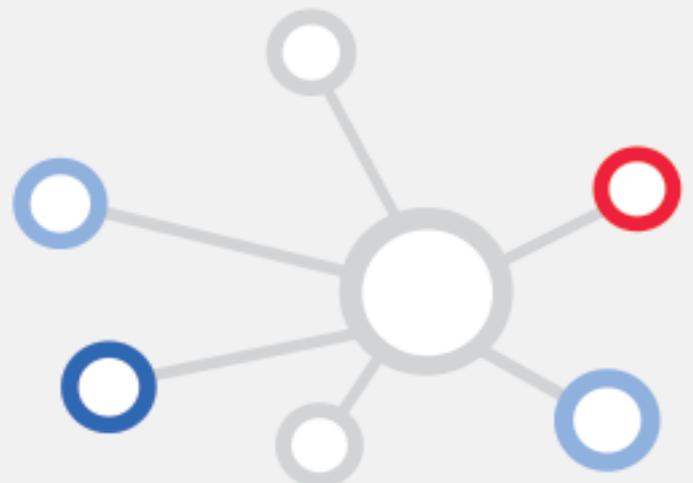


Pathways for Children with Developmental Delays

Phase Two Project Report

February 2019



HealthWest wishes to acknowledge the traditional custodians of the lands on which this work took place, the Wurundjeri, Boonwurrung, and Wathaurong peoples of the Kulin Nation. We pay our respects to their cultures and their elders past and present.

HealthWest also wishes to thank the many individuals who contributed their thoughts, time and effort to this partnership project, in order to make a real difference for children with developmental delays and their families.

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February 2019

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1. Project background

1.1. Background and current context

Early childhood development is a strong predictor of adult health, education and social outcomes. The provision of appropriate services and supports during early childhood can have significant, life-long impacts on children. The 2015 Australian Early Development Census (AEDC)¹ shows that a higher proportion of children in the local government areas of Brimbank, Melton and Wyndham were classified as developmentally vulnerable, compared to the Victorian and national state average. From 2009 to 2015, an increase was observed in each of these areas, with a significant increase in Brimbank in particular.

Pre-school aged children who are identified as having developmental delay are frequently referred to specialist public services for assessment, intervention and support prior to school entry. Across Melbourne's west, these services have been provided by community health services (IPC Health, cohealth and Djerriwarrh Health Services), hospital based services (Western Health, Melton Health and the Royal Children's Hospital) and Early Childhood Intervention Services (ECIS; funded by Department of Education and Training). Services in Melbourne's west experience high demand with extensive waitlists for some services. Often families access services outside the Western catchment. Overall, the service system is reported to be complex, confusing and disjointed with a lack of clarity about service eligibility and knowledge of the services offered by each organisation. This can lead to inefficiencies, duplication, gaps and confusion for both families and referrers.

A number of reforms and developments in the West will bring their own challenges and place additional demands on the service system and lead to shifting service provision and eligibility among the early childhood service system and more broadly:

- **Significant and sustained population growth**, accompanied by rapid urban development, with the population of Melbourne's west forecast to grow by 47.7% between 2014 and 2031².
- The **National Disability Insurance Scheme (NDIS)** is being rolled out in Western Melbourne and Brimbank-Melton areas from 1 October 2018, and is expected to be completed by 30 June 2019.
- The **Community Health Taskforce** was established in mid-2018 to review Victoria's Community Health Program in order to provide advice and propose actions to strengthen the community health sector³.

1.2. Project rationale

Due to the growing demand and reform environment in Melbourne's west, local services began reviewing their service provision to children with developmental delays. Partners of HealthWest

¹ Commonwealth of Australia, Australian Early Development Census, 2018. Available at <https://www.aedc.gov.au/early-childhood>

² HealthWest Partnership, Data report: Planning for growth and change in home support & community care in Melbourne's vibrant west, 2014.

³ Victorian Department of Health and Human Services, Community Health taskforce Terms of Reference, 2018. Available at <https://www2.health.vic.gov.au/primary-and-community-health/community-health/community-health-taskforce>

identified the need for a collaborative approach to this service review, to ensure local redesign initiatives were coordinated and in line with regional needs.

