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The Royal Children's Hospital (RCH) Melbourne's Submission to the Joint Standing Committee on the NDIS's inquiry into the provision of services under the NDIS Early Childhood Early Intervention (ECEI) Approach.

Contributed to by:

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Early intervention is of value because it promotes participation and enhances quality of life for individuals and their families, and in turn benefits the community. A responsive, needs-based service can prevent secondary impairments in children that will develop if not adequately addressed in the early years, as well as provide support to relieve stress and anxiety in parents and caregivers. This is essential if best outcomes from ECEI are to be realised.

As part of the committee's inquiry into the implementation, performance and governance of the National Disability Insurance Scheme (NDIS), The Royal Children's Hospital, Melbourne, will respond to each of the terms of reference identified for the provision of services under the NDI Early Childhood Early Intervention (ECEI) Approach.

Key Summary Points for this Submission:

- 1. Early Childhood Early Intervention services are critical to improving outcomes and minimising disability. An appropriately funded ECEI model is critical to the long-term sustainability and success of the NDIA as a whole.**
- 2. Growth and development of young children is at its most changeable in the early years. ECEI models and packages are required to be flexible and sensitive to changing needs of children and families.**
- 3. Children at risk of, or presenting with developmental differences should be equally eligible for entry level ECEI services, in addition to those children whose presentation falls within specific diagnostic groups.**

1. The eligibility criteria for determining access to the ECEI Pathway

Underpinning principles

In line with the Great Care commitments of the Royal Children's Hospital (RCH), early intervention should be accessible for all children and families with identified or suspected support needs. All children with developmental risk or differences should receive appropriate services, irrespective of diagnosis, location, culture, or socioeconomic background.

Challenges

Two key challenges for deciding eligibility to ECEI have been identified:

- variable developmental progress and hence service needs of young children
- potential overlap of services delivered by health organisations and ECEI

Recommendations

1. Eligibility for ECEI should be considered in terms of three service tiers. Tier 1 services would allow for further needs evaluation for children in which there is a lack of clarity or predictability, prior to entry into Tier 2 and Tier 3 ECEI. This would ensure timely access to first-stage supports for children with developmental risk, and an effective approach to assessing ongoing support needs whilst children and families receive needed services.
2. Eligibility to Tier 1 services should be based on identified developmental risk or delay in one or more developmental domains, including cognition, communication, motor skills, self-care, or social-emotional development. Children with the following characteristics would be suitable for Tier 1 funding:
 - i. a developmental difference in one domain with uncertain impact on other developmental domains
 - ii. developmental problems in two or more domains, with uncertain severity and impact of these differences on the child's needs, and for whom the optimal intervention is uncertain at the time of referral

Of note: children with a developmental difference in one domain (e.g. speech or fine motor skills) have traditionally accessed health services for support. These services have been provided by community health centres, Medicare-rebated interventions or health insurance-rebated intervention with a relevant health professional. As such, entry to Tier 1 NDIS ECEI services for a child with a difference in one developmental domain could reasonably require that prior engagement with community-based services has been sought, to address the specified area of difficulty. Information provided by that professional about progress and ongoing needs can then support entry into ECEI services.

3. Eligibility into Tier 2 and Tier 3 services could occur via two pathways; progress evaluations following Tier 1 service involvement, or clinical assessments by health care providers that quantify the degree of developmental delay, functional impairment, and/or diagnosis. Children and families known to be requiring specific ECEI services would receive these under Tier 2 service provision, and those requiring diagnostic specific or more intensive packages would receive these at Tier 3.

2. The service needs of NDIS participants receiving support under the ECEI pathway

Underpinning principles

Services achieve best outcomes when they are coordinated, team-based, and family-centred. ECEI should deliver programs developed by ECEI teams. ECEI services are provided to children and their families during a time of great change and unknown potential for developmental progress. ECEI services are also provided at a time when parents/carers are acquiring new knowledge of their child's abilities and needs. Familial stress and grief are important considerations in ECEI provisions, particularly as family functioning plays a pivotal role in a young child's service-related outcomes.

Challenges

Allocation of services should be responsive to the changing needs of the child and the specific needs of parents during the early years of their child's life. This is difficult if funding is allocated for 12 months duration and highly specific elements for the funding are itemised, blocking opportunities for trained service providers to make clinically appropriate changes.

