

Pathways for Children with Developmental Delays (PCDD)

Summary report

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BACKGROUND

Preschool 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 are provided by community health services (IPC Health, cohealth and Djerriwarrh Health Services), hospital based services (Western Health and Melton Health) and Early Childhood Intervention Services (ECIS).

This regional 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 leads to inefficiencies, duplication, gaps and confusion for families and referrers.

The Pathways for Children with Developmental Delay (PCDD) Project identified efficiencies and improvements to streamline current service provision to ensure that limited public resources are used as efficiently and effectively as possible. This is important work in light of the growing demand for services and the future introduction of the National Disability Insurance Scheme (NDIS). The two key objectives for the project were:

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.

The focus of this project was services for children:

- with a delay in one or more area(s) of cognition, speech/language, fine or gross motor, play, social/emotional, behavioural, nutrition/eating and self-care;
- where the developmental delay becomes evident subsequent to the postnatal period and through to the time of school entry; and
- living in the Local Government Areas (LGAs) of Brimbank, Melton, Maribyrnong, Wyndham or Hobson's Bay.

LOCAL CONTEXT

It is clearly recognised and documented that there is growing demand for these services in Melbourne's west due to population growth, increasing numbers of children with complex and chronic conditions, advances in medical services to premature and medically complex babies and infants, significant areas of vulnerability and socio-economic disadvantage, and high rates of cultural and linguistic diversity^{1,2}. The Australian Early Development Census indicates the growing demand and complexity in Brimbank, Melton and Wyndham (see Figure 1). This demand has not been reflected in funding changes.

Figure 1: Percentage of children developmentally vulnerable³

LGA	Developmentally vulnerable on 1 or more domain		Developmentally vulnerable on 2 or more domain	
	% 2015	% change 2009-15	% 2015	% change 2009-15
Brimbank	31	3.9	17.5	4.9
Maribyrnong	18.9	-6.4	7.5	-5.3
Melton	21	1.4	10.2	1.9
Wyndham	26.4	2.5	13.3	0
Hobson Bay	19.5	-0.5	8.7	-1.6

¹ Regional Health Needs Assessment (2016). North Western Melbourne Primary Health Network.

² The Brimbank Atlas of Health and Education (2014). Public Health Information Development Unit for the Mitchell Institute for Health & Education Policy.

³ Australian Early Development Census (2015). Available at: <https://www.aedc.gov.au/data/data-explorer>



METHODOLOGY

A project advisory group consisting of representation from western service providers, State Government, Royal Children's Hospital and Strengthening Hospitals for the West was established and provided guidance throughout the project. 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.

RESULTS AND RECOMMENDATIONS

The following describes the main areas where service system challenges were identified, the nature and implications of these challenges and key recommendations to address them.



ELIGIBILITY

KEY FINDINGS

The following is known about the current and future system:

- **There is no consistency** across the region in how the terminology in referral criteria is defined, interpreted and applied. This terminology typically includes:
 - The number of areas of developmental delay,
 - The severity of the delay (e.g. *mild, moderate, substantial*),but lacks consistency across the region.
- **Some developmental profiles do not clearly meet any of the service eligibility criteria.**
- **The developmental profile of some children is unknown**, making it difficult to determine eligibility:
 - The child may be too young for the full developmental profile to be clear.
 - A single appointment may not be sufficient.
 - The referrer may not have the skills or confidence to discuss their full concerns about the child with the child's carer.
- **Waiting periods vary between service providers** for an initial appointment. These differences can be significant.
- **People who do not have permanent residency in Australia will not be eligible for the NDIS**, including Asylum Seekers, people on Temporary Protection Visas (TPVs) and people on Safe Haven Enterprise Visas (SHEVs).

KEY CHALLENGES

The following challenges are experienced with the current system:

- Referrers are not confident which service to refer to.
- The same referral may be sent to multiple service providers.
- Referrers may understate the child's difficulties to ensure the referral is accepted and the child is seen in a timely manner.
- Some service providers receive significant numbers of ineligible referrals.
- Frequently children are seen by one service, found to be ineligible and re-directed to another.
- Referrers are frustrated when referrals are rejected.
- Some referrals do not clearly fit eligibility criteria for any service provider.
- Families may experience confusion and lengthy waiting periods, and may be at risk of disengaging.

RECOMMENDATIONS FOR ACTION

The following service improvements are recommended:

- Community health and hospitals align definitions of severity and 'areas' to domains used in the Australian Early Development Census 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 referral tool to communicate alignment of eligibility criteria and improve referrals.
- Regional consideration should be given to future service provision to children who are not permanent residents of Australia.
- Waitlists backdated and when families need to be transferred to an alternative service, clinicians to support this process.



REFERRAL AND INTAKE

KEY FINDINGS

The following is known about the current system:

- **Providers accept referrals from different sources**, this varies between providers. (e.g. parents, allied health, education, maternal & child health, paediatricians and GPs).
- **Providers have different referral requirements**. Each service provider has their own referral forms and some accept referrals over the phone.
- **Providers have different intake practices**. Some providers:
 - require parents to complete questionnaires prior to intake.
 - require families to see other professionals (e.g. a paediatrician) prior to intake.
 - collect additional information (e.g. clinical reports) or make phone enquiries during intake.
 - use clinicians, others have trained intake workers.
- **E-referral platforms are limited** in their interoperability, functionality and are not commonly used by all staff.

