Early Childhood Intervention Australia

National Disability Insurance Scheme

Response to the Rules Consultation Paper

1 March 2013

Submission prepared by ECIA National on behalf of:

ECIA ACT; ECIA NSW; ECIA QLD; ECIA SA; ECIA TAS; ECIA VIC; and, ECIA WA
Introduction

Early Childhood Intervention Australia (ECIA) is the peak national organisation promoting the interests of young children with disabilities and developmental delays and their families. It has a national and State/Territory structure, with the majority of members being early childhood intervention (ECI) professionals working in Government-funded agencies. These include small community organisations, large disability and children’s services agencies and various government departments, reflecting the diverse ways in which services to young children and their families are provided nationally. Our membership also includes family members of young children with disabilities and developmental delays. Members are based in urban, rural and regional centres throughout the country.

ECIA endorses practices that promote, encourage and support community inclusion for all children and their families. These lay the foundation for each individual’s successful participation as a valued member within our diverse community. This has been articulated in our recently launched joint Position Statement with Early Childhood Australia on the Inclusion of children with a Disability in Early Childhood Education and Care.¹

ECIA welcomes the ongoing opportunity to contribute to the discussions on the NDIS and would like to highlight the particular needs of young children with a disability and developmental delay and their families in relation to the National Disability Insurance Scheme Rules (the Rules). A successful experience in early childhood forms the basis of a comprehensive lifespan approach, relevant to people with a disability of all ages. The key is to get the right supports right from the start.

ECIA would also like to draw your attention to our previous submissions regarding the NDIS including our submission on reasonable and necessary support, the Act and our verbal evidence provided to the Community Affairs Legislation Committee - National Disability Insurance Scheme Bill 2012 Inquiry on the 21 February 2013.

What should the NDIS look like for young children and their families?

While there is evidence that the individual funding approach has benefits for adults who have a disability and their families as it increases their choice and control over services and supports.² There

² Buchanan, A. (2003). The predictors of empowerment for parents and carers of people with intellectual disabilities within the direct consumer funding model, Disability Services Commission, Western Australia, Perth.
is currently scant international or Australian research on the impact of an individual funding approach with families of young children.³

In principle, individual funding can be considered as compatible with family-centred practice which is based on the belief that each family is: unique; the constant in the child’s life; and the expert on their child’s needs, abilities and the priorities for the family (Rosenbaum, King, Law, King & Evans, 1998). **However, the following evidence based recommendations should be considered so that the NDIS properly supports children with young children and their families.**

1. The important role of the family in the lives of young children should be recognised. The participant in the scheme should therefore be broader than just the child. The family is the child’s first natural environment and the information and supports provided should therefore, include those that are essential for families to make the necessary adjustments and informed choices that will ultimately benefit their child.

2. In the early years, families are learning about their child’s strengths and needs and adjusting to possibly unexpected situations. Being new to a system that is often difficult to navigate, with a young child with a disability or developmental delay, families may find themselves in a disadvantaged position to judge what kind of support they or their children need. There is ample evidence to suggest that expecting families to make early decisions on interventions, only makes their situation more stressful. One of the main aims of early childhood intervention services during the early years is to help build the knowledge, confidence and capacity among families so that they are in a position to make informed choices on behalf of their children and themselves as their children get older. The NDIS should give consideration to family support services, which are currently not funded under current Commonwealth funding program.

3. Early childhood intervention is more than just the provision of therapy. While this is important and has a role during this time, one major risk of the proposed NDIS plan and funding model is that eligible families of young children will use money allocated as part of the NDIS to buy services that are child-focused rather than on services that build the family’s capacity to promote their children’s learning and development.

As outlined in the Centre for Community Child Health’s 2010 literature review on early childhood intervention reform, such a service-oriented approach is contrary to best practice⁴. The recent Commonwealth funding models of Better Start and Helping Children with Autism, which have an individual focus, while well intentioned, are contrary to previously discussed best practice, and according to anecdotal reports from ECIA members could be seen as having created more challenges for parents and ECI providers than they have solved.

