring to this service'" (Alliance member)*

Referrers and service providers are still in the process of discovering what the NDIS service system will mean for the eligibility of children with developmental delays for various services.

> *"NDIS will mean that ECIS will disappear … NDIS has residency requirements for participants but previously this was not the case … those clients will go to ECEI associated with NDIS and when they are rejected on the grounds of residency they will bounce back to the Department" (Alliance member)*
>
> *"Hospital allied health and ECIS have quite big referral forms so [referrers] would just put it through to the one that they thought would get through quicker … But with the NDIS they had to be with us [ECIS] … [the Referral Decision Aid] made it clear to do this AND this" (Alliance member)*

At the other end of the spectrum, there are potentially 'minor' revisions that can be made to the Referral Decision Aid, and, if this is the case, the Referral Decision Aid appears to have a role in providing referral information in the interim period as the NDIS rolls out. However, making minor or major changes to the Referral Decision Aid will require ongoing funding support.

> *"Put ECEI where it says ECIS … it's going to be very helpful" (Alliance member)*
>
> *"The tool will need updating … it will not be useful unless it gets updated" (Alliance member)*
>
> *"To be really useful in the long term it does require some support ongoing" (Alliance member)*

3.8 Key lessons learned

The findings of this evaluation point to a number of key lessons identified through the process of developing, designing, disseminating and using the Referral Decision Aid. These will now be outlined in turn.

- **A collaborative 'Alliance' approach is an effective means for bringing key players together to address system-level complexity but can be strengthened by ensuring that all parties feel represented and are part of the decision-making process**

The approach taken to develop the Referral Decision Aid was considered a positive experience for all of those who were directly involved. The approach taken may be suitable to projects in other regions and/or focusing on other health system referral pathways. The essential steps identified in Section 3.1 are key enablers to a successful outcome of a collaborative process and could be followed to ensure that the collaborative process runs smoothly. It is also noted that while it may be challenging to ensure that all staff at Alliance organisations are included in the process, it is also worthwhile taking steps to ensure that all key parties are involved and are heard.

- **As referrers are the key end-users of the Referral Decision Aid, their involvement in planning the dissemination of the tool is essential**

It was noted that referrers were involved in the PCDD project in the early stages but could have been invited to play a more significant role in the entire process of developing and disseminating the tool. A range of participants identified involving different types of referrers in planning dissemination strategies as something that would have been and continues to be beneficial. This was echoed by the referrers themselves, some of whom appreciated being involved in the evaluation so that they could also feel heard in this process.

> *"… It's nice to be validated and have a voice in it … I appreciate it" (Early Childhood Educator)*
>
> *"It's not every day that I read something and think this is really worthwhile" (Early Childhood Educator)*

- **Targeted dissemination requires process and may require increased dissemination capacity in order to ensure that the Referral Decision Aid reaches the more isolated referrers who appeared to consider the tool to be very valuable**

Following on from the previous lesson learned, the evidence points to a need for and benefits stemming from ongoing targeted dissemination. This appears to imply concentrated efforts 'in the field', drawing on existing relationships with referrers and developing new ones. In doing so, the Alliance can discover more about how to reach the referrers that would most appreciate the Referral Decision Aid and be most likely to use it.

> *"It's all about relationships with, for example, nurses … we have extremely close relationships with … we could spend time sitting with and going through [the tool] ... that would be ideal" (Alliance member)*
>
> *"Ideally … the feedback loop anytime we get an inappropriate referral … we have done this … we've said 'We feel that this client isn't appropriate for our service, here's the Referral Decision Aid … could you please refer elsewhere'" (Alliance member)*
>
> *"The other avenue is local PD sessions … if someone wanted to come and do a short presentation from HealthWest" (Preschool Field Officer)*

- **In the short term, the reach and uptake of the Referral Decision Aid may be difficult to track but in the longer term there will be a range of benefits of tracking of the impact of the Referral Decision Aid**

There is evidence to suggest that there are referrers who see the Referral Decision Aid as highly valuable and would use it immediately to support their referral processes. These referrers are seeing children on a daily basis and are seeing children fall through the gaps in the service system for a number of reasons.

> *"We have a form and have permission from the parents for the PSFO to come out and see their child … PSFOs do their best but they have so many children that they are having to see … If we can do the referrals ourselves it would be a whole lot easier … we have never been taught how to do that" (Early Childhood Educator)*

In order to maximise the opportunity to demonstrate the need for ongoing investment and concentrated efforts to reduce the number of children who are not being seen in a timely manner by supporting referrers to make appropriate referrals as soon as possible, there is a need for strategic data management so that referrals can be tracked along the entire referral pathway, and impact on referral outcomes can be detected.

> *"How would I know [whether the Referral Decision Aid has had an impact on inappropriate referrals] … [we] have been collecting data on inappropriate referrals but not attributable to the Referral Decision Aid … [it has not yet been] widely used enough … but there has been a reduction in inappropriate referrals"*

> *"We had a way of checking up using statistical linkage (they had a code) … we could compare once a month that everything was getting to the right place and we could follow up if necessary" (Alliance member)*

> *"[The Referral Decision Aid would] definitely would have had an impact in working towards better outcomes for children and families" (Preschool Field Officer)*

4 Recommendations

In light of the key findings discussed in this evaluation report, the following Recommendations are offered:

