

NDIS ECEI: Supporting young children and their families early, to reach their full potential.

Feedback from The Hive, Mt DrUITT

WHAT IS THE HIVE?

The Hive is the backbone organisation for the collective impact initiative 'Together in 2770' comprising of organisations and individuals who are working together in Mt DrUITT to ensure all children start school well. The Hive's backbone team coordinates the community development and early childhood focused work across the Mt DrUITT postcode. There are a range of partner organisations who work collaboratively with The Hive to achieve positive outcomes for children in our community. We believe that if we bring various parts of the system together, listen deeply to community concerns and work together on community and evidence informed solutions we can sustainably improve outcomes for disadvantaged children in this community. The Hive is guided in our early years work by evidence informed key intervention pathways for children aged 0-5 years alongside community voice to promote innovative and community focused solutions.

Our specific areas of work in helping children start school well includes:

- *The Check Ups Before School (CUBS) Program* to support access to developmental health checks and additional allied health services where required. The Hive also has a speech therapist two days a week on the program, and a 'Health Linker' who supports families to access their child's referrals, the NDIS and other family supports.
- *An Early Learning Linker Role* to support families to overcome barriers to access early education for their child. This includes working with families to seek information of early education options, navigating the childcare subsidy process, access birth certificates, provide brokerage support for bonds and any support to overcome any other barriers to support the family.
- *Quality training & professional development of early education centres.* The Hive have organized training for preschools in the 2770 postcode to provide opportunities for training and upskilling. The Hive have also established an Early Childhood Educators Network in collaboration with Western Sydney University for professional development and networking opportunities.
- *Community Development* work in the suburbs of Willmot, Lethbridge Park and Bidwill, to engage with families and work alongside local stakeholders to collaboratively support safe, healthy and child friendly communities for families to live in.

Our Involvement with NDIS ECEI:

There is a high proportion of children in the Mt DrUITT area with developmental delays or disabilities, with AEDC data reflecting 1 in 3 children are starting school classified as developmentally vulnerable on one or more domains. Our work with families through community engagement, linking to early education or through developmental health checks often demonstrates the harsh reality of these figures and the impact it has on children starting school well and their developmental outcomes. We regularly have contact with families who are already accessing the NDIS, require allied health for their children, or are eligible for the NDIS ECEI, and we often take the steps to support them to access the scheme.



Our CUBS Program has the most engagement with children eligible for ECEI through the identification of areas of developmental delays and we support families to access the relevant referrals which often includes the ECEI Scheme. We have found that the processes when they work, they work well for families. Unfortunately, our children and families are often experiencing vulnerabilities, disadvantage and complexities which mean there are additional barriers they must overcome or need assistance with to make this scheme accessible for them. We are grateful that the NDIS ECEI is reviewing its processes and are encouraged by some of the recommendations suggested particularly the increase in age and focus on supporting vulnerable families. We have outlined our experiences with families and the scheme and our thoughts to the recommendations in the report and hope these perspectives are received by the NDIS.

RESPONSES TO A SELECTION OF THE CONSULTATION QUESTIONS

4.1 GENERAL QUESTIONS

The proposed increase in age range for the EC Approach from under 7 to 9 years of age

We wholeheartedly support the proposed increase in the age maximum from 7 years of age to 9 years of age. We have repeatedly witnessed families struggle when their children are just getting settled into school and they are forced to lose their early intervention supports during this important transition time. This is an additional stressor to an already stressful period for families transitioning a child with disability or additional needs into the school environment. The additional benefit of this age increase is the fact that it gives time for the school, allied health supports and the family to have a clear, collaborative plan on how to support the child's needs in the home and school environment.

In our work with families and children, we have witnessed a high proportion of children with delays in certain areas of their development. Many of these children do not have a diagnosed disability, rather their families may have lacked the opportunities, health literacy or resources to be able to know how to support their child's development. Therefore, the child's need for allied health services or a possible disability is often only identified by the time the child starts Kindergarten, where they are close to the cut off age and only receive supports for a limited time, if at all due to extensive waitlists for services.