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As indicated in the work of the US Office of Special Education Workgroup on Principles and Practices and Practice in Natural Environments “assuming certain families need certain kinds of services, based on their life circumstances or their child’s disability” is NOT in keeping with the best practice principle that “all families, with the necessary supports and resources, can enhance their children’s learning and development”5.

4. A key worker model has been shown to provide the coordinated support families need at this time. A key worker model is where an early childhood intervention professional becomes a family’s primary contact point and the worker practices from a strengths-based, family-centred perspective that enables the family to be in control of their lives.6 It is important to note that from an early childhood intervention perspective a key worker is different to a case manager. As identified in ‘The Key Worker’ book, the key worker role has five key areas of focus:

- “Emotional support from family, friends and professionals;
- Information and advice which enables them to navigate services, understand professional terminology and access resources;
- Opportunity to identify and address their needs in parenting a child with a disability;
- Support and developing skills in advocating for the needs to their child and families; and,
- Support in service coordination.”7

A key worker also works within a trans-disciplinary team and undertakes planning that takes into consideration child and family strengths and needs when developing child and family goals with the family.

ECIA believes that the Rules could detail the above model for pre-school aged children and their families, through the allocation in the beginning of their engagement with the NDIS, a key worker.

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6 Stacey Alexander and John Forster (2012) The Key Worker: Resources For Early Childhood Intervention Professionals, Noah’s Ark, Melbourne.
7 Stacey Alexander and John Forster (2012) The Key Worker: Resources For Early Childhood Intervention Professionals, Noah’s Ark, Melbourne.
ECIA’s Preferred Model for NDIS Early Childhood Intervention Provision

This was developed by Dr. Tim Moore who is a member of the ECIA(VC) Executive and Senior Research Fellow at the Murdoch Children’s Research Institute, Melbourne.

When families of young children with disabilities have the diagnosis confirmed and become eligible for ECI services, they are likely to be in a state of some distress and disorientation. They will be unfamiliar with the ECI service system and uncertain of their role in relation to professionals. They will also likely to be lacking in confidence in their own abilities to help the child, and tend to defer to the knowledge of professionals.

Thus, at this point in time, they are not well placed to be able to make sound decisions about their own needs or those of the child, or about what forms of service would best meet these needs. It is unreasonable and potentially harmful to expect them to be able do so, or to manage funds to purchase appropriate services. Even with professional help in deciding what they need and in choosing services, the additional burden of managing funds is an unreasonable extra task that adds to the stress families are experiencing at this time.

At the point at which families leave the ECI system, their personal circumstances and skills will have altered dramatically. By then, most parents should be familiar with the service system, confident in their ability to help their children, able to articulate their needs, and able to work with professionals as partners. One of the major jobs of ECI services is to help families gain these skills and competencies. Since ECI services can work with families over several years, this gives them the time to support families as they gradually gain the skills and confidence they need to manage their child and family needs into the future.

As part of this journey, many parents can also gain the skills to manage the funds to purchase the services that the child and family needs. In the table that follows, four stages are described, beginning with an initial Entry phase in which the parent is most dependent upon professional support, and culminating in Final phase in which the parent is least dependent.