In response, the Pathways for Children with Developmental Delays (PCDD) project was created for core service providers and other relevant stakeholders to work in partnership. The work would support a clearer and more streamlined service system that meets the growing demands for services for pre school-aged children with developmental delays.

Phase One of the project (August 2016 to March 2017) focused on consultation and project scoping, while Phase Two (May 2017 to December 2018) sought to implement key systems changes identified in Phase One.

1.3. Partners and funding

The PCDD Project is a partnership project that involved the key public providers and funders of services for children with developmental delays in Melbourne's west, supported by a project worker based at HealthWest Partnership.

The project initially incorporated the local government areas of the HealthWest catchment including Brimbank, Melton, Maribyrnong, Wyndham and Hobson's Bay, with a particular emphasis on Wyndham, Brimbank and Melton where there is higher levels of need and growing demand. In phase two it was expanded to include Moonee Valley and Melbourne, thereby incorporating the Areas of Western Melbourne and Brimbank-Melton.

Project partners include:

- Western Health
- Djerriwarrh Health Service (including Melton Health)
- cohealth
- IPC Health
- Royal Children's Hospital
- Department of Education and Training - Early Childhood Intervention Service (ECIS) Intake and Brimbank-Melton Area
- Department of Health and Human Services - North & West Metropolitan Region and Western Melbourne Area

The PCDD project received funding from the Department of Health and Human Services Western Melbourne Area and North & West Metropolitan Region.

2. Phase One: Consultation and benchmarking

2.1. Objectives and activities

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

A consultative approach was undertaken with local service providers, referrers and stakeholders to provide a comprehensive overview of the system challenges and demands and to develop a set of recommendations to address these. Consultation took the form of focus groups, surveys, and collection of consumer case studies. Research and benchmarking against other like services was undertaken to inform the recommendations.

2.2 Outcomes

Overall, services and referrers reported significant service gaps in a system that is disjointed, with limited coordination across waiting lists resulting in duplication of services.

The consultation and benchmarking activity delivered some key outputs:

- Description of each public service stream providing support for children with developmental delays in Melbourne's West: eligibility and services offered.
- Recommendations for regional consistencies and efficiencies with intake processes across service providers, which
 - maximise access and equity for all with a particular focus on the most vulnerable consumer groups,
 - are not dependent on increased funding or EFT, and
 - which are appropriate in light of the impending commencement of NDIS.
- Description of pathways for Autism Diagnostic Assessments in Melbourne's West (including private options).
- List of service gaps, inefficiencies or areas needing improvement across the public services for children with developmental delay in Melbourne's west.
- Recommendations for ways to address these service difficulties, immediate and long term.

For more information on the consultation method, findings and recommendations see the Phase One Pathways for Children with Developmental Delays (PCDD) project report⁴.

⁴ HealthWest Partnership, Pathways for Children with Developmental Delays Project Report, March 2017. Available at <http://healthwest.org.au/projects/service-coordination/pathways-for-children-with-developmental-delay/>

2.3 Recommendations for service improvements

A series of recommendations for service improvements were made in the Phase One consultation report. These are laid out in Table One below.

Table One: Phase One recommendation for service improvements

Eligibility:
<ol style="list-style-type: none">1. Community health and hospitals align definitions of severity and 'areas' to domains used in the Australian Early Development Census and apply consistently.2. Community health and hospitals align eligibility criteria to ensure there are no gaps:<ol style="list-style-type: none">a. 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.b. Hospitals align criteria to include moderate to severe delays in two or more areas.3. Development and dissemination of a referral tool to communicate alignment of eligibility criteria and improve referrals.4. Regional consideration should be given to future service provision to children who are not permanent residents of Australia.5. Waitlists backdated and when families need to be transferred to an alternative service, clinicians to support this process
Referral and Intake:
<ol style="list-style-type: none">6. The adoption of a cross agency, clinician led face-to-face intake system for referrals where service eligibility is unclear.7. Improved use of existing and pending e-referral platforms8. Support for families with low health literacy (see next section).
Vulnerability:
<ol style="list-style-type: none">9. Development of shared indicators for vulnerability.10. Improved responsiveness to vulnerability, including reviewing processes which may create barriers to access and engagement.11. Build capacity of workforce to improve responsiveness to health literacy and vulnerability

