

Illawarra Shoalhaven Local Health District (ISLHD)

Response to the National Disability Insurance Scheme (NDIS) Consultation Paper:

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

Responses are provided in blue

4.1 General Questions:

- Do you have any specific feedback in relation to:
 - the increased focus on Short Term Early Intervention (STEI) outside of access to the Scheme
 - It is often unclear to clinicians and to families what 'Short Term Early Intervention' means. We are unsure of the frequency and duration of STEI.
 - Great to do more short term supports for complex referrals who need more assessment to see if they're leading to an ECEI plan
 - STEI is a good option for children who are delayed in one or more developmental areas, who don't have a diagnosis
 - Concern over whether this increased focus on STEI will further delay the timeliness of getting an ECEI plan if one is needed.
 - Is the increased focus on STEI at the expense of other children getting a plan?
 - Concerned that some children who access STEI may be better suited to access different services (Child Protection, trauma services, Mental Health services)
 - Will STEI be in lieu or in place of a plan, or prior to accessing a plan?
 - Many children need STEI, however aren't currently getting it as ECEI is focussing on developing plans
 - the proposed increase in age range for the EC Approach from under 7 to under 9 years of age
 - This is a very positive change which will allow easier access for children aged 7- 8 years. This is important as early years are also a crucial time when foundational skills are learned across all developmental domains. This will allow for continuation of supports rather than interruption.
 - This will assist with service continuity and improved transition to school.
 - This allows children whose developmental needs are not identified until they commence formal schooling to get support.
 - This allows refugee families access to intervention that they already have missed out on.
 - the desire to see more successful transitions from the Scheme to the next state of life.
 - This is a confusing question
 - If related to exiting ECEI, then the successful transition needs to be facilitated by the EC partner.
 - We are very much in favour of successful transitions, however it is not clear how this will occur and at what point?
 - There is currently very little documentation regarding the handover back to mainstream services (nil reports provided from ECEI back to Health)
 - Communication to mainstream services such as Health needs to improve

- For vulnerable families, case meetings should occur between ECEI and mainstream services if they are being exited from the ECEI scheme.
- 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.
 - Needs to be the role of everyone involved in ECEI approach to educate and support parents as they learn the meaning of these terms and how they apply in individual circumstances
 - With non-English speaking backgrounds, Health literacy, and general literacy skills need to be considered, terminology is a barrier and is confusing
 - Better practice around utilisation of TEACH-back, plain language and the use of interpreters (need to increase use of interpreters as they do not seem to be currently required)
 - Need to allow more time to more clearly explain roles and processes. The initial phone call is not enough.
 - Language of 'choice and control' is very confusing. This can be overwhelming for some families who have no/limited experience with certain terms.
 - The ECEI consent form is too long. It is six pages long and is confusing and a barrier to completion.
 - EC Partners need to spend more time explaining the process and explaining terms with families. Information on a website will not be read by everyone. Nothing replaces someone sitting with a family and explaining to them how to get the best for their child. Face-to-face and virtual meetings are priority.
 - We currently experience a large work load in Health in this area. We find our clinicians need to spend time explaining the ECEI/NDIS system and to explain these terms.

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 for their child?
 - We are unsure of what the current process is – it appears to differ for families and is very limited. In some cases we only find out after there has been inadequate levels of support.
 - To improve support, we would suggest:
 - Calling the family frequently (more than once every few months). Provide more support with family in support coordination phase (first 12 months).
 - The EC partners need to make genuine attempts to contact families.
 - Regular assessment of those goals through formal assessment with private providers that gets reported back to EC partners.
 - Concern with low-literacy/complex families who have difficulty understanding the process.
- Would a mandatory early childhood provider report developed between families and their provider be useful for tracking against their goals?
 - Yes sounds like an appropriate idea but there are few details on how this would work.

