

# Response to NDIS Consultation paper

# Supporting young children and their families early, to reach their full potential

Brotherhood of St. Laurence
February 2021

Brotherhood of St Laurence 67 Brunswick Street Fitzroy Vic. 3065

ABN 24 603 467 024

Ph. (03) 9483 1183

www.bsl.org.au

For further information or to discuss this submission, please contact:

#### **Prof. Shelley Mallett**

Director, Research and Policy Centre Brotherhood of St. Laurence Email: smallett@bsl.org.au

Ph. 0438 022 985

#### **Mr Rodney Weston**

Director, NDIS Services Brotherhood of St. Laurence Email: rweston@bsl.org.au

Ph. 0419 299 874

# **Summary**

The NDIS review of the Early Childhood Early Intervention (ECEI) Approach aims to ensure a better experience for young children and their families. The recommendations for a reset, developed with sector consultation, and the opportunities for input into the aims and recommendations of the reset have been welcomed by Brotherhood of St. Laurence (BSL) staff.

BSL fully supports 17 of the 23 recommendations. For these, we have made some specific observations, including the need to build Early Childhood partner capacity through a workforce strategy and resourcing to ensure successful implementation. BSL partially supports, or supports in principle, another five recommendations, with our reasons included in this response.

• We do not support recommendation 9 overall, due to limited information about such a significant change to key processes for young children, though we see merit in some elements of the recommendation. The issue of independent assessments has raised concerns for participants and their families, and services. It is not yet clear what is proposed for access and planning but there is support for a comprehensive assessment including observation, use of standardised tools and consideration of family capability and circumstances, but concerns about use of the results to inform access and planning decisions including budgets.

BSL suggests the concept of 'a plan for all' using NDIS Early Childhood Services. Such a plan would support a better experience for participants and families, as it could be used differently as needs change. A plan might or might not include funded supports, and could minimise the concept of transition as the plan would apply before, during and after their provision.

BSL welcomes the opportunity to continue to work with NDIA to deliver a better experience for NDIS Early Childhood service users including participants, and their families.

# 1 The Brotherhood of St. Laurence and National Disability Insurance Scheme

As an independent non-government organisation with strong community links that has been working to reduce poverty in Australia since the 1930s, the Brotherhood of St. Laurence (BSL) has a strategic focus on building community inclusion. This commitment is reflected in our role as an ECEI and LAC provider for the National Disability Insurance Scheme (NDIS) in the North Eastern Metropolitan, Hume Moreland, Western Melbourne, Brimbank Melton and Bayside Peninsula areas in Victoria. We have been delivering LAC since July 2016, and commenced as an ECEI provider in November 2016. Our engagement in this planning and community capacity building is driven by the recognition that people with disabilities are among the most socially and economically excluded Australians.

Through our Research and Policy Centre and in partnership with the Melbourne Disability Institute of the University of Melbourne we undertake research and evaluation activities with the aim of informing the successful implementation of the scheme in supporting people with a disability to live a good life. We also hold deep expertise in the implementation and function of human services markets through our policy and research work.

To maximise efficient and effective implementation of ECEI and LAC, we regularly consult with participants, staff and providers about their experience in the NDIS. The input from these three groups has shaped this submission and recommendations. In particular the response has been informed by our qualified and skilled professional workforce, including staff with children who are participants of the scheme Six group consultations were attended by over 110 people, and many individual responses were received through Zoom and phone interviews, and email.

## 2 Key issues for Early Childhood Reset

The review of the current Early Childhood Early Intervention (ECEI) Approach, and the recommendations for a reset were informed by a consultative process with sector representation that used a continuous improvement approach to identify a future state for the EC Approach. The process of sector consultation, and opportunities for input into the aims and recommendations of the reset have been valued by BSL staff. Our involvement in EC reset working groups has been a positive experience and built a commitment to service improvement, and we support the main aim of the reset to enable the future Approach to:

- fully support evidence based, best practice
- focus on and support the role and of parents and caregivers

children to participate meaningfully in all aspects of their lives (NDIS 2020, p. 10).

