

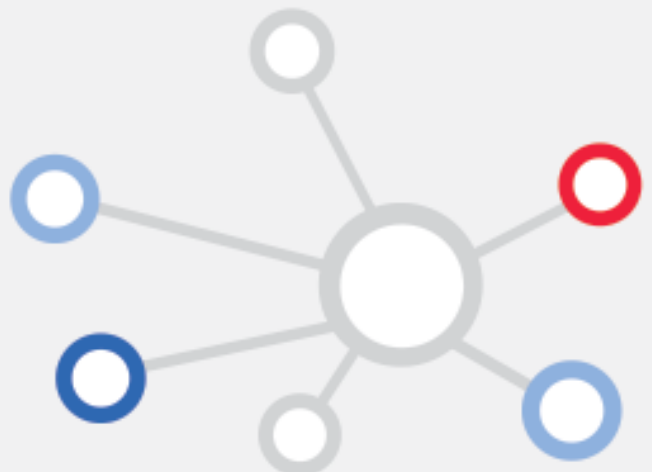
Pathways for Children with Developmental Delays (PCDD)

Project Report

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Prepared by:

Sally Butzkueven, Project Officer



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ABBREVIATIONS

| | |
|------|---|
| ASD | Autism Spectrum Disorder |
| ASQ | Ages and Stages Questionnaire |
| ATSI | Aboriginal and Torres Strait Islands |
| CAHS | Children's Allied Health Service (Western Health) |
| CALD | Culturally and Linguistically Diverse Backgrounds |
| ECEI | Early Childhood Early Intervention approach |
| ECIS | Early Childhood Intervention Service |
| LGA | Local Government Area |
| MD | Multi-disciplinary |
| NDIA | National Disability Insurance Agency |
| NDIS | National Disability Insurance Scheme |
| OT | Occupational Therapy |
| PCDD | Pathways for Children with Developmental Delays Project |
| PT | Physiotherapy |
| SP | Speech Pathology |

DEFINITIONS

The following terms have been defined as below for the purposes of this report:

| | |
|---------------------|---|
| Melbourne's west | Local Government Areas of: <ul style="list-style-type: none"> • Brimbank. • Melton. • Maribyrnong. • Wyndham. • Hobson's Bay. |
| Developmental delay | Delay in one or more areas of cognition, speech/language, fine or gross motor, play, social/emotional, behavioural, nutrition/eating and self-care. |
| Preschool children | Children below school age. The particular focus of this project is on delays that are identified subsequent to the antenatal and postnatal period. |
| Service Provider | Public services that provide specialist assessment, intervention and/or support to preschool children in Melbourne's West with developmental delay. These services are: <ul style="list-style-type: none"> • Community Health Services: <ul style="list-style-type: none"> – IPC Health – cohealth – Djerriwarrh Health Services • Hospital based services: <ul style="list-style-type: none"> – Western Health – Melton Health • Early Childhood Intervention Services |



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HealthWest would like to acknowledge the support of the advisory group throughout this project. This group worked cohesively to consistently reinforce the aims and activities of the project and contribute valuable feedback at each stage. The group included a wide representation from regional service providers, the Department of Health & Human Services, the Department of Education & Training, Strengthening Hospitals in the West project and The Royal Children's Hospital.

This project was funded by the Department of Health and Human Services.



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.

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.

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 |

FUTURE SYSTEM CHALLENGES

NDIS roll out for Melbourne's west is scheduled for 1st October 2018. This will bring significant change to service provision in the region. ECIS funding will roll over to NDIS and the funding that Western Health currently receives from the Community Development & Assistance Program will cease. Services currently provided by hospitals are likely to take a different form. The detail of these changes and impact of these changes is yet unknown, but there are concerns that there may be additional pressures on other existing services to change their eligibility criteria, service models and staffing profiles.

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: www.aedc.gov.au/data/data-explorer



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) approach⁴ 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.

PROJECT DESCRIPTION

Introduction

The Pathways for Children with Developmental Delays (PCDD) project was created to work collaboratively with core project partners and other relevant stakeholders to develop a suite of recommendations to be used by key stakeholder organisations to develop a clearer and more streamlined service system that better prepares for meeting the growing demand for services for children with developmental delays. 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 project incorporates the local government areas of the HealthWest catchment including Brimbank, Melton, Maribyrnong, Wyndham and Hobson's Bay. Particular emphasis is on the growth areas of Wyndham, Brimbank and Melton where there is growing demand.

The project includes services provided:

- for children aged 0 – school entry;
- with developmental delays in one or more area(s) of cognition, speech/language, fine or gross motor, play, social/emotional, behavioural, nutrition/eating and self-care. The particular emphasis is for children where the delay is identified subsequent to the antenatal and postnatal period;
- by allied health/educational staff; and
- at the following services;
 - Department of Education & Training (Early Childhood Intervention Service)
 - Community Health Services:
 - cohealth (Braybrook site only)
 - Djerriwarrh Health Services
 - IPC Health
 - Hospitals:
 - Melton Health
 - Western Health Children's Allied Health Service

⁴ More info: www.ndis.gov.au/ecei



Methodology

Phase 1: Data collection

Meetings were held with a manager at each service provider to gather information about current service provision and to gain an understanding of eligibility, referral and intake processes and the services offered at each organisation.

A series of focus groups were held to gather information about the current difficulties, issues that impact on efficiency and effectiveness of service provision and potential solutions. Participants in these focus groups were clinical staff who work within the above organisations as well as those who refer children to these services. There was representation from:

- Early Childhood Intervention Service intake team
- Early Childhood Intervention Service agencies
- cohealth
- IPC Health
- Western Health
- Preschool Field Officer service
- Enhanced Maternal and Child Health service

Where a focus group was not possible, the same information was gathered via survey with participation from:

- Djerriwarrh Health Services
- Melton Health
- Mercy Health
- Paediatric fellow program
- Universal Maternal and Child Health service
- Private allied health professionals

Information representing the consumer perspective was obtained via the collection of consumer stories supplied by clinicians from service provider organisations. During focus groups, the consumer voice was also represented through comments made to staff about the parent experience with the service system.

Results from focus groups and surveys were grouped thematically to identify the core issues that impact on regional service provision. These results were presented to the advisory committee.

Additional work was conducted with benchmarking, consideration of services for vulnerable families and further investigation of potential impacts of the National Disability Insurance Scheme (NDIS).

Phase 2: Recommendations for future service provision

A series of follow up meetings were held with the advisory group and service provider agencies to commence discussions on the key recommendations from the project, with a key focus on service eligibility and face-to-face intake. The advisory committee has agreed to continue to meet approximately quarterly over the next year to further discussions and recommendations from the project.



CURRENT SERVICE SYSTEM

Services currently provided by the organisations listed above have been described in Appendix 1 including:

- Geographical area serviced
- Eligibility criteria
- Referral sources
- Referral and intake processes
- Services offered

The information shows there is significant variation between services.

Strengths of current regional service provision as identified during data gathering are:

- Most services backdate referrals between services. When children are transferred between services in the region, the original date of referral to the first service is honoured meaning that children do not serve double waiting periods.
- High quality of service provided.
- Passion and commitment of clinical staff.
- Overwhelming desire to achieve real outcomes from this project, and for services to work together rather than in silos,
- Significant service modifications undertaken by all agencies to date aiming to improve service provision.
- Strong working relationships between service providers.
- Broad scope of services across region.

FINDINGS

A child attended an assessment appointment with a paediatrician. The paediatrician determined that the child had complex difficulties and referred the child to a service for children with severe delays (Service A). Later, the same child was also seen by the maternal and child health nurse for a routine check-up where delays were also identified. The nurse was unaware that the child had already seen a paediatrician or that the child had been referred elsewhere, and subsequently referred the child to Service B. Clinicians at the Service B commenced service delivery with the child, but become aware that the child's developmental pattern was not consistent with their eligibility criteria. The mother reported that the child saw a paediatrician and the clinician followed up to obtain a copy of the report. The report outlined that a referral was made to Service A and the clinician attempted to contact that service to discuss the child, but was unable to obtain any information as they were not the original referrer. The mother is very confused about the different services, their roles and what is being recommended for her child.