- EC Partner would need to follow up with families to ensure they understand the contents of the reports. Would there be an auditing process and who would do this?
- How can we better support families to connect with services that are either funded or available to everyone in the community?
 - Support with handover and better referral support.
 - More time to assist families in using their plans and finding services. There are very thin private provider markets in many areas.
 - NDIA needs to be more proactive with private providers being registered as NDIS providers.
 - EC Partners need to research and be aware of what is available in their local community
 - NDIA / local EC Partners could develop area-based apps to assist families with finding private providers these
- How can we make the process of transitioning out of the NDIS something to celebrate?
 - There is concern that if families exit NDIS they won't have support. Need to emphasise that it's a good thing. Reports can assist to reassure families.
 - Case and family conferences throughout plan and well before end of the plan
 - Responsibility lies with private providers to work with families to discuss goals and progress
 - Funding for exit review at specified time, for limited time.
 - Role of service provider to provide recognition and affirmation to child and family that progression and success has been achieved (with ECEI support)
 - Adequately fund mainstream services e.g. Health, so we could offer therapy services if indicated. Currently there are long waiting times in mainstream services so families are rightfully concerned if they lose funded support for their child.

4.3 Targeted supports:

- 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?
 - Telehealth
 - More recruitment and better support for isolated private providers.
 - Contract expert teams for 2 – 3 day visits initially, to assess, educate and provide support to local teams and support workers. Follow up with virtual care
 - Send support teams out twice-monthly, upskill other rural staff, provide support programs
- How can our Early Childhood partners and mainstream services best support peer-to-peer connections?
 - Seek permission to contact and connect with people
 - Set up forums/supported support groups that people could access if they wish
 - Provide information in newsletter and social media to local areas
 - Organise forums, including playgroups. Provide families with updates on support groups
- Are you interested in helping us co-design an approach that would make peer-to-peer networks easier to find and join for people?
 - Resourcing is difficult and would require funding, staffing, monitoring, updating and promotion
 - Suggest consideration of resourcing connectors, or dedicated positions and hours to this role
- 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?

- First step is to identify families that are vulnerable. We are not sure how well this is currently done by EC partners.
- Develop safety net strategies for families who don't have resourcing to advocate for their child. We have seen many vulnerable families miss out because they were not able to understand the system.
- Offer face-to-face support. Go to the families homes or see them in centres.
- Use interpreters where necessary
- Have more flexibility and support pathways where families are identified as vulnerable and are given more contact attempts.
- Training early childhood educators and early childhood nurses, GPs etc. to identify these families and put vulnerable pathway (additional supports) in place to ensure referrals to EC partners are responded to quickly.
- Ensure EC Partners and all staff have training in trauma-informed care. The impact of trauma on families requires a different approach when assessing them.
- Link with other involved providers, keeping input clear, ensure low/minimal cost to families
- Ensure guidelines are followed regarding appropriate number of attempts to contact, not discharge due to inability to contact. EC partners need to alert referrers if they cannot contact families.

4.4 Tailored Independent Assessment (IAs) approach:

It is recommended that the Agency implement a tailored Independent Assessments (IAs) approach for young children to support consistent access and planning decisions. Specifically, we are planning to:

- Commission Early Childhood partners to administer Independent Assessments for young children rather than use a separate IA Assessor workforce
- Use IAs for young children above 1 years of age
- Use the following tools (as outlined in an appendix to the previously published [Independent Assessment Tools Paper](#)):
 - Ages and Stages Questionnaire (ASQ-3) **OR** Ages and Stages Questionnaire -Talking About Raising Aboriginal Kids (ASQ-TRAK)
 - PEDI-CAT (Speedy) **OR** PEDI-CAT ASD (Speedy)
 - Vineland-3 Comprehensive (Interview Form)
 - Young Children's Participation and Environment Measure (YC-PEM) for children under 6 years
 - Participation and Environment Measure - Children and Youth (PEM-CY) for children 5+ years
- Do you have any feedback on this recommendation and/or any suggestions on how this proposed approach would work best for young children and their families/carers?
 - Many of these tools are generally used as one part of a comprehensive assessment approach, rather than a stand-alone assessment.
 - All of these assessments are based on parent interview / parental opinion which may not be an accurate assessment of the child's abilities. Parents can often over and under report on assessments.
 - Strong concerns with families not understanding the process of the independent assessment, and the implications of this for their funding.

