



## SUPPORT PATHWAYS FOR CHILDREN WITH DISABILITY IN NSW

### WORKSHOP 18 SEPTEMBER 2024

A workshop with community-based service providers across the early childhood and disability sectors

NSW Department of  
Communities and Justice

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## Introduction to the Workshop

### This report

This report is an account of the *Support Pathways for Children with Disability in NSW* workshop held on 18 September 2024 at the National Centre for Indigenous Excellence (NCIE). Representatives of services from across the early childhood and disability sectors were invited to share their experiences and suggestions for an enhanced disability ecosystem.

The face-to-face interactive workshop was co-facilitated by:

- The Department of Communities and Justice, represented by Anne Campbell, Deputy Secretary and Zoe Dendle, Executive Director, of the Strategy, Policy and Commissioning division.
- National Disability Services (NDS), represented by Lesley Patton, Sector Development and Support Consultant, and
- The Child and Family Supports Alliance NSW (CaFSA), represented by the co-chairs Stacey Touma, CEO of Kindred and Morgan Fitzpatrick, CEO of Koorana.

Participants included members of the National Disability Service and CaFSA, the Early Childhood Intervention Best Practice Network, as well as organisations delivering the Partners in the Community program in NSW, including the Early Childhood Partners and Local Area Coordinators.

### Welcome and Acknowledgement of Country

Grant Cameron, CEO of the NCIE welcomed participants to the venue and delivered an Acknowledgement of Country. He provided a comprehensive account of the services and initiatives the Centre provided for the local community of Redfern and its surrounds. In particular, the NCIE delivers service to Aboriginal children and young people to build their skills, confidence and social connection. Many of the initiatives focus on connecting young people to Elders and transmitting culture across the generations. He introduced Nathan who manages the facilities gym. Nathan expressed his gratitude for the positive mentorship provided by the NCIE and illustrated how it has helped him establish a strong future path. Many participants said this established a positive and productive frame to the day.

### Purpose of the Day

Anne Campbell, Deputy Secretary explained that the workshop was intended as one component within a suite of consultations across the sector to explore future support pathways for children with disability in NSW. In July 2024 DCJ co-hosted an online workshop with NDS which many participants had also attended. A follow-up to this workshop will be planned later in 2024.

The primary purpose of the day was to:

- Better understand how the current service system operates for children and families in NSW
- Hear from service providers about the current challenges and opportunities, and
- Continue to build relationships and collaboration between NSW Government and the sector.

### Context

Morgan Fitzpatrick introduced the Child and Family Support Alliance (CaFSA) NSW as a collaborative body of leaders from NSW's mainstream and specialist community-based and not-for-profit sectors, including national parenting support services.

CaFSA was established to advocate for, design and implement foundational supports tailored for children with developmental differences and their families. In May 2024 the group convened a Roundtable to identify principles and priority areas essential for developing an effective disability support system. Following that, CaFSA released a Position Paper and convened a subsequent Roundtable at Parliament House in August 2024 which was attended by counterparts from other jurisdictions. Minister Shorten (Minister for the National Disability Insurance System) and Bruce Bonahady (head of the 2023 NDIS Review) also presented their vision for the disability ecosystem.

Morgan explained that the headline theme arising from the Canberra Roundtable was the need for 'national equity' - a concept which goes beyond national consistency and recognises the importance of local flexibility and fairness. She announced that the Australian Child and Family Support Alliance (ACaFSA) had since been established with membership from all Australian jurisdictions to progress CaFSA's agenda on a national scale.

Lesley Patton introduced the National Disability Services (NDS) as Australia's peak body for disability service organisations, representing more than 1000 service providers across the country. NDS has a broader scope than CaFSA focusing on people with disability of all ages, which includes children and their families. They work collaboratively with their members to drive innovation, support change and explore ways to improve the sector.

## Journey Mapping

The workshop was framed around three separate Family Stories that reflected the types of circumstances experienced by the families of children with disability.

In small groups, participants considered how the family might engage with different services and supports under the *current* system. They discussed the key challenges and barriers the family might experience and identified the strengths and enablers in the current system.