The table below also shows how the allocation of funds might progressively be handed over to the parent. In the Entry phase, the bulk of funds would be allocated to ECI agencies, with only a small proportion available to families for discretionary spending. In the Final phase, parents would be managing the entire funds themselves.
<table>
<thead>
<tr>
<th>PHASE</th>
<th>PARENTAL EXPERIENCE</th>
<th>CHILD EXPERIENCE</th>
<th>SERVICE NEEDS</th>
<th>FUNDING ALLOCATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>ENTRY</td>
<td>• Initial distress and confusion</td>
<td>• Completely dependent upon parents and caregivers</td>
<td>• Key worker allocation</td>
<td>• 80% to ECIS agency</td>
</tr>
<tr>
<td></td>
<td>• Unfamiliar with the system</td>
<td></td>
<td>• Introduction to the ECI / ECEC service system</td>
<td>• 20% to parents (for additional needs)</td>
</tr>
<tr>
<td></td>
<td>• Unfamiliar with their role</td>
<td></td>
<td>• Introduction to ECI philosophy and their role as partners</td>
<td></td>
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<tr>
<td></td>
<td>• Lack of confidence in their abilities to help their child</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>EMERGING</td>
<td>• Learning about their role</td>
<td>• Child engaged as partner in developmental activities</td>
<td>• Key worker and full ECIS team available</td>
<td>• 50% to ECIS agency</td>
</tr>
<tr>
<td></td>
<td>• Beginning to gain confidence in ability to help child</td>
<td></td>
<td>• Support in identifying child and family needs</td>
<td>• 50% to parents (for some services and for additional needs)</td>
</tr>
<tr>
<td></td>
<td>• Learning about the ECIS system</td>
<td></td>
<td>• Help in selecting most appropriate services to purchase</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Learning to manage funds</td>
<td></td>
<td>• Help in managing funds</td>
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<td></td>
<td></td>
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<tr>
<td>TRANSITION</td>
<td>• More confident about their role and abilities to help child</td>
<td>• Child engaged as partner in developmental activities</td>
<td>• Key worker and full ECIS team available</td>
<td>• 20% to ECIS agency</td>
</tr>
<tr>
<td></td>
<td>• Parent now familiar with ECI / ECEC system but not school system</td>
<td>• Child beginning to be able to articulate their needs and preferences</td>
<td>• Introduction to school system and options</td>
<td>• 80% to parents</td>
</tr>
<tr>
<td></td>
<td>• Able to manage most funds</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FINAL</td>
<td>• Sure of their role and confident to their ability to help their child</td>
<td>• Child supported in articulating their needs and preferences</td>
<td>• Flexible service system available</td>
<td>• 100% to parents</td>
</tr>
<tr>
<td></td>
<td>• Able to articulate child and family needs</td>
<td></td>
<td>• Range of service options for parents to choose from</td>
<td></td>
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<tr>
<td></td>
<td>• Familiar with the service system</td>
<td></td>
<td>• Key worker available for consultation support</td>
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<tr>
<td></td>
<td>• Able to negotiate with professionals</td>
<td></td>
<td>• Transition resources and support available</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Able to manage all funds</td>
<td></td>
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The different functions of the NDIS

Rule

1. The rule may prescribe matters for and in relation to this chapter (relating to the types of assistance for people with disability provided by the Agency). (Clause 17)

Questions

What sorts of general information and referral services should the Agency provide for people with disability who approach the NDIS?

The NDIS goal of client-led decision making is a positive however, we need to build capacity of young children and their families and take them on a journey to arrive at this point where they have the capacity to choose the services that they most require. In early intervention under the NDIS ECIA would like to see the introduction of a key worker model and support for families at the point of their initial contact with the NDIS as this will provide an intervention based on best practice but also an economically efficient introduction to the NDIS. This model is detailed above.

The Agency must ensure that people providing support have relevant qualifications for the age-group they are supporting. For example, that a percentage of Agency staff (reflective of the population demographics) have an early childhood qualification and that a number of staff also have expertise in working with families.

The role of families must be acknowledged and respected, as they are approaching the Agency for support for their entire family, not just their child/ren with a disability or developmental delay. Families are an intricate part of a young child. Just as intervention with the child will influence the family, intervention and support to families will inevitably influence the child. For families of young children with a disability and/or developmental delay the role of families is at the core of the success of early childhood intervention. This is why in the early years the family should be viewed as the NDIS participant and receiver of early childhood intervention, rather than simply the child receiving the intervention in isolation. If the Act and the Rules do not recognize the family as participant, it is important that a balance be struck between the participant (which is the child according to the Act in its current form) and the family. During the early years families will require access to a range of services to enable them to support themselves and their child, such as parent to parent support, diagnosis support, counseling, and so on.

