

Joint Standing Committee on the National Disability Insurance Scheme

Provision of Services under the National Disability Insurance Scheme Early Childhood Early Intervention Approach

**Children and Young People with Disability Australia
Submission – August 2017**

INTRODUCTION

If it wasn't for these services and the positive programs in place my son's transition to school would not have been a smooth transition.

My child thrived with the intervention. It would be a shame if other families [did] not get the same opportunities.

We missed the window of opportunity for early intervention when our income suddenly disappeared via a redundancy. We will have to try even harder to get my daughter to the point she would have been at with early support, if that is even possible now.

Disability emerges in children differently. Some children are born with disability. For some it evolves over time. For others it is acquired throughout childhood. Disability is experienced differently by every child and every family. Families also respond to disability differently. There is little predictability in the journey children and families travel. A common element and well recognised value add in this journey is access and availability of quality early childhood early intervention services and supports. Families of children with disability frequently acknowledge how critical information, support and expertise is throughout these early childhood years in setting the scene and laying the foundations for life opportunities and expectations for both the child and family. Additionally there is a strong and robust evidence base which demonstrates the significant and positive outcomes quality early child early intervention affords children and families.

The National Disability Insurance Scheme (NDIS) is currently transitioning to full implementation by 2019 according to an ambitious rollout schedule. Trial site data showed that a higher than expected number of children were entering the scheme.¹ The Early Childhood Early Intervention (ECEI) Approach was put in place in response "to ensure that only those children who meet the eligibility criteria of the NDIS become participants of the scheme".² The ECEI Approach is intended to connect children and families to services and supports and help children enter the NDIS if required.³

Access and availability of ECEI is different for children and families, a key variable is whether the NDIS has commenced where they live. In areas where the NDIS is yet to rollout some continue to access existing state and territory based services. In all areas, families may partially or fully self-fund ECEI services, some still receive inadequate levels of services or supports or others miss out completely.

Direct experience reported to Children and Young People with Disability Australia is that this period of change has left some children and families in a state of limbo, either placed on waiting lists or receiving limited services during the transition.

This submission is informed by the direct experience of children with disability and families. This includes feedback specifically obtained through a recent survey conducted by Children and Young

¹ Productivity Commission 2017, *National Disability Insurance Scheme (NDIS) Costs*, Position Paper, Canberra, p. 17

² Ibid, p. 22

³ Australian Department of Human Services, 'Early Childhood Early Intervention: How the NDIS can help your child', viewed 28 August 2017, <https://www.ndis.gov.au/html/sites/default/files/Early-childhood-Early-Intervention.pdf>

People with Disability Australia (CYDA) regarding issues raised in this inquiry. CYDA thanks the Committee for the opportunity to provide information about this critical aspect of the National Disability Insurance Scheme.

CHILDREN AND YOUNG PEOPLE WITH DISABILITY AUSTRALIA

Children and Young People with Disability Australia (CYDA) is the national representative organisation for children and young people with disability, aged 0 to 25 years. The organisation is primarily funded through the Department of Social Services and is a not for profit organisation. CYDA has a national membership of 5300 and a growing social media presence with 22 500 followers across the three major platforms of Facebook, Twitter and LinkedIn.

CYDA provides a link between the direct experiences of children and young people with disability to federal government and other key stakeholders. This link is essential for the creation of a true appreciation of the experiences and challenges faced by children and young people with disability.

CYDA's vision is that children and young people with disability living in Australia are afforded every opportunity to thrive, achieve their potential and that their rights and interests as individuals, members of a family and their community are met.

CYDA's purpose is to advocate systemically at the national level for the rights and interests of all children and young people with disability living in Australia and it undertakes the following to achieve its purpose:

- **Listen and respond** to the voices and experiences of children and young people with disability;
- **Advocate** for children and young people with disability for equal opportunities, participation and inclusion in the Australian community;
- **Educate** national public policy makers and the broader community about the experiences of children and young people with disability;
- **Inform** children and young people with disability, their families and care givers about their citizenship rights and entitlements; and
- **Celebrate** the successes and achievements of children and young people with disability.