### Sammy

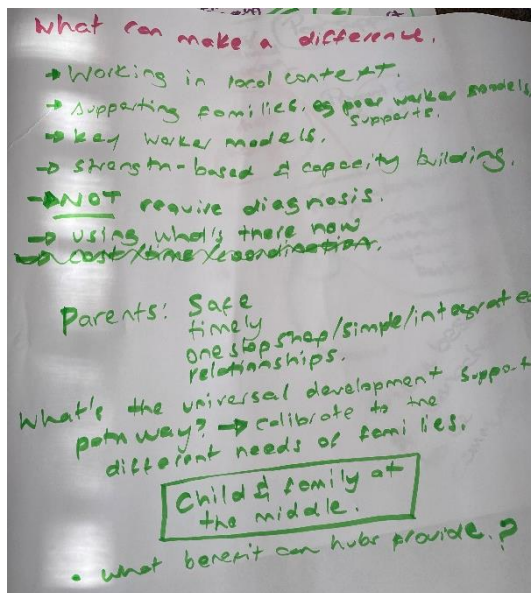
*Sammy is 24 months old and is described as a happy, healthy child. He is meeting all of his gross and fine motor milestones. His emotional and social skills are developing largely typically, although he has been prone to biting other children at day care and hitting.*

*Despite support from his educators, this behaviour is becoming increasingly common with at least one occurrence a day. In terms of language development, he has a vocabulary of approximately 5 words that he uses regularly, but has not advanced beyond that point.*

*He uses non-verbal gestures such as pointing, waving and shaking his head to communicate otherwise. His day care educators have suggested to his parents that his language is behind his peers. His parents are unsure where to go next.*

The group made the following observations:

- Sammy requires both physical assessments and testing by a GP or other health professional.
- There would also need to be a broader assessment of his family situation, including their cultural background, their visa status and associated eligibilities or any other hardships.
- This might reveal the need for inclusion support, which can be provided through early childhood education and care.
- The parents may also benefit from capacity building, or connection to a peer worker program.



- If this suite of services were provided together they might help guard against social isolation.
- But the services Sammy requires are not currently connected to one another and might send the family onto conflicting pathways. For example, he might be channelled into an NDIS pathway depending on assessment of his speech and hearing, which might divert the family away from localised supports.
- Under the current system his family would likely have to tell their story to multiple providers.
- This is likely to be expressed in a 'what's wrong' narrative, which is unlikely to be

empowering for the family.

- The family should not have to wait for a diagnosis to access supports, but in the current system they are likely to face significant waits and may have to travel multiple distinct pathways.
- Sammy's experience could be improved if his family was placed at the centre of his support, with a Key Worker to assist them to navigate the ecosystem and build family capacity to advocate for their needs.

## Georgina

Georgina was born full term at 41 weeks 3 days. Her development was considered typical in her first year, progressing to sitting independently at 6 months and crawling at 8 months. She presented as a happy, healthy baby, although she did have some sleep challenges that continued into her first year of life.

At 16 months, she was not able to stand independently, cruise with support, and was not yet saying more than a handful of words and sounds. Her parents began seeing a private speech therapist, and a physio through the public health system, but little improvement was seen. Georgina had ongoing issues with gastric emptying and constipation.

At 18 months, Georgina began having seizures in which she would lose full consciousness. They began seeing paediatric neurologists who completed a series of medication trials, an MRI and have ordered genetic testing. They have just received the results of the genetic testing indicating Georgina has a genetic condition that will affect her development. Her parents are now evaluating where to get support.

The group made the following observations:

- Georgina's family have already been connected to a number of services and are seeking specialist support through a paediatric neurologist.



- They could have arrived there through multiple pathways- such as a GP or Community Child and Family Health. Where the family enters the ecosystem will greatly impact where they are referred and the associated outcomes.
- Specialists will work with the family from a very specific focus, and the family may not have access to broader support.
- They need assistance to help them understand what interventions and supports to expect, where they can go for more assistance and what is available to them at various stages.
- Because Georgina is on a medical pathway, the family are likely to face challenges such as being on wait lists, referrals to fee-for-service providers and Medicare restrictions.
- The public and community-based systems are quite siloed, so there may be the assumption that Georgina's family are already under the other system's care. One way to address that is to establish partnerships between community-based providers and the public health system/hospitals.
- Georgina's family might have benefited from some informed and connected pre-natal touchpoints. This could come from a GP or midwife, but might also be an Elder in community or someone else with similar experiences of disability or family adversity (such as Domestic and Family Violence or Substance Abuse).