3. Phase Two: Objectives and activities

Following on from Phase One, PCDD project partners felt it was important to address key concerns raised during the consultation, and to continue to monitor the system for changes and challenges and respond collectively. The PCDD project was continued into a second phase to do so.

3.1. Pathways for Children with Developmental Delays (PCDD) Alliance

The PCDD Alliance was established at the start of Phase Two in order to:

- Drive and advise on actions to progress the recommendations from the first phase of the PCDD project.
- Collectively monitor system changes and respond to challenges resulting from the rollout of NDIS.

The PCDD Alliance evolved from the PCDD project advisory group. Alliance members are listed under section 1.3.

3.2. Phase Two objectives

The objective of Phase Two is to work with members of the PCDD Alliance to advance recommendations from Phase One for action, with a specific focus on:

1. Embedding of regional efficiencies with intake processes including eligibility and referral pathways.
2. Collectively monitoring system changes and challenges resulting from the rollout of NDIS.
3. Development and piloting of shared indicators for vulnerability with a view to understanding how vulnerability, including risk and protective factors, can be measured with this cohort.
4. Building the capacity of the workforce to improve responsiveness to health literacy and vulnerability.

3.3. Phase Two activities

Phase Two delivered on project activities through three key activities:

❖ Development of a Referral Decision Aid

In order to progress recommendations regarding service eligibility and referral pathways, it was decided to develop a tool that would support clear and consistent eligibility and referrals across the region. A partnership approach was used to develop the Referral Decision Aid, with key providers and funders of children's allied health services working together to develop this tool, in consultation with their clinical staff.

❖ Monitoring systems changes and challenges

The PCDD Alliance met quarterly to discuss systems changes and challenges, and address issues as they arose. This was done through the combination of a Register of Issues, Opportunities and Risks and open

discussions at Alliance meetings. Responses were discussed during Alliance meetings, with either Alliance Members or the project worker tasked with following up on key actions.

❖ Addressing vulnerability in Melbourne's west

Initial scoping work was conducted to explore the concept of vulnerability, and the potential to develop shared indicators for vulnerability for use in Melbourne's west. In addition, services were encouraged to support staff to be more responsive to health literacy and vulnerability needs of families.

Each of these activities and outcomes are detailed below, followed by a series of key recommendations for future action that have fallen out of this work.

4. Referral Decision Aid

It was decided that a decision aid would be developed, to support the referral of preschool-aged children with developmental delays to appropriate services in Melbourne's west, in a timely manner. The Referral Decision Aid was designed to be worked through by referrers in a step-wise manner:

- **Step 1:** identify three domains of delay based on Australian Early Development Census (AEDC) domains.
- **Step 2:** Functional definitions to help referrers determine the severity of delay
- **Step 3:** A step-by-step flowchart directing referrers to appropriate service type
- **Step 4:** A list of available services with contact details

Each step was developed in a collaborative manner, requiring consensus from all organisations involved. Through this process, service gaps were identified and closed, with services agreeing on a consistent set of eligibility criteria across the region. All services signed off on the final version of the Referral Decision Aid.

This Referral Decision Aid can be found on the HealthWest website⁵ in Figure One (page 10 of this report). This tool was launched electronically in October 2017 and at a launch event in November 2017. In addition, the tool was promoted and at a range of events by the project worker and project partners.