- Cultural factors and language barriers need to be considered. Some families will downplay the level of support their child needs. Cultural sensitivity of the assessment tools needs to be considered. This may create new barriers for some families.
- Additional clinical / medical information needs to be considered in addition to the use of these assessment tools, for example: Reports from other health professionals.
- Is there capacity for additional functional information e.g. health professional reports, therapy reports, diagnostic letters? How would this be weighted?
- Vineland requires specific professionals to administer. It is not a stand-alone assessment and is used in the context of other clinical information and assessments.
- ASQ-3 is a screening tool not an assessment tool
- Concern over expertise, competency and discipline of independent assessors. Assessors need to be appropriately trained health professionals who are highly skilled and able to interpret in the context of each child's situation and needs. There could be challenges with rapport with families to discuss really personal and possibly negative matters. Culturally responsive training and trauma-informed care training would be essential.
- Nil information regarding children under the age of 1 and how they would be assessed.

4.5 Greater transparency on providers of best practice:

It is recommended, from the previous consultation leading to this paper, that a range of mechanisms be considered to enhance providers' compliance with best practice standards and to provide greater transparency on which providers, both registered and unregistered, are following Early Childhood Intervention best practice.

- What mechanisms do you think could help achieve this?
 - This is a complex area to manage as there are very few oversight mechanisms and a free market approach.
 - Greater transparency is needed regarding what private providers are offering families.
 - We are aware that many private providers lock in plan funding even if the child is on a waiting list for their service. Parents don't understand and consent to this. Private providers shouldn't be able to 'lock funds'
 - Provide more training courses for providers. They should receive appropriate training and pass minimum competency level to ensure they show evidence of awareness of the requirements of the role in providing early intervention specific services to their profession.
 - Establish local clinical supervision groups where cases can be discussed and shared confidentially to facilitate best practice intervention standards
 - Better oversight is required with more auditing of private providers. Experts in the field to assist in auditing process.
 - More governance from NDIA to support private providers
 - Feedback loop for families, possibly through a portal
 - A multi-disciplinary approach at the same centre would be a much more effective way to help many of these children and families
 - Not funding private providers who are not complying with programs of best practice e.g. sensory integration
 - Better checking in with families by EC Partners to see if families are using their plans, how they're tracking with the goals

- Better mechanism for mainstream services, for example: Health to raise concerns about therapies provided. Currently the only mechanism for this is through the NDIA Quality and Safeguards commission, which many people would find intimidating.
- Better processes for ECEI providers to step in and support families if there are concerns about how funds are being used
- Who would be best placed to lead the development of, and manage, any additional complementary mechanisms?
 - Should happen locally with EC partner, with guidance from NDIA
 - The EC partners require highly skilled and experienced allied health professionals with an interest and passion in this area.
- What do you think of the following ideas for potential mechanisms? What are the benefits or concerns with these potential mechanisms?
 - Provide greater information to families about the benefits of using providers registered by the NDIS Commission.
 - This could be seen as a backward move.
 - Many private providers in our area are not registered with NDIA due to the substantial reporting and financial overheads for NDIA registration.
 - Establish an industry-led 'best practice accreditation system'.
 - May be beneficial, but how would this look/work? Is it just reviewing current evidence and helping parents understand which therapists are appropriate
 - Good idea if cost of being a registered provider is not prohibitive and the process is rigorous and able to identify those with appropriate training and experience
 - What is acceptable vs what is not acceptable (EBP vs non-EBP), perhaps individual professions or professional bodies need to make comment on what is considered best practice
 - How is it managed if someone is working outside of this evidence-based approach?
 - Establish a 'quality feedback / rating system'.
 - Like the idea of a quality feedback/rating system, would need to make sure this wasn't skewed by private providers
 - Good idea if parent feedback can assist other families to find right service
 - Open to problems. All allied health professionals under AHPRA are bound by strict guidelines around advertising and promotion of their services
 - A quality feedback system doesn't guarantee quality.
 - Make registration with the NDIS Commission mandatory for all providers operating in the EC space.
 - If registration is mandatory, then they need a complete overhaul of what the registration process looks like and costs
 - Good idea if cost is not prohibitive and there is better education on how this can be achieved for those wishing to become providers
 - Require self and plan-managed participants in the new Early Childhood approach to use only registered providers.
 - Not enough registered private providers in our region, because of the documentation and cost involved in becoming a registered private provider
 - Being an NDIA registered provider doesn't guarantee a good service
 - Large companies with new graduates with inadequate clinical supervision may register and provide care which is not evidence based.

- Would need to change how providers receive funds
- Would reduce almost 95% of allied health providers in the Illawarra if enforced
- Some therapies which are not considered evidence-based will not be available to some families