KEY CHALLENGES

The following challenges are experienced with the current system:

- Referral information is not always consistent with the child's presentation when seen for assessment by service provider clinicians.
- Clinical information in referrals may be brief or incomplete, making it difficult for intake to determine eligibility.
- Submitting referrals can be time consuming for referrers, particularly if referrals are rejected and different referral requirements apply.
- Difficulty re-directing referrals due to differing referral requirements and limitations associated with e-referral platforms.
- Some parents find it challenging to complete forms, particularly if they have low health literacy.
- Multi-step referral processes can be complex and overwhelming for parents.

RECOMMENDATIONS FOR ACTION

The following service improvements are recommended:

- The adoption of a cross agency, clinician led face-to-face intake system for referrals where service eligibility is unclear.⁴
- Improved use of existing and pending e-referral platforms.⁵
- Support for families with low health literacy (see next section).

⁴ This recommendation needs to be considered in the context of the pending rollout of NDIS and the introduction of the Early Childhood Early Intervention (ECEI) approach. Whilst it is still in development, ECEI may assist with determining appropriate referral pathways for children whose developmental profile is unknown.

⁵ This recommendation needs to be considered in the context of pending State Government initiatives to improve the e-referral infrastructure and interoperability across the state.



VULNERABILITY

KEY FINDINGS

The following is known about the current system:

- **There are high levels of vulnerability** and complexity for children and families in Melbourne's west.
- **Vulnerability can be difficult to identify** at the first point of contact or via paper based methods.
- **Vulnerability can be interpreted differently**, from a population perspective (e.g. refugee, asylum seeker, Aboriginal and Torres Strait Island, etc.) as well as by consideration of certain features (e.g. capacity to make change, self-manage or advocate for own needs etc.).
- **Vulnerability can be considered in terms of risks and protective factors** (e.g.: family strengths).
- **There is no standard measure of vulnerability** or agreed prioritisation practices.
- **It can be difficult for some families to engage** with services due to a range of vulnerabilities.
- **Health literacy responsiveness** of an organisation may impact accessibility to services. (e.g.: Written documents and forms commonly used by services may be a barrier).
- **A range of methods** may be needed to engage vulnerable families.
- **Lack of transport** options is a significant barrier for some families.

KEY CHALLENGES

The following challenges are experienced with the current system:

- Services can be overwhelming for some families.
- Some vulnerable families may drop off waiting lists or not engage with services.
- Outreach service provision is not offered by all services or may be very limited.
- Written documents and forms are challenging for families with low health literacy.
- It can be difficult for services to accurately identify vulnerability at the point of intake.
- Due to service demands and constraints, sometimes services may be limited in their flexibility to assist vulnerable families.

RECOMMENDATIONS FOR ACTION

The following service improvements are recommended:

- Development of shared indicators for vulnerability.
- Improved responsiveness to vulnerability, including reviewing processes which may create barriers to access and engagement.
- Build capacity of workforce to improve responsiveness to health literacy and vulnerability.



FUTURE SYSTEM CHALLENGES

NDIS roll out for Melbourne's west is scheduled for 1st October 2018, although the rollout may commence earlier. NDIS will bring significant change to service provision in the region. ECIS funding will roll over to NDIS and other funding changes may occur. The detail of these changes and impact of these changes is yet unknown, but there are concerns that there may be additional pressures on services to change their eligibility criteria, service models and staffing profiles. Analysis of service usage data and waitlists from ECIS and DHHS funded services is required to gain a better understanding of the potential impacts of future system challenges on providers, referrers, the workforce, children and families.

The rollout of the NDIS also offers many opportunities, with the promise of improved choice, control and certainty for families who access the scheme. There are opportunities for service providers also, to become 'partners' and NDIS 'providers'. The Early Childhood Early Intervention (ECEI) approach⁶ is a new addition to the NDIS model. Whilst it is still in development, ECEI may assist with determining appropriate referral pathways for children whose developmental profile is unknown. Service providers are encouraged to consider the ECEI model in future system planning.

CONCLUSION

Services in Melbourne's west provide a high quality service to preschool children with developmental delay whilst managing waiting lists and high demand for service. Despite this, there is a lack of coordination across different service providers leading to fragmentation of the service system as a whole, confusion and inefficiencies for families, and frustrations for those referring children into this system. The pending introduction of NDIS in late 2018 places increasing emphasis on the need for service system improvement and to ensure that the region is well prepared.

This project sought to collectively explore ways to improve the integration of the regional service system to improve efficiency. Key areas for improvement were identified in eligibility, referral/intake and support for vulnerable families. Service providers have demonstrated a high commitment to considering service improvements with draft changes to eligibility criteria being currently considered. There is a commitment by service providers to progress this work through continuing cross agency meetings over the upcoming year. Analysis of service usage data will be important to contribute to this forward planning.

ACKNOWLEDGMENT

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⁶ www.ndis.gov.au/ecei

