

**Submission  
No 38**

## **IMPROVING ACCESS TO EARLY CHILDHOOD HEALTH AND DEVELOPMENT CHECKS**

**Organisation:** The Hive Mt Druitt (United Way Australia)

**Date Received:** 29 February 2024



# PARLIAMENT OF NSW Improving Access to Early Childhood Health & Development Checks

The Hive, Mt Drutt (United Way Australia)

For further information or questions about this submission please contact:

[Redacted contact information]



February 2024

# Contents

<b>Executive Summary:</b> .....	<b>3</b>
<b>The Hive, Mt Druitt</b> .....	<b>4</b>
<b>Changes needed to address gaps in outcomes for vulnerable children, including those in rural and remote communities, Aboriginal communities, and culturally and linguistically diverse communities.</b> .....	<b>5</b>
Place-based health & development services within the community. ....	6
Partnership between NSW Health and early education and care services and community organisations.....	7
Embedding family support roles such as Child Health Linker will provide greater wrap around support and success for children from areas of disadvantage. ....	7
Increased Medicare rebates for low-income families .....	8
Increased investment in supporting parental health literacy.....	9
Investment across the ecosystem of the child’s life. ....	10
<b>Barriers that affect parents’ access to routine health and development checks that track their child’s progress against developmental milestones.</b> .....	<b>11</b>
Lack of knowledge of the existence or importance of child health & development checks .....	11
Family stressors.....	12
Lack of Transport .....	13
Fear of being judged for their parenting or reported to child protection if a child is delayed ....	14
Previous negative experiences with services.....	14
Solutions to overcome the barriers: .....	14
<b>Conclusion:</b> .....	<b>15</b>
<b>Appendix:</b> .....	<b>15</b>

*The Hive, Mt Druitt acknowledge that we engage in deep work on the unceded land of the Darug People, and we pay our respects to Elders both past and present. We pay respect to and thank our First Nations children, families and communities that contribute to our knowledge of the strengths and challenges facing the Mt Druitt community, and we hold their knowledge and stories with respect and care. We commit to pursuing equity and justice alongside First Nations People, advocating for policies and programs that are just and that promote First Nations voices.*

## Executive Summary:

The Hive Mt Druitt have extensive experience in supporting a community of high developmental vulnerability and socioeconomic disadvantage through direct support to families through a Child Health Linker role, an innovative Check Up Before School (CUBS) Program to provide child health development checks in the community, and a paediatric outreach clinic. The following are our recommendations and responses to the first two terms of reference items for this inquiry.

We reference our evaluation of our CUBS Program and a consultation regarding parental health literacy and access to developmental services that have significant relevance to this inquiry. These are attached as appendix items. The Hive Mt Druitt welcome further opportunities to share from our learnings in Mt Druitt with the NSW Parliament.

### **Changes needed to address gaps in outcomes for vulnerable children, including those in rural and remote communities, Aboriginal communities, and culturally and linguistically diverse communities:**

- Place-based health & development services within the community will increase the number of children in areas of disadvantage accessing early intervention prior to school.
- Partnership between NSW Health and early education and care services and community organisations will increase the trust the community have with child health services.
- Embedded family support roles, such as Child Health Linker, will provide greater wrap around support and success for children from areas of disadvantage.
- Increased Medicare rebates for low-income or families experiencing vulnerabilities will reduce the financial burden of accessing necessary assessments and therapies for their children.
- Increased investment in supporting parental health literacy will result in an increased awareness of health & development services, and children will be greater supported in their development.
- Investment across the ecosystem of the child's life not just direct health programs will have a significant impact upon vulnerable children's overall health & development.

### **Barriers that affect parents' access to routine health and development checks that track their child's progress against developmental milestones:**

- Lack of Transport
- Fear of being judged for their parenting or reported to child protection if a child is delayed.
- Previous negative experiences with services
- Family Stressors & lack of support
- Lack of knowledge of the existence of, or importance of, the child health & development checks

Solutions to overcome these barriers:

- Place-based health & development checks
- The provision of community transport by community health centres
- Linker support (also known as navigators) provided to vulnerable families
- Simple and accessible information about children's development
- Partnership between NSW Health and ECEC services and community organisations

## The Hive, Mt DrUITT

The Hive, Mt DrUITT (United Way Australia) is a place-based, Collective Impact initiative operating in the suburbs of the Mount DrUITT postcode in Western Sydney, NSW. The goal of The Hive is for all children in Mt DrUITT to start school well, with equal opportunity to learn, be healthy and participate in quality community life. We believe that if we bring various parts of the system together, listen deeply to community concerns and work together on community informed solutions we can sustainably improve outcomes for children in this community.

The Hive believe that to reach this goal a holistic approach is required to support families through innovative programs and initiatives, but also addressing the social determinants of complex social issues that families experience and advocating for system change. The Hive is guided in our early years work by evidence informed by the Australian Research Alliance for Children and Youth's (ARACY) key intervention pathways for children aged 0-5 years, alongside community voice to promote innovative and community focused solutions to break cycles of disadvantage. The Hive authentically listen and learn from local families about their experiences and then collaborate with local stakeholders to address these, create innovation solutions, and advocate to relevant systems to create meaningful change.

### **Our specific areas of work directly supporting children's health & development include:**

- *Child Health Linker:* The Child Health Linker (CHL) provides a place-based and relational solution to support Mt DrUITT families to access developmental services for their child before they start school. The CHL assists families to overcome barriers in accessing developmental health services for their children. The CHL partners with families to answer questions about their child's development, provide information about and referrals to early intervention services, provide support to obtain a developmental assessment of their child and access subsequent allied health therapies if required. The CHL can also provide brokerage for families to overcome barriers to diagnostic and therapeutic assessments.
- *Check Ups Before School (CUBS) Program:* The Hive partnered with Western Sydney Local Health District to implement an innovative approach to overcome barriers and increase participation in developmental health checks, to increase the early identification of developmental delays and disabilities prior to school. A nurse and speech pathologist were integrated into early learning and community hubs to leverage trusted relationships families had within the community. The Hive's Health Linker also supported children and families post assessment. A formal evaluation was completed by Western Sydney University which supported the Hive to advocate for CUBS Program to be integrated into mainstream WSLHD's community nursing strategy for Mt DrUITT which successful in 2022 and inform the state-wide Brighter Beginnings Preschool Check program.
- *Willmot Paediatric Clinic:* The Hive sought partnership with Mt DrUITT & Blacktown Hospital's paediatric outpatient clinics to strongly advocate for a place-based paediatrician in Willmot. The Hive & members of the collective had been transporting families and paying for paediatricians privately due to the financial and practical barriers faced in getting their children assessed in the Mt DrUITT area. This advocacy was successful and a 1 day a week clinic was established at the Willmot Hub in 2023 to provide developmental assessments and has since obtained permanent funding.

## Changes needed to address gaps in outcomes for vulnerable children, including those in rural and remote communities, Aboriginal communities, and culturally and linguistically diverse communities.

There is substantial evidence that children in areas of disadvantage experience higher levels of developmental delay compared to their counterparts in more affluent areas. Mt Druitt serves as a pertinent case study in illustrating this issue. These communities of entrenched socioeconomic disadvantage, such as Mt Druitt, often experience significant inequities across various domains, including outcomes in health, education, employment, income, housing, and access to services.

These inequities have an impact upon the development of children within the community including their access to early intervention services. The Australian Early Development Census (AEDC) data from 2021 revealed that children in the Mt Druitt area face significantly higher levels of developmental vulnerability, such as in the suburb of Willmot where 62% of children are considered developmentally vulnerable when starting school compared to 21% of NSW children.

The Hive, Mt Druitt have listened to the families within the Mt Druitt community and understood the specific barriers they face in accessing child health and development services such as blue book checks and paediatrician assessments. The Hive launched the pilot Check Ups Before School (CUBS) Program in collaboration with Western Sydney Local Health District (WSLHD) to increase the number of children accessing child health & development checks and advocated to, and partnered with, WSLHD to launch an outreach Paediatrician Clinic, both in areas of significant developmental vulnerability. Each of these programs are outlined further below and demonstrate some of our recommendations in practice in what we find is most effective for children in vulnerable communities.

### **PLACE-BASED CASE STUDY: Check Ups Before School (CUBS Program)**

The CUBS Program was started by The Hive in response to the increasing number of developmental delays in children starting school in 2770, and a low number of families accessing early childhood health & development checks. Families were not accessing the checks due to fear of government services and being judged for their parenting, lack of transport, low health literacy and understanding of the checks, and navigating complex family stressors such as domestic violence, financial stress, housing instability and poor mental health. The CUBS Program leveraged existing trust held with local community health and Early Childhood Education & Care services and embedded a child & family health nurse into the service to conduct Ages & Stages Development Checks on the children. A speech pathologist was added to the team to complete screeners and provide initial therapy with the children, and a Health Linker (social worker) supported families post assessment who required further assessment for their child's needs. This program was highly successful and was evaluated by Western Sydney University and eventually embedded into mainstream Community Nursing delivery in the Mt Druitt area. The CUBS Program also informed the design of the Brighter Beginnings model of preschool health checks across NSW.