This consumer story is just one of the many stories related by clinicians that illustrate difficulties with current service provision. These stories raise issues such as multiple referrals, complex and confusing eligibility criteria, amount of time spent by service providers following up about children, and families being shuffled between services. Further consumer stories are contained in Appendix 2.

The following is a summary of key themes identified during focus groups and from surveys.



Eligibility

The following challenges were identified related to eligibility criteria for service provision:

1. Terminology

Current terms to define service eligibility include severity ratings such as “mild”, “moderate”, “severe” or “substantial” as well the need to specify the number of “areas” of delay. This terminology was consistently reported to be ambiguous, subjective and open to differing interpretation based on the background and experience of the individual. There does not appear to be a common understanding by either clinicians within services or referrers as to what the severity terms mean or what defines an “area” of delay.

2. Inconsistency

Frequent inconsistency was reported regarding which referrals are accepted by services, with reports that two children with similar presentations may not receive the same response by the same service at the point of intake.

3. Service gap

Current eligibility criteria are reported as not addressing the full range of developmental presentations seen in children. There is a sense that there are three main cohorts of children:



Single/ discrete/ isolated area of developmental delay



More than one area of developmental delay – unclear extent or severity



Diagnosed disability
Delay causing substantial functional limitations
May have multiple areas of significant difficulty

Referral pathways for the first two groups are much clearer than for the third “grey” cohort. This “grey” cohort can be further broken down, as below.





| KNOWN | KNOWN BUT NOT STATED | UNKNOWN |
|--|---|---|
| <p>Either:</p> <ul style="list-style-type: none"> Multiple mild – moderate difficulties but not significant enough to cause substantial functional limitations; OR One main area of need and one or more other areas of milder need. | <p>Child's difficulties are known by the referrer to be more complex than a single discrete difficulty, but either:</p> <ul style="list-style-type: none"> The referrer is not confident to discuss these needs with the parent; OR The parent is judged to not "be ready" to have a discussion about the extent of the child's difficulties. | <p>Includes:</p> <ul style="list-style-type: none"> The child may be young and the developmental needs are still emerging More time may be needed to understand the child's presentation (eg: highly anxious child); The referrer does not have sufficient knowledge or information to determine the child's needs; OR Assessment results may be needed to help determine the child's needs |

The impacts of these eligibility issues for parents, referrers and service providers are listed below.

| Parents | Referrers | Service providers |
|--|--|---|
| <ul style="list-style-type: none"> Frustration. Confusion about where to take their child for help. Confusion about their child's needs. Time wasted attending multiple appointments. Need to repeat same information to multiple people. Shuffled between services. May receive multiple assessments and limited intervention. May be offered services and then have them withdrawn. No overall case management across services. | <ul style="list-style-type: none"> Frustration. May prioritise having referrals accepted by "a" service, even if this may not be the most appropriate service. May learn the "right words" to use to get referrals accepted. May not fully report all areas of the child's difficulty in the referral. May refer to the service with the shortest waiting list. May refer to multiple services. May "give up" referring to services due to the perceived number of exclusions, past history of referral rejection or lengthy waiting times. | <ul style="list-style-type: none"> Frustration. Time spent duplicating services provided elsewhere. Time spent investigating services provided elsewhere for the child, and sometimes limited by privacy restrictions. Time spent transferring referrals to alternative services. Less time to service other children on the waiting list. Staff morale. Inconsistency between clinicians as to when to transfer a client to an alternative service. |



Referral and intake

Referral processes vary between services, as do the steps taken at the point of intake to the service. E-referral platforms have limited interoperability, functionality and are not commonly used by all staff. Below is a list of challenges identified relating to referral and intake.

Parents report:

- Multi-step referral processes can be difficult, complex and overwhelming.
- Filling out forms can be overwhelming for some parents. Some parents may not know what their child can or cannot do.

Referrers report:

- Parents often need help filling in forms.
- Submitting referrals is very time consuming.

Service providers report:

- Intake is time consuming.
- Paper based referral/intake processes do not always ensure referrals are appropriate for the service. Sometimes when the child is seen for assessment, the presentation does not match the information on the referral or the parent/ referrer completed checklist.
- It can be difficult to interpret what service is required if the information provided on referrals is incomplete, brief or ambiguous.
- Difficulty re-directing referrals due to differing referral requirements and limitations associated with e-referral platforms.

Information was reported from a range of stakeholders about advantages and disadvantages of sending out information to families at the point of intake which then needs to be returned prior to an appointment being offered. These include:

Advantages

- Can be a time efficient way to triage referrals.
- Service providers gain additional information about the child's strengths and weaknesses.
- Allows parents an opportunity to provide information about their child.
- Encourages parent buy-in to referral process.
- Prepares service providers for assessment.

Disadvantages

- Creates accessibility difficulty for vulnerable groups or people with low English literacy.
- Requires time to send/receive/track documentation.
- Information may be out of the date by the time the child is seen.
- Parents may not have a clear understanding of their child's strengths and weaknesses.
- Parents may require additional support from referrers to ensure information is completed and returned.
- Risk of vulnerable children being discharged due to lack of follow through.



Vulnerability and Accessibility

It is widely reported that there are high levels of disadvantage and vulnerability for children and families in Melbourne's west and stakeholders reported a sense that some of these children and families may be 'falling between the gaps'. Information was sought from stakeholders about issues that impact on accessibility of services in order to identify potential ways to minimise barriers. The following themes emerged:

1. Overwhelming

Services can be overwhelming for some families due to:

- Lack of understanding of what the service is for.
- Don't know where the service is or how to get to it.
- Unsure what will happen.
- Too complicated.

2. Identification of vulnerability

Vulnerability can be difficult to identify at the first point of contact or via paper based methods and there is no standard measure of vulnerability or agreed prioritisation practices.

3. Health literacy difficulties

The need for support for service providers in how to communicate in an accessible way for people with low health literacy. E.g. those from culturally and linguistically diverse backgrounds, parents with low literacy levels, and parents who may be able to read the information but find it difficult to understand.

4. Cultural

Cultural issues including stigma, culture of disability, or difficulty getting interpreters in certain locations/language groups.

5. Transport

Transport can provide a barrier for families to access services. E.g.

- Families without a car or where the only car is used for travel to work.
- Lack of public transport options in some areas.
- Difficulty of taking public transport with multiple young children, some of whom have developmental difficulties.

6. Discharge

The need for services to balance the needs of empowering families to have buy-in to service provision versus assisting families with accessibility issues who may require a more supported pathway.



Greater support for vulnerable families

Information presented in this section is based on outcomes from focus groups, discussion with coordinators from two programs which support vulnerable families in Melbourne's west (Busy Bees –Djerriwarrh Health Services and Hungry Caterpillars -IPC Health) and information presented by Associate Professor Virginia Lewis from Latrobe University at a HealthWest Partnership forum in May 2016⁵.

Vulnerable consumers could be defined as: "Persons whose demographic, health, geographic, economic, and/or cultural characteristics impede or compromise access to and/or the quality of services that they receive."⁶ Vulnerability can be considered from both:

1. Population perspective: identifying groups where large numbers are likely to have characteristics of vulnerability. Groups that are frequently identified as vulnerable are⁷:

- Aboriginal and Torres Strait Island (ATSI) people.
- Refugees / Asylum Seekers.
- People with Culturally and Linguistically Diverse (CALD) backgrounds.
- People with an intellectual disability.
- Children in out of home care.
- People experiencing or at risk of homelessness.
- People with a serious mental health issue.

It is recognised that there may be individual variation between people in these population groups and that the level of vulnerability for individuals can fluctuate with time.

2. Features which indicate vulnerability include:

- Basic daily needs not intact (e.g.: shelter, food, income etc.)
- Low internal resources/capacity to:
 - make change
 - self-manage
 - advocate for own needs

Due to a range of factors including but not limited to:

- mental health difficulties
- intellectual disability
- drug and alcohol difficulties
- gambling
- trauma
- violence
- Limited family/social supports.
- Low health literacy and ability to navigate the service system.
- Complex multiple coexisting issues.

⁵ Lewis, V (2016) "Vulnerability". Presented at HealthWest Partnership Forum, 25th May 2016. Australian Institute for Primary Care & Ageing, Latrobe University.