The early childhood sector continues to experience challenges. These have impacted on the success of the ECEI approach to date, and must be carefully addressed to deliver the full intent of the reset. These challenges include:

- system approach vs NDIA approach. There are differences between state services and models, and between NDIA and mainstream and community services, which can result in overlap or gaps
- provider issues including service shortage, variable quality and aggressive marketing
- how to balance respect for family choice with 'best practice'
- ensuring access and supports for harder to reach groups, including Aboriginal and/or Torres
   Strait Islander children and families, children and families experiencing family violence,
   children involved with child protection or in out-of-home care, or from CALD communities.
- needing to build capacity of community and mainstream services to provide appropriate support for young children with disability or developmental delay, and their families
- developing and strengthening families' connections to mainstream and community supports, to reduce demand for funded supports, consistent with insurance model
- tension in sector between potentially expanded role of EC Partners, and missed opportunity
  for providers of NDIS-funded services. We acknowledge that increasing the capacity of EC
  Partners is intended to reduce the need for funded supports.

BSL supports many, though not all, of the 23 recommendations in the consultation paper, Supporting young children and their families early, to reach their full potential (NDIS 2020). Our responses to those, and to questions posed in the paper are outlined in the following sections.

The issue of independent assessments has created concern for many families. It is not yet clear what is proposed for access and planning, but we support a comprehensive assessment including observation, use of standardised tools and consideration of family capability and circumstances. We have some concerns, however, about use of the results to inform access and planning decisions.

In addition, BSL suggests the concept of 'a plan for all' using NDIS Early Childhood services, whether or not these include funded supports. This could create a better experience for participants and families, who could be supported differently as needs change, and minimise the problems of transition, changing the focus from abruptly 'exiting' the scheme to a fluid, less ominous option.

BSL welcomes the opportunity to continue to work with NDIA to deliver a better experience for NDIS Early Childhood service users including participants and their families.

## 3 Response to recommendations

Our responses to each recommendation are supported with quotes from BSL staff, captured during consultation sessions.

## Our responses to overarching recommendations 1–9

**Recommendation 1:** Explain, rename and promote the NDIS Early Childhood Approach – and stop using the term 'gateway' – so families understand and follow a clear pathway with a mix of early childhood support options available.

Supported.

The choice of language can influence people's willingness to engage with services, and their expectations of services. Use of the term 'intervention' also should be replaced by 'support', consistent with working in the early childhood sector, rather than a medical model.

Having the Scheme called the National Disability Insurance Scheme is not helpful. Most of our parents do not regard their child as being disabled – and mostly at this time they are not – they have a developmental delay, not a disability.

**Recommendation 2:** Clearly and consistently communicate the intent of the new Early Childhood Approach and the Agency's support for best practice, so families understand how the approach informs positive outcomes for young children.

#### Supported.

Challenges with changing provider and community attitudes are not new. Proactive, focused communication is needed to inform and influence the sector.

I'm still getting paediatrician reports about Helping Children with Autism and Better Start funding, so families are confused with what they can access.

In NEMA [North Eastern Melbourne Area] it's four years since launch and we've been focusing on this since Day 1. We are still talking about terms, running information sessions for families, working with NDIA, handing out flyers.

**Recommendation 3:** Develop and publish new Early Childhood-specific Operating Guidelines – so our decision-making processes and best practice evidence are transparent and implemented consistently by partners and NDIS planners.

#### Supported.

Transparent decision-making processes will support families to understand decisions, especially those related to reforms of assessment, eligibility and planning.

It will help if we can make these [reasons for decisions] available for families to reference.

**Recommendation 4:** Create a distinct delegate/planner workforce that is exclusively focused on young children and their families, to improve the way families are supported.

**Supported**, noting that there are already significant challenges recruiting for early childhood knowledge and experience across the sector. Creation of a specialist workforce will require a workforce strategy and investment in training and development.

It would be good to have people who understand [child] development, but where will they come from?

**Recommendation 5:** Continue to work with federal, state and territory governments to identify gaps and strengthen the role of mainstream services, so all young children receive support from the appropriate system when they need it.