Recommendations

Building on the tiered service model described above (see Figure 1 below) would allow for some flexibility within a twelve month funding cycle. At the time of funding allocation, the ECEI package would be based on tier allocation, with the addition of a specific budget to cater for particular needs, such as group therapy programmes, mobility aids or continence support. This would allow ECEI providers flexibility in the interventions provided within that tier level of funding. With further changes in funding allocation (see suggestion point 4) even greater flexibility could be possible.

The assumption in this model is that some children will "exit" ECEI. Others are likely to require ongoing or increasing NDIS support. Though not all children would move through all tiers, the different tiers would cater for the highly variable needs of all children accessing ECEI.

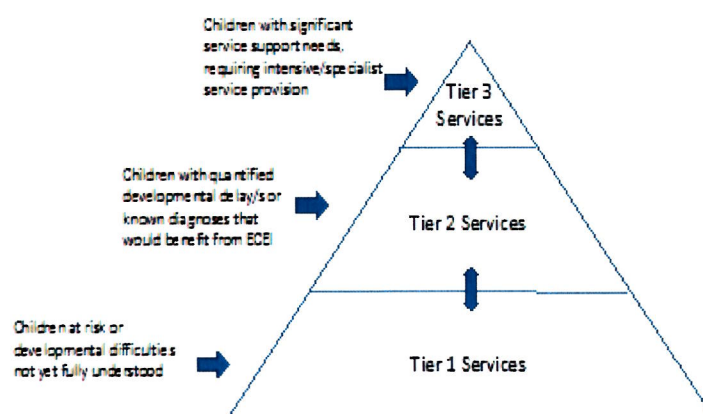


Figure 1

Also assumed is that ECEI care providers are highly trained professionals with the knowledge and experience to assess and adjust ECEI provided, and will do so in a child and family's best interest. This could be monitored at appropriate time intervals, based on expected outcomes, by NDIS.

3. The timeframe in receiving services under the ECEI pathway

Underpinning principles and relevant background information

Each child and family accessing ECEI will have unique service and support needs. As such, it is difficult to define a universal time-frame for ECEI for each consumer. Family-centred decision making, in partnership with ECEI service providers should be at the centre of determining time periods for intervention and review.

In the past, some parts of Victoria saw waiting times for early intervention that exceeded 12 months. Such waits would impact negatively on the overall outcomes NDIS is aiming to achieve if they were to reoccur.

Challenges

There will always be a tension between providing services to all children and families who would benefit from intervention, and timely access to services for those requiring them the most.

Recommendations

1. All children should be able access Tier 1 ECEI services within 3 months of the referral being made
2. Ongoing assessment of emerging or diminishing support needs will need to occur to deliver timely appropriate services
3. Those charged with planning and reviewing responsibilities require clear pathways to simplify the planning process while at the same time ensuring a child and family's needs are met. If a simplified process, such as allocation to one of three tiers with specific indications for each tier, is not adopted then NDIS ECI Partners require an understanding of child development, inclusive of what levels of functioning are appropriate at specific ages, across developmental areas.

4. The adequacy of funding for services under the ECEI pathway

Underpinning principles and understandings

It is acknowledged that the NDIS has delivered a significant improvement in the investment for early intervention compared with previous state-wide or federally funded models. In line with suggestions made above, whilst funding may be adequate, there is concern that funding parameters such as frequency, duration and type of services do not take into account the changing needs of participants who will be accessing ECEI.

Recommendations

1. It is recommended that funding for services be flexible and allocated to individuals based on changing service needs. It is important that regular assessment is linked with the intervention process, as would be usual practice for ECEI teams, as ongoing evaluation informs intervention refinements.
2. Review periods of 3-6 months are recommended, to explore appropriate funding allocations for individual children, whilst taking into account potential variation in intervention and support needs within a 12 month funding cycle. A model that allocates funding to services based on the number of children and predicted percentage within each tier would allow for service providers to review, with families, each child's intervention and support needs more frequently and modify accordingly within their service's budget. The expectation is that for some children, needs will increase during any 12-month period, whilst it may decrease for others. This funding approach would allow ECEI providers, as the experts, to make changes based on child and family needs within the annual funding cycle, even if this involves offering ECEI that is outside the allocated tier for that child; so long as their service funding balances overall. A process of indicating variations outside package tier for a child could be developed. Packages without this flexibility may result in too much expenditure in for some individuals, and insufficient service provision for others.