For families approaching the NDIS who are already receiving services the Agency will need to provide clarity regarding existing services that children and families are receiving and the relevant changes. These changes need to be provided in a timely and consultative way to the non-government organisations and Government Departments that are currently delivering said services. Many families are trying to work out what is going to change and are fearful that they will end up back on waiting lists for services under an NDIS, despite already being in receipt of a service under the pre-NDIS service system. In addition, it is critical that the Agency is knowledgeable that existing services may be
delivering a good service. There has been discussion that parents will think because something is now under the NDIS, it will be better than the service they currently receive.

Clarity is required for participants around whether there will be a residual service system under the NDIS. It is naïve to assume that there will be no waiting list and people need to be informed of the possibility of waiting lists when they approach the agency, and residual services that exist to support them while they are waiting for NDIS funding. The Rules must address the issue of waiting lists.

**What guidance should the rules provide the Agency about how to support people in referring them to community or mainstream supports, or to other support systems?**

The Rules need to support the Agency to provide referral to a range of services and supports that they work in partnership with, particularly, in the case of young children and the families to universal services such as preschool and long day care, playgroups, maternal and child health services, community health and parenting services. **Services that the Agency refers to also need to be of a high quality and affordable for families to access.**

The principles of the Act, which the Rules will also reflect, reinforce that people with a disability should be supported to receive assistance outside of the NDIS and that these supports be coordinated with the NDIS supports of which they are in receipt. This principle raises the crucial questions regarding the role of universal services such as health services, or in the case of pre-school aged children, Early Childhood Education and Care (ECEC) services. There needs to be recognition that just because something is classed as a universal service does not mean that the service automatically is able to meet their obligations towards including children with a disability and/or developmental delay. **Therefore services that the Agency refers to need to be able to include children with a disability and/or developmental delay to functionally participate in that environment.**

The extent to which universal services currently provide services to children with disability and/or developmental delay is different in each state of Australia. For example disability funded services in South Australia provide significant services to the childcare and education environments of children to support the child’s inclusion and to assist with the child’s access to the program/curriculum. This is not currently funded through education or health. The way inclusion is funded in universal services looks different in each jurisdiction. The mechanisms for referral and the historical arrangements within each location will affect the support that is required.

### Inclusion in Universal Services:

**How early childhood intervention and universal services work together.**

When supporting the inclusion of children into care environments (Long day care, ASC, BSC, Vacation Care, Family Day Care); the service, and the Commonwealth funded Inclusion and Professional Support Service rely on the child’s regular early childhood intervention team being able to visit the centre and put in place the additional supports that are required. Examples are considerations of the environment
and making recommendations for specialized equipment; adding this care environment to the child and family’s support plan with any changes needed; examining the transfers and lifts that a child may require in this environment and so on. A lot of this work usually takes place when a child first commences care or even prior during their transition visits so that everything is ready to go. Educators are trained by the therapists in safe lifting, transfer and feeding techniques, along with how to best support the child’s health, wellbeing, learning and development needs in the particular setting. A therapist then comes back out to the care environment because the specialized equipment cannot be used in that setting until the therapist adjusts the equipment to fit the child and demonstrates how to use it and trains the educators in safe lifting techniques and transfers. Later they may re-visit to do re-adjustments or equipment recommendations, and they will also continue to visit the service provide early childhood educators with ongoing strategies to enhance the child’s development.

To date this practice has often been provided to parents as part of early childhood intervention service, in partnership with universal services, where the bottom line is that everyone is looking out for the best interests of the child and his/her family through the provision of a consistent and holistic approach.

However what will this look like in the future? Will this be retained as part of block funding allocated to the sector or will families have to purchase these additional therapy services for their child through NDIS? And if so will families see the true value of this service? Will families be provided with the information they need to realize the benefits of inclusion and naturalistic settings? Who will tell them? This is why it is so vital that Agency staff have early childhood qualifications and experience, and that a key worker model is adopted.