**Supported in principle**, but it is unclear how this will work in practice as states have responsibility for mainstream service provision, with inconsistency of services between states.

A coordinated national approach is needed across mainstream sectors including health, education and child protection, for all children. There is a risk of services viewing NDIS EC services as an opportunity to reduce their waiting lists and diverting children to NDIA; in Victoria this is particularly the case with Community Health.

"The goal is all young people receiving support from the appropriate system when they need it will require considerable investment to achieve."

"People like the Scheme as they can get good quality stuff, better services and choice; the capacity and resources of mainstream services – maternal and child health nurses, early education – are so limited."

**Recommendation 6:** Consider a range of mechanisms that will enhance compliance of providers with the NDIS Practice Standards on Early Childhood Supports and increase awareness by families of providers that adopt that best practice framework.

#### Partially supported.

The current focus on the assessment and supports for the child rather than the family is not consistent with best practice, which recognises the family as the child's ecosystem and seeks to build the family's capacity to support the child. We support enhancing provider use of practice standards, but understanding best practice is not simply an issue for providers. There are tensions between support for best practice, and respect for family choice, with providers delivering what families want and demand.

"We might recommend a key worker and capacity building supports, but families prefer an expert worker model, and 1:1 therapy intervention."

**Recommendation 7:** Improve sector wide understanding of how to identify families and young children experiencing disadvantage or vulnerability and tailor culturally appropriate services and resources so they can benefit from early interventions support.

#### Supported.

This is ongoing and challenging work that could be supported through partnerships with state services, such as maternal and child health, child protection and early childhood education, to build on work already in progress, or completed.

Overall, the families who have the highest information/support needs are least likely to be assisted by a one-size-fits-all process. Complex systems and inaccessible information compound this issue. Mapping the identification/referral/assessment journey and researching the points where families disengage can support the engagement of these families.

"A service system that actively outreaches to vulnerable families and reduces the hard edges does it most usually through the understanding and superior/diverse interpersonal skills of their frontline staff. These frontline staff are known broadly in the wider field as flexible and helpful, and particularly by professionals who have daily contact with vulnerable families."

Children from vulnerable circumstances who experience developmental delays are more likely to not be identified until they reach school, so extending the age to enter the EC stream without a diagnosis to 8 years would make a difference to identification.

"A dad insisted on doing the referral verbally. What he didn't say is 'I have the verbal skills but not the written skills', or 'I don't have a working printer', or 'I can't work out how to do this online due to using a smartphone".

"If the scheme can support as many children from vulnerable backgrounds with developmental delays such as communication concerns as well as impact of trauma, then an early intervention approach could be a life changer for some children. Juvenile justice and jails have many people with undiagnosed disabilities and communication difficulties."

**Recommendation 8:** Implement tailored methods of delivering supports for young children and their families living in remote and very remote areas to strengthen access to services.

#### Supported.

"After COVID, we know that we can support children and families via phone and /or video calls. Might increase capacity in areas where services are not available."

This is a long-term issue and has been difficult to address. A creative, targeted and measured strategy is required to improve availability of services in remote areas. There is an opportunity for collaboration between metropolitan EC Partners with more specialist workforces and remote EC Partners, to support virtually with secondary consultation and short-term supports.

**Recommendation 9:** Implement a tailored Independent Assessments (IAs) approach for young children to support consistent access and planning decisions.

#### Not supported overall, support for some elements.

There is limited information about this significant change to key processes for young children, how context and family capability will be considered, the formula or criteria to be used to determine eligibility and assign funding as a result of IAs, and the process of review.

"Observational practice in natural environments is the most powerful and usually informative tool."

"Best practice is about building parent capacity and confidence, but it's hard to measure."

The proposed reforms risk undermining the human rights approach of the Scheme, replacing it with a welfare model, with funding based on limitations and impairments instead of a capacity building model and a focus on increasing participation.

"We need to consider what we measure, or there's a risk of becoming a welfare scheme."