### **PLACE-BASED CASE STUDY: Willmot Paediatrician Outreach Clinic**

Members of the Together in Willmot Collective gathered to address the rising issue of children starting school and childcare with undiagnosed disabilities. Parents expressed difficulties to access a paediatrician with barriers including transport, financial cost, fear of services, lack of awareness of the role of paediatricians, and how to access a referral. Different organisations had been utilising their own brokerage funds, case workers and transport to ensure children had access to these services but this was insufficient to meet the need and an unsustainable solution. Families and workers reported experiences of judgemental paediatricians and poor-quality assessment of the presenting concerns. The group advocated and met with the Paediatrics Department from the local health district and were successful to launch an outreach paediatric clinic in the Willmot Community Hub one day a week, with a trauma-informed paediatrician who leveraged the trust and relationships families had with local staff and the community. The paediatrician liaises successfully with the CUBS Program nursing staff, case workers, school and childcare staff, resulting in coordinated care for the children and support within the family, education and community environment. In 2024 this program received permanent funding due to the successful partnership and place-based approach.

### **Place-based health & development services within the community will increase the number of children in areas of disadvantage accessing early intervention prior to school.**

Place-based approaches have been highly recommended for addressing ‘wicked problems’ in areas of entrenched social disadvantage. Place-based approaches consider the unique area in which the target population reside and understand deeply the challenges community face in accessing supports, and design solutions that are equitable and accessible for the community rather than mainstream universal programs. Place-based approaches have been utilised by child and family nursing through embedding nurses and doctors in schools to reach the community that need the program. However, these approaches are not available in many areas of significant developmental vulnerability and should be considered when aiming to improve child health outcomes. These approaches offer a multitude of benefits and overcome a range of barriers faced by families. Two examples of place-based programs designed for an area of high developmental vulnerability are outlined below.

## **Partnership between NSW Health and early education and care services and community organisations will increase the trust the community have with child health services.**

The CUBS Program highlighted in the previous recommendation demonstrates the effectiveness of a collaborative approach between NSW Health and the people, organisations, and services that families already trust. Currently there is minimal partnership or outreach in communities across local health districts beyond sharing flyers or sporadically visiting a playgroup. Families with young children are attending early education, community events, playgroups, or community hubs, and these are relationships that each local health district should be leveraging and building upon. Partnerships with these stakeholders will result in greater awareness of the health and development checks, as well as increasing the trust and safety perceived by families, particularly vulnerable families, of NSW Health and these developmental checks. Partnership will also allow for support post assessment, with the nursing team able to reach out to the child’s early learning centre or caseworker to ensure the family is supported to access referrals and embed any specific learning strategies in the classroom or home environment.

### **Family’s reflections on the impact of collaboration to support their child’s health and development needs:**

- *“It was good because it was at the pre-school ... I didn’t have to take my child anywhere else and it was a familiar environment for her” – CUBS Evaluation*
- *“What was really helpful was to have the school and The Hive Linker to help me who knew the steps I had to follow and help me understand. This made it easy, nothing else was too hard because of this.” – The Hive Parental Health Literacy Consultation*
- *“I got help from chatting to someone from The Hive who then directed me to a community health nurse for a check and then to a paediatrician. The Hive Linker helped me access the NDIS and then I started getting speech therapy for him.” – The Hive Parental Health Literacy Consultation*

## **Embedded family support roles, such as Child Health Linker, will provide greater wrap around support and success for children from areas of disadvantage.**

For communities of disadvantage, universal programs are often not accessible to all families who are facing additional stressors such as financial stress, housing insecurity, lack of technology access, domestic or family violence or poor mental health. These families are in ‘survival mode’ and services such as child and development checks are considered ‘too hard’ and not a priority. These families may also struggle to support the developmental needs of their children in accessing the necessary appointments, follow up care and possible connection to general family support services. Health & development check programs that include multidisciplinary professionals such as a social worker or allied health therapists can be proactive in identifying the children who require early intervention and can support their connection to the necessary services.



The Hive have a 'Child Health Linker' on our team who provides support to families to navigate the early intervention system if they have concerns for their child's development. This support can include connecting the family to a child & family health nurse for a developmental check or a paediatrician for a diagnostic assessment. They also then support the family to navigate additional supports such as accessing the NDIS, allied health therapists, Medicare rebates, and ensuring their early learning centre or school environment is equipped to support the child. The Child Health Linker can provide brokerage to overcome financial barriers, transport to get to appointments and support with technology or paperwork. This support is vital for families experiencing disadvantage as the early intervention system can be confusing and families can be unsure on what they should do to support their child's development. The Child Health Linker supports the family emotionally as well as practically throughout this journey, acknowledging that it can be overwhelming to understand a child has a delay or disability, especially if the family are experiencing other stressors.

*"We were very lucky that The Hive helped to find a paediatrician after the development check and then were able to pay for the initial assessment...I've had help from them with the NDIS, I've had help with the paediatrician, I've had help with getting their hearing checked and it's put me in touch with a couple of other organisations." – CUBS Evaluation*

#### **CASE STUDY: The Hive's Child Health Linker**

A Mother attended a community sporting activity with her 5-year-old son. She mentioned to The Hive staff that she had concerns about her son's development and wanted help as he was starting school next year. The Hive's Child Health Linker (CHL) met the mother and child, and it was evident the child had severe developmental needs as he was non-verbal, drooling, displayed no eye contact, and did not show interest in activities. The mother did not seem too concerned apart from his lack of speech. The family were migrants to Australia and had a different understanding of child development and had limited understanding of English. The CHL gently discussed his needs with the mother and supported to book and pay for a developmental paediatrician appointment to assess for an Autism diagnosis. The CHL kept in regular contact with his mother to support by filling in paperwork ahead of the paediatrician appointment. The CHL attended the appointment with the mother and provided emotional support throughout the appointment where he received a diagnosis of Autism Spectrum Disorder Level 3 and Global Development Delay. The CHL supported the family to access the NDIS and connecting to relevant allied health therapists and family support services, as well as ensuring the school receive the information to prepare for the child to start school next year.

### **Increased Medicare rebates for low-income or family's experiencing vulnerabilities will reduce the financial burden of accessing necessary assessments and therapies for their children.**

Accessing a diagnosis is the first step to meet the evidence requirements to access the NDIS, as well as inclusion supports within preschools and primary schools. The costs for a paediatrician or psychologist for a developmental or diagnostic assessment can be expensive and impossible for many low-income families to afford resulting in children with undiagnosed delays and disabilities, and therefore without the ongoing supports that a diagnosis can open. Medicare provides rebates

however some medical centres require upfront payment before a rebate is given, and even with this it can be difficult for families experiencing financial stress. There are limited bulk-billing paediatricians or psychologists available, and those that do bulkbill have extensive waitlists which prolongs when a child could access support. To reduce the gap in developmental outcomes for vulnerable families, Medicare should introduce a consideration of a family's income and to increase the rebate amount for diagnostic assessments and allied health therapy for children in low-income families.

### **Increased investment in supporting parental health literacy will result in an increased awareness of health & development services, and children will be greater supported in their development.**

In areas of disadvantage, some families may not have the resources or health literacy to be able to support a child's development, identify a developmental concern, and be aware of what services are there in the community to support children's development.

*"We want to help our kids, but we need to be taught first so we can".*

The Mt Druitt area has significant levels of developmental delay as evidenced in the AEDC data, and it is possible that due to the population wide delay, as well as the complex challenges that Mt Druitt families may be facing, children's developmental delays are not being identified or prioritised early by families due to a normalised population wide delay which hides the delays of individual children. Additionally, families are often caught in survival mode as they navigate challenges such as financial stress, domestic violence or poor mental health which doesn't leave mental space for parents & carers to consider preventative developmental services such as child health checks. While there are multiple brochures and websites that provide information about services and childhood development, not all families may have access to technology or high literacy levels and therefore other strategies customised to what will work for specific communities should be implemented to ensure families are accessing the information in ways that are accessible to them.

In a consultation by The Hive regarding parental health literacy, the following ideas were provided by local parents on how to receive information about child development:

- A resources library that has different tools that families could borrow instead of having to buy e.g., speech cards.
- How to's of how to access services. E.g. paediatricians, SP, NDIS
- Need a timetable of in person activities to take children to.
- Local services being available in the community instead of families having to leave the area
- Mothers' groups with the purpose to have fun, share common experiences, get information, and have some time out.
- Information sessions at the community hall on certain topics: Eg. SP, OT, behavioural therapists to get tips and tricks.
- A one stop location or service of where to get help, where Mums can go to access activities or support.