THE EARLY CHILDHOOD EARLY INTERVENTION APPROACH

The ECEI Approach under the NDIS provides support to children aged 0 to 6 years who have a developmental delay or disability and families "to help children develop the skills they need to take part in daily activities and achieve the best possible outcomes throughout their life."⁴

A key component of the ECEI Approach is the "ECEI Partners", designated to be a first contact point for families.⁵ ECEI Partners work with families to identify community based and mainstream

⁴ Australian Department of Human Services, 'Early Childhood Early Intervention', viewed 28 August 2017, <https://www.ndis.gov.au/ecei>.

⁵ Ibid.

supports that can support children; facilitate the provision of short-term funded intervention; assist to request NDIS access; and, where applicable, work with families to develop a NDIS plan.⁶

DIRECT EXPERIENCE

CYDA has received extremely varied feedback regarding the experiences of children and families using the ECEI Pathway and accessing ECEI outside of this service stream. Many families who are not NDIS participants report that it can be costly and extremely hard to access, with some children missing out or experiencing significant delays in receiving services. Further, some families state that there simply are not enough “funded places”. There is real concern amongst many families that their children will receive less support once the NDIS rolls out in their area, with funding being withdrawn from existing state and territory based services. Other families say that the process of accessing effective services and support has been an uphill battle because there is a lack of recognition and acknowledgement of the concerns that they have about their child’s development.

Feedback from families of children who are NDIS participants has been more positive.

Other key issues raised in regard to ECEI include:

- Lack of appropriate and affordable services for children who are found ineligible for funded support through the NDIS or an ECEI Partner;
- Lack of clear information about where to access services and supports and the full spectrum of available options;
- Families paying privately for the significant costs associated with diagnosis and assessment;
- A narrow approach based on diagnosis being taken to decisions about supports and funding;
- Very limited choice for children and families who are not NDIS participants or cannot afford to pay for ECEI privately; and
- Families reporting that ECEI supports received through an NDIS plan are reduced compared to what was received previously.

TERMS OF REFERENCE – SPECIFIC RESPONSES

a) the eligibility criteria for determining access to the ECEI pathway

The information on the NDIS website states that the ECEI approach is available to children aged 0 to 6 years who have a developmental delay or disability and their family and ECEI Partners will work with children and families to assist with accessing services and supports.⁷ To date there is considerable uncertainty amongst families regarding the eligibility criteria for children to receive short-term funded interventions through an ECEI Partner. It would be of considerable benefit to children and families if this information was clearly defined and publicly available so navigation of service pathways and options is as easy and as transparent as possible.

⁶ Australian Department of Human Services, ‘Early Childhood Early Intervention: How the NDIS can help your child’, viewed 28 August 2017, <https://www.ndis.gov.au/html/sites/default/files/Early-childhood-Early-Intervention.pdf>

⁷ Australian Department of Human Services, ‘Early Childhood Early Intervention’, viewed 28 August 2017, <https://www.ndis.gov.au/ecei>

In summary eligibility for the NDIS under the ECEI pathway requires:

- Firstly, the child must have one or more identified “intellectual, cognitive, neurological, sensory or physical impairments that are, or are likely to be, permanent”; or “one or more identified impairments that are attributable to a psychiatric condition and are, or are likely to be, permanent”; or be “a child who has developmental delay”.
- Secondly, the provision of early intervention supports must be likely to benefit the child “by reducing their future needs for supports in relation to disability”.
- Thirdly, the provision of early intervention supports must be likely to strengthen or improve the child’s functional capacity or available supports, to alleviate the impact of their “impairment” upon their functional capacity, or to prevent deterioration in their functional capacity.⁸

A child will be taken as automatically meeting these requirements if they have a condition in ‘List D’,⁹ published in the NDIS Operational Guidelines. List D is intended to allow streamlined entry to funded NDIS support under the ECEI pathway.¹⁰ CYDA believes there should be greater transparency regarding the process and criteria used to establish List D. It is unclear to CYDA what the criteria are for inclusion in this list and this information does not appear to be publicly available.