The role of universal services under the NDIS has constantly been referred to, particularly for those people who are not eligible to receive support under an NDIS, however how this will be resourced and monitored to ensure the inclusion of all children has not been articulated in the Act or in any supplementary documentation. This must be addressed in the Rules and a clear mandate for inclusion must be given and adequately resourced across all jurisdictions. What role will the Agency play in advocating with universal services to ensure inclusion?

The importance of the inclusion of children with a disability and/or developmental delay in universal ECEC services is reinforced in the ECA and ECIA Position Statement on the Inclusion of Children with a Disability in Early Childhood Education and Care. In the development of the ECA and ECIA Position Statement one of the barriers to inclusion that was identified throughout the consultation process was the lack of coordination of supports and services provided for the child with a disability and their family. One of the key roles of an early childhood intervention service is to assist in coordinating the supports for families, particularly at the point of transition, for example into universal services or from universal services to the school setting, however this vital role is underfunded, or for those unable to access a service due to waiting lists this coordination is not provided. It is vital that the NDIS improve this coordination; otherwise the true return on investment from the NDIS will never be realized.
It should not be assumed that children who do not meet the NDIS criteria do not have challenges accessing the range of universal services or that these services have the skills/resources to support all children. The NDIS should consider an allocation of funding to build the capacity and skills of universal services.

It is unclear how the Rules will ensure that universal services (often funded by either State or Commonwealth jurisdictions) meet their obligations to include children with a disability and their families who are also accessing NDIS funded services. The importance of universal early childhood education in relation to children’s learning and development, along with the role of allied health professionals, particularly in supporting young children’s development, must be clearly articulated in the Rules.

The NDIS has a strong focus on funding an individual’s choice and access to disability support services. However, early childhood intervention needs to be viewed as part of both disability-focused and education-focused services. The research reminds us that early childhood intervention must be viewed as part of an education service, with a learning and development focus. Many jurisdictions have a strong model of ECI service provision predicated on a health, wellbeing, learning and development orientation. Learning and development is crucial to all children, including those who may not have a disability diagnosis, but this focus is lacking in the Act. Therefore it must be reflected in the Rules. It is vital that this approach to ECI is protected and promoted under an NDIS rather than watered down to be seen as a solely disability focused service.

What guidance should the rules provide the Agency about funding of persons or organisations so that those persons or organisations may assist people with disability to realise their potential, and participate in, all areas of life

The Act was unclear in its description which details that the Agency may provide funding to persons or entities. The definition of entity which limits it to a partnership or unincorporated association should be expanded. The limited definition is confusing particularly when you take into account the detail of the explanatory memorandum which presents an example of an organisation that receives funding as an entity. The entity in this example could be seen as an incorporated association or a not-for-profit company limited by guarantee. ECIA would like to see the definition of entity extended to include not-for-profit organisations as we believe that this would enable many ECI services to continue to provide valuable services to children and families.

As we have mentioned throughout our submission we believe that an ECI key worker should be funded as a core service for all young children and their families who are participants in the NDIS, and accompanied with a discretionary component to allow the exercise of choice and control of other services as required. Should this model be adopted this would require ECI agencies to be directly funded by the Agency. ECIA would like to see that only organisations that are government-owned or not-for-profit, who have expertise and are able to meet best practice in ECI guidelines, are able to be directly funded by the Agency as this will ensure thorough compliance, governance and connection to community.
Becoming a participant

**Rule**

2. Age requirements for specific locations within Australia during launch. Clause 22(1)(2)

**Question**

*Should the rule also set out the types of information the Agency will need to establish that a person meets the age requirements?*

While age requirements for young children will be launch-site dependent there are some areas that ECIA would like to highlight:

- The definition of developmental delay raises significant questions for ECIA regarding what happens to children once they turn six and no longer meet the age requirements for developmental delay. What will the level of supports be for these children and their families once they turn six and will they have to transition out of the NDIS or reapply? ECIA is concerned about what this will mean for children and families. It is important to remember that the diagnosis of developmental delay is very complex and children may be classified as having a developmental delay for over a decade without receiving a formal diagnosis. There are also significant grey areas when determining what is deemed to be a developmental delay. This certainly requires further research and discussion with the field by the Agency and clarification in the rules.