## **Investment across the ecosystem of the child's life not just direct health programs will have a significant impact upon vulnerable children's overall health & development.**

It is known that there are many complex social and environmental factors that influence the development and health outcomes of a child (ARACY 2015:32). The non-medical social determinants of health can include financial instability, quality of housing and community infrastructure, access to education and social connections. This highlights the need for not only targeted health interventions to improve child developmental outcomes, but rather the application of an ecological model whereby a child's family, community and the broader systems receive investment (Bronfenbrenner 1977).

Investing in families provides crucial support structures that promote positive parenting practices, healthy attachments, and nurturing environments for children. Programs offering place-based services like parenting education and family counselling in trusted places families can easily reach can empower parents with the knowledge and resources needed to support their child's development effectively.

Communities play a vital role in shaping the environments where children grow and learn. Investments in community resources, such as libraries, parks, recreational facilities, and community centres, provide safe and enriching spaces for children to explore, play, and socialise. Additionally, fostering strong social networks and partnerships within communities enhances access to support services and promotes collaboration in addressing local challenges. This represents an opportunity for child and family health services to reach vulnerable children through supported playgroups and other non-government early childhood services (Edwards et al 2020:2).

Investing solely in children health programs is not enough to improve developmental outcomes. Investment across the ecosystem of a child's life acknowledges the interconnectedness of factors influencing early childhood development and fosters a coordinated, intersectional approach to support children's optimal growth and well-being. By addressing the needs of children comprehensively and investing in the environments where they live, learn, and play, society can unlock the full potential of every child, laying the foundation for a healthier, more prosperous future.

## Barriers that affect parents' access to routine health and development checks that track their child's progress against developmental milestones.

There are multiple barriers that may affect parents' access to health and development checks for their children. Limited public transportation options and financial constraints make it difficult for families to travel to healthcare facilities and afford associated costs. Additionally, some parents may lack awareness of the importance of these checks or have limited health literacy, while others experience difficulties navigating healthcare systems due to cultural and linguistic barriers. The availability and accessibility of healthcare providers offering paediatric services may be limited in disadvantaged areas, further impeding parents' ability to access timely care. Stigma and mistrust of healthcare systems due to historical institutional failures also contribute to the challenges of seeking routine health and development checks for children.

The evidence overwhelmingly indicates that children in areas of disadvantage, such as Mt Druitt, face greater levels of developmental delay due to systemic factors. Urgent action is needed to address these issues through targeted interventions that ensure equitable access to healthcare, early childhood education, and supportive environments for all children, regardless of their socio-economic status. Failure to address these disparities perpetuates inequality and deprives countless children of the opportunity to reach their full potential.

### Lack of knowledge of the existence or importance of child health & development checks

NSW parents receive their child's blue book at birth which outlines the recommended child health & development checks. The family will often engage in the 6-week check however following this may only look at the blue book for immunisations and will receive these at their local GP, and the family often will consider the check having been completed. Each GP will approach these checks differently with some completing a thorough check, and others only administering the vaccination and completing the measurements. Families rarely will consider seeking a further child health and development check from their community health centre, and many put away their blue book and will forget to look at it.

The Hive asked local Mt Druitt families about their experience with the community health centre and the blue books, and their responses highlighted the minimal utilisation of the service:

- *"I didn't know where to go for help, if someone hadn't suggested the community health nurse I wouldn't have thought to go there"*
- *"I knew about the blue book but I did not really use it except for when we go for immunization and they ask for it."*
- *"I've heard of the blue book, but I never looked through it apart from the kid's information at the front of the book. I sometimes took it to visits."*
- *"Have heard of the blue book. I've read it and know they have different checks in there, but we haven't done them. I forget about them. I looked at it the other day for my 2-month-old to remind myself of the immunisations. I just use it for proof of birth and immunisation records."*

Western Sydney University's evaluation of the CUBS Program similarly explored the knowledge of child health & development checks in the Mt Druitt community which demonstrated that families did not have a strong understanding of what the check could provide and why they were important.

- *"My kids are just healthy ... the health check, is it if they are sick?"*
- *"A further barrier to participating in screening programs was the belief that child development would happen in its own time, and not something a parent should worry about too much."*
- Parents did not subscribe to the notion of well child healthcare and expressed concern that if they took up the time of a busy GP for a child who was not sick, they were "wasting" the GP's time: *"I'd much rather their time go to a new parent who's struggling"*

## Family stressors

For vulnerable families experiencing complex stressors such as financial hardship, domestic violence, mental health concerns, and housing instability, they are living in survival mode and focusing on ensuring their children are safe and healthy. As blue book developmental checks are an optional form of early intervention, families in survival mode will rarely consider these a priority especially if they face additional challenges to access these such as catching public transport. Without wrap-around support to make these checks happen and support the families after the assessment, these families will struggle to engage with the service.

The Hive asked Mt Druitt families about the barriers to accessing blue book checks or child health services, and most of the barriers identified related to various family stressors and the developmental checks not taking priority at this time:

- *"Getting the information and diagnosis from the paediatrician was really hard, I had no transport unless The Hive drove me, not a lot of information available, not knowing what services I can access, the cost of appointments and scripts."*
- *"My own health isn't great, I'm burnt out"*
- *"There's no after school care available so I can't get help with my other kids [while I take the youngest for the appointment]"*
- *"I don't have time amongst caring for all the other kids. Need to feed the baby, manage the kids naps, I'm tired."*
- *"My partner is incarcerated, and I'm trying to support my kids and put food on the table while trying to cope myself."*
- *"It was nerve wracking and a really hard process to get help"*

## Lack of Transport

Mt Druitt is an area of entrenched disadvantage, severely lacking in place-based public services, and has insufficient access to public transport (Pawson and Davison 2014). With many families not having access to a car, a poor public transport system hinders family's ability to access developmental checks.

Inadequate public transport infrastructure may force families to rely on alternative, less safe modes of transportation, such as walking long distances or be exposed to harsh weather events. In Greater Western Sydney, it is typically 6-10°C hotter than the rest of the city during extreme heat events (Adapt NSW 2021), commonly exceeding 40 degrees in Summer. The challenges with public transport are immense, with infrequency of buses, cancellations of services and poor bus routes extending the travel time for families often over three times the travel time it would be to drive the same distance. Taxis are too expensive for many families, and most companies do not provide car seats which then presents a safety concern.

For families experiencing complex stressors the added task of navigating public transport, particularly with a child who may have behavioural challenges or developmental delay as well as younger siblings, can be too overwhelming for a family to be motivated to access a developmental check. Without the ease of a car, the challenges with navigating public transport out balance the desire for a routine developmental check, especially if a family does not hold any concerns for the child.

Investing in transport will reduce health disparities by ensuring equitable access to healthcare services for all families. By eliminating transportation barriers, vulnerable and marginalised populations will have equal opportunities to access child development checks and receive appropriate support and interventions.

### **CASE STUDY - Transport:**

Mary is a mother of three children under 5 years old. The preschool has raised serious concerns regarding the children's development. The mother receives support to book and pay for a paediatrician for the eldest child as he is about to start school. The mother does not have a car and is unsure how to attend the paediatrician. While the appointment is only a 20-minute drive, public transport to the paediatrician would be complicated and very stressful as the mother would need to catch 2 buses and a train and would also need to take all three children with her which is stressful, especially with the eldest child having severe behavioural challenges. Taxis are organised to transport the family to the paediatrician's office, with a Health Linker going with the family to offer support on the journey and assist with the children. On the journey, the children are incredibly unsettled and disruptive in the taxi, resulting in the taxi drivers yelling at the children and the mother becoming overwhelmed, upset, and embarrassed. The family make it to the appointment with the mother emotionally exhausted and struggling to engage in the assessment. The family then must repeat the taxi journey back home, leaving the mother exhausted by the end of the journey and hesitant to repeat the process for her other child.

## Fear of being judged for their parenting or reported to child protection if a child is delayed

Accessing a new service can be an anxious experience for many people. For vulnerable communities, some families may feel especially worried when accessing a new service as they may feel fearful that they will be reported for child protection concerns. Due to repeated fear of child protection in the community, parents and carers can correlate a child having a developmental delay with being perceived to be a neglectful parent and fear negative repercussions if they seek support. This stigma and fear can become entrenched within communities and prevent families from wishing to seek support.

*"I'm scared I will be reported, it's happened before when I've asked for help."* – The Hive Parental Health Literacy Consultation

## Previous negative experiences with services

When a person has a negative experience with a service or organisation, it has an impact and can leave an individual unwilling to visit that service again. With an organisation as broad as 'NSW Health', unfortunately a family can be hesitant to engage with any branch of the organisation if they had a negative experience with one in particular. Similarly some families may consider the child health system all to be interlinked, and if they had a negative experience with a GP or paediatrician, they may not wish to see a child health nurse. When families are experiencing complex challenges at home such as poverty, domestic violence or housing insecurity, gathering the energy to research and try again is difficult. Child health nurses conducting developmental checks need to build the trust with families and communities to take the burden off families needing to advocate for themselves.