⁶ Lewis, V (2016) "Vulnerability". Presented at HealthWest Partnership Forum, 25th May 2016. Australian Institute for Primary Care & Ageing, Latrobe University.

⁷ Categories used by The Community Health Program, Victorian Department of Health and Human Services, as described in Lewis, V (2016) "Vulnerability". Presented at HealthWest Partnership Forum, 25th May 2016. Australian Institute for Primary Care & Ageing, Latrobe University.



The following issues were raised for consideration:

- Direct questions at the first contact with families may not reveal vulnerabilities.
- Labels and paper based methods may not be the best ways to identify vulnerability. A family may be identified as having many risk factors yet have high levels of protective factors including internal resources and supports and may be managing well. Conversely another family may appear on the surface to be coping well, yet have a number of issues impacting on their ability to cope.
- Families may not self-identify as being vulnerable.
- In some situations it can take time to identify that a family is vulnerable, and it is not until the family becomes comfortable with a service provider that their vulnerabilities become evident.
- No single approach works for all families.
- Accessibility to services is impacted by both abilities specific to the individual and the characteristics of the health service (approachability, acceptability, availability, affordability and appropriateness)⁸.

The following are reported to be aspects which are successful in supporting vulnerable families in current programs:

- A “drop-in” approach promotes a feeling of welcomeness and accessibility.
- Parents can find support in a group setting to make connections and observe role modelling by other parents.
- A playgroup style format is a soft entry option and not as overwhelming as a formal appointment, and may be a more appropriate setting to form relationships with vulnerable families.
- A venue in the community is less overwhelming than a clinical building.
- Active follow up for non-attendance where possible is very important for successful engagement and linking in of families.
- When the structure of the service is known, families feel more comfortable, to know what to expect, to trust the service and to feel safe.
- Having flexibility to arrive late at times is helpful.
- Having the option of attending with a support worker can be helpful for some families.
- The “No Wrong Door” principle allows consumers to present with any issue.
- Having one key worker ensures that consumers do not get “bounced around” between services.
- Encouragement and reinforcement motivate families to remain engaged (e.g.: incentive prizes for attendance, resources for home use etc.).
- Families appreciate knowing that the service will continue to support them even if things are hard or their child is considered to be “difficult”.

Consideration could be given to the use of a scale to assess vulnerability. Examples of this may include ‘*The Global Assessment of Functioning*’ or the 9 point rating scale developed by an interstate program: referral is rated on three domains - family issues, child issues, and environment.

⁸ Categories used by The Community Health Program, Victorian Department of Health and Human Services, as described in Lewis, V (2016) “Vulnerability”. Presented at HealthWest Partnership Forum, 25th May 2016. Australian Institute for Primary Care & Ageing, Latrobe University.



National Disability Insurance Scheme (NDIS)

Looking ahead to when the National Disability Insurance Scheme (NDIS) is introduced in Melbourne's west, there will be changes with some of the services currently being offered. The nature of these changes is still being determined, and future service provision should take into account these known changes as they become clearer.

The following information is available about the NDIS scheme^{9,10,11,12}:

- NDIS will roll out in Melbourne's west from 1st October 2018.
- The Early Childhood Early Intervention (ECEI) Approach will be implemented to deliver early childhood intervention for children aged 0-6 years.
- The NDIA will engage Early Childhood Providers called 'Early Childhood Partners' who will work with the family and use their clinical and specialist expertise in Early Childhood Intervention to understand the child's developmental delay or disability and the impact on their everyday functioning.
- The Early Childhood Partners are suitably experienced and qualified organisations with strong local knowledge and understanding of the needs of children and their families to deliver the ECEI Services.
- The Early Childhood Partner will be the first contact point for families. The Early Childhood Partner will discuss with the family the most appropriate supports that would benefit the child.
- The NDIS Early Childhood Partners may:
 - Provide information.
 - Refer the family to a mainstream service such as a community health Service, playgroup or peer support group.
 - Identify if a child may benefit from some short term (6-12 months) intervention and provide those services. For example, if a child has developmental delay with a primary speech delay, some initial speech therapy can be provided by the early childhood partner which, over time, will assist to inform the child's longer term support needs.
 - Identify that a child requires long-term specialised early childhood intervention supports then assist the family to request access to the NDIS, submitting the required information and evidence to the National Access team.
 - Undertake the planning process with families who receive access to the NDIS.
 - Coordinate a combination of the options above.
- Referrals to Early Childhood Partners can be made by professionals or self-referral by parents.

The ECEI approach offers a soft entry option into the NDIS for children where it is not known whether they will qualify for NDIS or where families are not ready to discuss the full NDIS. Children who are clearly eligible for other community services (e.g.: those eligible for community health) would not be taken on by the partner.

⁹ <https://www.ndis.gov.au/ecei.html>

¹⁰ <https://ndis.gov.au/html/sites/default/files/documents/Research/NDIA-ECEI-Approach-1.pdf>

¹¹ <https://ndis.gov.au/html/sites/default/files/Early-childhood-Early-Intervention.pdf>

¹² <http://livestream.ssc.gov.au/ndis/5april2016/>



In 2016, research was conducted by the Social Policy Research Centre in the Nepean Blue Mountains and Hunter Regions in NSW¹³ to examine the impact of the introduction of the NDIS. The focus was on changes experienced from both the perspective of the family and NDIS service providers.

Themes emerged in the areas of:

- Growth in demand.
- Some concern that vulnerable children may be missing out.
- The need to maintain soft entry options for disadvantaged families.
- Overwhelming system for some families.
- ECEI approach offering support for children who did not qualify for NDIS, although there were some challenges with funding for this.

An interstate service¹⁴ was identified which has recently been modified from a therapy service to primarily an assessment service with the aim to:

1. Identify if a child presents with a delay, and if so
2. Identify the correct pathway of NDIS, other therapy or parent workshop.

This service uses a drop in model with an initial face-to-face consult followed by one or more assessment sessions. The Ages and Stages Questionnaire is also used as part of the assessment process.

A number of questions have been raised during the current project about how NDIS will translate into Melbourne's west. NDIS will bring significant change to service provision in the region and some ECIS funding will roll over to NDIS. Some services may take a different form. The detail of these changes and impact of these changes is yet unknown, but there are concerns that there may be additional pressures on other existing services to change their eligibility criteria, service models and staffing profiles.

Additional questions that have been raised include:

- Acceptance of a service that contains the word "disability" by families.
- Likely demand for assessment services.
- Potential for multiple referrals for the same client.
- Supports for vulnerable families and those whom are ineligible for NDIS.

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) approach 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.

¹³ <http://www.ecia-nsw.org.au/documents/item/1587>

¹⁴ Further information, email: Child.Development@act.gov.au



BENCHMARKING

The following has been identified through discussions with a range of service providers from different locations across Victoria and interstate.

Eligibility

Discussions with other regions have identified that:

- There is variation between community health services' eligibility. Some services define eligibility as one main area of need, whereas others accept also referrals for mild-moderate multi-disciplinary difficulties across several developmental areas.
- There is variation between rates of inappropriate referrals received by Community Health services. Several services report figures as high as 25% inappropriate referrals, although one service (who accepts multi-disciplinary referrals) stated that only a minority of children are found to have more complex difficulties and be ineligible for the service. This service reported their intake workers to be highly trained.

Referral

Information about a range of “No Wrong Door” models was sought to further understand the strengths and challenges of this service provision:

- A Victorian regional centre has been working on a “No Wrong Door” model across a number of different service providers, using:
 - A common screening tool.
 - A common web-based platform to allow sharing of referral information.
 - Joint planning between services to ensure children and families receive the most appropriate services.
 - A warm referral process that ensures that families presenting to any agency are linked to the supports they require.
 - An agreement between agencies to accept joint responsibility for children and families seeking support.

This work is still in progress. Two factors have been identified as required to ensure success: i) having one lead organisation to drive the project, and ii) written commitment and sign off from all organisations and the overall governance group.

- The Brimbank Melton Connect program “No Wrong Door” model: consumers can present to a service with any issue. Central to this model is having one key worker for the family to ensure that agencies work together to ensure the client is not lost or shuffled between services.
- Youth services commonly use “No Wrong Door” models. They include a common screening tool to identify the young person's needs which the worker then uses to help the person navigate through the system. Workers describe the system as effective for young people who may not clearly meet criteria for services and who would have previously slipped through the gaps¹⁵.