An external evaluation of the Referral Decision Aid was conducted in July-August 2018 by First Person Consulting⁶. The development of the Referral Decision Aid was evaluated against four key aspects:

1. **Process and partnership:** While identifying some key areas for improvement (more consistent involvement of clinicians and referrers in the development, wider dissemination), the evaluation found that the Alliance model used to develop the Referral Decision Aid was collaborative, cooperative and effective for this purpose.
2. **Reach, uptake and usability:** Dissemination was not as effective as desired and would have benefited from a longer, more comprehensive planned process. However the Referral Decision Aid was seen by those who had used it as clear, easy to use and fit-for-purpose, with a number of adjustments suggested.
3. **Outcomes and Impact:** Findings indicated that the Referral Decision Aid had an impact on referrers and services, with referrers reporting that it had increased their knowledge of referral pathways. It also tended to increase the confidence of referrers to refer to the appropriate service, particularly among those less familiar with the existing service system including early childhood educators. However, the Referral Decision Aid's impact on developmental outcomes for children was seen as limited due to the extended wait times for many children's services in the West.

⁵ Available at <http://healthwest.org.au/referral-decision-aid/>

⁶ First Person Consulting, Evaluation of the Referral Decision Aid, September 2019. Available at <http://healthwest.org.au/referral-decision-aid/>

4. **Unintended and unexpected outcomes:** The RDA had a number of positive unintended outcomes for referrers and families. The RDA was used to support communication with families of children being referred, to understand why the referral was occurring. It was also used by services and intake workers to support service planning and intake processes. This had a positive impact on health literacy of organisations and families of children with developmental delays. It was also used to build cross-sector competencies, with referrers from the early childhood education sector reporting increased confidence and empowerment to refer children to health-related services.

The Referral Decision Aid was developed prior to implementation of NDIS in Melbourne's west. Implementation has since commenced in October 2018 and is scheduled to be complete by July 2019. NDIS rollout and accompanying funding and service changes mean that referral pathways and services described in the Referral Pathways are no longer representative of the service system in Melbourne's west.

Evaluation findings show that a Version Two of the Referral Decision Aid would likely be of benefit to referrers. Any work to develop a Version Two should consider the following key points:

- Early Childhood Early Intervention (ECEI) services should replace Early Childhood Intervention Service (ECIS) Intake, as the pathway into NDIS for those with more severe delays.
- The Alliance model of development should be re-utilised with a few modifications including:
 - The Brotherhood of St Laurence should be involved, as the ECEI Partner for Western Melbourne and Brimbank-Melton areas.
 - Clinicians and referrers should be more consistently included in decision making across Alliance organisations.
- Referral pathways should be reviewed in light of a number of changes:
 - NDIS roll-out
 - Community Health Program review
 - Service changes at Western Health, including launch of the Joan Kirner Hospital in May 2019, cessation of DET funding for children's allied health services and launch of a new service model.
- The resource should be available in a digitised format, linking directly with referral forms and service intake processes.
- Dissemination should be carefully planned in consultation with referrers and potential users. It should also link with existing state-wide and regional networks and resources (examples include Health Pathways and Raising Children Network).

It also suggested that the information in the Referral Decision Aid could be used in a consumer-facing resource, supporting families to understand the service system and eligibility requirements. Due to the transformative nature of current system reforms, it is recommended that any major review and redevelopment not occur until the sector has had some time to stabilise.

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
<ul style="list-style-type: none"> – Fine motor – Gross motor – Coordination – Self care – Dressing – Toileting – Sensory – Eating, drinking and swallowing 	<ul style="list-style-type: none"> – Understanding – Using words and language – Speaking clearly – Voice, fluency (including stuttering) – Thinking, ideas and learning skills – Problem solving – Play skills 	<ul style="list-style-type: none"> – 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 [1]

MILD	MODERATE	SEVERE	MILD	MODERATE	SEVERE	MILD	MODERATE	SEVERE
<input type="checkbox"/>								

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.