*"I had to be persistent, I made sure I was not only listened to but heard."* – The Hive Parental Health Literacy Consultation

## Solutions to overcome the barriers:

Understanding the barriers faced by families in specific communities will assist in creating solutions that will work for those families. The barriers outlined are from The Hive's learning in the Mt Druitt context and the following solutions are ones we believe would have a great impact for the Mt Druitt area, however also could be applicable for other areas of disadvantage.

- **Place-based health & development checks** to overcome transport barriers and increase the trust the community can have with child health nurses in their own community.
- The **provision of community transport** by community health centres for families will increase the number of families accessing child development checks particularly those who are at greater risk of developmental vulnerability.
- **Linker support** (also known as navigators) provided to vulnerable families will increase the awareness of developmental checks and increase the support family's receive post-assessment to connect to specialist supports the child needs.
- Simple and **accessible information about children's development** will increase parents' health literacy and awareness of the services available to them.
- **Partnership between NSW Health and ECEC services and community organisations** will increase the trust and awareness the community have with child health services.

## Conclusion:

The Hive Mt Druitt have spent the past seven years understanding barriers families have faced to access the resources and services that will assist their children to start school well. We value the service that NSW Health provide through child health & development checks and have placed resources into promoting access these in our community, as well as deep listening to understand family's perspectives and understanding of these checks. We know that children who would most benefit from these checks are often the ones that struggle to access them, and so innovative approaches must be undertaken to ensure that these children aren't left behind. Focusing on strategies that are place-based, relational, accessible, and equitable will overcome the barriers that families face in accessing development checks and will ensure that children are starting school developmentally on track and with supports in place.

The Hive Mt Druitt are incredibly passionate about this issue and would welcome any opportunity to share our learnings and our family's stories with the NSW Parliament to support a system that supports children getting the best start.

If you have any questions about what we have shared here, please contact [REDACTED]  
[REDACTED]

## Appendix:

- Western Sydney University - Check Ups Before School (CUBS) Program Evaluation
- The Hive Mt Druitt - 'Parental Health Literacy Conversations': Understanding the barriers families face in knowing when and where to access early intervention services for their children and exploring possible solutions.



**Attachment included with submission**

R Grace, C Woodrow, C Johnston, C Ballantyne, [Check-Ups Before School \(CUBS\): Final report of the pilot study](#), Western Sydney University, July 2022



THE HIVE, MT DRUITT

# Parental Health Literacy Conversations

Understanding the barriers families face in knowing when and where to access early intervention services for their children, and exploring possible solutions

May 2023



# Table of Contents



01 Executive Summary

02 Why is this important?

03 How did we listen?

04 What did we hear?

19 What do families think should happen next?



# Executive Summary

The Hive provide community and individual support to families in the Mt Druitt area whose children have developmental delays or disabilities. The Hive have found that many of these families were unaware of their child's delay until a concern was raised by a family member or staff member such as an early educator or caseworker. Other families may have been aware of the delay but had been unsure how to access an assessment or been aware of their eligibility for supports through Medicare or the National Disability Insurance Scheme (NDIS).

This consultation was undertaken by The Hive to gain an initial understanding of parental health literacy in Mt Druitt, and the barriers families face in accessing supports, in the hopes that this could inform future initiatives to support families and their children access services early and possibly prevent developmental delays from developing or increasing in severity. The consultation methods included an online survey, individual interviews, focus groups and five pop up 'dot voting' opportunities at local community events.

The consultations highlighted barriers in accessing services and obtaining information about childhood development including:

- Financial cost for services
- Fear of judgment for their parenting
- Lack of transport to access services
- Confusion about the process, where to start, who could help and what they are eligible for.
- Waiting lists for services
- Family stressors
- Parental literacy levels to understand information and complete forms.

Families indicated their most trusted sources for support and information being family members, friends who have a child with a delay/disability, their GP, social media, and the internet.

To overcome the barriers, there was not a unanimous idea from families as it highly depended on family's confidence and access to technology, their literacy levels, and the time they had available. Ideas that were provided included:

- An app with a resource of local services, developmental milestone information and information about eligible services and how to access.
- A Facebook page which provides information such as helpful activities for development, information on how to access services such as the NDIS and where to go for support.
- Workshops or courses hosted by allied health professionals or services to impart knowledge to caregivers.
- Tip sheets and flyers with relevant information distributed in local community services.
- In person support from a 'Linker' type role who can understand their situation and connect to the necessary supports.

This report offers valuable insights into challenges families face in accessing services, as well as their own awareness of child development, and when they should access support for their child's delay. The findings in this report offers The Hive and others working with families in the Mt Druitt area a starting point for designing new resources and initiatives that consider the unique perspectives and needs of Mt Druitt families. Further consultation should be undertaken once a prototype or idea has been developed to cross check with families that it would be an appropriate service or resource.

# Why is this important?

The Hive, Mt Druitt (United Way Australia) is a place-based, Collective Impact initiative operating in the suburbs of the Mt Druitt postcode in Western Sydney, NSW. The goal of The Hive is for all children in Mt Druitt to start school well, with equal opportunity to learn, be healthy and participate in quality community life.

According to the Australian Early Development Census, in certain Mt Druitt suburbs, 2 in 3 children start school considered developmentally vulnerable which is significantly higher than the national rate of 1 in 5 children. Living in a region of socioeconomic disadvantage, many children are starting school already behind compared to children from other communities, and without significant investment for Mt Druitt communities, these children will struggle to break out of the cycle of poverty.

In addition to the population level data, The Hive have repeatedly heard from families, educators, community workers, as well as witnessed first hand that many children in Mt Druitt have various developmental delays and disabilities, with majority of these having not accessed early intervention specialists prior to starting school. It is possible that due to the population wide delay, as well as the complex challenges that Mt Druitt families may be facing, children's developmental delays are not being identified or prioritised early by families due to a normalised population wide delay which hides the delays of individual children. Families are often caught in survival mode as they navigate challenges such as financial stress, domestic violence or poor mental health which doesn't leave mental space for parents/carers to consider implementing intentional activities around promoting childhood development.

The Hive have collaboratively worked with local stakeholders to listen to families and have attempted to overcome barriers families face to accessing supports such as through their Health Linker role and the Check Ups Before School (CUBS) Program, as well as working with local early educators to build their capacity to support children with additional needs. Through the CUBS program the team theorised that many of the delays the nurse was identifying weren't necessarily due to a diagnosed disability or 'genetic' delay, but rather a lack of exposure to activities or resources that promote healthy development and build the child's skills. This comment aligns similarly with reflections from educators and community stakeholders who have mentioned that families often don't realise their child is delayed, as well as families reflecting the belief that education occurs when the child commences preschool or Kindergarten and thus have often not engaged in intentional play-based activities at home until that point.

The Hive want to understand how to support the development of parental health literacy, that is how parents and carers can obtain knowledge about supporting childhood development, key milestones, where to seek information and access services. We know that Mt Druitt families love their children and wish to understand how to support them to have access to the knowledge, skills, and resources they need to help their children thrive.

There is a long history of parenting courses and programs being delivered in Mt Druitt, as well as a range of evidence-based resources delivered by the government, so before The Hive consider providing any form of program or resource, we wanted to listen to families to understand what specific areas they want information on, the barriers they face in accessing help, and how they would best like to receive the information. A series of consultations was conducted in various ways to capture the voice of local Mt Druitt families and the learnings are reflected in this report.

# How did we listen?

Parents and carers in the Mt Druitt community are resilient, strong, and love their children deeply. However, like many families in under resourced communities they face a range of barriers throughout raising their young children.

Multiple forms of consultation were undertaken to capture a wide variety of voices and insights within the community. The following strategies were undertaken throughout December 2021 – to June 2022 to listen to families:

- Survey Monkey: A short online survey using SurveyMonkey was made available via The Hive Facebook page in December 2021 inviting any family from the 2770 postcode with children under 5 years to participate. Responses were anonymous and the aim was to get brief responses on the themes of where families accessed information about their child's development, the barriers they face in accessing support, if they accessed blue book checks for their child, the services they access, and their experience in navigating services. 11 parents/carers participated in this survey.
- Informal Community Consultation Pop Ups: Informal 'dot voting' consultations were conducted at 5 community events where families were asked two questions "What information would you like more of to help you in raising your child?" and 'what are the best ways for you to make getting this information easier?'. Families were invited to 'vote' by placing a sticker on their first and second priority, and where possible longer conversations were had around the topics.
- Focus Groups: 3 focus groups were held to explore deeper conversations around the barriers that families face to accessing information and services when raising their child, and what support they would like and how this could be delivered in their community.
- Interviews: 6 individual interviews were held with families who have a child with additional needs to understand their experiences of accessing support for their child, and what the positive and negative aspects were to this, and what they found most helpful through the process, and what they wished was easier.