¹⁵ <http://www.nowrongdoor.com.au/>



Intake

A Victorian service was identified that has funding to provide both community health services and services for ECIS eligible children, and directs referrals into the most appropriate stream. The process for this service is:

- a) The child attends a “First Steps” session. These are 90 minute sessions, attended by four children, held weekly and staffed by a speech pathologist and early childhood educator. The child is observed, informal screening is conducted as well as the completion of developmental milestone checklists.
- b) Staff determine which stream is most appropriate for the child. If there is doubt, it is suggested that the child sees a paediatrician or attends one of the other group options run by the service (PlayConnect, music therapy).
- c) If required, the child may change to the other stream, but this is rarely required. The above processes are successful in identifying the correct stream for the majority of children. Feedback from staff at this service is that face-to-face intake is critical to ensure children are directed to the right service.

A project was completed interstate some years ago with the aim of streamlining service provision across several services to ensure the right child was referred to the right service. The key features of this project were:

- Intake completed either:
 - Paper based: where the referral was comprehensive and the needs of the child were clear.
 - Face-to-face: where the needs of the child were unclear or more information was required.
- Face-to-face Intake interviews were 30 minutes in duration and involved a short clinical interview and observation of the child.
- Following intake, the referral was allocated a prioritisation rating on a scale of 0-9 with three domains: Family issues, child issues, and environment.

Findings of the project were:

- Face-to-face clinician led intake was demonstrated to be effective in ensuring the right child was seen at the right place.
- The time investment at the point of intake was judged to be worthwhile given the increased efficiency achieved.
- The service was valued by clinicians and families.

The following processes are used at community health services in other regions to determine if referrals are eligible for the service:

- Phone questionnaires (self-made) completed by the intake team asking questions about areas where they may be delays. It was reported that when administered by *highly trained* intake workers, this system can identify some children with more significant delays, but not all. Some children can only be identified when seen face to face.
- One service trialled a 30 minute face-to-face intake interview for *every* referral, however this was not continued as parents were frustrated at not receiving a “service” for their time, and the staff completing the interviews were not fully trained in how to identify signs. Reverted to phone interviews conducted by trained intake workers.



Service providers included in the PCDD project that currently use or have trialled a form of face-to-face screening include:

- IPC Health Toddler Screening Group.
- Western Health Children's Health Services – clinician phone call at intake.
- cohealth drop-in clinic (for centres in other regions: Fitzroy, North Melbourne, Avondale Heights).

Summary

Benchmarking and other readings have identified:

- Services in other regions also struggle with ways to ensure the right child is seen at the right service.
- There are benefits of face-to-face clinician led intake with a subgroup of referrals.
- Highly trained intake workers are a valuable component of triaging a significant component of referrals.
- No other specific commercially available tools or checklists are being used at the point of intake.
- “No Wrong Door” models are effective, but need to be well supported.
- Vulnerability can be defined in many ways and can be difficult to identify.
- Features that support vulnerable families have been identified.
- The NDIS ECEI pathway offers additional supports for children who may not demonstrate clear eligibility for NDIS, although there may be some challenges with funding this support.
- An interstate service saw a benefit in re-designing their service as an assessment only service to determine NDIS eligibility.



SOLUTIONS

Focus groups, advisory committee discussions and input from surveys have identified the following areas of consideration for regional service improvements.

Primary recommendations

Eligibility

- Community health and hospitals align definitions of severity and 'areas' to domains used in the Australian Early Development Census community health guidelines 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.
- 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). Regional consideration of service provision for these children should be given.
- Waitlists backdated and when families need to be transferred to an alternative service, clinicians to support this process.

Intake

- The adoption of a cross agency, clinician led face-to-face intake system for referrals where service eligibility is unclear.

Support for vulnerable families

- Development of shared indicators for vulnerability.
- Improved responsiveness to vulnerability, including reviewing processes which may create barriers to access and engagement. These may include but not be limited to:
 - Use text rather than voice calls to mobiles to limit calls to families from "unknown" numbers.
 - Inform referrers of upcoming appointments so they can support attendance.
 - Contact referrer prior to discharge due to lack of follow through.
- Build capacity of workforce to improve responsiveness to health literacy and vulnerability

Secondary recommendations

Eligibility

- Explore new electronic systems (e.g. Patchwork) or extend current de-identified key system to track involvement of services and eliminate multiple referrals.

Intake

- Service created to provide short term support for grey cohort to help determine most appropriate service.
- Improved use of existing e-referral platforms (pending statewide improvements to infrastructure and interoperability).
- Support for families with low health literacy (see next section).

Support for vulnerable families

- Develop one page handouts about each service designed for parents with low health literacy and distribute to referrers to hand out to parents.
- Outreach/satellite clinics.
- Flexibility with service provision where possible.



CONCLUSIONS AND NEXT STEPS

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.



APPENDIX 1: CURRENT SYSTEM

Note: Information contained below represents service delivery for preschool population at the key service providers in Melbourne's west current at the time of commencement of the PCDD project. Information on services that cater specifically to the Aboriginal and Torres Strait Islander population is contained in Appendix 4.

| SERVICE PROVIDER | GEOGRAPHICAL AREA SERVICED | ELIGIBILITY (must be prior to school entry, unless otherwise indicated) | REFERRAL AND INTAKE PROCESS | INELIGIBLE REFERRALS | DISCIPLINES AND SERVICES PROVIDED |
|---|--|--|---|---|--|
| Children's Allied Health Service (CAHS) – Sunshine Hospital | LGAs of Brimbank, Maribyrnong, Wyndham, and Hobsons Bay. | <p><u>Single disciplinary care:</u></p> <ul style="list-style-type: none"> • SP – feeding only (0-school entry). • Physiotherapy (PT) Neurodevelopmental (up to 18 months of age). • Dietetics (0-16 years). • Neuropsychology (2-12 years). <p><u>Multidisciplinary care:</u> Identified needs in two or more of the following areas:</p> <ul style="list-style-type: none"> • Expressive and Receptive Language. • Self-care. • Cognitive Development. • Motor Development. • Play and social skills. • Behaviour. • Eating and Drinking. | <p>Referrals accepted from professionals only and in writing only.</p> <p>Required: Completed referral form. Form requires:</p> <ol style="list-style-type: none"> 1. Indication of reason for referral of i) Autism Assessment, ii) Multi-disciplinary allied health screening assessment, OR iii) Single discipline service. 2. Description of child's skills in a range of developmental areas. <p><u>Step 1</u> Intake worker:</p> <ol style="list-style-type: none"> 1. assesses for eligibility according to age, geographic catchment, not yet commenced school, no involvement with another service provider. 2. confirms referral meets eligibility criteria for either <u>single discipline</u> (according to age and for SP, that referral is for "feeding") OR <u>multi-disciplinary care</u> (evidence of needs in more than one developmental area). 3. adds name to the waiting list. <p>Single discipline referrals are directed to individual disciplines for further management by specific clinicians.</p> <p>For multi-disciplinary referrals:</p> | <p>When referrals are identified as clearly ineligible at the time of referral, re-direction of the referral to the most appropriate service is facilitated by the intake with parent/referrer consent and knowledge.</p> <p>Where it is unclear if the referral is eligible at the time of referral, the referral is accepted pending a clinician gathering further information from the family and/or referrer to clarify if referral is accepted or declined.</p> <p>When the referral is accepted and the child is then seen for assessment:</p> <ul style="list-style-type: none"> • The majority of single discipline referrals are found to be eligible for the service, although sometimes they are identified as having additional difficulties in other developmental areas (and therefore eligible for multi- | <ul style="list-style-type: none"> • Dietetics. • Neuropsychology. • Occupational Therapy. • Physiotherapy – Neurodevelopmental. • Speech Pathology. <p>1. <u>Assessment</u></p> <ul style="list-style-type: none"> • Single discipline or MD as indicated by referral. <p>2. <u>Therapy:</u></p> <ul style="list-style-type: none"> • individual and group. • Single discipline and conjoint. |