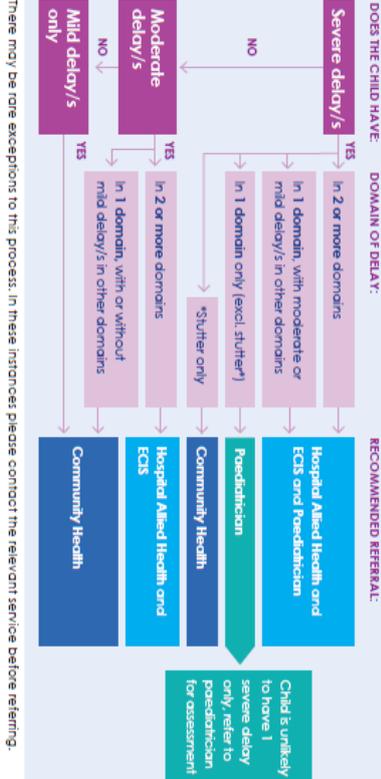
MODERATE

- 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



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 Moorbyong, Moonee Valley, Melbourne and parts of Birmbank (when cohealth is the closest service)

Phone (03) 9448 5521

Fax 7000 1827

Email serviceaccess@cohealth.org.au

www.cohealth.org.au

Dienhwarth Health Service

Melton Community Health Centre and Caroline Springs Community Health Centre

LGA Melton

Phone (03) 9747 7609

www.dlhs.org.au

IPC Health

LGAs Birmbank, 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

Dienhwarth Health Service (Melton Health)

LGA Melton

Phone (03) 9747 7603

www.dlhs.org.au

Western Health (Sunshine Hospital) Children's Allied Health Service (CAHS)

LGAs Birmbank, Hobsons Bay, Moorbyong 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 Birmbank, Melbourne, Hobsons Bay, Moorbyong, Melton, Moonee Valley and Wyndham

Phone (03) 8397 0263 (Duty Line)

Email ecis.intake.svr@education.vic.gov.au

Mail P.O. Box 2141, Footscroy, 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 One: Referral Decision Aid, front and back

5. Monitoring systems changes and challenges

The PCDD Alliance utilised a Register of Issues, Risks and Opportunities to monitor system changes and challenges, and identify solutions. As system issues, risks and opportunities were identified by Alliance members, they were discussed at an Alliance meeting and actions identified to address the issue, if required. The register was reviewed and updated at PCDD Alliance meetings, ensuring items were addressed in an ongoing manner and outcomes shared.

A number of system issues were identified and addressed collectively in this manner by the PCDD Alliance, including those related to:

- Uncertainty regarding where clients with more complex feeding/cleft palate /swallowing delays should be referred.
- Questions around the use of developmental assessments by the ECEI Partner.
- Concerns about service eligibility and referral processes.
- Funding opportunities.

However, a number of ongoing concerns were identified, that are also relevant at a state or national level:

- A desire for clearer direction from DHHS Central regarding expected eligibility and referral pathways for children with developmental delays
- The need for effective translation and interpreter support to be provided under NDIS for service users with low English proficiency.
- The need for effective communication strategies to engage with vulnerable families.
- Uncertainty around Continuity of Support funding beyond June 2019, and its impact on service planning, workforce and those currently receiving government support under this scheme.
- Misunderstandings about NDIS services and supports due to insufficient communication with service users, and use of jargon and acronyms.

While the PCDD project has ceased, Alliance members stated a value for meeting together, and indicated a preference to continue meeting to connect with each other, while expanding to include the Brotherhood of St Laurence.

6. Addressing vulnerability

During the Phase One consultation, stakeholders reported a sense that some disadvantaged or vulnerable children and families may be ‘falling between the gaps’. One of the resulting recommendations was that the PCDD Alliance address this by developing and piloting shared indicators for vulnerability, with a view to understand how vulnerability, including risk and protective factors, can be measured within the cohort of families with children with developmental delays.