- UNSUSTAINABLE.  
 - ASSUMING THERE IS CONNECTION AMONG SERVICES.  
 - PARTNER IN HEALTH/HOSPITAL TO DIRECT TO A SERVICE - GET PEER SUPPORT - MEET OTHER FAMILIES.  
 INTEGRATED COMMUNITY HUB  
 - NO COMMUNITY GATHERING, ECOSYSTEM WHERE FIND ALL TYPES OF SUPPORT  
 - FUNDING GAPS IN THE WHOLE SYSTEM.  
 - DEPENDS ON WHERE THEY ENTER THE SYSTEM - THAT WILL DETERMINE WHERE THEY ARE REFERRED.  
 - NO CONTINUITY OF TRANSLATORS ETC - SO CONFUSING  
 - REFUGEES OFTEN IN RURAL + IF NO VISA THEN HAVE TO PAY FOR ALL PUBLIC SERVICES.

## Alicia and Matt

Alicia and Matt are pregnant with their first child. During routine antenatal screening, they elected to have the Harmony test and have been given advice that their child has a genetic condition. It is not clear, and will not be until after birth, what impacts will be experienced.

Alicia and Matt are unsure what support exists now during the antenatal period to prepare them.

The group made the following observations:

- Pre + ante natal journeys can be very different.  
 - Medical model. Stays in the health space. Referrals to orgs + supports in community rare.  
 - Current model delays involvement with support groups + orgs  
 - Recognising the family unit. Relationship between parents and with their child under pressure. Mental health risks Potential to isolate even further.

- Alicia and Matt are already on a positive track by having access to prenatal genetic testing.
- They may have received this information through their family or cultural networks, or through a GP or child and family nurse.
- Some families may be isolated from this type of support or information- so it becomes important who 'sees' the families and their baby before and after birth.
- Families may experience appropriate support while they are in hospital, but there may not be adequate referral or continuity of care.
- If the baby is identified as potentially having a disability, they may be channelled towards an NDIS pathway from the outset, which is focused on deficit.
- The NDIS pathway was described as a more transactional model, which might silo the family away from 'soft' community-based supports (such as playgroups).

- Around the time of birth families may face mental health risks and relationships may be under pressure.
- A medical pathway can delay other forms of social supports, so families need to have the capacity and emotional resources to advocate for their child.

## Report back and discussion

The groups identified a number of issues that were common across all the family stories.

### Challenges and barriers in the current system

- Siloed systems make it difficult to create a seamless support pathway for families. Services are all funded differently and don't always 'speak the same language'.
- Not everyone has access to the same level of information:
  - Families struggle to access relevant, succinct and targeted information when they need it. This is compounded when there are language and literacy challenges, family hardship and geographic barriers.
  - Services do not have a comprehensive list of services available in their area, or visibility of what is being delivered by other providers.
- Families are encouraged to consider individualised NDIS packages to be the most desired type of support.
- However, they may face significant costs associated with accessing the NDIS with no guarantee of receiving a package. These include:
  - Time spent on waitlists costs the family time in which they could be receiving targeted and effective service
  - Assessments and intervention through the private market
  - Travel and accommodation costs for families who live outside of metropolitan areas
  - Financial hardship and cost of living, especially where families do not get support to navigate the system or who don't have systems literacy.
- If a family is not eligible to be an NDIS participant they may struggle to find timely and quality information and support. The time spent pursuing a diagnosis for NDIS may result in lost opportunity for the child to receive other supports suitable to their needs and functioning.
- Families become fatigued by having to repeatedly tell their story and reach out to multiple services.