| SERVICE PROVIDER | GEOGRAPHICAL AREA SERVICED | ELIGIBILITY (must be prior to school entry, unless otherwise indicated) | REFERRAL AND INTAKE PROCESS | INELIGIBLE REFERRALS | DISCIPLINES AND SERVICES PROVIDED |
|------------------|----------------------------|--|--|---|-----------------------------------|
| | | <p>which results in the need for a coordinated range of services to support the child's development and the child's family.</p> <p>The majority of these children are also eligible and referred to ECIS services.</p> | <p><u>Step 2 (where required)</u> A clinician contacts the referrer and/or family if further information is needed to determine eligibility.</p> <p><u>Step 3</u> Clinician (same as in step 2) phones parent and conducts brief pre-screening checklist. This includes:</p> <ol style="list-style-type: none"> 1. Has audiology assessment been completed? If no, referral completed with parent consent. 2. Has the child seen a paediatrician? If no, referral completed with parent consent. 3. Is child accessing any other <i>like</i> public services intervention? If yes, decline referral. 4. Is child on the waiting list for early intervention? If no, and indicated by referral, referral completed with parent consent. 5. Identification and discussion of any other risk factors. 6. Brief discussion of reason for referral and parent concerns, to identify areas requiring immediate action, and also to determine if child is on the waiting list for the most appropriate service. <p><u>Step 4 (completed where discussion is required to determine most appropriate pathway/service)</u> Clinician presents case at fortnightly complex case discussion meeting. Pending outcome of discussion, amendment may be made to the waiting list entry if appropriate.</p> <p><u>Step 5</u> Active waiting list management to:</p> <ol style="list-style-type: none"> 1. Update parents on likely waiting time. 2. Follow up any actions that had been previously recommended (e.g.: to see a paediatrician). | <p>disciplinary services at Sunshine Hospital).</p> <ul style="list-style-type: none"> • Most multi-disciplinary referrals are found to have multi-disciplinary needs and be eligible for the service, although a significant number are referred to the Autism Assessment service at Sunshine Hospital*. Most children are also eligible for Early Intervention Services, and will be provided a time limited intervention service. • When a child is seen for assessment and found to be eligible for a different service, the clinician refers and transitions the child onto the appropriate service with parent consent. | |

| SERVICE PROVIDER | GEOGRAPHICAL AREA SERVICED | ELIGIBILITY (must be prior to school entry, unless otherwise indicated) | REFERRAL AND INTAKE PROCESS | INELIGIBLE REFERRALS | DISCIPLINES AND SERVICES PROVIDED |
|--------------------------------|--|--|---|---|---|
| | | | 3. Ascertain if there have been any changes since last contact (e.g.: been seen at another service). Phone calls can be made up to 6.00pm to capture families who are not home during the day. | | |
| cohealth (Braybrook site only) | Maribyrnong LGA plus limited service to areas of Brimbank LGA where the cohealth site is the closest geographically. | Mild to moderate delays or difficulties (or at risk of developing difficulties) in a single developmental area OR in one main area plus a mild delay in a second area. Developmental areas are: Communication, Social/emotional, Play/Learning, Motor skills, Self-care, Sensory, Eating. | Referrals accepted from parent or professional by phone or in writing. <u>Phone:</u> <i>Parent referral:</i> Member of intake team completes referral form with parent over the phone. Referral form requires: <ul style="list-style-type: none"> • Identification of allied health discipline required. • Description of main concern. • Description of child's skills in a range of developmental areas. <i>Professional referral:</i> Requested to complete referral form and send to cohealth. <u>In writing:</u> Required: Completed referral form. Intake team member contacts referrer and/or family if further information is needed to determine eligibility. | When referrals are identified as clearly ineligible at the time of referral, the parent/referrer is informed of the more appropriate service and recommended to contact them directly or to forward referral there. Where it is unclear if the referral is eligible at the time of referral, the intake team member discusses the referral with a clinician to make a decision about eligibility. When the referral is accepted and the child is then seen for assessment, approximately 13% children are found to have more significant difficulties and to be ineligible for cohealth. The clinician then refers and transitions the child onto the appropriate service at an appropriate time and with parent consent. There is some variability between clinicians and children as to the timing of the transition. | <ul style="list-style-type: none"> • Occupational Therapy. • Speech Pathology. Also: <ul style="list-style-type: none"> • Dietetics. • Podiatry. NB: No dedicated paediatric funding for these services, but can access if need indicated by referral. 1. <u>Assessment:</u> <ul style="list-style-type: none"> • Mostly single discipline, with MD as required. 2. <u>Therapy:</u> <ul style="list-style-type: none"> • Mostly single discipline, with MD as required. • Individual and group (single discipline and MD). • Generally term on/term off with flexibility as appropriate. • No cap to service. |

| SERVICE PROVIDER | GEOGRAPHICAL AREA SERVICED | ELIGIBILITY (must be prior to school entry, unless otherwise indicated) | REFERRAL AND INTAKE PROCESS | INELIGIBLE REFERRALS | DISCIPLINES AND SERVICES PROVIDED |
|--|---|---|--|---|--|
| Djerriwarrh Health Services | Melton | <p>Mild to moderate difficulties in one area of development of Speech Pathology or Occupational Therapy.</p> <p>Note that OT services are offered for up to 8 years of age.</p> | <p>Direct referrals for Djerriwarrh Health Services are accepted from parents and professionals on a referral form which requires identification of the area of need (SP or OT).</p> <p>Where a family phones directly to self-refer, the intake worker fills out the referral form with them over the phone.</p> | Re-directed to Melton Health | <ul style="list-style-type: none"> • Occupational Therapy. • Speech Pathology. <p>If necessary, staff can refer to psychology and social work at Melton Health, but this is not a common occurrence.</p> <ol style="list-style-type: none"> 1. <u>Assessment</u> 2. <u>Therapy:</u> <ul style="list-style-type: none"> • individual and group. • Individual and conjoint. • Block on, block off. • Home and kindergarten visits available. |
| Early Childhood Intervention Services (ECIS) | All 5 LGAs of Brimbank, Melton, Maribyrnong, Wyndham, and Hobsons Bay are serviced as part of the South Western Victoria ECIS region. | <p>Either:</p> <ol style="list-style-type: none"> 1. A diagnosed disability or: 2. A developmental delay which is the result of an impairment and causes substantial functional limitations, and - who requires a coordinated, long term, multidisciplinary service response. | <p>Referrals accepted from parent or professional in writing only.</p> <p>Application form must be completed in full, including statements of Concerns AND Impacts in Developmental Areas. Application MUST be signed by Parent or Carer. Additional reports may accompany application form.</p> <p>Intake worker:</p> <ol style="list-style-type: none"> 1. ensures that a signed ECIS application form is submitted. 2. assesses for eligibility according to age, geographic catchment, not yet commenced school, no involvement with another service provider. 3. confirms referral meets eligibility criteria. | <p>When referrals are identified as clearly ineligible at the time of referral, alternative pathways are suggested to the parent/referrer and recommended to contact them directly.</p> <p>Where it is unclear if the referral is eligible at the time of referral, the intake worker contacts the family and/or refer to gather more information to make decision about eligibility.</p> <p>When the referral is accepted and the child is subsequently allocated to</p> | <p>Transdisciplinary keyworker model service in child's environment. One key worker is matched as closely as possible to child's main need. Consultations from other team members are provided as appropriate. The provision of direct "therapy" varies between ECI service providers. Families and keyworkers set goals collaboratively, with the family</p> |