Elements of the proposed approach that BSL does support are:

- the use of consistent assessment tools to inform access decisions
- all applicants having access to assessments at no cost to them or their families/carers

 completion of assessments by EC Coordinators, as this is preferable to external assessor unknown to the child and their family/carers, as proposed for children 7+and adults

"A natural fit as we [EC Coordinators] are already engaging with families."

#### Increasing Early Childhood partner capacity

The successful implementation of these recommendations will require a whole-of-sector approach, given the existing workforce challenges for EC Partners and for the sector. Both an Early Childhood sector workforce strategy and investment in training and development are needed to address existing and future staff shortages, and to minimise competition between providers and partners for the same limited workforce.

A consultative approach similar to the one used for the EC Reset would assist to identify and agree on appropriate resourcing for the expanded roles, including what is a manageable workload; and help to ensure EC Partners can deliver on the volume and diversity of roles being proposed for them.

"We need a lot more people! People with experience and [we also need] training of staff."

#### Recommendations 10–15 for early support (including NDIS access)

**Recommendation 10:** Increase Early Childhood partner capacity to identify and help young children and families from hard-to-reach communities or those experiencing disadvantage or vulnerability, so they can connect to – and benefit from – early intervention supports.

#### Supported, noting that this will require additional resourcing and workforce strategy.

"Finding hard to reach children – it's really complex work – the needs of those children are significantly higher. We need more referrals direct to us; able to be genuine in our response; additional hours to reach and build trust, outreach – based in local communities and services."

**Recommendation 11:** Increase Early Childhood partner capacity to connect families and young children to local support networks and services in their community.

#### Supported, noting that this will require additional resourcing and workforce strategy.

This is not only about EC Partner capacity. Considerable waitlists for local services impact ability of partners to connect families with services.

"A barrier to plan implementation is the shortage of quality providers; connecting more quickly is difficult if [you] can't control market supply or service quality."

"Families where skills and confidence are low experience greater delay as they don't know where to start."

**Recommendation 12:** Increase Early Childhood partner capacity to provide short term early intervention (STEI) support to eligible young children and families for longer.

Supported, noting that this will require additional resourcing and workforce strategy.

Implementing this will require clear eligibility criteria, and a consistent approach to providing short-term support across regions.

**Recommendation 13:** Clarify the interpretation of the developmental delay criteria under Section 25 of the NDIS Act (2013) to improve the consistency and equity of Agency decision-making. Establish thresholds for key criteria using Independent Assessments.

#### Partially supported.

BSL supports clarifying the interpretation, using simple language that is inclusive rather than restrictive, for more consistent and equitable decisions.

However, we do not support the use of thresholds for key criteria using IAs, as decisions need to be informed by individual needs, including capacity of informal supports and consideration of environmental factors.

"It's like using IQ of 70 for school supports. A child with IQ of 71 still has significant needs, but misses out. It should be needs-based."

**Recommendation 14:** Increase the age limit for children supported under the Early Childhood Approach from 'under 7' to 'under 9' years of age, to help children and families receive family centred support throughout the transition to primary school.

#### Supported.

"I think it's great that it's being extended in age as some children's need for EI doesn't show until they hit school."

**Recommendation 15:** Use the early intervention criteria under Section 25 of the NDIS Act (2013) to make decisions around access to the NDIS for all young children.

#### Supported.

This is consistent with the EC Approach and the objective of transition from funded supports for children who do not meet requirements of permanent disability under Section 24 of the NDIS Act. Children with permanent disability and substantially reduced functional capacity will require a simple process for transition from early intervention to accessing funded supports under the disability requirements (Section 24 of the Act) as they approach age 7 now, or 9 after planned changes to age range.

"I think this is needed because parents do not come to NDIS equal in resources and skills that are needed to understand the complexity of NDIS, and what is being asked of them to participate in EI."

#### Recommendations 16–20 for planning and implementation

**Recommendation 16:** Increase Early Childhood partner capacity and flexibility to tailor the level of support provided to families to implement a child's plan and more quickly connect to the right supports and services.

Supported, noting that this will require additional resourcing and workforce strategy.

"We spend a lot of time with the planning process and don't feel we have enough time to follow up with families and work with those who struggle to connect to providers."