The interpretation and application of these early intervention requirements is an issue which has been raised by members and other stakeholders with CYDA. Some families have been left feeling uncertain about what the requirements are for moving from receiving support through an ECEI Partner to being a NDIS participant. Other families have said that decisions about eligibility for the NDIS, focused solely on diagnosis and did not give consideration to their child’s functional needs and capacity. Some families report that ECEI Partners did not assist them to access the NDIS, even though they have numerous assessments and documentation recommending extensive ECEI for their child.

The confusion which exists around eligibility is reflected by this family’s experience:

We were referred to an Early Childhood Partner for an NDIS application and were told it would be up to 5-6mths wait for them to review things. All assessments recommended early intervention services and yet the Early Childhood Partner indicated they wouldn't support our NDIS application and recommended referrals for chronic disease management and mental health care plans. This was unhelpful as these have already been used. The Partner said they couldn't recommend anything further, other than remaining on the waiting list for community health.

As discussed in the recent Productivity Commission Position Paper on NDIS Costs, the ECEI pathway was implemented in response to the higher than expected number of children entering the NDIS in trials.¹¹ There has also been extensive reporting of this issue, particularly in relation to children with autism.¹² It is important to consider issues in relation to eligibility in light of the insurance principles

⁸ *National Disability Insurance Scheme Act 2013* (Cth), s. 25.

⁹ Australian Department of Human Services, *Operational Guidelines – Access to the NDIS*, viewed 28 August 2017, <https://www.ndis.gov.au/operational-guideline/access/early-intervention-requirements.html>. This list is prescribed under r. 6.11 of the *National Disability Insurance Scheme (Becoming a Participant) Rules 2016*.

¹⁰ Productivity Commission 2017, *National Disability Insurance Scheme (NDIS) Costs*, Position Paper, Canberra, p. 22.

¹¹ *Ibid.*

¹² Examples include: R Morton 2016, ‘Surging Autism a Headache for NDIS,’ *The Australian*, viewed 12 April 2017, <https://goo.gl/JkkE3U>, R Morton et al. 2016, ‘Autism Explosion Leaves NDIS in Disorder,’ *The Australian*, viewed 12 April 2017, <https://goo.gl/fPBIJR>.

that underpin the NDIS. These principles seek to provide access to disability and mainstream support services in order to support the future social and economic participation of people with disability.¹³

CYDA believes that it is critical to recognise that inadequate access to ECEI for children and families may be a risk regarding the long term sustainability of the NDIS. Timely access to quality supports in the early childhood years decreases children's dependence on disability supports throughout their lives. Further, inadequate ECEI services and supports for children and families will often contribute to increased costs for other services such as in education, health, justice, homelessness, child protection and welfare.

b) the service needs of NDIS participants receiving support under the ECEI pathway

It has been acknowledged that the rollout schedule for the NDIS is highly ambitious and that this schedule has compromised the integrity of planning processes.¹⁴ The direct experiences of transition reported to CYDA, as well as discussions in the community and media coverage of participant and service provider experiences, indicate that the NDIS, in this early stage, is highly stressed. Feedback received by CYDA suggests that the tension between meeting the sudden and increasing needs of people entering the scheme and realising the intent of the NDIS is felt equally by children and families receiving funded NDIS support under the ECEI pathway.

CYDA has received a number of positive reports from families whose children are NDIS participants. Some have expressed relief and gratitude on finally being able to access funded support from the NDIS, often after a long wait. Others have noted they are afforded more control over supports and services for their child which leads to more tailored and effective interventions for their child.

The below comments reflect these experiences.

Thrilled to receive the NDIS. We were waiting 8 months for approval.

It was good five years ago also that everything has been in a state of change leading up to the NDIS. I'm glad to have our plan and choose more experienced staff now.

Under the NDIS we have received high quality services that assist our entire family in building our capacity to support the development of our son.

The recent survey conducted by CYDA elicited a range of feedback regarding poor experiences for those accessing early intervention through ECEI Partners. Families concerns cover a range of administrative and operational areas which mean there appears to be great inconsistency between experiences and outcomes of those utilising the ECEI approach. These include concerns regarding: the way in which ECEI Partners have used clinical assessment tools to make decisions about funding and supports; the inclusion of inadequate or inappropriate supports in plans; and supports that are either under or over funded.