| SERVICE PROVIDER | GEOGRAPHICAL AREA SERVICED | ELIGIBILITY (must be prior to school entry, unless otherwise indicated) | REFERRAL AND INTAKE PROCESS | INELIGIBLE REFERRALS | DISCIPLINES AND SERVICES PROVIDED |
|---|--|---|---|--|---|
| | | | <p>In the rare instances when a family phones directly to self-refer, the intake worker sends the application form to the family to be completed and returned.</p> <p>The intake process includes drawing up an intake plan in collaboration with family, which may list early supports and referrals to be accessed during the waiting period.</p> <p>While on the waiting list, families are contacted by intake workers at scheduled intervals to check on their situation. Families are given information about services (including private therapists, supported play groups etc.) that they might wish to access while they are on the waiting list.</p> | <p>a service, the vast majority of referrals are found to be appropriate for the service. A small number of referrals are found to be eligible at the time of referral but then make developmental gains in the time they are on the waiting list and are no longer eligible at the time the service is offered.</p> | <p>nominating their preferred goals/outcomes.</p> <p>Visits with the child and family are most often fortnightly, but vary depending on the needs of the child and family.</p> |
| IPC Health (formerly ISIS Primary Care) | LGAs of Brimbank, Hobsons Bay and Wyndham. | Delays or difficulties in one main area of need in the areas of Speech Pathology (SP), Occupational Therapy (OT) or Developmental Psychology (Psych). | <p>Referrals accepted from parent or professional by phone or in writing.</p> <p><u>Phone:</u> <i>Parent referral:</i> Member of intake team completes checklist with parent over the phone. Checklists for each age (1, 2, 3, 4 and 5 year old) have been developed by IPC Health staff and ask a series of Yes/No questions about whether the child does or does not demonstrate skills in areas related to SP, OT and Psych. Where a child does not display the skill, this is ticked as “no” in a shaded column. Intake worker refers to risk map to determine eligibility for the service. If there are ticks in one shaded column, this indicates the child is eligible to receive that service. If there are many ticks in the shaded boxes in two or more columns, the child may not be eligible for services at IPC Health. There is no specific number of ticks that define whether a child is eligible or ineligible. The criteria is defined as “one main area of need”.</p> | <p>When referrals are identified as clearly ineligible at the time of referral, the parent/referrer is informed of the more appropriate service and recommended to contact them directly or to forward referral there.</p> <p>Where it is unclear if the referral is eligible at the time of referral, the referral is closed and family is recommended to see a paediatrician. If the paediatrician reports that the difficulties are in one main area, the child can be re-referred and the original referral date will be honoured.</p> | <ul style="list-style-type: none"> • Audiology. • Occupational Therapy. • Psychology. • Speech Pathology. <p>1. <u>Assessment</u> 2. <u>Therapy:</u></p> <ul style="list-style-type: none"> • individual and group. • Mostly single discipline. • Very small amount of multi-disciplinary (MD), but not core feature of the service. • Term on/term off. • Maximum 5 blocks of therapy. |

| SERVICE PROVIDER | GEOGRAPHICAL AREA SERVICED | ELIGIBILITY (must be prior to school entry, unless otherwise indicated) | REFERRAL AND INTAKE PROCESS | INELIGIBLE REFERRALS | DISCIPLINES AND SERVICES PROVIDED |
|------------------|----------------------------|---|---|--|--|
| | | | <p><i>Professional referral:</i> Requested to complete referral form and checklist and send to IPC Health.</p> <p><u>In writing:</u> Required: Completed referral form containing basic identifying information and a completed checklist. Intake team member contacts referrer and/or family if further information is needed to determine eligibility.</p> | <p>When the referral is accepted and the child is then seen for assessment, up to 20% children are found to have more significant difficulties and to be ineligible for IPC Health. The clinician either:</p> <ol style="list-style-type: none"> 1. Directly refers and transitions the child onto the appropriate service. There is some variability between clinicians as to the timing of the transition. OR 2. Provides feedback to the referrer about the child's presentation with a recommendation to refer to a different service. | |
| Melton Health | Melton | <p>Delay in two or more areas as identified by scores on the 'Ages and Stages Questionnaire' (ASQ) (= black rating on ASQ). Approximately 70% of these children are also eligible and referred to ECIS services.</p> <p>Note, OT services are provided up to 16 years of age.</p> | <p>Referrals to Melton Health are accepted from GP, Paediatrician or other allied health professional only in the form of a letter.</p> <p>Where the referral is not from a paediatrician, the family is sent the ASQ to complete and send back. This is then scored by an intake worker with three potential outcomes:</p> <ol style="list-style-type: none"> 1. Waiting list for Melton Health services IF: ASQ rating of two black areas. 2. Assessment by paediatric registrar IF: ASQ rating of three or more grey areas or one black area and another grey area/s. The paediatric registrar will then determine whether the referral is more appropriate for Melton Health or Djerriwarrh Health Services. 3. Re-directed to Djerriwarrh Health Services | Re-directed to Djerriwarrh Health Services. | <ul style="list-style-type: none"> • Audiology (subcontracted to HEARLINK). • Dietetics. • Occupational Therapy. • Physiotherapy. • Psychology. • Social Work. • Speech Pathology. <p>Four key areas of service provision:</p> <ul style="list-style-type: none"> • Autism Spectrum Disorders. • Developmental. • Feeding. |

| SERVICE PROVIDER | GEOGRAPHICAL AREA SERVICED | ELIGIBILITY (must be prior to school entry, unless otherwise indicated) | REFERRAL AND INTAKE PROCESS | INELIGIBLE REFERRALS | DISCIPLINES AND SERVICES PROVIDED |
|------------------|----------------------------|---|--|----------------------|--|
| | | | IF: ASQ rating of white or up to two grey areas. | | <ul style="list-style-type: none"> • Behavioural. <p>Services include:</p> <ul style="list-style-type: none"> • assessment clinics (ASD and developmental assessment - single discipline or MD). • feeding clinic. • intervention: 6-12 sessions while awaiting ECIS. Intervention offered as both Individual and group therapy. |

*To date, up to 50% children seen for a multi-disciplinary assessment were found to have features of Autism and were consequently then referred to the Autism Assessment service. The clinician phone call at the time of intake and active waiting list management strategies were new initiatives at the time of writing and may lead to a decrease in this figure.

APPENDIX 2: CONSUMER STORIES

The following case studies were provided by clinicians as examples where difficulties with the service system have impacted on the consumer journey. Issues raised by these case examples are described. These cases have been de-identified.

1. A 3 ½ year old child attended a check-up at the maternal and child health centre but was reluctant to participate in the assessment and it took over an hour to complete the test. The child is from a Vietnamese family but his mother speaks good English and no interpreter was required. Based on his performance on the test, it appeared the child had significant delays and was referred to a service (Service A) for children with complex difficulties. When the intake worker from Service A spoke to the mother, it was determined that the child was not appropriate for the service and the intake worker referred the child to a Service B for therapy and Service C for an assessment. The child was seen for service at both Services B and C without either service initially being aware of each other's involvement. The mother was very confused and she did not understand all the paperwork she had been given. Clinicians spent considerable time following up with each other to determine the most appropriate service for the child.

Issues: Multiple referrals with no ability to track referrals made centrally, more than one session required to determine the child's needs, time wasting for the family, multiple assessment sessions with no provision of therapy.

2. Service A received a referral for an assessment for a 3 year old girl. The referral stated single discipline concerns only, yet the service is for children with multi-disciplinary difficulties. Based on the information contained in the paper referral, the child was redirected to service B as this was felt to be a more appropriate service. A clinician from Service B saw the child over several sessions and determined that a multi-disciplinary service and a paediatrician was the most appropriate management for this child. The child was referred back to Service A for an assessment and also to Service C – a service for children with more significant difficulties.

Issues: Incomplete information in original referral, paper based system did not determine most appropriate service for the child.

3. A maternal and child health nurse assessed a child found to have difficulties in a range of areas including speech, attention, gross motor and anxiety. The child was referred to a multi-disciplinary Service A for assessment and found to have mild multi-disciplinary difficulties, however the service referred to Service B due to Service A not having a discipline in their team that was most appropriate to the child's needs. The child was seen by one discipline at Service B (family declined offer to see other discipline which precipitated the referral) but did not engage well with therapy. Family elected to seek private assessment for autism and was referred to Service C for long term support.

Issues: Minimal case management provided to the family, multiple assessments and limited intervention, increasing confusion for a family who was reluctant to engage with services, lack of all disciplines at Service A.

4. A two year old child from a non-English speaking background presented at a hospital emergency department due to reduced oral intake and tooth abnormalities. The emergency physician referred the child to Service A for developmental assessment and dietetics management. The physician noted a range of developmental concerns. Upon assessment at Service A, the clinicians determined that a paediatric fellow had also seen the child and had subsequently made a referral to another multi-disciplinary service - Service B. Service A recommended the child be placed on the waiting list for an Autism assessment service and offered short term therapy support to the family. The family were unable to take up this offer due to living some distance away, reliance on public transport and safety (absconding) concerns.

Issues: No centralised tracking of referrals, referred to multiple services, referred for general assessment rather than Autism specific assessment, transport difficulties.