1. The PCDD Alliance should continue to invest time and resources into improving referral outcomes for children with developmental delays
2. The PCDD Alliance should continue efforts to build relationships with a range of referrers and find out more about how to reach Early Childhood Educators and investigate their current obstacles and challenges in making referrals
3. The PCDD Alliance should invest in planning for ongoing strategic dissemination of the Referral Decision Aid **after** the Alliance has considered the most appropriate next steps in light of the NDIS transition and any necessary changes to the Referral Decision Aid
4. A second version of the Referral Decision Aid should be developed in collaboration with the NDIS ECEI Partner, incorporating changes to referral pathways implied by the NDIS transition to ensure referral pathways remain as smooth as possible during transition
5. The PCDD and NDIS ECEI Partner should identify referral pathways for children who will not be eligible for support through the NDIS, such as those who are ineligible on the grounds of residency status
6. The PCDD Alliance should advocate for funding and support to review the role of, and capacity for, early childhood educators to create referrals
7. Targeted dissemination efforts should include and focus on networking events for Early Childhood Educators, such as those organised by Early Childhood peak bodies
8. The PCDD Alliance should review mechanisms for incorporating feedback from a range of clinicians within Alliance organisations into the processes of revising and agreeing on the content of the Referral Decision Aid
9. The PCDD Alliance should review mechanisms for communicating changes in the Referral Decision Aid and agreed domains and definitions back to clinicians and child health teams at Alliance organisations as referrers and clinicians will need clear information and support during the transition to the NDIS
10. The PCDD Alliance should advocate for funding and support to identify next steps in addressing system weaknesses such as excessive waiting times and the increasing need in the region for timely early intervention services for preschool children
11. The PCDD Alliance should present these findings to the Department of Health and Human Services and seek clear guidance about State-wide strategies to address regional system gaps such as children being referred to the wrong services and compounding impacts on excessive waiting times

"I really hope it can be used far and wide in future … I think really valuable and haven't seen something like this before in my own experience as a professional … I hope reaches a wide audience" (Preschool Field Officer)

Appendix 1 Detailed methodology

This evaluation was carried out over a six week period between July and August 2018. The key steps taken are outlined in detail below.

Document review and initial stakeholder consultation

FPC reviewed and analysed a range of documents that related to the Referral Decision Aid and the history and context of the Pathways for Children with Developmental Delay project.

We then carried out short telephone interviews with four of the key members of the PCDD Alliance in order to 'set the scene' for the evaluation. These conversations directly informed our evaluation planning and the identification of a range of key factors to be considered in the data collection process. In addition, these conversations provided an opportunity for us to explore how the Referral Decision Aid was developed so that we could evaluate this process and learn more about the steps taken and what worked and what did not work.

Development of evaluation framework and evaluation plan

We then developed an **evaluation plan**, which included:

- Nominated key evaluation questions
- A comprehensive evaluation framework including indicators, data sources, and proposed data collection roles and timeframes for data collection
- Possible participant groups and their relationship to project

Data collection

The PCDD Alliance had already developed an evaluation outline which proved useful in designing and delivering the evaluation. We focused on including in our scope the key items on the evaluation outline that were assigned to the evaluators, namely:

- A follow up survey sent to referrers and other key stakeholders who may be aware of the Referral Decision Aid (referred to as the evaluation survey) (n=29)
- Collation of data collected by HealthWest in the form of:
  - Two feedback surveys, one for clinicians (n=10) and one for referrers (n=3), circulated in May 2017
  - A 'first impressions' survey designed and distributed in November 2017 (before this evaluation commenced) (referred to as the HealthWest survey) (n=5)
- Interviews with a sample of referrers to explore the usability of the tool, their personal-professional experiences of using the tool, and the outcomes of using the tool (n=5)
- Interviews with clinicians who were willing to provide feedback and reflections on the Referral Decision Aid and its impact and reach so far (n=3)
- Interviews with a sample of representatives from the PCDD Alliance to find out a) whether they have noticed any changes in the referrals they have received and b) their reflections on the process used to develop the Referral Decision Aid and what worked and what did not work in this process (n=3)

Data analysis

Data was analysed using thematic analysis of open-ended survey responses and qualitative data collected via interviews. Closed-choice question survey responses were analysed using very simple

descriptive statistical analyses and by presenting key findings in graph form where appropriate throughout the report.

Meeting with HealthWest to present preliminary findings

When data collection and preliminary analysis was complete, we held a meeting with HealthWest to present and discuss preliminary findings and explore how these should be presented in the report. This meeting was held face to face with the PCDD Alliance at HealthWest. The meeting provided an opportunity to explore the findings and share additional insights with HealthWest. We also discussed the format of the report and ensured we were in agreement on this before we completed the drafting process.

Final evaluation report

Data for the final report was then synthesised and presented in response to the evaluation questions in the evaluation plan. Evaluation findings and recommendations are provided in non-technical language that can understood easily by a range of audiences. The final evaluation report includes:

- Executive summary
- Program background information
- An overview of the methodology
- Detailed presentation and analysis of the findings and discussion of the evaluation questions
- Summary of key findings
- Outlining successes and opportunities for change within the further development and dissemination of the Referral Decision Aid
- Recommendations for future action including:
    - Future versions of the Referral Decision Aid
    - Potential areas for ongoing development under the PCDD project, including clearly identified supports referrers may need to make appropriate referrals
    - Key features of the process used to develop the Referral Decision Aid, and its potential to be adapted or replicated in other regions
- Appendices (including, for example, the methodology in detail)

A draft final evaluation report was provided for feedback and review. After receiving comments, a final full and comprehensive version of the evaluation report was developed, integrating any feedback and suggestions from the PCDD Alliance.