By making access to the NDIS ECEI easier for families and increasing the length of the available support, this would allow children to catch up to their peers, their parents to increase their own knowledge and skills, transition successfully into the primary school environment, and ultimately let some children transition out of the NDIS.

Examples of stories from our work with families to demonstrate the benefit of the age increase:

Family example 1 from Hive team member:

One family we worked with held their son back from school an additional year due to his speech and social skills delay giving him extra time to catch up while accessing supports through the NDIS, and therefore he was 6 years old when in Kindergarten. The mother called a member of The Hive stressed asking what would happen next year and I had to confirm the NDIS funded speech therapy he was receiving would cease as her son does not have a diagnosis. The mother was unable to afford to pay privately with the therapist her son had relationship with, and the local community health



speech therapists had an 18 month wait. The child's speech had improved so much already through 12 months of NDIS funded speech therapy, and with an additional year or two of schooling alongside speech therapy, he would be ready to transition out of the Scheme but at 7 years old, this was too soon.

Family example 2 from a local family caseworker:

I have recently been supporting a family with a child who was approved for ECEI NDIS support at age 6 and were then "transitioned" out from their funding at age 7. The family reported that they did not realise the funding would end so quickly and felt they did not realise they were eligible for funding until it was "too late". This left the family feeling anxious and stressed, as the funding was short-term and they did not feel as though they received clear information or pathways on both how to reapply for funding and/or how to continue accessing the support that their child still needed, such as speech therapy and OT. This family also felt that it was taking longer for their child to "achieve" the goals they had set out at the beginning phase of the funding. The support needed for the child, exceeded the funding arrangement, and did not allow enough time for the family to transitioning into other support. The family ended up having to wait 8 months on a waiting list to continue speech therapy and in the end felt that they could not remember the goals that they had set out to achieve in the beginnings of their ECEI funding.

4.2 SUPPORT WITH ACHIEVING GOALS

What is the best way for us to check in with families and carers on how their child is tracking to meet the goals of their child?

A recurring theme we hear from families is that they do not feel supported by their Early Childhood Coordinator and they often feel lost in the process and are not sure where they can go to ask questions. We have often been contacted to support parents to connect to the NDIS, explain their plan to them and connect their child to their supports. We have seen families not accessing the required and funded supports as they do not know where to find available services, what questions to ask, or how to overcome barriers such as transport to their early childhood partners.

We have also heard from residents that the 'goal conversations' often felt rushed and families did not know where to start in attempting to achieve them. Residents often feel that there is minimal follow up to support the day-to-day achievement of these goals, or support to access the appropriate supports throughout their plan.

When we have prompted families about their plan coordinators, they have stated they do not know who they are as their coordinator is often inconsistent and changing as staff regularly move on from the organisation, they do not know how to contact them, what their role is, or do not feel confident that they could contact them for support or information.

One family stated:

"I reckon I could never get in touch with support when I needed it most and it kind of made me give up trying to ask for it. But in the end, I didn't really know what I was doing with the funding."

Plan coordinators have an important job in introducing families to the scheme and their plan, however it appears the experience is inconsistent and often not enough support is provided. If there



was to be a review of how to support families and carers throughout their child's plan, the following would be advised:

- Increase the amount of contact families have with their NDIS ECEI coordinator. Rather than yearly reviews, a coordinator could check in with families monthly at the start of the plan to ensure the family is connecting their child to relevant supports, and then perhaps quarterly or six-monthly meetings to review the goals and provide advice if the child is not on track with their goals.
- Ensure where possible that families have consistent ECEI workers so the families can build trust and be clear of who they can contact for further support and their ECEI coordinator would therefore know the family and can work with them to track their child's goals and offer additional support when needed.
- A relational and flexible approach to these more regular check ins would be of greater support to families, and they would feel more comfortable to ask questions if there was a trusted relationship.
- Have multiple options of how coordinators could contact the family to check in. Vulnerable families often have experienced negative interactions with services and can often result in appearing 'distant' or 'disengaged' by not answering calls from unknown numbers or may not reply to emails where perhaps this is not as accessible. We have found having the flexibility to text, not call from private numbers, conduct home visits, send letters and emails have been helpful for families and increased engagement.
- Increase contact and check ins with families that are experiencing disadvantage or vulnerabilities, being aware that they may be experiencing additional challenges or complexities which may then impact their capacity to support their child access their supports. We have met families that have not used their child's funding because they have been focused on other concerns such as domestic violence, housing instability or financial stress. This is understandable, however not accessing their supports will impact their child's ability to reach their goals, and increased contact and support for families could reduce this.
- Utilize visual or interactive tools when discussing goals with families as this could support some families with low literacy, or who are new to the NDIS process understand the goals and next steps easier.