5. The evidence of the effectiveness of the ECEI Approach

Understandings

NDIA have previously consulted with expert researchers and reviewed relevant literature to support ECEI planning for specific diagnostic groups. Evidence is also emerging to highlight the long-term individual, family and socio-economic benefits of early intervention provision for children "at risk" of developmental delays or disabilities, in particular children with an early brain injury with high risk of developing cerebral palsy.

Recommendations

1. We encourage ongoing literature reviews and consultation with early intervention researchers regarding ECEI practice, for specific diagnostic and 'at risk' groups. It is important to ensure evidence-based practice is supported for all children, including those with less predictable needs or outcomes.
2. Rapid reviews may be appropriate ways for policy makers to address specific questions relating to ECEI practice. See <https://www.saxinstitute.org.au/news/rapid-reviews-for-evidence-informed-policy-10-top-tips/> for further recommendations.

6. The robustness of the data required to identify and deliver services to participants

Underpinning principles

Data collection and analysis is critical to the planning and evaluation of ECEI services. Data should be valid and reliable and include available information from service providers as children enter and progress along ECEI pathways. The perspectives from all key stakeholders including relevant service providers, and families, should be included.

Recommendations

1. The primary data set for ECEI should include pre-defined outcomes that the service aims to achieve for a consumer. This can take the form of valid and reliable, standardised tools for measuring outcomes, based on the intervention goals established.
2. Though a functional approach to outcomes is desirable, it is important to recognise that functioning and independence should be considered differently in an ECEI model, as a young child's ability to "function" in the world around them is still developing. Many functional measures do not adequately describe or predict the relevant support needs of young children and their families.
3. Extreme caution should be taken in relying on any one "measure" or "functional tool" to determine service eligibility, progress, or exit points in relation to ECEI or NDIS.
4. As ECEI services should be family-centred, evidence-based and flexible, data upon which to determine service allocation should equally contain these qualities. Goal-focused, family-centred data collection tools and methods are recommended, with data collected at ongoing time points to capture changing abilities and progress.

7. The adequacy of information for potential ECEI participants and other stakeholders;

Underpinning principle

Information for participants and stakeholders is key to the success of the ECEI programme. Information needs to assist decision making for participants, planners and referrers to the NDIS ECEI.

Recommendations

1. Information should be delivered in a variety of ways, languages and at appropriate time points for those requiring relevant details. To ensure that families from cultural or linguistically diverse (CALD) background are not disadvantaged, translated material should be made available. This can include brochures, decision trees, and summary statements, in online and paper-based formats. Information regarding services should be relevant to the child's age, presenting difficulties, and evidence-based. Links to information should be available regarding services that are related to, but outside of the NDIS, such as Medicare rebates and alternative, community based services that may be relevant to consumers prior to during or after their involvement with ECEI.
2. Additionally, consideration of the development of materials that are easily accessed via smartphone should be prioritised to ensure accessibility for families whose prime means of engaging online is through the use of their phone rather than a computer.
3. It is imperative that NDIS planners are trained in delivery of information as appropriate to the family's needs, with a reasonable understanding of child development and ECEI frameworks. Additionally, planners and EI providers should be trained, in a standardised manner, in eliciting family-centred goals and creating and environment of consumer choice.

8. The accessibility of the ECEI Approach, including in rural and remote areas, and the principle of choice of ECEI providers;

Underpinning principles and understandings

Equity and choice should be a cornerstone of the ECEI approach, and all reasonable efforts should be made to ensure consistent wait times, service availability and service quality regardless of geographical area. It is hoped that our proposed model may help to achieve the goal of equitable and culturally appropriate ECEI services across the country. Information provision that is appropriate to the reader and delivered in a variety of modalities, will be essential in achieving this goal.

It is important, however, to recognise the risk that too much choice and information can create a landscape of confusion and further difficulties for children and families, particularly in a competitive market place. Decision making is complex, and itself requires support from professionals trained in family support and goal-setting principles.

It is also critical that regulatory systems are in place to ensure consumer choice is balanced with a system that supports families to access the best, evidence based supports available to them. This is again challenging in a competitive marketplace subject to commercial imperatives and promotional strategies.

Recommendations

1. ECEI services should be tasked with transparency around their models of service delivery and the evidence base they draw upon. This will allow consumers to make informed choices about services deemed appropriate for the child's presenting needs.
2. Whilst standardised assessments and questionnaires are useful in quantifying developmental issues, they do not always provide an indication of a family's service needs. Family-centred decision making should be built in to all aspects of ECEI service delivery, and particularly at points of transition into, between or when exiting from specific tiers of service.

John Stanway
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