- What support will be provided for families of children in-utero who are diagnosed with a disability? As they are not yet born, and the mother does not have a disability, how will support be provided under the NDIS? The Rules will need to provide an answer to this question.

- While this is not necessarily directly related to the age requirement it does refer to participant status. The Rules should also address what happens to the family of a child accessing the NDIS who may pass away. How will the NDIS support this family with the after-effects of the loss of the child, along with transitioning out of the NDIS? There have been number of families who have accessed early childhood intervention service who have experienced the loss of a child and have felt that all of the supports they often relied on for a number of years fell away.

- In the case of the South Australian launch site that is focussing on young children, what will happen to young children who age out of the trial and what supports will be provided as they transition out of the NDIS launch? The Rules will need to clarify this scenario. In addition, there is a concern about those vulnerable families who may not have the resources themselves (personal or financial) to follow up on anything once their child has been identified as a child at risk and needing early intervention. Without the dedication and persistence of current funded agencies with the capacity to provide visits/support/therapy in the home environment, these children are likely to miss out and not reappear until they appear in the formal school system. How will the NDIS ensure this doesn’t happen? This is where the allocation of a key worker to
families with young children, and the employment of those with appropriate qualifications, such as early childhood or social work, will be important.

Residence requirements

**Rules**

3. What alternative or additional criteria may be used to determine that someone is resident in a launch site. Clause 23(1)(c).

4. On what date or date in a time period should a person need to be living in a launch location to be considered a resident. Clause 23(3)(a)

5. How long a person may need to have lived in a particular location to be considered a resident. Clause (23) (3)(b)

6. Whether a person needs to continue to live in a launch site to be considered a resident. Clause 23(3)(c)

**Questions**

What factors should be taken into account in deciding whether a person meets the residence requirements? What types of evidence are appropriate to determine if a person meets the residence requirements?

What boundary issues between launch and non-launch locations are likely to arise and how could these be resolved in developing the rules?

Many children won’t be able to meet the residence requirements due to their age, for example, for newborns they won’t have lived in the launch site for any time at all. Perhaps residency could be based on parent/guardian residence and if the child was born while they were residing in launch site.

During the launch stage the criteria should be flexible enough to consider the environment and community that the person has significant involvement. Of concern in the South Australian launch area are cross border arrangements for children who live across the border in Victoria but attend preschool and receive health and disability services from Mt Gambier in South Australia for example. The rules need to also accommodate the considerations of the Indigenous population in the APY lands (the top of SA, lower part of NT and west part of WA).

The Rules also need to address the broader issue of residency in Australia. While ECIA recognises the need for the rules to look at residency, we note that the provision of early childhood intervention services is a fundamental human right. Consequently, some ECI services have supported children whose parents are not Australian citizens. For example, it may be that the family visa is being processed, or the children themselves have been born in Australia. In these cases, the ECI service currently might offer support to such children by using alternative funding, such as fundraising, to
ensure that the needs of the child are addressed in accordance with the United Nations Convention on the Rights of the Child.

**Continuity of support**

**Rule**

7. The time period during which the previously existing supports need to have been received, and the programs under which the previously existing supports need to have been delivered, for a person to meet the access criteria and be eligible for the NDIS. Clause 21(2)(b)

**Question**

What factors should be considered in deciding whether the NDIS should provide continuity of support to someone who has been receiving assistance under other programs, but who would not otherwise be eligible for NDIS support?