5. An 18 month boy was referred to Service A by his maternal and child health nurse due to eating difficulties and toe walking. When seen for assessment, his parents raised additional concerns with behaviour and self-care and the clinician identified red flags for Autism Spectrum Disorder. The clinician contacted the maternal and child health nurse to share these concerns. After several sessions, the clinician discussed the ASD concerns with the parents and consent was given to place the child on the Autism waiting list.

Issues: Limited information contained in original referral, referrer may not have been aware of or confident to discuss other issues with the parent.

APPENDIX 3: ISSUES RAISED THAT ARE BEYOND SCOPE OF PCDD PROJECT

The following issues were raised during data collection but do not fall within scope for this current project:

FUNDING:

- Call for more funding to increase EFT at service provider organisations.
- Long waiting lists.

TIMELINESS OF IDENTIFICATION OF DEVELOPMENTAL DELAYS

- Developmental delays being identified too late:
 - Children presenting at kindergarten without difficulties being identified prior to this point. Limited time to offer services at preschool level (may be also restricted by waiting lists).
 - Children presenting at school without difficulties being identified prior to this point. Problems may have become entrenched by this time and may be more difficult to resolve. In many cases red flags were present at an earlier stage but were not acted upon.
- Newly graduated teachers may find it hard to identify delays in children.
- For some CALD children, difficulty determining if the child presents with a delay versus difficulty with speaking and understanding English.

TERMINOLOGY

- Wide use of the generic term “Developmental delay”. Impacts can include parents being reluctant to consider another diagnosis at a later time, or to accept that their child has a “disability”. This can also cause difficulties when the child starts school and support is offered for children under the term “disability”. Also the term “Developmental delay” does not qualify children for Centrelink supports.

INFORMATION TECHNOLOGY

- Differences in IT systems between different organisations.

PRIVATE THERAPY

- Many families cannot afford private services.
- Difficult for CALD families to access private services due to lack of interpreters.
- Too much choice in private sector – can be overwhelming for parents.

SERVICE SPECIFIC ISSUES



- Inconsistent understanding of the transdisciplinary key worker model. Concern that this is not promoted as best practice to families and that families are repeatedly told they need “therapy”.
- No clear discharge criteria for ECIS aside from school entry, even when only small concerns remain.

OTHER SERVICES FOR CHILDREN WITH DELAYS

- Long waiting lists for public paediatricians.
- Universal services need to work better together.
- Difficulty keeping up to date with all the services, groups etc. available for children and families. Additionally, eligibility criteria often change or funded ceases for these programs.
- Families needing to go to multiple service providers due to specialist issues. Eg: one place for vision support, another for hearing support.
- Difficulty finding playgroup opportunities for children with Developmental Delay. Regular playgroups may not meet their needs, and many other supported playgroups have focus on Autism or have high numbers of children with Autistic features.
- Criteria for “Flexible Support Packages” have become much tighter and have limited capacity for this funding to be used to provide assistance for children on long waiting lists for services.
- Public service providers feeling onus on them to initiate communication with other providers.
- Lack of service for children who have witnessed domestic violence.
- Limited availability of therapists with an ESL background.

APPENDIX 4: SERVICES FOR ABORIGINAL AND TORRES STRAIT ISLANDER CHILDREN

The following services are available for preschool Aboriginal and Torres Strait Islander children in Melbourne's west. This may not be an extensive list, other services may be available.

| SERVICE PROVIDER | ELIGIBILITY AND REFERRAL | SERVICES OFFERED | FURTHER INFORMATION |
|--|--|---|---|
| cohealth Aboriginal and Torres Strait Islander Paediatric Clinic. Fri 1.00 – 5.00 pm. | GP referral required. cohealth can assist with this if required. 0-18 years. | Staffed by a paediatrician and an Aboriginal support worker. | https://www.cohealth.org.au/health-services/aboriginal-torres-strait-islander-health/childrens-clinic/  ATSI paed clinic final (003).pdf |
| cohealth Koolin Balit Children's Clinic. Friday mornings. This is a pilot project currently running until June 2017. | Aboriginal children living in Out of Home Care (Kinship/Foster and Residential) up to 18 years of age in the Western metro area. Referrals can be made by case managers, parents or kinship carers. | The clinic is supported by an Aboriginal health worker and consists of a paediatrician, social worker, speech pathologist and a coordinator. The child attends a 2-3 hour multi-disciplinary Assessment in the areas of physical growth, speech, language and psychological well-being. After the assessment, a health management plan is developed with recommendations for follow up treatment. This may include referrals to mainstream services. If ongoing care from a paediatrician is required, the child can continue to be seen by the same paediatrician at the ATSI Paediatric clinic (see above entry). | https://www.cohealth.org.au/health-services/aboriginal-torres-strait-islander-health/out-of-home-care-childrens-clinic/  Flyer for Koolin Balit Children's Clini |
| The Gathering Place. | Aboriginal and Torres Strait Islander community residing within the catchment areas of Maribyrnong, Hobson's Bay and the Shire of Melton, Brimbank, Wyndham and Moonee Valley. | A range of medical and allied health practitioners deliver services from this site at set times each week. These include: GP, podiatrist, physio, SP (only for 0-6 year olds), audiologist, dietitian, psychology and counselling. Note: Information about this service was obtained via The Gathering Place website | http://www.gatheringplace.com.au/services.html |

| | | | |
|---|---|---|---|
| Wadja Health Clinic Royal Children's Hospital. Wed 1.30 – 4.30 pm. | GP referral required. For children who require specialist medical care. | A general medical outpatient clinic for Aboriginal children which provides medical, social, cultural and emotional assessment. Child and parents seen jointly by a paediatrician and an Aboriginal worker. Note: Information about this clinic was obtained from the Royal Children's Hospital website. | http://www.rch.org.au/uploadedFiles/Main/Content/afsu/Updated%20Wadja%20brochure%202014.pdf |
|---|---|---|---|

Additional programs:

Autism Queensland

Autism Queensland hosts a national project funded by Department of Social Services as part of the Helping Children with Autism program which aims to increase the awareness of Autism and diagnostic pathways in the Aboriginal and Torres Strait Islander community. Community workshops are run for parents covering topics such as the features of Autism Spectrum Disorder and how to follow up if a parent is concerned. In Victoria, these workshops are organised through Carers Victoria and Melton Health.

Koolin Balit Projects

Two large scale consortium projects specifically targeting the early years projects are currently running in Melbourne's west. One is in Melton and the other project works across the other council areas.

Koorie Engagement Support Officers

Koorie Engagement Support Officers (KESOs) are an integral part of Victoria's state education system. KESOs support Koorie children and their families with assistance to make the journey through primary and secondary school as seamless as possible. KESOs focus specifically on the engagement of Koorie students, families and communities within the government school and early childhood systems, as well as kindergartens and other areas of early childhood.

KESOs support families and their children to attend playgroups and kindergarten programs and with transition into the school system. They are available to assist families to identify the closest kindergarten to where the family lives and support the child's attendance. Applications can also be made through Koorie Kid Shine to pay fees for kindergarten programs run by a teacher with a bachelor qualification, thereby allowing attendance at kindergarten at no cost to the family. This funding is also available for a second year if the child requires a second year of kindergarten before commencing school.

Further information:

<http://www.vaeai.org.au/support/dsp-default.cfm?loadref=92>

<http://www.education.vic.gov.au/about/contact/Pages/wannikregional.asp>

Background and Project Description

A number of different services provide support for preschool children with developmental delays in Melbourne's west. Partners of HealthWest report the current regional service system to be complex, confusing and disjointed. There is 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. In order to ensure that limited public resources are used as efficiently and effectively as possible in light of the growing future demand for services, the Pathways for Children with Developmental Delays project is being conducted to focus on identifying efficiencies and improvements to streamline current service provision.

The project incorporates the local government areas of the HealthWest catchment including Brimbank, Melton, Maribyrnong, Wyndham and Hobson's Bay.

During initial scoping, the project was defined to include services:

- for children aged 0 – school entry
- with developmental delays in one or more areas of cognition, speech/language, fine or gross motor, play, social/emotional, behavioural, nutrition/eating and self-care
- where the delay may be present from birth or is identified during the preschool years.