In order to explore feasibility and appropriateness of this work, some early scoping work was conducted:

1. **Review of relevant literature and policy:** The concept of ‘vulnerability’ varied widely across the literature and within Victorian policy. Different definitions and frameworks were used to understand the concept in different settings and sectors, including child and family services, health, mental health, family violence, child protection and disability.
2. **Progress conversations with the PCDD Alliance:** It was essential to understand interest and capacity of project partners to continue in this work, as well as identify perceived needs of their service users. Again, key services in Melbourne’s west did not use a consistent definition or approach to vulnerability. All organisations were undertaking work to understand or address vulnerability among their clients, often across multiple areas and levels of the organisation. However, conversations did not point to a common area of focus for a regional project.
3. **Scoping existing work to identify and address vulnerability:** Vulnerability among children and families has been identified as a focus for a number of other partnership platforms within Melbourne’s west and at a State level, that have the scope and ability to progress regional conversations about vulnerability. Platforms include:
 - a. DHHS West Division
 - b. Better Health Plan for the West
 - c. Western Melbourne Children and Youth Area Partnership

It was acknowledged that a consistent understanding of vulnerability across the region was necessary before commencing work to develop shared indicators of vulnerability. Given the lack of this consistent understanding, and the high volume of existing regional work, it was decided by the PCDD Alliance not to pursue further work in this space at this time. Instead, HealthWest Partnership and individual PCDD Alliance members participated in existing regional activities, advocating for PCDD project findings and recommendations as appropriate. Developing a consistent understanding of vulnerability and its impacts on service users remains an important priority, worthy of future investment.

Concurrent to this work, HealthWest undertook project work to support services to be responsive to client and community need. This was specifically in the areas of health literacy, consumer-directed care in a reform environment, and workforce mutuality, a new approach to workforce diversity. Initiatives and opportunities were circulated broadly, with PCDD Alliance organisations involved in each of these projects⁷.

⁷ Read more about HealthWest’s project work at <http://healthwest.org.au/projects>

7. Recommendations for action

A series of recommendations for action have been identified through Phase Two of the Pathways for Children with Developmental Delays project.

Recommendations for providers of services for children with developmental delays in Melbourne's west

1. Develop a Version Two of the Referral Decision Aid that outlines new services, eligibility criteria and referral pathways following current regional service reforms. Referrers should be effectively included in this process. Dissemination should be strategic, planned with referrers and other potential users.
2. Develop a client-facing resource to support families to develop a better understanding of the service system, eligibility requirements and referral pathways.
3. Continue to identify, monitor and address system issues at a regional level, in light of ongoing changes to funding, service delivery and system reform. This includes monitoring service access among different population groups, to support access to appropriate services for *all* children with developmental delays. The ECEI Partner for the region, The Brotherhood of St Laurence should be included in this approach.
4. Support regional or state-wide efforts to develop a consistent understanding of vulnerability, including how broader vulnerability impacts experiences and outcomes for children with developmental delays.
5. Develop and pilot shared indicators to identify and respond to vulnerability after a shared understanding of vulnerability exists. This work should seek to understand how vulnerability risk and protective factors can be measured within the cohort of families with children with developmental delays.

Broader recommendations for service providers, funders and policy makers

6. High and increasing demand for services for children with developmental delay in Melbourne's west should be addressed. Action to increase efficiencies and reduce duplication is unlikely to have significant impacts on child and family outcomes, if services are not resourced at sufficient levels to address overall need.
7. The early childhood education, health and disability sectors should continue to explore ways of working together to support early identification and intervention for children with developmental delays, simplify referral pathways, and reduce barriers for children and families navigating the complex system.

8. Regional and state-wide work should continue to develop a shared and comprehensive approach to vulnerability among children and families. It is important that this work not occur in silos but be consultative and coordinated, in order to provide a truly shared approach to vulnerability.
9. Funders of services for children with developmental delays should consider providing clearer guidance regarding service delivery, eligibility and referral pathways. While it is important to allow some regional flexibility, insufficient guidance can lead to system inefficiencies and gaps, and confusion for service providers, referrers and families.
10. There is a strong need in Melbourne's west for effective supports to be provided under NDIS for service users with low English proficiency. Provision of translation and interpreter services, as well as utilisation of a culturally diverse workforce should be a planned and core aspect of system reforms such as NDIS.
11. Clearer and earlier communication around funding changes such as Continuity of Support funding, is beneficial to service providers and users. This will enable more effective planning to support service delivery, workforce and those currently receiving services under this scheme.