Dominant concerns reported to CYDA relates to contact with the National Disability Insurance Agency (NDIA) and ECEI Partners. Significant challenges include: emails not being responded to;

¹³ National Disability Insurance Agency 2015, *2015-2019 Corporate Plan*, Geelong, p. 7.

¹⁴ Productivity Commission 2017, *National Disability Insurance Scheme (NDIS) Costs*, Position Paper, Canberra, pp. 11-14.

significant wait times after lodging an enquiry before they are contacted by the ECEI Partner; long wait times on the information line; and planning meetings being conducted over the phone.

CYDA remains concerned by ongoing and consistent feedback that some ECEI Partners are basing decisions about supports and funding on diagnostic assumptions rather than the functional impact of disability for the child concerned.

CYDA is also concerned that processes for monitoring and coordinating support provided via the ECEI pathway do not appear to be well known to families. CYDA members report that they have not received support coordination as approved in plans and that they are unaware of the monitoring processes regarding the early intervention services and supports being received.

The following family experiences reflect these issues.

PEDI-CAT is an abysmal tool that asked inappropriate questions and didn't gather the relevant information for our situation.

Lack of funding has limited the access to supports in general and excluded some others. Our child's plan was cut from \$32000 to \$16000 in the second year and this has had a major impact.

We have just applied for the NDIS and received a first package which is half of what we applied for. We are currently launching an appeal.

The service provider we were allocated to was of no assistance at all. We were not guided as to what services could be utilised for different needs nor will be assisted in any way to locate and access services. I was under the impression that they would act as a type of support coordinator who would guide us through everything we would need to know and the types of services we could use, and none of this happened.

In CYDA's view there is a great need to ensure that personnel operating in the ECEI Approach area have related professional qualifications and expertise or are provided with improved professional development on childhood development and evidence based practice approaches in ECEI. It appears this has been the clear intent of the NDIA yet families consistently report that they believe there is limited expertise within many aspects of the current ECEI system.

It is the understanding of CYDA that assessment tools are used to inform decisions about functional impact for children. It is CYDA's views that there needs to be transparency regarding what assessment tools are used, for what purpose, and the expertise of those undertaking these tasks. It would be highly problematic, possibly unethical, if assessment tools are being interpreted and applied by personnel who do not have the required professional qualifications and clinical expertise.

c) the timeframe in receiving services under the ECEI pathway

Minimal information is publicly available about the expected timeframe for delivering services under the ECEI pathway generally. According to timeframes prescribed under legislation, the NDIA must in general decide whether prospective NDIS participants meet the NDIS eligibility criteria within 21 days of receiving their application, including under the ECEI Pathway.¹⁵ ECEI Partners are required to

¹⁵ *National Disability Insurance Scheme Act 2013* (Cth), s. 20. Longer periods are permissible in some circumstances where further information is needed to determine an access request: s. 26.

start preparing participants' plans in accordance with the NDIS "phasing rules" in each area,¹⁶ or otherwise "as soon as reasonably practicable".¹⁷ The NDIA is required to also approve the supports children and families are to receive "as soon as reasonably practicable" after receiving the proposed plan.¹⁸

The direct experiences of CYDA members in accessing ECEI services and supports under the ECEI Pathway are highly variable. Whilst CYDA has heard from some members that they have received timely access to services, other constituents have reported having to wait significant periods, including up to 18 months, before accessing services. Based on recent feedback, some families receiving services through an ECEI Partner have been placed on long waiting lists, whilst others have received services relatively quickly.

CYDA is concerned that delays in accessing services have been particularly pronounced for NDIS participants. Families have reported having to wait for up to twelve months to have their plans finalised. Lack of prompt follow up or administrative errors by some ECEI Partners during the planning process has been a concern, and some parents have had to persistently contact planners to facilitate plan approval. Some families then experience additional delays before their child is able to access services and supports, of up to 6 months or more in some cases. The direct experience of CYDA members indicates that these delays in accessing services are often due to waiting lists for funded services and supports or particular types of services.