A number of factors will need to be considered regarding continuity of support including how long they have been receiving the support; and also how long will the continuity of support continue. For the majority of the children that the ECIA membership represents and works with, whether that be under the current education, health or disability sector, they will fall under the eligibility criteria of the NDIS. It is also important to note that there are large numbers of families accessing early childhood intervention services without a formal diagnosis that may have concerns about their child’s development and are being support through the process of diagnosis. In fact in some jurisdictions over half of the families that access early childhood intervention do not have a diagnosis at the time of referral and some do not get a diagnosis for 2-3 years for example. The NDIS needs to be able to support and accommodate these families.

The issue of concern here is how rigid the boundaries will be between education, health and the NDIS will be for young children. The concern here is if elements of the child’s reasonable and necessary supports are deemed an education or health support need – and historically, dependent on what jurisdiction you live, the previous funding arrangement may have seen a disability agency provide that service. If this is the case then there will be a gap in the support needs for that child and their family.

There should be the option for families who would like continue to receive the current services that they have to be able to do so until their child commences school. While the majority of children in receipt of current ECI services will be eligible under an NDIS, if some children are not deemed eligible the services that they are currently receiving cannot just fall away. Given what the evidence tells us about the value of ECI on determining the trajectory and outcome of children and their families it would be unfair to cease service delivery.

While it may fall out of the direct scope of the Rules, eligibility and continuity of support also provides an opportunity to direct funding to natural environments and community capacity building to be inclusive of all abilities.
Disability requirements

Rules

8. The criteria to be used to determine that the impairment or impairments are permanent or likely to be permanent. Clause 27(1)(a)

9. The criteria to be applied to determine that one or more impairments substantially reduce a person’s functional capacity, or their psychosocial functioning, in relation to one or more activities such as communication, mobility, or self-care. Clause 27(1)(b)

10. The criteria to be considered in assessing whether and to what extent social and economic participation has been affected. Clause 27(1)(c)

Questions

What criteria/factors should be taken into account in determining whether a person meets the disability requirements?

ECIA would like to see the disability requirements for children and young people in the Act be linked to the World Health Organisation’s International Classification of Functioning Disability and Health – Children and Youth (ICF-CY). It is not appropriate to be measuring children’s functionality based on the World Health Organisation’s International Classification of Functioning, Disability and Health (ICF), as proposed by the Rules consultation paper, as this is the same scale as one used for adults. ECIA believes it is vital for the NDIS to determine the disability requirements of participants using a children and youth specific measure, and for assessments to be made by those with specific knowledge of the tool. By using the ICF-CY, rather than simply a set of accepted diagnoses, children will not be excluded. In current funding programs, such as the Commonwealth Helping Children with Autism packages and the Better Start program, children with often complex and greater needs are excluded because they do not meet narrow and prescriptive diagnosis definitions and criteria.8

When it comes to children, ECIA believes that the NDIS needs to have reasonable expectations of what families provide all children vs. what they provide in addition to children with disabilities. Families are often deemed ineligible for current supports, such as the Commonwealth Carer Allowance and Carer Payment because the narrow definitions do not recognize the added stressors and complexities of having a young child with a disability or developmental delay, compared to a typically developing child. These narrow parameters should not be replicated under the NDIS.

When determining NDIS eligibility and adherence to the Act’s disability requirements for young children, it is critical not to simply look at the child in isolation, but rather in the context of his or her family. It is important to examine the impact of a child’s disability or developmental delay within the family milieu, taking into account the impact on both primary carers and also siblings. The NDIS has a

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responsibility, as early childhood intervention now has, to support families as whole entities, as this provides the best opportunity to support children’s learning and development. Both the Act and the Rules need to reflect this responsibility.

Early childhood intervention programs and services are delivered by professionals in natural environments in partnership with families as an extension of existing family support. Early childhood intervention focuses on building families’ quality of life and supporting children in developing their skills and abilities to participate in and enjoy daily life.