### Strengths and enablers in the current system

- There is significant expertise and good will in the existing sector.
- Local services can develop a good knowledge of the families they are working with and develop their trust.
- Where there is a clear diagnosis or assessment, a child and their family can usually get the treatment that they need (especially through health pathways).
- Key Workers and Support Co-ordinators do exist in some areas, usually in the form of social workers and child and family nurses.
- There are strong peer and advocacy organisations that can assist with specific disabilities.

### Opportunities in the current system

- The above strengths can be leveraged in a renewed disability ecosystem.

- Families often have good outcomes once they are inside a government-funded system, especially the NDIS or NSW Health. Pathways into those systems could be improved for those who would benefit most from intensive supports and/or the medical model of support.
- A community-based sector could flourish if their expertise and independence is recognised. The sector would not be perceived as filling a gap, or a stepping stone into NDIS, but rather as a preferred or priority model.
- Changes to funding models (in both the government and non-government sectors) could minimise the siloed nature of service delivery and facilitate professional connection.
- Place-based and Interagency forums could provide an opportunity for sharing of information (such as waitlists), professional insights, data and trends analysis. This could improve outcomes for families by streamlining referrals and providing timely updates.
- The current workforce is skilled and experienced, but face system limitations. There needs to be incentives to recognise and retain existing workforce and build upon it to meet anticipated demand.
- There is much to be learnt from models that have worked in the past. There are many examples of models and programs that were discontinued that could be reviewed and revived and others that could be expanded.



## Applying principles in practice

CaFSA members recommend a systems-wide, principles-based approach to reform of the disability ecosystem. This was expressed in their July 2024 position paper as a series of principles.

### Key Principles for Foundational Supports Design

CaFSA recommends a system-wide approach to Foundational Supports for young children and their families that incorporates the following key principles:

**1. Utilisation of Existing NSW and National Services:**

Recognise and leverage the deep experience and collaboration within the current service system to prevent duplication and fragmentation.

**2. Seamless Integration:** Ensure that Foundational Supports are seamlessly integrated into early childhood services, avoiding silos of support.

**3. Timely Early Intervention and Early Childhood Intervention:**

Prioritise early intervention and early childhood intervention strategies and services, particularly focusing on the critical first 2,000 days of a child's life, to enhance developmental outcomes and build the capacity of families to support their children.

**4. Ease of Navigation and Accessibility:**

Implement a community-based navigator role that is codesigned with CaFSA and other stakeholders to meet the unique needs of children and their families. This role will facilitate entry points and connections in trusted place-based community-based settings, simplifying the navigation process for families, particularly those deterred by the complexity of the existing NDIS systems that have been designed for adults.

**5. Peer and Parent-Led Initiatives:**

Increase support for peer work and parent-led organisations, recognising the value of lived experience and direct family involvement in service design and delivery.

**6. Equitable Service Model:**

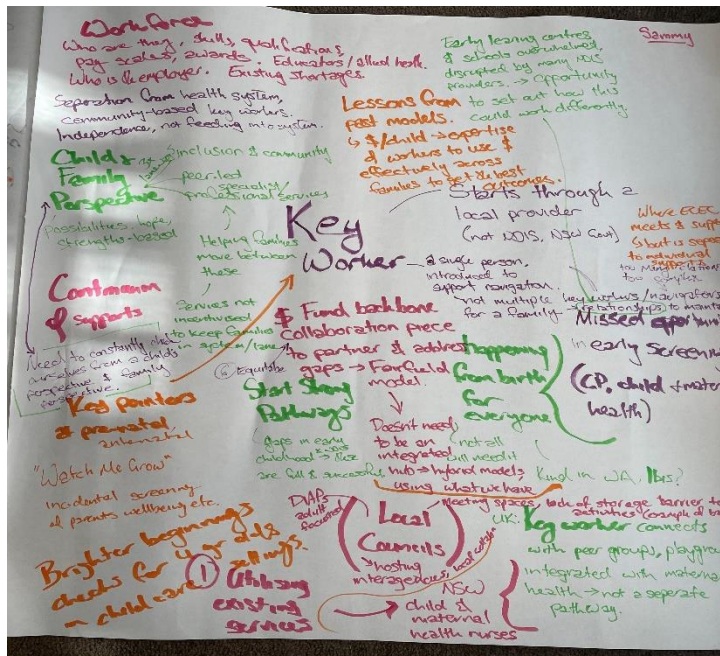
Prioritise a state-based, block-funded not-for-profit service model that promotes collaborative place-based approaches, ensuring equitable access and integrating services across educational, health, and social sectors.