The following families report experiencing significant delays.

The process of having a plan approved took about 6 months and only through constant pushing and advocating for an immediate plan and funding for supports.

It took a whole year to access supports, but everything was booked out so my son's first plan was wasted. He used hardly any of his first plan because of waiting list times!

Over a year wait for a meeting that they then did via phone call, then it took six weeks to get the plan.

The NDIS takes a ridiculously long time to approve and go through the planning process considering it's for early intervention and the earlier we get kids extra help the better.

If your child needs assistive technology, you need to be prepared to be waiting a year for it. The stress that you have to go through is ridiculous.

The ECEI Partner sat on the plan for over a month and did not submit all the supporting documentation.

Delays in the delivery of ECEI services significantly undermine the fundamental learnings and purpose of early intervention. Early childhood is a well-established pivotal time for development and it is critical that children and families have timely access to expertise, services and supports during

¹⁶ *National Disability Insurance Scheme Act 2013* (Cth), s. 32(2); National Disability Insurance Agency, Operational Guideline – Planning, viewed 28 August 2017, <https://www.ndis.gov.au/operational-guideline/planning/timeframes-preparing-plan.html>.

¹⁷ *National Disability Insurance Scheme Act 2013* (Cth), s. 32(3).

¹⁸ *National Disability Insurance Scheme Act 2013* (Cth), s. 33(4).

this time. CYDA is thus extremely concerned that significant delays in receiving services under the ECEI Approach is a common scenario.

d) the adequacy of funding for services under the ECEI pathway

CYDA has welcomed feedback from a number of families who report that the NDIS has made a positive impact for their child and family. However, CYDA has received numerous reports from other families accessing services under the ECEI pathway indicating that the funded services available for their child are extremely limited. Further, direct experience reported to CYDA indicates that some children are missing out on accessing ECEI during the transition stage due to funding arrangements. As previously mentioned, many families are concerned that funding for services will cease for their child once the NDIS has rolled out in their area, because of withdrawal of funding from existing state and territory based services.

Families referred to mainstream services from the ECEI pathway have informed CYDA that they have had to pay significant amounts to ensure their child receives ECEI. Some families report being unable to afford the ideal level of support for their child, both in terms of the range of supports accessed and the frequency required.

This is reflected in the following experiences.

We were very fortunate to be able to pay for private therapies before the NDIS rolled out here. We were never offered public therapies and were told waiting lists were too long.

Our child has not yet transitioned to the NDIS.... We have been supported by a local non-profit but they can no longer provide services unless we have funding.

The service provider wants to help but can't due to insufficient funding. The pending rollout of the NDIS means they are paralysed.

I am truly saddened about the privatisation of [the existing state based service] and fear future children won't have the quality of assistance we have benefited from.

I am very happy with the services we receive currently, however they are very expensive and our daughter needs to access these more than once per week which is very costly for us.

CYDA has also heard from some families whose children are NDIS participants where the funding is insufficient to cover the range of supports that their child needs.

Families shared the following experiences with CYDA:

We had to have a review three times before we were able to access a reasonable amount of therapy, even though the funding is still not enough. She wasn't initially given enough funding for guide dogs or occupational therapy. Also she wasn't initially given funding for assistive technology for such things as magnifiers, a cane for low vision, or a sloping board. She also used to have sessions through the [Royal Institute for Deaf and Blind Children], however we had to stop this as there was not enough funding from the NDIS to continue.

I was participating privately prior to NDIS. The NDIS then decided what services we were eligible for funding for and we have found it to be extremely limiting. We have not been provided with sufficient funding for things such as equipment.

We still pay a fortune on sensory supplies that the NDIA deems not reasonable.