**Recommendation 17:** Introduce a 'capacity building support in natural settings' item in the NDIS Price Guide to encourage families and early childhood providers to prioritise supports delivered at home or other natural settings.

#### Supported, noting this is just one step in a change process required.

The item will need to provide a benefit for providers over their current business model to support change. Achieving the aim of prioritising supports delivered at home or other natural settings will also require a change management and communication strategy for families and providers, including an explanation linking these to best practice.

"Families are pushed into a business model of 1:1 appointments and moving away from capacity building of natural supports."

**Recommendation 18:** Publish new guidance about what is considered 'reasonable and necessary' when making decisions around support for children on the autism spectrum, based on evidence found in the Autism Cooperative Research Centre (CRC) 2020 report.

#### Supported.

Publicly available guidance for reasonable and necessary supports for children on the autism spectrum will support consistent understanding and decision making for families, providers, EC Partners and delegates.

"I had a request for \$155K for [behaviour supports]. The family came to the meeting with a provider costing, and it's hard to challenge."

**Recommendation 19:** Empower Early Childhood partners to provide families with clear advice about the best providers for their child and situation so families can make more informed choices.

#### Partially supported.

We support families having advice about the best providers for their needs, but consider it will be difficult to ensure currency, accessibility, accuracy and relevance for specific needs. There is no system available to support EC Partners to deliver on this change to the current position of proving information about providers, but not recommendations. Provision of advice about best providers for any child (that is, to recommend specific providers) would require NDIA to develop a system to capture and evaluate evidence of performance and outcomes for all providers, to support consistency and transparency and reduce for the risk of undue influence.

**Recommendation 20:** Undertake further ongoing research and study on the outcomes of young children after receiving early intervention support, to inform future policy and operational changes.

#### Supported.

Alongside this, BSL supports ongoing independent research into quality monitoring and evaluation of the revised approaches, including independent assessments, and thresholds for access and plan budgets. Such research will determine whether these approaches are suitable for the proposed use, and are delivering consistency and equity.

#### Recommendations 21–23 for transitions

**Recommendation 21:** Improve the existing annual progress review process for young children, to support families to celebrate the achievement of reaching their goals and outcomes, and transition out of NDIS supports to the next stage of their lives.

**Supported, noting that transition out is not a goal for all young children**. Some will have lifetime or long-term care and support needs.

This will be more successful if families have confidence their child can access NDIS-funded supports again in future if they require additional support with life transitions.

**Recommendation 22:** Ensure providers are using the recently introduced 'provider outcomes report', as a mandatory measure to evaluate the effectiveness of their supports and services.

#### Support for the aim, but not the reporting tool.

BSL supports mandatory measurement of provider outcomes, but not the use of the provider outcomes tool. The reporting format is long and completing it requires a considerable amount of potential intervention/support time and funds. Most fields are qualitative with descriptions of services but little evidence for effectiveness of supports.

#### There is a need for

- consistent outcome measurement
- effective implementation and evaluation
- capturing feedback from participants and families
- auditing of (self-reported) outcomes.

"Quality of completion varies considerably. [Providers] would need training to understand concept. Currently, our [EC Coordinator] work includes lots of capacity building of providers."

**Recommendation 23:** Offer families of young children a 'transition out' plan for up to 3 months' duration, to support them to transition to the next stage of their lives, if they are no longer eligible for the NDIS.

#### Supported.

BSL believes expectations of transition need to be set from service commencement. Staff need to explain to families the process of assessment, referral to mainstream and community services, short-term supports, then transition so they expect to graduate from Scheme. The keys are clear messaging from the beginning, and ensuring right supports for families are in place at this time. However, there is also a need to ensure support is still available if the circumstance change.

"Transition could be considered as a celebration for achieving the outcomes."

"Mostly children would be transitioning at school age, and I think 3 months would mostly be a good time frame, apart from the end of year; maybe 4 months is a better length of time while we have a shortage of services."

# 4 Responses to consultation questions

Following are BSL responses to some of the questions and issues raised in the consultation paper, with quotes and questions from staff involved in consultation sessions.