The following activity asked participants to consider how those principles might be applied in the context of their Family Story. They were encouraged to think about practical implementation of the principles.

Groups approached this task through a holistic lens, noting that many of the principles were most impactful when considered together. Many participants noted that the principles were complementary to one another and could not be considered in isolation. For example, effective implementation of one principle may be dependent on other principles. Similarly, strong delivery of another principle might provide the uplift required to effectively implement another principle(s).

## Sammy

The group made the following observations:



- A Key Worker would be central to supporting Sammy and his family to access and navigate through a complex ecosystem.
- Sammy could be connected to a single local provider who can co-ordinate the support and connect the family to a range of other supports.
- The Key Worker could also connect Sammy's family to other families.
- Social connection is important for promoting childhood play and 'honouring the child voice', so that children like Sammy don't miss out on a healthy, happy childhood.
- The key worker could be empowered through a backbone collaboration model that encourages local services to collaborate to

address gaps.

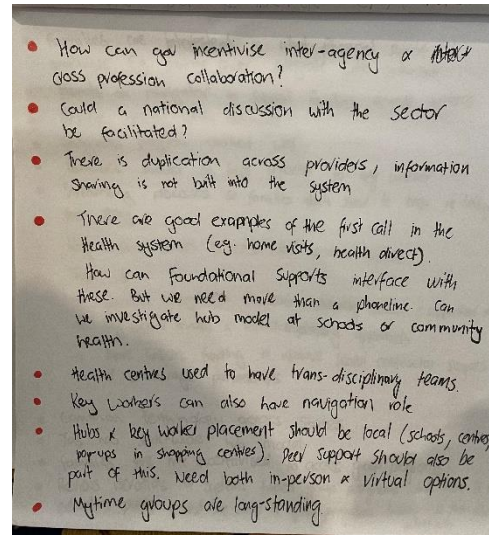
- There are many different models for integrated service delivery. These might be a combination of integrated hubs, peer groups or playgroups.
- Each should be adapted to the local context, depending on services available and infrastructure.
- A key worker, operating in a place-based local context, could provide continuity for the family. Currently services are not incentivised to keep families in the system.
- A universal early screening model would identify children with disability or delay as early as possible, so that families can be connected as soon as possible, even at birth.
- This could be complemented by incidental screening of parent wellbeing to ensure the family has their own support and capacity.
- There may need to be some workforce enhancement as there are existing shortages. But that also requires consideration of skills, qualifications and pay scales and awards.

## Georgina

The group made the following observations:

- Georgina's family would benefit from access to a single, trusted point of contact who can take their story. That intake worker can then recommend a specialist Key Worker or Navigator who will work with the family's specific needs and co-ordinate their journey.
- The absence of a centralised repository of services is a challenge for anyone trying to connect a family into a range of supports.