The common reports of families having to financially subsidise, fully or partially, early intervention is concerning and requires further analysis. Australia has developed a new disability service system after recognition that the previous system was unfair, inadequate and underfunded yet still it is far from uncommon that significant gaps exist. It is critical to establish why access and service delivery is still so fragmented and at times characterised by the same problems we are trying to leave behind.

e) the costs associated with ECEI services, including costs in relation to initial diagnosis and testing for potential ECEI participants

Families are frequently reporting to CYDA that they are incurring significant costs to obtain initial diagnoses and eligibility for services and supports, whether through the NDIS, an ECEI Partner or existing state and territory based services. Some families are able to recover some of the costs through Medicare, others source and pay for assessments privately because of long waiting lists for funded assessment processes. CYDA is of the view that it is unreasonable to assume that timely assessments can be made and covered through the health system.

Family experiences include:

Specific costs during our son's assessment process included paying a psychologist, a speech pathologist, an audiologist and paediatrician to establish a diagnosis to access early childhood intervention services and support.

We self-funded occupational therapist, psychologist and speech pathologist assessments as the NSW Health waiting list was too long – 12 months plus.

Assessment by the psychology clinic and paediatrician cost about \$600, paid by me.

It has been 18 months and I have privately sourced aides, reports and specialty services.

CYDA has also heard from families who are concerned about wasted costs for assessment when a child has a funded plan through the NDIS. This occurs when there is a requirement for an allied health professional to provide a report or assessment to justify a purchase of equipment or home modification. Some families' state repeated assessments need to be obtained to access routine supports and equipment.

The below experience is an example of this circumstance.

Autism has sensory processing problems as one of the major impacts yet sensory toys and regulation tools are not approved unless a script is written for them, meaning I have to pay an occupational therapist each and every time my child breaks or wears out a chewy tube or a sensory sock or a crash bag or weighted blanket! This is costly and time wasting. We should be able to pay for them outright when we need them.

f) the evidence of the effectiveness of the ECEI approach

At this early stage in the NDIS transition, it is difficult to gain a clear picture of the effectiveness of the ECEI approach. Families have reported to CYDA that they have not been able to provide feedback on the services they are accessing, apart from informal discussion with ECEI providers, and do not know how to request a review or changes in services and supports. Significant administrative and operational concerns about the implementation of the NDIS to date have been raised in many forums by both participants and service providers. The survey CYDA recently conducted about access to ECEI indicates that the ECEI approach is still very problematic for many children and families.

Some families have reported to CYDA that their children are accessing increased supports than were previously available to them. Anecdotally, the ECEI approach appears to be achieving more positive results for families who have been found eligible for NDIS supports or funded short-term intervention through an ECEI Partner, a number of whom have expressed satisfaction with the supports now in place for their child, after having worked their way through the initial stages of contact with the pathway.

However, CYDA is concerned by reports from many young families about numerous barriers to accessing ECEI for their child and the difficult and confusing nature of the process. Issues raised, some of which have already been referred to in this submission, include: lack of information about the available services and supports and how to access them; existing services being in a state of flux during the transition period; uncertainty about whether children will continue to receive funded service once the NDIS rolls out; long waiting times for assessments, approval of NDIS plans, and to access services; inadequate advice and help from some ECEI Partners, or ECEI Partners not being operational in some areas; very limited supports being funded to support children's development and in some cases reduced supports than were previously accessed; and poorly coordinated and integrated services and supports.

The below comments provide examples of the wide-ranging difficulties encountered by families.

The actual service providers we use are excellent. The system is difficult and confusing. The portal needs to be made more user friendly.

NDIS is a nightmare. I have the worst mental health since my child started on the NDIS. The supports are great once you spend so long fighting for them. When you finally get them you are broken and exhausted because of all the stress.

Experience and waiting times for early intervention defeat the point. It has been frustrating and expensive.

There was a little support at the start but now we are waiting to transition to NDIS there is even less support and we are in limbo.

Still waiting, we are up to 5 months so far. In the meantime only very limited services are being provided and not frequent enough – only therapy every three weeks instead of more frequently.

The planner tried to control the process. We are currently appealing the plan. We are worse off.

There seems to be a lack of coordination among organisations with oversight and coordination of individual plans. Seems to lead to clients not receiving integrated service provisions.