Tailored Independent Assessments (IAs) approach – feedback on this recommendation and/or any suggestions on how this proposed approach would work best for young children and their families/carers

The assessment tools to be used for the IAs approach have been specified, but information about the overall assessment process is limited. Best practice in early childhood assessment is an ongoing process that involves collecting authentic data in natural settings through a variety of methodologies, including observation and standardised assessment tools, over multiple sessions. The paper provides no information regarding how the approach will be tailored; whether it includes consideration of environmental factors, family capacity and individual circumstances; how these will be assessed to ensure consistency (and therefore equity); and how results are to be used to support consistent access and planning decisions.

It is also not clear whether an approach similar to the proposed policies for those aged 7+ is being considered for children under 7 years of age. The *NDIS Consultation paper: Access and eligibility Policy* with independent assessments notes the 'policy, and independent assessments will come into effect in the middle of 2021 for all applicants over 7 years of age' (p. 3), and the *Consultation paper: Planning policy for personalised budget and plan flexibility* states: 'Separately we are considering our policy approach to children under 7 years of age, who are supported through the ECEI Approach' (p. 3).

There is no publicly available evidence available to support the proposed use of independent assessments for decisions related to funding of supports for young children. This was not a stated aim of the trial, and children 0–6 years were excluded from the trial.

The provision of assessment tools may support consistent decision making, but this alone will not achieve consistent or equitable supports. Family capabilities – including parent/carer education, socioeconomic status, carer fatigue (or strength of informal supports), ability to advocate, willingness to complain to the Minister – also influence their ability to navigate the complex early childhood service sector and to access NDIS Early Childhood services. Providers can also influence family expectations and decisions around services and supports.

"If functional assessments are completed by different people, won't there still be different outcomes for families?"

"What about the families that are struggling and overwhelmed and can't explain clearly what [their child's situation] is?"

"It goes back to the bad old days of ISPs, when parents were coached to withhold medication, limit sleep so child would show 'their worst self' in order to get funding."

Staff involved in our consultations raised questions that were not addressed in the paper, and some concerns:

"The agency has said there needs to be transparency of how funding decisions are made. That means people will need access to their assessment results and know how these were interpreted for access and funding. Will they be able to repeat the IA if they don't agree with the outcome?"

"Will we be able to insist a child be seen face to face with an EC coordinator? This is not currently the case when recommending access to the Scheme."

"Will young children also have plan flexibility? What if it is spent on services that won't address needs or make less impact? I can see lots of trampolines and swing sets."

"I think this sounds like we engage families and the plan will be a cookie-cutter approach and remove the holistic plan built with child's needs and family considerations."

# Specific feedback in relation to the increased focus on STEI outside of access to the Scheme

BLS prefers the term 'short-term supports' (STS), to avoid the medical connotation of the term 'intervention'.

The increased focus on delivery of STS/STEI is closer to the original intentions of ECEI, and will have benefits for children and families, and for workforce.

The shift in focus for EC Partners away from planning to greater emphasis on delivering STS will be a positive one for the workforce. In particular, this may prove more attractive for allied health workers, as it will help them meet requirements for professional registration. Feedback has often been that focus on plan development rather than supporting child development and family capacity building is not an appropriate use of their skills.

An STS Policy and operational guidance are required to support families to understand the service model and promote consistency between and within EC Partner organisations.

Suggestions and questions from staff consultations included:

"Need to build perception that ST supports does not equal lesser service."

"Providers are not taking on children with complex needs due to difficulties engaging – how would we transition/refer/cease [these children]?"

"How do we prevent becoming/replacing [Victorian] community health screening, prevention roles?"

# Specific feedback in relation to the proposed increase in age range for the EC Approach from under 7 to under 9 years of age

BSL ECEI and LAC staff warmly supported the increase to age 9 for ECEI.

"0–8 years of age fits with early childhood sector, positive but concern re numbers of children who will be with Partners, and impact on workforce."

"In line with WHO definitions; and after school transition is positive."

"Especially useful for families with multiple children using services."