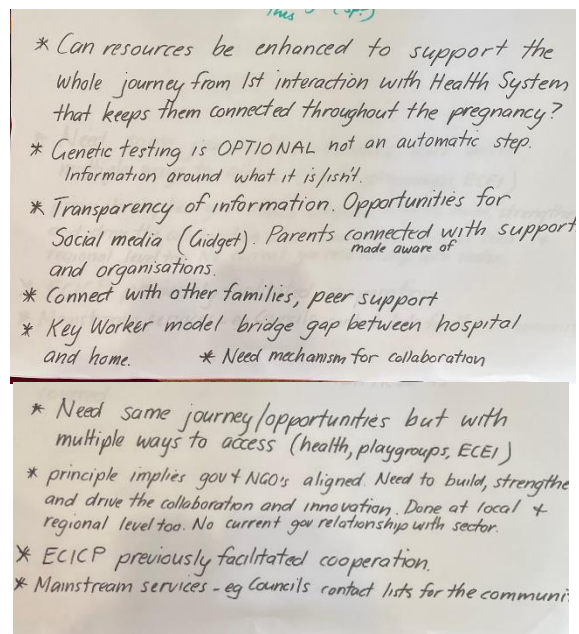
- Information sharing is not built into the system, resulting in duplication across providers.
- Collaboration could be greatly enhanced through integrated databases of both national and local supports, and incentives for providers to work together.
- One model of collaboration that has worked in the past is place-based interagency forums which include both government and non-government providers. These should also be multi-disciplinary.
- Many funding contracts restrict the making of recommendations to specific services. This sometimes places the onus on families to compare and select providers without a good knowledge base.
- Georgina's family could benefit from capacity-building to help them advocate for themselves and make independent decisions. This could also be in the form of systems-literacy.
- Some families will benefit from online resourcing or serviced inquiry lines, but others will need home visiting or more personalised services.
- Hubs and other integrated service models need to be genuinely accessible by families- such as in schools, health care centres and even pop-ups in shopping centres.



### Alicia and Matt

The group made the following observations:

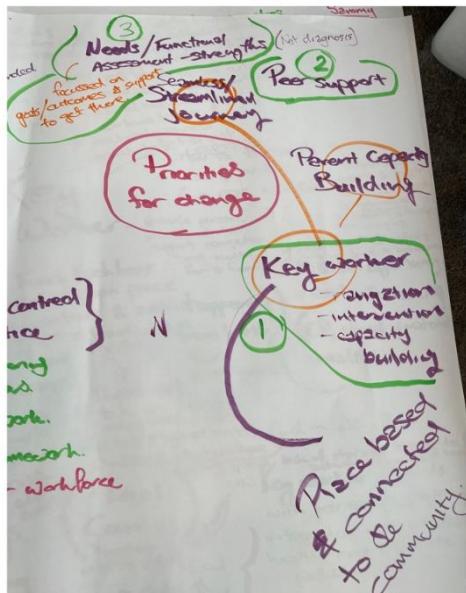
- Seeking support during pregnancy is an opportunity to engage a range of supports early.
- Scans at 12 and 20 weeks are the key touchpoints for the health service to provide transparent information and connection to supports and services.
- As NSW Health is the common agency at pregnancy, they can have an early co-ordination role.
- Under the current system there is no mechanism for collaboration across the health and community-based support systems.
- A Key Worker can ensure continuity of support, and act as a bridge between hospital and home. They can also connect the family with peer support and other families to build social connection.
- The family needs the same opportunities regardless of how they access the ecosystem. It can be especially confusing for culturally and linguistically diverse and Indigenous families.
- This requires better collaboration between government and non-government services (such as playgroups and ECEI providers) and connection into existing information sources such as Local Councils.





## Three key areas for change

At the end of the session, groups were asked to nominate three key initiatives government could undertake to activate the principles and positively change the disability ecosystem.



### Sammy

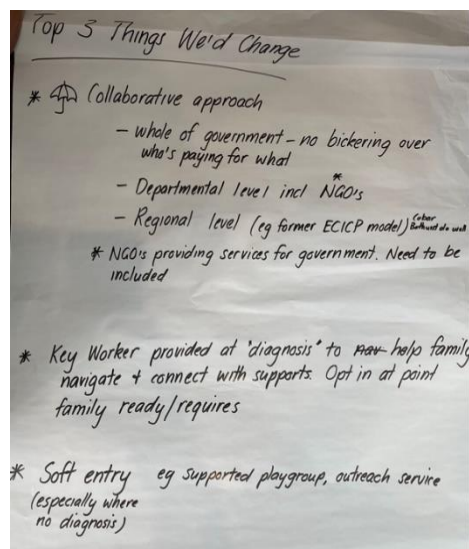
- Establish a **Key Worker** role that provides both navigation and intervention. If properly resourced, this role could both build parent capacity to make decisions independently and provide the best care for their child, as well as streamline their journey through assessment and beyond.
- A **Peer Support** model aligns with the concept that a Key Worker should be place-based and connected to the community.
- Children are **assessed** based on their needs and their functioning, rather than a diagnosis. This would be a strengths-based model, rather than a deficit-model, and would be focused on achieving outcomes.