Participants were compensated for their time and sharing of their stories through vouchers at the completion of their consultation.

# What did we hear?

## Survey Monkey

The survey briefly explored a range of themes regarding information sources, barriers, services accessed, and experiences of accessing services.

11 parents/carers participated in this survey.

Overview:

- Families reported the most common sources of information regarding their child's development as their friends/family & a Nurse/Doctor, with the Internet and social media following these options.
- The top source of support if a parent had a concern for their child's development was overwhelmingly a Doctor/Nurse which all participants indicated, followed by Friends & Family.
- All participants except for one stated that they had been recommended at least one type of specialist support such as paediatrician, NDIS or allied health. Over half the participants responded that speech therapy had been recommended, with just under half indicating a paediatrician and/or the NDIS was also recommended. Only one participant responded stating that no supports had been provided to their child.
- The most reported barrier in accessing these specialist supports was cost, closely followed by their child's behaviour, and not wanting to be judged. Not knowing where services were, finding the process confusing and transport were also mentioned by multiple participants.
- In asking what information families want more of, nearly half the participants indicated 'knowing how to find allied health supports and use NDIS funding'. The second most common response was a three-way tie between 'ideas of what I can do at home to help my child develop their skills', 'how to know if I can access the NDIS and how to do it' & 'how to make sure my child gets extra support before they start Kindergarten'.
- The best ways to receive this information was overwhelmingly a 'Facebook/social media page' with 'text messages' also strongly favoured. Options such as an app, groups or posters received a couple of votes but not strongly indicated.

There was a surprisingly high response indicating that parents utilised their child's blue book to inform their knowledge of their child's development and had also accessed the Mt Druitt Community Health Centre for child health checks which contrasts with what The Hive have heard elsewhere. In the short open answer responses, four of the families indicated either the blue book or health centre is what informs them if their child is on track with their development, with other common answers being the child's teacher or online sources such as 'Google'. This relationship with the community health service and blue book differs to anecdotal data that The Hive has previously heard so this would be a topic of value to explore in the qualitative interviews and focus groups to understand how these resources are used by families.

# Survey Monkey – continued

Some responses indicated a high level of parental literacy regarding understanding of milestones and knowledge of activities to support development. This is different from The Hive’s conversations with families and stakeholders and could indicate the questions were not phrased the clearest or could have been better explored through conversation rather than a closed question, or could indicate reporting bias from parents. For example, there were the questions ‘Are you aware of when your child should be reaching certain milestones? E.g. when they should walk, start speaking, use a pencil etc’ and ‘Were you aware that playing with your child at home can help your child develop their skills and prepare for school?’ All participants answered yes to these questions, however we know many children start school without being able to complete some of these tasks, so families perhaps didn’t feel comfortable to answer truthfully, or this highlights a disconnect between knowing the information and feeling confident to seek help if a milestone wasn’t reached or implement specific activities to encourage development.

**The following quotes are samples from the open response questions.**

**‘What have you found challenging when you have tried to get help for your child?’:**

“Specialist are too far away and cost too much”

“Awful judgmental paediatricians, takes too long, my mental health and the behaviour of my other kids at appointments.”

“Waiting times for paediatricians, NDIS, speech therapy, and lack of availability (waitlists mentioned by four families)

“At the moment it's only allowing the child needing assistance to be there as I have another child that I can't get watched/babysat”

“Contacting the service but they never got back in contact with me”

**What advice would you have for other families trying to get help for their child?:**

“Trust your child’s doctor and don’t leave it too late to get help”

“Need to be honest and direct with questions. Even in times of high anxiety for myself I need to take a step back and think of the best outcome for my child”

“Find a good person that gets to know you and your children, and no matter how big or small ask the doc any questions and raise any concerns.”

**What is needed to help support families to make this easier?**

“I need just one person to help do it all with me, not to go multiple places. Or why can't it be done in school for working parents or single parents.”

“More family days where moms get to meet other moms and kids get to meet other kids. I have no family here and it was tough the first few years with my eldest.”

“If there was an app that had local information with lists and phone numbers”

“A step by step on what to do.”

“Non-judgemental staff.”



# Community Consultation Pop Ups

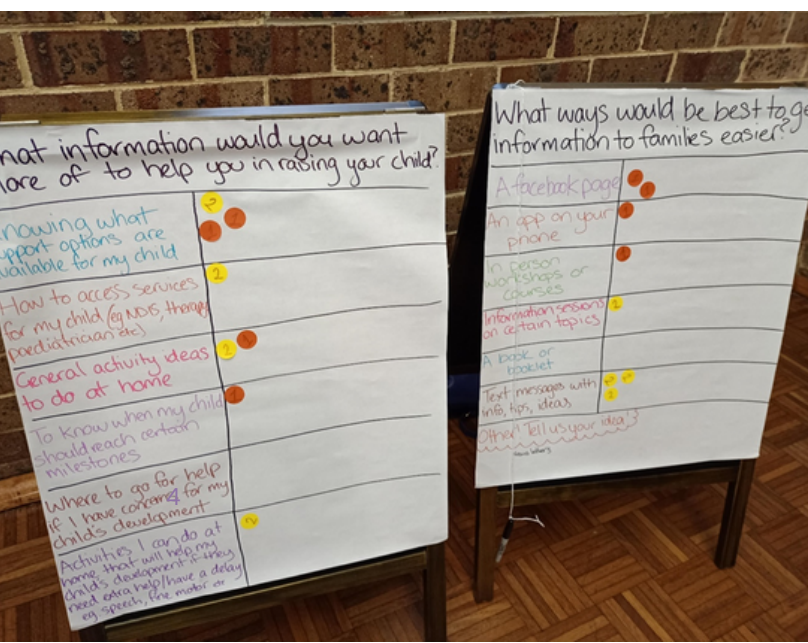
Five existing community engagement activities were leveraged as opportunities where families naturally gathered and where trust was held between families and Hive staff to ask some simple questions. Where families were dropping their children at events, they were offered the opportunity to answer two questions on A-Frame signs by 'voting' with stickers indicating their first and second preferences to each question. Where possible, conversations were held with families to understand their vote and their experiences.

The first question asked was 'What information would you want more of to help you in raising your child'. The overwhelming priority response across the consultations was to 'know what support options are available for my child'. Many families who responded stated they don't know what was available, or where to start to find out what could be available, what their child needs, and where to start looking for support. 'How to access services for my child (e.g. NDIS, therapists, paediatricians etc.)' and 'Activities I can do at home that will help my child's development if they need extra help/have a delay or disability' were the next popular options indicated.

The second question explored how families might want to access information about these topics, with the question being 'What ways would be best to get information to families easier?'. The top preferred answers for this question were 'A Facebook/social media page' and 'text messages with info, tips & ideas'. Very close to this was 'In person workshops or courses'. The remaining options did not get many votes across the board.

The conversations that arose from these consultations were insightful, with many parents sharing their personal experiences of trying to understand what support was available in the community for their child and their experiences with services in the area such as GPs, NDIS, and paediatricians. There were conflicting and mixed comments from families regarding how to get information, with some parents having strong preference for texts or social media, while others preferred in person workshops or physical flyers or booklets.

These responses often reflected the parent's current access to technology or if they had social media accounts. For example some families said **"Facebook is best because I'm on there anyway so I would see helpful information when I'm scrolling"**, while others said **"I don't have data or home internet so an app or Facebook wouldn't be helpful, I'd prefer flyers or posters in common locations"**.