# Specific feedback in relation to the desire to see more successful transitions from the Scheme to the next stage of life

BSL suggests the concept of 'a plan for all' using NDIS Early Childhood Services, which may or may not include funded supports. Such a plan would support a better experience for participants and families, as it could be used differently as needs change, and minimise concept of transition.

We believe that expectations of transition should be explained and agreed with families at the beginning. This should include:

- process of assessment, ensuring right supports for families are in place at this time (including referral to mainstream, short-term supports) then transition to informal, community and possibly funded supports
- diagnosis and initial criteria won't change, but what might change is need for funded supports
- children may move in and out of funded supports according to need informed by IAs
- re-assessment will occur at transition points including commencing kinder and school
- discussion around capacity of carer/family and skills to tackle what's coming
- success seen as achievement of goals, rather than transition
- building in a goal of establishing support, whether this is funded through NDIS or community/mainstream.

"Being a participant should not be being equated with not being successful."

"Families are already expressing interest and concern that children may not be able to continue in the Scheme."

Strong connections between mainstream services and EC services – even co-locations – will build a perception of a continuum of interconnected services, to support effective transitions between services.

"Consider where EC is positioned structurally, within mainstream system or as a disability specialist service. Connect within hubs / service centres, where services are; links with education, MCHN, child protection, integrated family services; co-location."

### How can we help families and carers better understand some of the terms the NDIA and Early Childhood partners use such as best practice, capacity building, natural settings, and/or evidence?

"This is about accessibility, which is critical for all information. The question really should be why do we need to use jargon."

One idea is to use common, simple words that describe the concept:

- Best practice = what we know makes a difference
- Capacity building = learning new ways/things so we can do better

"We don't usually talk about kids' capacity building, so why are we applying this term to kids with disability? Mostly kids are learning and developing."

- Natural settings = where children live, learn and play
- Evidence = how we know

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

Supporting children and families to connect with community and mainstream supports acts as a Scheme 'guard rail': the availability and use of those supports reduces the likelihood that a child with disability or developmental delay will require funded supports as a Scheme participant. A considerable investment of time may be required from a support person to enable these connections. It takes time for research, capacity building and individualised introductions required to do this well, but the return on investment may be a reduced need for funded supports.

The focus of NDIA, and its expectations of partners, including the performance measures in the Outcomes Assurance Framework prioritise numbers and timeliness of access and planning over this vital work. This emphasis has made it difficult to assign already stretched staff resources to support families to make strong connections with mainstream and community services.

"More vulnerable parents have a greater need for breaking information into chunks."

"Families with limited English need more support work to find culturally appropriate services and supports, and interpreters take double time."

"Families struggling to engage, struggling to stay connected. need support and a personal touch."

"Providers give up on families that have trouble attending appointments."

If you live in a remote or very remote part of Australia, what are some ideas you have on how we can get early childhood supports to work in your community or communities like yours?

Though BSL ECEI doesn't work in remote communities, members of our team can draw on their wider experience. Their ideas include:

- Identify strategies that have been effective in attracting services /providers (e.g. local community approaches, differential funding) and promote these
- Fund trials of innovative service models, including funding travel for outreach
- Develop and implement strategies to recruit and retain workers, such as mentoring, videoconferencing for supervision and secondary consultation, additional funding for training and development, financial incentives for relocation
- Consider building on experiences of other innovative service models that seek to build capacity in rural mainstream services such as the Rural Allied Health Generalist program <a href="http://sarrah.org.au/ahrgp">http://sarrah.org.au/ahrgp</a>
- Conduct specific campaigns for areas of greatest need
- Share expertise between EC Partners, with allied health professionals and/or experienced practitioners providing secondary consultation where other partners may have in-house expertise
- Evaluate availability and effectiveness of virtual/telehealth supports during COVID-19, as this has changed both families' and providers' expectations of what works.
- Evaluate effectiveness of virtual approaches to providing packages of support, group education, peer support. Allied health professionals have reported that virtual sessions in people's homes were successful as they could reference their natural environment and use familiar resources.