Would a mandatory early childhood provider report developed between families and their provider be useful for tracking against their goals?

We believe families require deeper communication from their child's early childhood provider about their child's progress and how they can support the child in the home environment. Families have reported to us that they 'think' their child is improving their skills or they 'think' the therapy is working but they often do not understand what is happening in therapy or how to notice the change. This is particularly prevalent in situations where children are receiving their therapy or supports without the parent present such as in a childcare setting or closed therapy setting. We are aware that early childhood providers have inconsistent engagement with families, and it may rely on proactive and family focused providers to provide this information and support to families, however this means some families miss out if they do not have these proactive providers.

With these reflections in mind, we believe that having a mandatory early childhood provider report developed collaboratively with families could be incredibly beneficial in terms of increasing family



understanding of the service, offering opportunities for families to ask questions and help them understand their child's progress towards the set goals which could then assist with their annual planning meetings with their ECEI Coordinator. This process could also build trust and relationship with families over time and ensure they are involved in their child's development.

How can we better support families to connect with services that are either funded or available to everyone in the community?

As mentioned above, consistency is incredibly important when working with families for multiple reasons, including building trust and building a deeper understanding of the family's needs and context. We have found the biggest need for families when receiving an NDIS plan is knowing what to do next in terms of connecting to allied health providers or other supports. We are led to understand that this is what ECEI coordinators are meant to do, or could at least connect to a support coordinator, however this rarely happens and can result in families not accessing required supports.

We believe ECEI coordinators should not just assist families to access a plan, they need to also understand a family's needs and assist them to research and connect with the required services. Vulnerable families require an increase in information and support to know the supports they are eligible for, what is nearby in their area, how to find out waitlist times, and how to be aware of various service delivery options. E.g., At a clinic, in their community, at their home or at their child's early learning centre. We are not caseworkers or support coordinators for the NDIS, but too often we are approached by families to assist them in reviewing their plan, researching allied health providers, and calling to book them in. We are aware that this task is often falling to early educators, community workers or other services, as the gap in support after receiving the plan to accessing services is too great.

A member of The Hive team is also an educational leader at a local preschool, and she reflects the following:

"I find that not all ECEI coordinators are the same. I suppose it is ideal that the coordinators do support families by connecting them to relevant allied health providers, but this has not been the case. As the educational leader from a preschool, I have found myself connecting families to allied health. We even opened a clinic within the preschool just to support NDIS children attending our preschool. However, it can be tricky when the children are about to go to primary school, because then families will have to find new providers. There are a lot of services, but the waiting list can be quite long. I believe that the coordinators must be supporting families to find what is available so there is a smoother transition for children."

Many families we have worked with that have NDIS ECEI engagement are experiencing disadvantage and may not have an existing caseworker or family supports. The ECEI coordinator may be the first service that the family have engagement with and therefore have an opportunity to connect a family to wider supports. This could be done by:

- Increasing the on the ground engagement by local staff with local services to understand what supports are available to families at a local level, not just at a broad LGA level. We are aware of community of practice meetings that occur however this is not for staff that have contact with families, and often missing local level services that provide casework or family support.



- Include screening or assessment for vulnerabilities or complexities in the intake process to know early on if families require additional supports. This could allow for the coordinator to also ensure that families are connected to supports. If the family is connected to supports, then they will be in a greater space to support their child.
- Have support for families funded in the child's NDIS plan if there are broader complexities known.
- Have Support Coordinator roles for all families who have certain vulnerabilities or risk factors to support families to connect with services in their local area and ensure they are sustainable to access. E.g., Accessible by public transport

4.3 TARGETED SUPPORT

How can we better reach and get support to young children and families who experience vulnerability and remove barriers so they can receive outcomes in line with other children and families?