### Georgina

- **Simplify the system** to minimise the 'bounce around' for both families and service providers. This might be achieved by a funding model that does not centre on billable items and is less restrictive about the services that can be provided. This would provide an opportunity to deliver wholistic services to a family and meet them 'where they're at'.
- **Build the capacity of the infrastructure** to facilitate more timely and focused referrals. This could include data integration, transdisciplinary hubs, co-location and flexible delivery options (including in-person, online and outreach).
- **Incentivise partnerships when funding services** so there is greater collaboration across disciplines and services can amplify what they are able to offer to families.

- Families are interested in what financial support is available. Eg. savings funds, integrate with Centrelink
- Hands on navigator to support families across systems
- Flexible delivery within outcomes
- Familylinks program worked well
- Families should go from referral to key worker
- Streamlining processes so families don't need to keep re-telling their story
- Key workers should be embedded across sectors
- Top 3
  - ➔ Seamless integration in terms of streamlining access & supported
  - ➔ Key worker model & interdisciplinary approach
  - ➔ More holistic funding to remove siloed contractor sequences & encourage partnerships
- Common terminology across states
- Tas has state-wide hub model
- Families are not incentivised to access group programs
- Previous iterations of systems funded group programs but there is an education piece about the value of group programs. Invisage is an existing program

## Alicia and Matt



- A **collaborative approach** would need to occur at all levels of government and be inclusive of non-government organisations. This would be more than just working together, it would need to be genuine commitment to finding solutions, rather than enforcing funding boundaries.
- A **Key Worker** is available for families when they are ready and/or when they are required. This may mean pre-natally when a family becomes aware of potential disability or delay. The key worker can assist them to navigate and connect with supports.
- Provide **soft entry points** for families to access supports, especially where there has been no diagnosis or confirmation of functioning or need. This might be supported playgroups or outreach services.

## Close and Next Steps

### Update from the Cabinet Office

Shenuka Wraight, Director Disability Reform with the Cabinet Office introduced the work her team is undertaking to progress the development of new systems within the disability ecosystem. She explained that they have been tasked to work collaboratively with DCJ, Health, Education and other NSW Government partners to better understand the context of disability reform.

A key component is a rapid service mapping project to gain a deeper understanding of the disability service sector. The intention of this work is to achieve a clearer picture of the current service landscape in NSW to understand where opportunities and gaps exist across the state. Work to date had been focused on the services provided or directly funded by government agencies, and this workshop has provided valuable insights into the non-government service sector.

The Cabinet Office would appreciate continuing the discussion with any interested service providers especially relating to:

- Locations where early childhood services are provided (such as metropolitan, rural, regional and remote)
- The broad types of services that are provided, and
- Utilisation of services by children and their families.

The Cabinet Office is also undertaking a rapid evidence scan and workforce analysis which will complement the service mapping work. They will send an email to all participants outlining these insights and data gathering exercises and information about how they can inform this work.

### Further consultation

The Commonwealth Department of Social Services (DSS) are also opening consultation on General Foundational Supports, which includes information, advice and capacity building supports. They are hosting an introductory webinar on 20 September 2024.

DSS will be conducting some face-to-face consultation in NSW, however those dates have not yet been confirmed. Participants can register for the webinar and find out more about the Commonwealth communication strategy through the DSS Engage website ([www.engage.dss.gov.au/foundational-supports/](http://www.engage.dss.gov.au/foundational-supports/)).

### Thankyou for Participation

Thankyou to all participants who generously shared their expertise and experience. Thankyou also to other NSW government representatives who participated on the day:

- Matthew Barden, Director, Disability Policy and Reform, DCJ
- Shenuka Wraight, Director, Disability Reform, NSW Cabinet Office
- Kristie Brown, Director, Access and Inclusion ECEC Department of Education
- Sarah Morton Director, Disability, Youth and Paediatric Health from NSW Health
- Steffanie, Manager, Disability Reform, DCJ
- Chloe Duncan, Assistant Director, Disability Reform, NSW Cabinet Office