How can our Early Childhood partners and mainstream services best support peer-to-peer connections? Are you interested in helping us codesign an approach that would make peer-to-peer networks easier to find and join for people?

Young children and their families need to be at the centre of any proposed approach, with EC Partners and mainstream services supporting them to exercise their choice and control over how they wish to be supported. Support for peer-to-peer connections should take into account the current capacity of the family.

Many families have the capacity to locate peer-to-peer support independently, or after receiving information to identify the most appropriate group for their needs, whether face to face or virtually, through advocacy organisations, disability-specific organisations, local networks, social media and others.

However, there are families who are typically not engaged through peer-to-peer approaches, including people who are time-poor or stressed, people with language barriers and people who experience social anxiety or other mental health issues.

BSL would welcome an opportunity to be part of a co-design process that seeks not to replicate existing services but to address gaps, and enables participants and families who have not joined existing services to identify and/or establish a peer-to-peer network. The co-design process should include children and families who experience discrimination, are at risk or are vulnerable. BSL's approach to co-design would build on our strong relationships with sectors such as DHHS, child protection and homeless services and Aboriginal and /or Torres Strait Islander and CALD community organisations.

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?

"Smooth access to NDIS is for English-speaking, well-educated families, with reports available [but] convoluted for others, where kids are falling through cracks."

Current barriers to assistance seeking, and reaching and supporting young children and families who experience vulnerability include:

- limited interagency cooperation
- lack of clear, simple, consistent and accessible information, including in languages other than
   English
- challenges accessing documentation and lack of flexibility to deal effectively with this, resulting in loss of contact, denied access requests and disengagement
- ongoing issues with lack of EC sector knowledge and referrals to ECEI
- limited/no access to technology
- cost to providers of using interpreters.

"Many of these children fall through the cracks when getting support either through school or NDIS because they don't have enough evidence of delayed functioning or a diagnosis due to limited service engagement."

"There are challenges engaging families if linked with DHHS [Vic.]. This needs interagency cooperation."

"There are complexities working with children in out-of-home care, including ensuring there is legal documentation before attempting contact, moving from foster carer to foster carer, changing court orders, high staff turnover."

"For example, parents fleeing domestic violence as they are unable to get access as they often don't have identity documents, on move, changed phone numbers, etc. DV is a glaring omission in CALD training; [there is a] perception that if child has disability it's someone's fault or lack of knowledge of services. These are all barriers to assistance seeking."

Options to address these barriers include:

- specialist support team and process for those where documents are not available
- community engagement and creative outreach outplacement and co-location (e.g. public housing, playgroups, child care centres etc.) – to detect families with children with developmental delay who may not connect
- EC Partner role on local mainstream service groups (e.g. child protection panels).

#### Greater transparency on providers of best practice

There are two issues to address: increasing provider compliance with best practice, and how to help families and others identify those providers who are following the best practice approach.

Compliance could be increased through a quality framework that includes an assessment and rating system established by NDIA &/or NDIS Quality and Safeguarding Commission. Reviewing and publishing information about provider practices, including best practice compliance, would support families and others to access this information

To be most effective, this would need to be mandatory, and linked to payment.

Mandatory compliance, and/or provider registration is likely to increase service quality, but would add to costs and may create an additional barrier to entry for providers. In many areas (e.g. Melton) there are already long waiting lists for providers, making access more difficult and giving the child and their family less choice and control over service decisions.

In particular, mandating compliance requirements for service providers could compound the challenges for vulnerable families, who may already live in areas with limited mainstream and community supports, and providers.

"We should learn from experiences privatising education and childcare, which resulted in lower quality services and poorer outcomes for poorer children and families."

A specific concern is that many families are choosing the traditional expert model, rather than best practice. Creating change may require community change of attitudes, and a careful long-term plan.

## Reference

National Disability Insurance Scheme 2020, *Supporting young children and their families early, to reach their full potential,* consultation paper, November 2020, Version 1.0, downloaded 5 January 2021 https://www.ndis.gov.au/community/have-your-say/supporting-young-children-and-their-families-early-reach-their-full-potential