# Community Consultation Pop Ups – continued

Results of the pop up voting from 23 parents/carers:

Q1. What information would you want more of to help you in raising your child?	
Knowing what support options are available for my child	Top vote: 11 Second vote: 3
How to access services for my child (e.g. NDIS, therapists, paediatricians)	Top vote: 4 Second vote: 3
General activity ideas to do at home	Top vote: 3 Second vote: 1
To know when my child should reach certain milestones	Top vote: 3 Second vote: 1
Where to go for help if I have concerns for my child's development	Top vote: 1 Second vote: 4
Activities I can do at home that will help my child's development if they need extra help/have a delay or disability. E.g. speech or fine motor activities.	Top vote: 1 Second vote: 6

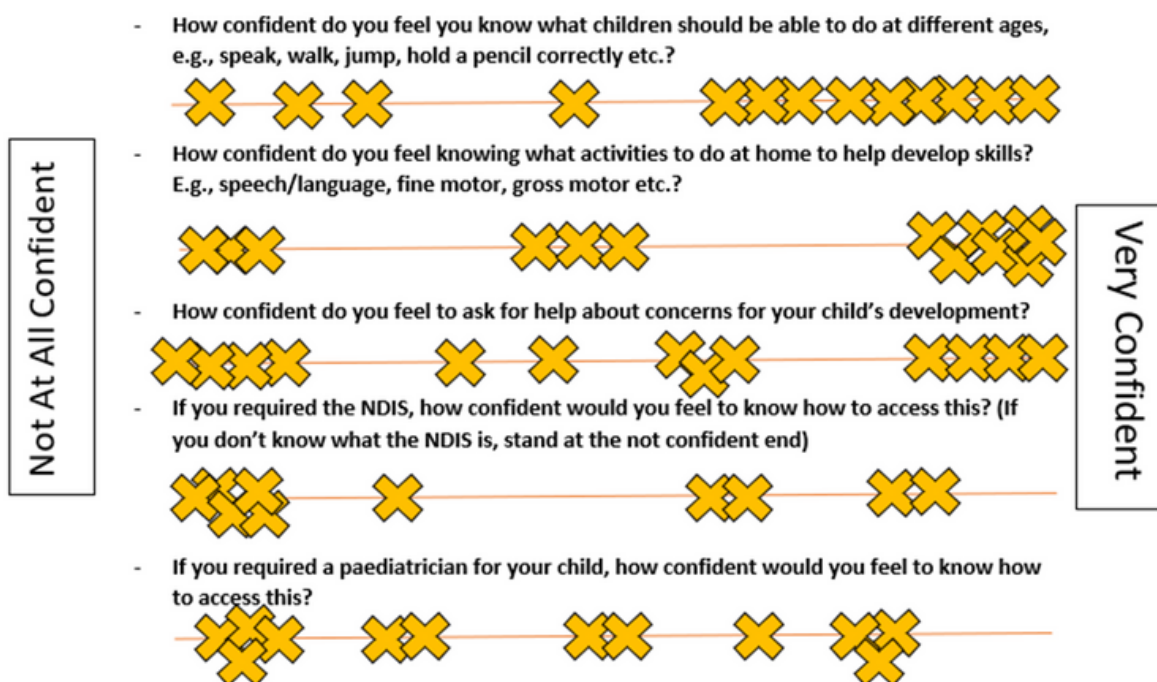
Q2. What ways would be best to get information to families easier?	
A Facebook or social media page	Top vote: 7 Second vote: 5
An app for your phone	Top vote: 1 Second vote: 1
In person workshops or courses	Top vote: 5 Second vote: 3
Information sessions on certain topics	Top vote: 2 Second vote: 3
A book or booklet	Top vote: 0 Second vote: 5
Text messages with information, tips & ideas	Top vote: 5 Second vote: 5
Other: Tell us your ideas	1 response: Newsletter

# Focus Groups

3 focus groups were held across the suburbs of Bidwill, Tregear & Willmot, with a total of 13 mothers and 1 grandmother carer attending to share their experiences of raising young children and their knowledge of child development. The focus groups consisted of two interactive activities that were designed to understand parent's knowledge of child development and navigate various supports.

## **PART A: Activities**

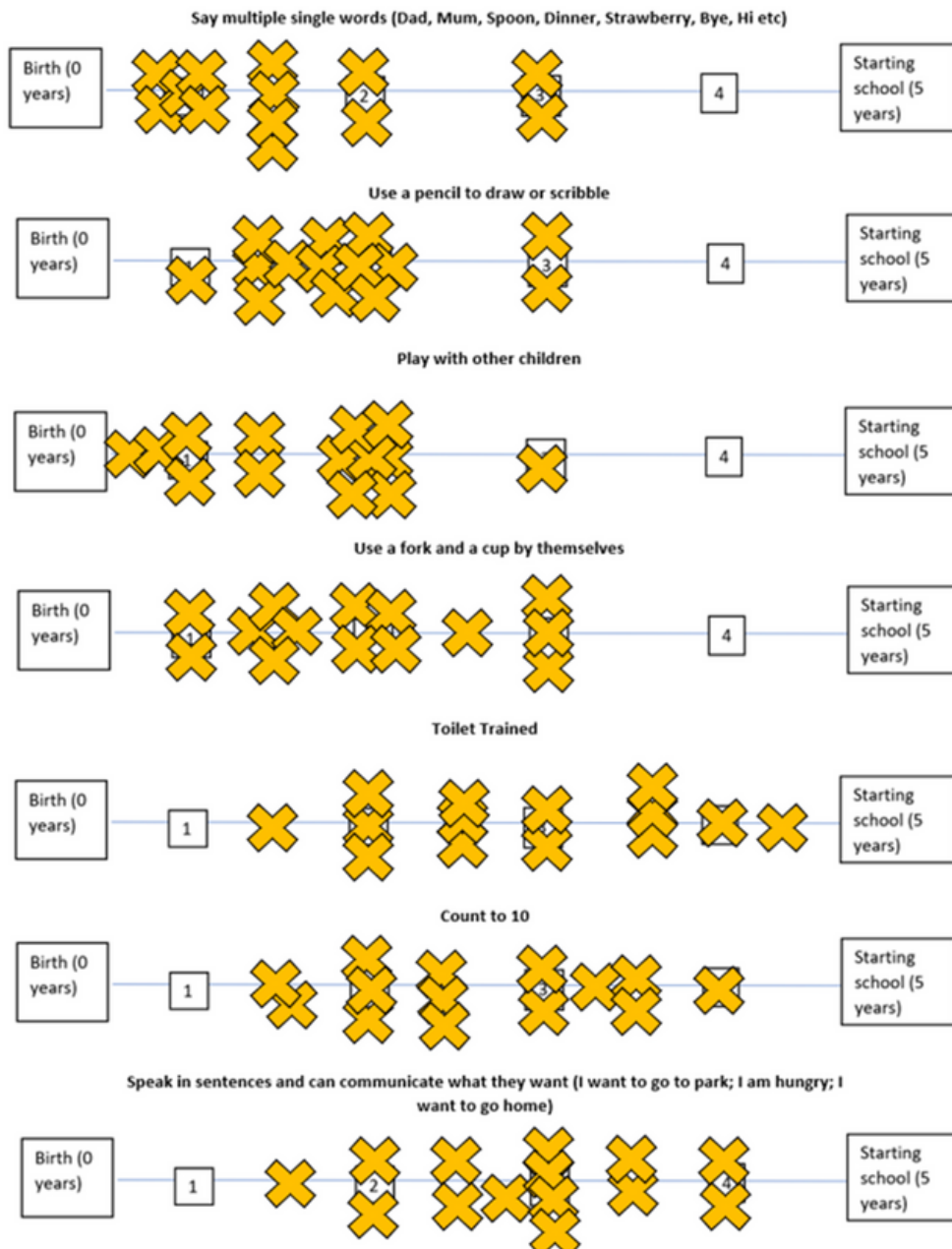
The first activity was to understand the level of parental health literacy. This was completed by asking the mothers a range of questions and asking them to stand on a line representing a scale from 'very confident' to 'not at all confident'. The results greatly varied, and this appeared to be based on if the mothers have had to already navigate these topics or services, and how much support they had around them. The combined results for all 3 groups are below with each X correlating to where the mother stood.



# Focus Groups – continued

## PART A: Activities – continued

The second activity asked the mothers to anonymously indicate on a handout when they believed their children should reach certain developmental milestones. This activity was prefaced with the statement that there was no right or wrong answer as there is often a range in where children will reach different milestones, and there was no expectation for the mothers to share their responses. In general conversation after the activity, mothers reflected that it was harder than they thought and that they had different children who reached milestones at different ages. A common reflection was that younger children reached milestones earlier, believed to be due to the influence of their older siblings. There was a range of responses in this activity also which indicates that there is not clear understanding of when children should reach developmental milestones, which could then be hypothesised to contribute to later access of health services for further assessment and access to therapy if required.



# Focus Groups – continued

## PART B: Focus Group Discussion

### Where to receive information

Families were asked where they currently received information about their child and where they would go if they needed help. This brought up a wide range of responses including, The Hive, their school or preschool, staff at the IFamilies were asked where they currently received information about their child and where they would go if they needed help. This brought up a wide range of responses including, The Hive, their school or preschool, staff at the local community spaces, Google, their GP, family members, parenting courses, online forums, flyers, playgroups, the community health centre, Facebook pages, particular websites such as parenting.com or the Raising Children's Network.