Project developments

The following activities were undertaken during the first phase of the project:

1. Service mapping of current service provision
2. Focus groups with managers and clinicians from service provider organisations, as well as those who refer children to these services
3. Thematic analysis and synthesis of qualitative data
4. Presentation to the advisory group

Results of data collection found there to be two main cohorts of children:

Group 1: Babies and infants where the developmental difficulties are identified at birth or soon after, or where there is a risk of developmental delay from birth, and

Group 2: Children where the developmental difficulties become evident subsequent to the postnatal period and through to the time of school entry.

Findings – Group 1: Babies and infants

The babies and infants cohort most commonly have a period of inpatient care at birth or soon after birth due to either prematurity or other medical difficulties. This inpatient care may be provided at a range of hospitals, depending on the circumstances of the birth and postnatal care, including those within Melbourne's west (Western Health, Werribee Mercy Hospital, Melton Health), as well as a range outside the region (e.g.: Royal Women's Hospital, Royal Children's Hospital, etc.). Babies/infants whose families live in Melbourne's west but are inpatients at a hospital outside the western region, may be referred to a local service for ongoing follow up and care either as an inpatient transfer or after discharge.

Babies/infants with developmental difficulties fall into two main groups:

1. Where developmental delay is known at the time of birth or postnatal period.
These babies/infants may receive a formal diagnosis and are frequently referred to Early Intervention Services at birth or soon after.

2. Where the baby/infant is at risk of developmental delay but the delay is not yet evident. These babies/infants require a service to monitor their progress until such time as a delay becomes evident or the child is found to be developing within normal limits.

Data collected during focus groups and surveys specific to this second group identified the following issues for further consideration¹⁶:

- Over time, more babies/infants are being referred meeting this description.
- This is a highly complex group of babies/infants, with frequent additional family and social complexity. Overall complexity appears to be increasing over time.
- Staff working with this group of babies/infants require specialist knowledge and skills.
- Services to this cohort may be impacted by available funding by each service provider.
- Where care is provided initially by one service provider in Melbourne's west then the baby/infant is referred to another western service provider, there may be benefits in considering greater consistency around timing of this transfer.
- There can be an impact on the care provided and family stress when families are required to travel significant distances to receive services.
- When a referral is received from a hospital in another region, sometimes the information provided in the referral is insufficient to allow appropriate planning for care and services.
- Coordinated multi-disciplinary care is important.

Next steps

Findings from data collection showed that the areas identified for service system review for children in Groups 1 and 2 are specific to each cohort with little cross over. Additionally, topics related to the babies/infants cohort are relevant to only some of the service providers included in the Pathways for Children with Developmental Delay (PCDD) Project. A decision was therefore reached that the focus for the remainder of the PCDD project will be the second cohort of children (postnatal period and older). It was recommended that the above information be forwarded for consideration as part of the Strengthening Hospitals in the West initiative.

¹⁶ Note that these findings are based on only a limited amount of data collected, as the main focus of the Pathways for Children with Developmental Delays Project is children whose developmental difficulties become evident at a later stage. Detailed discussions about the babies/infant cohort have not been held with all service providers and further discussions are recommended to explore this area further.

APPENDIX 6: AUTISM DIAGNOSIS IN MELBOURNE'S WEST

Background and Project Description

A number of different services provide support for preschool children with developmental delays in Melbourne's west. Partners of HealthWest report the current regional service system to be complex, confusing and disjointed. There is 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. In order to ensure that limited public resources are used as efficiently and effectively as possible in light of the growing future demand for services, the Pathways for Children with Developmental Delays project is being conducted to focus on identifying efficiencies and improvements to streamline current service provision.

The project incorporates the local government areas of the HealthWest catchment including Brimbank, Melton, Maribyrnong, Wyndham and Hobson's Bay.

Project developments

The following activities were undertaken during the first phase of the project:

5. Service mapping of current service provision
6. Focus groups with managers and clinicians from service provider organisations, as well as those who refer children to these services
7. Thematic analysis and synthesis of qualitative data
8. Presentation to the advisory group

Information was gathered regarding service delivery for children who present to these services. During this process, it was identified that some points raised were more generic in nature whereas others pertained to a specific cohort of children. One such cohort was children who are referred for or subsequently identified as needing a diagnostic assessment for Autism Spectrum Disorder.

Findings - Autism diagnostic services

ASSESSMENT OPTIONS

Autism diagnostic services for children in Melbourne's west are detailed below. Please note that paediatrician only assessment options are not included for the purposes of this report.

| PUBLIC SERVICES | PRIVATE SERVICES |
|---|--|
| <p>The following services provide multi-disciplinary Paediatrician / Allied Health team assessments</p> <ul style="list-style-type: none"> Western Health – Children's Allied Health Services Melton Health | <p>Information about specific services provided by individual practitioners or practices has not been collected during this project.</p> <p>Overall, private allied health clinicians report contributing to autism assessment processes by:</p> <ul style="list-style-type: none"> Writing reports on request describing assessments already completed and observations of the child Speaking by phone with paediatricians or other professionals Completing an Autism Diagnostic Observation Schedule (ADOS) or another assessment for the purpose of contributing to a diagnostic assessment process in the private sector |

Royal Children's Hospital only conduct Autism diagnostic assessments for children living in the west if there is a significant complexity, if the child is otherwise involved with Royal Children's Hospital or if there is a need for a second opinion for complex psychosocial reasons.

Note that another list of public and private assessment options has been collated by a clinician at IPC Health and may be a helpful reference. Contact IPC Health for more details.

KEY THEMES IDENTIFIED

The following challenges and potential solutions emerged from the consultations.

Waiting lists

Waitlists for autism diagnostic services across the region were reported to be a significant challenge in the current system.

| <u>Challenges</u> | <u>Potential solutions</u> |
|---|---|
| <ul style="list-style-type: none"> Lengthy waiting lists Many children on the waiting list receive no support/intervention whilst waiting. Calls for additional funding to increase number of public assessment appointments. Where services have an upper age limit to their eligibility criteria, this can result in older children being prioritised above younger children. | <ul style="list-style-type: none"> Group based service for children on the waiting list for purposes of providing intervention and input into the assessment. More private/public partnerships to provide more timely assessments at a subsidised cost. |

Disciplines involved in team assessments

In order for children to qualify for funding at school in the category of Autism Spectrum Disorder for the "Program for children with disabilities", there is a Department of Education and Training requirement that there be a signed report from a psychologist. Not all teams that provide public assessments for preschool children have a psychologist on their team.

| <u>Challenges</u> | <u>Potential solutions</u> |
|---|--|
| <ul style="list-style-type: none"> Where the diagnosis is provided close to the start of school entry or parents only become aware of this requirement just prior to school entry, there is little time to arrange an additional assessment with a psychologist. Stressful for families. Some families cannot afford the cost of a private psychologist. Some school psychologists may be unable to provide a signed report. Need to access psychology for the sole purpose of confirming a diagnosis, when psychology may not be the main priority for intervention for the child at that time. Fear that the child will miss out on additional funding for school or the opportunity to attend their school of choice due to this requirement. High demand for private psychology appointments in the time leading up to school entry. | <ul style="list-style-type: none"> Consistency between public assessment team disciplines and Department of Education and Training requirements via amendment to assessment team members OR amendment to Department of Education and Training requirements. |

Purpose of assessment

Some stakeholders discussed factors related to the current “Helping Children with Autism” funding and the upcoming transition to the National Disability Insurance Scheme (NDIS) for consideration.

| <u>Challenges</u> | <u>Questions for consideration</u> |
|--|--|
| <ul style="list-style-type: none"> • Reports that “Helping Children With Autism” funding package has placed additional pressures on need for diagnosis. | <ul style="list-style-type: none"> • Will the demand for diagnostic services change when NDIS commences? • Should the focus be on service delivery and intervention rather than a system that differentiates based on diagnosis? |

Next steps

At its second meeting in November 2016, the Project Advisory Group determined the main focus for the second half of the project to be issues related to general eligibility, referral and intake for children presenting with developmental delays as these issues are common to all service providers. It was decided that Autism specific services would not be focussed on as a separate area in the second phase of the project as not all providers involved with the project offer these services. This report summarising the key themes will be disseminated to service providers to assist with future planning.