It is evident from the direct experience of families that improvements are needed in the monitoring and review processes for services and supports provided at the individual level. It is simply unacceptable that families are in some instances being hamstrung by the inadequacies of an emerging new service system. Ultimately, families are responsible for and the decision makers for their children in the early years, not an ECEI partner delegate or “the system”. There needs to be a very clear feedback mechanism where early intervention can be constantly monitored and reviewed to enable the best possible outcomes for children and families. Moving forward there is clear need to ensure the ECEI pathway enables ongoing review which occurs in constant partnership with families and that flexibility exists to respond in a timely manner to changing and emerging needs of children and families.

Further, system wide evaluation of the ECEI approach is needed to address the significant administrative and operational concerns now raised. CYDA acknowledges that it is very early days to be able to assess the effectiveness of the ECEI pathway but there are many early indications that the system in transition is very problematic for too many children and families.

h) the adequacy of information for potential ECEI participants and other stakeholders

The early childhood years are a critical time when families typically experience a steep learning curve in gaining an understanding of how best to meet the individual needs of their child. For some children there is no definitive diagnosis for many years. Some families go through a period of denial and find it difficult to engage. For others there is cultural stigma related to disability which needs to be considered. Others make it their business to be well informed, but it is often a difficult road as one goes about learning and becoming familiar with services and supports available. Some families struggle with the many pieces of advice and varied information they receive in the process. All families have an emerging understanding about what this means and capacity to take in information, and it is certainly not a linear or predictable process for any family.

Direct experience reported to CYDA indicates that families obtain information about ECEI services and supports from a variety of sources. A range of service providers and practitioners, such as General Practitioners, health and allied services and practitioners, community services and other families. In addition specialist disability services may play a role in this process. CYDA has heard from families of difficulties accessing clear information about ECEI, including where to access services and supports and the full spectrum of available support options. Specific feedback has been provided that this information is not readily available or easy to understand and that some families have needed to rely solely on their own independent research and internet searches to acquire knowledge.

The ECEI Partners are intended to be organisations with strong local knowledge and expertise around early intervention.¹⁹ However concerns have been raised with CYDA that in some jurisdictions appointed ECEI Partners do not have the knowledge or expertise stipulated for organisations undertaking this role. Some families have reported receiving minimal or poor

¹⁹ Australian Department of Human Services, ‘Early Childhood Early Intervention’, viewed 28 August 2017, <https://www.ndis.gov.au/ecei>.

information from ECEI Partners, or being directed to a particular service without adequate explanation of the different options available.

Examples of these experiences are provided below.

No early intervention services or supports were offered or suggested.

How do we find out the type of services to try? The GP and paediatrician have not been able to suggest services.

[Specialist] organisations that provide services proved to be unhelpful, especially as they are the ones with staffing issues.

It is especially difficult to find the right supports for your individual child's needs.

The ECEI Partners could provide more information on options for support workers and other areas where we require multiple options.

Bare descriptors were given by the ECEI Partner, and heavily biased towards a particular service.

CYDA believes that there is a great need to revise the information that is publicly available online and through ECEI Partners with a view to improving its accessibility, clarity and quality. In CYDA's view there is also a need for improved professional development for NDIA employees and ECEI Partners to enhance their knowledge of relevant services, supports and approaches to ECEI.

It is also important to acknowledge that families often need support to discuss options and areas of support available for their child. This need is often a frequent one during the early childhood space as it is typically a rapid time of change and development for any child, where strong foundations and skills are developed which will have a significant impact on a child's future. This need occurs in a highly variable family context who, as discussed previously, all respond differently to having a child with disability. It is thus critical that support and expertise is available for families to consider and critique the information which is made available during this vitally important time.

i) the accessibility of the ECEI approach, including in rural and remote Areas

Minimal feedback has been received on the experiences of children and families in rural and remote areas regarding access to ECEI. Typically we know, in relation to general feedback from CYDA members, are that there are exaggerated difficulties with access and range of services and supports available. This also has been many more general discussions about the availability of services and supports in rural and remote areas in relation to the broader NDIS. Discussion regarding accessibility of the ECEI approach has been discussed extensively in the early section of this submission

Further experiences which demonstrate the breadth of issues relating to accessibility include:

Canberra, although metropolitan, has very limited services available. I often get told there are staffing issues – Parent from a metropolitan area.