Mothers were also asked what services or groups they currently attended for their child which was a range of parenting groups (HIPPIY, Fusion Families Course), playgroups, childcare, a GP, paediatrician, allied health therapists, or some families mentioning they didn't attend anything unless they were told by a trusted person, and they knew someone else attending or could go with them. Families indicated they found out about these groups and services from pamphlets, social media, flyers, the school or preschool, or specific trusted people who helped them connect to the service. The theme of a lack of knowledge and distrust of services was present in all three of the focus groups

The group explored who were the services, sources of information or people that they did trust, these responses included the names of many local staff from The Hive, community hubs and preschools, parenting courses, their caseworker or GPs. Other people mentioned were paediatricians, nurses, family members, childcare centres and schools, however these options were also indicated by others in the groups as people they did not trust, demonstrating the influence of personal experience on accessing future help and support.

The groups were asked how they would expect to recognise if their child was behind in their development and needed support. There were many similar responses for this question across the groups which included receiving comments from trusted community centre staff, family members, teachers, and the childcare. A few mothers mentioned that they would compare their child to other siblings or children at the park or playgroup, while others mentioned their 'gut instinct' to know when something wasn't right.

*"There are things out there but we don't know about it"*

*"I don't trust no one"*

*"I don't know unless someone tells me...I wouldn't have come today unless XX called me"*

*"I was only able to come here today because XX picked me up"*

# Focus Groups – continued

## PART B: Focus Group Discussion – continued

### Barriers to access help

A discussion was held around barriers that families had faced when they had attempted to access information or services for their child, or anything that stops them from asking for help. The results were insightful, and aligned to what The Hive had heard in other consultations. The common themes that arose were:

#### **Fear of being judged or reported to child protection**

- “I’m scared I will be reported, it’s happened before when I’ve asked for help.”

#### **Transport to be able to access services**

- Those with school age children mentioned this was an added complexity as there was only a short window of time available to access services between drop off and pick up.
- “Taking kids to get help, the transport and additional needs make it hard”

#### **Long waitlists for services which was a ‘turn off’ from trying to access supports**

- “I had to keep advocating for myself to find faster services”

#### **Negative experiences with services**

- “Not getting calls back from services when they say they will”
- Calling services and getting someone who is rude
- Receiving conflicting advice from different services about what help was required. *“Our GP says there’s no issue, but preschool says there is, and my family members also say there’s not. Who am I meant to believe?”*

#### **Eligibility and criteria to access services:**

- “Often will take a certain age range which means some of my children can attend but not all of them”
- “I don’t fit in the eligibility for the free services, but can’t afford the private ones. We’re not poor but we’re not rich.”

#### **Family stressors or priorities**

- “My own health isn’t great, I’m burnt out”
- “No after school care so I can’t get help with my other kids.”
- “I don’t have time amongst caring for all the other kids. Need to feed the baby, manage the kids naps, I’m tired.”
- “My partner is incarcerated and I’m trying to support my kids and put food on the table while trying to cope myself.”

#### **Parental literacy levels**

- “I can’t fill out forms myself, there’s so many of them when you need help”
- English as a second language. Doubted ability to explain their concern or understand the information



# Focus Groups – continued

## PART B: Focus Group Discussion – continued

### How families wanted to receive information and support

The groups were asked which information and support do local families need more of. A common theme was an increase of access to information and available services, as well as locally based groups and activities for families and children which were free and run by trusted, non-judgemental people. Families also expressed the desire for somewhere they could come and relax with other parents as a break from the stressors in their lives.

Other specific examples of information or activities families wanted more of included:

- A resources library that has different tools that families could borrow instead of having to buy e.g., speech cards
- How to's of how to access services. E.g. paediatricians, SP, NDIS
- Need a timetable of in person activities to take children to.
- Local services being available in the community instead of families having to leave the area
- Mothers' groups with the purpose to have fun, share common experiences, get information, and have some time out.
- Information sessions at the community hall on certain topics: Eg. SP, OT, behavioural therapists to get tips and tricks
- A one stop location or service of where to get help, where Mums can go to access activities or support (food/clothing/emergency relief), NDIS, Paed.
- ***"Somewhere to have others do the SP & OT activities. I could learn but I don't have the energy or time to do this at home"***

One parent made the comment that a literacy program for parents would also be of great importance in the process of accessing support for children as ***"We want to help our kids but we need to be taught first so we can"***.

Families strongly suggested that information could be better provided to parents through text messages with information, parenting groups and courses, having trusted local people as 'guides' to provide information, a local Facebook page with activity ideas, information sessions run by different therapists would also be helpful. Other sources mentioned included GPs, flyers, videos, the hospital at the child's birth, banners, childcare centres, social media, mothers' groups, open days for services to learn what they offer, a local hotline for information, a magnet with local numbers, or ages and developmental milestone information.



# Individual Interviews

Interviews were individually conducted with six mothers who have a child/children with a developmental delay or disability and have navigated obtaining supports for them. The mothers shared their experiences of getting support their child's needs, the facilitators & barriers, information they would like more of, and their ideas for what could be designed to make the process easier for families.

It should be noted that all mothers were known to the two Hive staff who conducted the interviews and had received support from them to access these supports. This could impact the results as these families possibly didn't reflect the process was too difficult due to them having this support to provide information and obtain services. However the staff acknowledge that the families required their support due to struggles in navigating the situation independently. This is an important insight as it shows the necessity and importance of having a relational 'guide' through the process.

## How did you know your child's development wasn't on track, and how did you get help?

All but one family responded stating that they became aware of their child's delay by a trusted service or person in their life including: The Hive staff, preschool teachers, playgroup facilitator, and family members who started the process of accessing assessments and support. The remaining mother indicated she had her own concerns and went to their GP which resulted in a paediatrician referral.

Many families reflected that they had a 'gut instinct' that something was 'wrong' with their child's development but didn't necessarily feel equipped to articulate this or where to seek support on this. Whereas two parents said they had no idea until the preschool informed them.

- ***"I knew he had a delay. He wasn't speaking. Family members said that it was normal in our family for "boys to be late talkers""***
- ***"I thought there might be 'something wrong' but I also thought all kids just learn and act different"***
- ***"I see my GP all the time, but I was told that he was just young and will develop eventually"***



# Individual Interviews – continued

## Sharing Experiences of Accessing Support

A strong theme that emerged from the interviews of a 'positive' in the process of accessing support was having trusted people to help understand the options available and how to access these, to provide transport, make referrals and support to access therapists. The difficult or 'bad' parts from the help seeking experience were commonly the lack of knowledge of where to go, how to access and navigate supports, as well as cost and transport.

### **What was helpful:**

*"What was really helpful was to have the school and The Hive Linker who knew the steps I had to follow and help me understand. This made it easy, nothing else was too hard because of this."*

*"It was a lot easier to access NDIS through the preschool. I wouldn't know how to fill out forms, a lot of information and I did not know where to start if I did not receive support from them."*

The Health Linker *"had all the information and helped to guide me"*

*"There's less stress if things are set up and getting done [by someone else], others helped me to get things set up and also to get transport to appointments."*

*"After a meeting with the preschool and school staff, they introduced me to The Hive which helped to set up the paediatrician and appointments from there"*

*"I got help from chatting to someone from The Hive who then directed me to a community health nurse for a check and then to a paediatrician. The Hive Linker helped me access the NDIS and then I started getting speech therapy for him."*

*"It was easy to access these supports because I got help to know about them and to book the appointments and fill out the confusing forms. I wouldn't know where to start if I didn't have this help."*

*"I have not encountered major issues as the preschool supported me all through out."*

### **Negative Experiences**

*"The bad would be the paediatrician was not very good with us so I had to find a new one."*

*"I have funding for lots of speech therapy but even though we are connected to a therapist, even they don't have time to give my child extra hours because they have such high demand."*

*"GPs are not helpful in getting referrals. I want to have someone go with me. The GP has often referred me to my 'regular GP' to get a referral, but I don't have a regular one."*

*"I feel like I am treated differently because of my race (Aboriginal). I've had to wait longer for appointments when I've seen others in the wait room go in first."*

### **Emotional**

*"I had to be persistent, I made sure I was not only listened to but heard."*

*"It was nerve wracking and a really hard process to get help"*

*What was hard about the experience was hearing the diagnosis and report from the paediatrician. It was hard to hear and realise my child had a disability that I didn't know about."*

*-"I don't feel comfortable to ask for help. I wouldn't go to you for help unless I knew you. "*

# Individual Interviews – continued

## Sharing Experiences of Accessing Support – continued

### Family Stressors

*“Getting the information and diagnosis from the paediatrician was really hard, I had no transport unless The Hive drove me, not a lot of information available, not knowing what services I can access, the cost of appointments and scripts.”*

*–I still need to find OT for my child, but I don’t have time to research and find the options and call around because I work and have other kids that I’m looking after.”*

### The Process was overwhelming and confusing:

*“I didn’t really know where to go for help.”*

*“The NDIS is really confusing and I didn’t know anything about this before I started.”*

*“Sometimes it seems like there’s not a lot of help out there but there actually is, it’s just hidden”*

*“The services and NDIS exist and I have heard of some of them but no idea how to access them, or if I’m eligible etc.”*