The 2770 postcode has a high proportion of vulnerable children, Aboriginal children, and children with additional needs. These children typically have a higher representation of developmental delays and therefore should be a priority to early intervention services through the NDIS to help their children thrive. Our suggestions for improving support to these children include:

- Partner deeper with local services who can identify vulnerable children who would benefit from the NDIS and may fall through the cracks otherwise. For example, educating NSW Health child and family health nurses and early educators about the scheme and how to support families to access. We have had multiple conversations with nurses, early educators and teachers who have had incorrect understandings of the scheme, particularly about eligibility and belief a diagnosis is required. These services also know the issues and barriers facing local families and could help partner with coordinators to support families holistically.
- Embed local area coordinators or NDIS community engagement workers within local suburbs, early childhood centres and community centres in areas of disadvantage to increase accessibility of the scheme and information to families.
- Include screening or assessment for vulnerabilities or complexities in the intake process to know early on if families require additional supports. This could allow for the coordinator to also ensure that families are connected to supports.
- Embed family support workers into the assessment process to help families link to other supports in their community. These workers would be focused on the parents rather than just the child where the NDIS funds are typically allocated. A holistic lens is essential for supporting vulnerable families, and for the child to receive the best outcomes, support must also be considered for the parents and carers to ensure they are equipped to support their child's development at home.
- Ensure approaches by coordinators and ECEI process are culturally appropriate and accessible for Aboriginal families and other culturally diverse families.
- Have transport available in the child's package for vulnerable families. We have been informed that this could not be included in the child's plan as it is considered the 'parent's responsibility'. This approach is not equitable for vulnerable families where there is no available transport, and where the children are often in the most need. This is an area that we regularly must go beyond our scope to ensure children and families can access services.



- Encourage or create incentives for allied health services to be embedded within local spaces that are accessible for families including early education centres, community centres, family homes and schools. As mentioned above transport is one of the largest barriers for our children. There are many early education centres and community centres who are desperate for allied health to be available locally, so services are willing, and families are desperate for access and this is therefore an easy way to increase supports for vulnerable children.
- Have a consideration for families with younger children who are not on the scheme and how this could be impacted in service's funding. We supported a single mother who had two young children, one of whom was on the scheme and one who was not. The mother did not have a car and access to services was therefore difficult due to the child's high behavioral needs. We were able to find a service that offered transport for the child and the mother, however, was unable to transport the younger sibling that was not on the scheme. This family was incredibly vulnerable, and the supports were desperately required for the child however this was a barrier that could not be removed.
- Increase the frequency of check in's and reviews to get updates from the family, ensure they understand and ensure they are accessing the required supports and provide an opportunity for the family to ask questions.

GENERAL FEEDBACK/OTHER AREAS FOR CONSIDERATION:

- The long wait times to obtain an NDIS assessment and access to a NDIS plan are often extensive and at such an important time in a child's development everyday counts. I was once informed through the LifeStart provider, there was a 3 month wait to get an access assessment, and then a further 4 months to get a plan. When there are also long waitlists for allied health services to access necessary supports, this process is far too long and exhausting for families.
- There is a lack of support for the parents/carers in the NDIS funded supports, and we believe this is an overlooked yet important area particularly for vulnerable families where a holistic view needs to be upheld. There should be supports for parent educators/families support services such as Zest Care, where parents and carers are equipped to support their child's needs at home.
- These supports seem to exist in the NDIS funding packages (Key Worker); however, we have repeatedly attempted to advocate for these for very vulnerable families and they have never been approved.

FINAL WORDS:

The Hive is grateful to be able to share our learnings and experiences on behalf of families and our partner casework organisation with the NDIS as part of this review. We are encouraged by the themes that are emerging around support for vulnerable families and the increase in age as we recognize the benefits of these for our vulnerable children. The Hive would be willing to engage in any further conversations around the NDIS ECEI and continue to share our learnings from the Mt Drutt area.

If you have any questions about what we have shared here, please contact Laura Faraj at laura.faraj@unitedway.com.au