We have our package and are yet to utilise it due to lack of services in our area. There is really only one service and with the rollover it's lost its best traits and is no longer what we need. The service has stated the NDIA won't approve things so I'm going to have to go interstate – Parent from a regional area.

If it were not for Early Childhood Intervention Service (Tas) then my boys both with autism would not be where they are. Utter shame and horrifying that the NDIS is shutting them down at the end of 2018. Their services are invaluable to us and many other families. Also the only time my kids get to be around other kids as other services aren't an option for us. We can't afford them and our kids wouldn't cope in other groups – Parent from a rural area.

CYDA encourages, in some instances, consideration of alternatives including block-funding and direct commissioning of disability supports to complement the market-based model, to ensure that the range and quality of ECEI supports is bolstered in areas where there are currently gaps in services.

j) the principle of choice of ECEI providers

Enabling people with disability to exercise choice and control in the planning and delivery of their supports is a central objective of the NDIS,²⁰ and a critical means of giving effect to the rights of children with disabilities and their families. There are high expectations that as the new service sector evolves from the previous block funding model to the provision of individualised funding packages, choice and control for people with disability will be a fundamental aspect of all components of disability and mainstream service systems.

CYDA has heard a range of concerns from families accessing supports and services from ECEI Partners about being offered very limited choice of ECEI providers. In some cases, families have reported being allocated a provider without being given any choice at all. Based on overall feedback to CYDA, families whose children are NDIS participants have had the most positive experiences in terms of ability to choose ECEI providers, particularly those who are self-managing their plans. However, some NDIS participants have commented that their planner has exercised complete control.

Consistent with some of the concerns raised above in relation to costs and funding of services under the ECEI Pathway, and service accessibility, it appears that choice of ECEI provider often depends upon the availability of services in particular areas and the ability of families to privately cover the costs of services over and above those that are funded. CYDA reiterates that there is a need to establish why access and service delivery is still so fragmented and to strengthen the ability of the service system to uphold the principle of choice and control over services and supports for children with disability and their family in a more equitable manner.

²⁰ *National Disability Insurance Scheme Act 2013* (Cth), s. 3(1)(e).

CONTACT

Stephanie Gotlib
Chief Executive Officer
20 Derby Street
Collingwood VIC 3066
03 9417 1025
stephaniegotlib@cyda.org.au
www.cyda.org.au

BIBLIOGRAPHY

Australian Department of Human Services, 'Early Childhood Early Intervention: How the NDIS can help your child', viewed 28 August 2017, <https://www.ndis.gov.au/html/sites/default/files/Early-childhood-Early-Intervention.pdf>

Australian Department of Human Services, 'Early Childhood Early Intervention', viewed 28 August 2017, <https://www.ndis.gov.au/ecei>

Australian Department of Human Services, *Operational Guidelines – Access to the NDIS*, viewed 28 August 2017, <https://www.ndis.gov.au/operational-guideline/access/early-intervention-requirements.html>

Morton, R 2016, 'Surging Autism a Headache for NDIS,' *The Australian*, viewed 12 April 2017, viewed 28 August 2017, <https://goo.gl/JkkE3U>

Morton, R et al. 2016, 'Autism Explosion Leaves NDIS in Disorder,' *The Australian*, viewed 12 April 2017, <https://goo.gl/fPBjR>

National Disability Insurance Agency 2015, *2015-2019 Corporate Plan*, Geelong

National Disability Insurance Agency, Operational Guideline – Planning, viewed 28 August 2017, <https://www.ndis.gov.au/operational-guideline/planning/timeframes-preparing-plan.html>

Productivity Commission 2017, *National Disability Insurance Scheme (NDIS) Costs*, Position Paper, Canberra

Early Childhood Intervention Australia, *National Guidelines for Best Practice in Early Childhood Intervention*, viewed 28 August 2017, <https://www.ecia.org.au/resources/best-practice-guidelines>