*“It was easier to have other people doing it on my behalf because they have more resources and knowledge of what is available”*

*“I kept getting stuck, I wouldn’t know where to go or how to access support”*

*“The calls on the phone with the NDIS was hard because they were very long, and bad reception made it hard to understand.”*

*“The information services had was helpful but very overwhelming for me.”*

*“The forms were confusing, I had people to help me prefill paperwork and help with referrals and explain to me what services would do.”*

*“Some people don’t tell you information about the services that are provided or help with accessing them”*

*“The information from all the orgs I connected with were overwhelming”*



# Individual Interviews – continued

## Information that was the most helpful in supporting the child

The information that families indicated was the most beneficial in supporting their child was overwhelmingly having information about what support services and pathways were available. Families reflected that they found the process confusing and valued information and support throughout the whole journey, whereas others stated they just needed help accessing the initial information of where to start and they were then confident to navigate the rest themselves

- ***“Knowing where to go for help, if someone hadn’t suggested the community health nurse I wouldn’t have thought to go there”***
- ***“Knowing the first step to start the process of getting help. Getting direction to see the health nurse and start the NDIS referral was enough for me to get everything else organized.”***

Another common theme from many of the mothers was receiving information about how they could support their child at home. This primarily was surrounding the topic of speech and language development, and the mother’s stated that activities and tools provided by their speech therapist or preschool had an impact on their confidence to support their child/ren.

- ***“My Speech Therapist gave me visual tools to explain to my older son routines and activities. Because I was able to access services and activities for my him, I have started to use the tools I got there at home with my younger daughter because I’m more confident.”***

In exploring what further information they felt they didn’t have access to, or would have appreciated being easier to find, many of the families reflected that they didn’t have any concerns with this due to the fact they had a trusted person such as the Hive Health Linker or a preschool educator supporting them through the process.

- ***“I did not really get confused because Ms. XX helps with forms then I know exactly what to do. If I had to do it myself, I’d probably just be confused.”***
- ***“I did not feel confused as everyone was supportive and was explaining everything to me”***

Whereas other families indicated they’d like more information to know what services were available and what support they could provide, as well as the steps after a diagnosis.

- ***“The criteria was too confusing and there was too many which makes it harder to get help”***
- ***“I needed more information to explain what the diagnosis meant. I actually didn’t even know that he had a disability or the impact of it until years later when a NDIS worker picked up on it.”***
- ***“I didn’t know what an ENT was and that I could have accessed one at GWAHS the whole time.”***
- ***“Services should offer help if extra help is needed not just send me away. Like if you don’t have a certain document, offer ‘let me help you get that’.”***

# Individual Interviews – continued

## Exposure to existing programs and activities

Families were asked about their experience or exposure to existing programs or resources that are designed to provide information about children's development and where to go for help such as the Blue Book, Raising Children's Network Website, Love Play Talk Sing app. All families were familiar with the Blue Book but had not heard of the others. Some families stated they take the blue book with them to their GP appointments and for immunisations, however only one family mentioned utilising the developmental checks. One mother stated that she looked at the Blue Book for information about milestones which is where she first realised her son may have a speech delay. However, the interviewer noted that this information did not lead to the mother to seek support for this.

- ***"I knew about the blue book but I did not really use it except for when we go for immunization and they ask for it."***
- ***"I've only heard of the blue book, but I never looked through it apart from the kid's information at the front of the book. I sometimes took it to visits."***
- ***"Have heard of the blue book. I've read it and know they have different checks in there, but we haven't done them. I forget about them. I looked at it the other day for my 2-month-old to remind myself of the immunisations. I just use it for proof of birth and immunisation records."***
- ***"Bluebook checks – this is where I got connected for my son who had autism."***

Families indicated that the resources they accessed for information were typically people, their preschool educators, or therapists. A couple of the parents mentioned that they would use 'Google' or the internet to try and find answers, otherwise one parent acknowledged they don't have internet or smart devices so would rely on word of mouth for knowing what services are available.

Information that families would like more of greatly focused on the themes of knowing how to support a child's needs and how to know what supports are available. Families would like to know:

- ***"To know what a delay is. "I know my child has a delay but not what that actually means"***
- ***"How to support my child when they get angry and emotional really easily. What can I do and who can I go to about this?"***
- ***"How to support a child who is non verbal. I knew that I could possibly help to correct noises if they said them wrong, but there was no speech at all, just pointing. What to do here?"***

# Individual Interviews – continued

## Ideas for a new project to help families access information

Families were asked if there was a new resource or project developed to help families access information, what information should be included and how would they imagine this could best be provided.

The information that should be included echoed previous reflections:

- Knowing where to go for help or advice.
- What services exist and how to access them
- Activities they can do at home with their child particularly if there is a developmental delay.

In terms of how families wanted to access this information, there were different opinions presented based on the family's technology access and literacy levels.

A phone app:

- Three of the mothers identified that a phone app would be helpful so they could access information at home or when out and about.
- The app could have a search function to easily find local paediatricians, therapists, and services in the Mt Druitt area.
- Videos and pictures to give ideas of activities they could do with their children.
- Tips available to know who the 'point of call' was for certain concerns.
- A forum platform for parents to share their worries or concerns.
- Search platform for topics or services

Physical pamphlets or flyers:

- One mother suggested having physical pamphlets or flyers to advertise information and available services would catch her eye and assist her.
- There could be one big flyer with all different services, and then occasional flyers and posters on certain topics of support.
- These would be shared in mailboxes and hung up at local preschools, community centres and the shops.

The other two parents did not have specific ideas of a new idea, however both mentioned that in person options were easier for them to access information.

Themes that many mothers recognised would be important in any future project included having simple language, options for information available in other languages, visuals such as photos or videos rather than text, options for those who don't have technology access, and a range of information available.

# What do families think should happen next?

As to be expected in a broad community with diverse experiences, resources and needs, there is a wide range of information and support desired by families. Families had varying levels of confidence to seek out support themselves and varying levels of technological literacy and access to devices and internet. Any future initiative aiming to increase the health literacy of parents and carers in Mt Druitt must take a multifaceted approach to cover a range of areas as well as be accessible to those with and without technology access, and for those that English is a second language.

There was not one clear answer from the participants about how to increase parental health literacy. Ideas raised by participants about what could help Mt Druitt's families included:

- **Workshops** facilitated by allied health professionals to raise awareness of how to identify developmental delays, where to go for assistance, what support allied health professionals can provide, and teaching parents & caregivers various skills to build their capacity of how to support their child's development at home.
- **An app** that holds Mt Druitt specific information on available allied health services, milestone checkers, tip sheets on a range of topics, chat forums with other parents to share experiences, and information about how to access services such as NDIS and Medicare rebates.
- **Flyers** explaining various child milestones, how to identify delays, and information about available services to access help.
- Partnership with and **advertising information** at GP services through adding parental resources with the existing flyers and information in waiting rooms, as well as informing the GPs about what services may be available so they can inform the families.
- Increased individual support through '**Linker**' roles such as the Hive's Health Linker, which would be available at community and early education locations where families could walk in and request support for their specific situation. Support would include information, brokerage, advice, transport and referrals.
- A **Facebook Page** which provides content around services and parenting groups in the Mt Druitt area, as well as infographics, specific tips, guides and activity ideas to do at home with a child with a delay or disability.
- **Resource packs** that families can access with activities that families can use with their child who has a delay. These could be similar to a 'toy library' where families pick up resources from a community location and then return them, or could be similar to the Dolly Parton Imagination Library where they receive a new pack of ideas each month.

These ideas have been identified by local families and should therefore be strongly considered by The Hive and any organisation working in the Mt Druitt area or a similar community about how to increase parental health literacy. Additional consultation needs to be undertaken to understand the specific format and information to be provided on any of these new projects. The Hive thank the Mt Druitt families who have participated in these consultations for their input and sharing their personal stories.

# Acknowledgements

The Hive acknowledges that our staff live across many unceded Aboriginal lands, with The Hive engaged in deep work on Darug Country. We acknowledge the custodians whose knowledge, cultures and customs have nurtured, and continue to nurture land and peoples since the dreaming. We pay our respects to Elders, past and present and to all Aboriginal and Torres Strait Islander Peoples whom we work alongside. We endeavour to work together as one to strengthen local communities and we respect the cultures and traditions of all Aboriginal and Torres Strait Islander Peoples. We commit to the journey of reconciliation, admitting we may not always get it right, but approach the process with open and humble hearts, and the intention to do better.

Compiled by Laura Faraj (*Advocacy & Innovation Lead*)  
July 2023

**The Hive, Mt DrUITT**  
24 Anderson Ave,  
Blackett, NSW 2770  
<https://thehivemtdruitt.com.au/>  
[hive@unitedway.com.au](mailto:hive@unitedway.com.au)