If the scheme and the Rules were to look at the ‘participant’ being the child and their family the assessment would be valuable to have a weighting for a range of environmental and biological risk factors, particularly for vulnerable families such as those with a history of trauma; poverty; newly arrive communities; poor access to services; an absence of networks and supports available to the family; and, the low functioning of parents/carers. The work of Guralnick also provides a developmental systems framework that looks at the role of family resources and would provide useful criteria to take into account when determining eligibility.  

**Should there be any guidelines on people being able to provide existing assessments to meet the disability requirements?**

For those children and families that are already accessing State or Commonwealth funded early childhood intervention services, the assessments that have already been conducted to determine eligibility for these services (or the ongoing assessments undertaken during service delivery), should be able to be used to determine eligibility for the NDIS.

**What should be considered in developing a rule on the types of persons who should conduct assessments?**

Any therapist usually associated with children’s assessments who is able to demonstrate recent and sustained experience/practice of working with children in this age group. People should not just be able to complete an assessment simply because they are qualified in a certain discipline. The typical disciplines available in early childhood intervention currently should be eligible with the proviso of experience and knowledge. We do not however want assessments to be undertaken as part of a solely medical paradigm. It is also important to remember that discipline specific professional organisations are not able to monitor quality of practice directly, so there needs to be monitoring of practice by the Agency. This monitoring could be based on the Early Childhood Intervention Statement of Practitioner Competencies, developed by ECIA Victorian Chapter.  

**What should be considered in developing a rule on the kinds of assessments that could be provided or undertaken as part of meeting the disability requirements?**

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ECIA would like to draw attention to the challenges facing many Australians, particularly young children and their families, in accessing timely, affordable and accessible assessment. In particular, ECIA would like to see the Agency have the capacity to pay for costly assessments for those applicants who require assistance; currently in some jurisdictions assessments are funded. ECIA wants to alert the Agency to the challenges in accessing assessments in rural and regional Australia and to the extended waiting times for assessment appointments. Children and families must be provided with some level of support, if required, while undergoing lengthy assessment timelines. It is important to consider the workforce implications associated with the potential demand increase for assessment under the NDIS. This needs to be planned for and adequately resourced.

Need to consider the type of assessment being completed and there should be guidance on what assessments are suitable – these should be authentic assessments and functional, which we have put forward previously. The concern is that discipline specific assessments will be used that will not provide additional information for what services and supports may be useful for the family.

In relation to the types of assessment that could be undertaken we would like to reinforce the value of the ICF-CY to measure children’s functioning. Based on the ICF-CY, assessments funded be for measuring and assessing activity and/or participation. Any assessments that are used also need to be normed on Australian populations, rather than assuming that US or UK measures automatically apply to our population. It is also important that assessments encompass both a formal assessment and a functional assessment component, as many children may often perform well in a controlled environment but are challenged by real world environments.

Given ECIA’s belief that families of young children should also be viewed as scheme participants, family functioning could also be measured as part of the assessment process. Measures such as the Family Environment Scale of the Family Impact of Childhood Disability Scale could be drawn upon to measure a family’s level of function and coping capacity as part of the eligibility determination process.

**How can we make sure the rules determine disability on the basis of a functional assessment of what a person can or aspires to do, rather than on the basis of diagnosis?**

This is why it is important to have Agency staff with a qualification and experience in early childhood development when determining NDIS eligibility. As previously discussed we would like the Rules to articulate that the ICF-CY used as a tool for assessments for children and young people.
Early intervention requirements

Rules

11. Criteria for determining if early intervention supports are likely to reduce a person’s future need for supports in relation to disability. Clause 27(1)(d)

12. The criteria to be considered in assessing whether a support is likely to mitigate, alleviate or prevent of an individual’s function capacity to undertake communication, social interaction, learning, mobility, self-care or self-management. Clause (27(1)(e)

13. Criteria for determining if early intervention supports are likely to strengthen the sustainability of the informal supports available to the participant, including through building the capacity of a carer. Clause 27(1)(f)

Questions

What criteria would be useful for considering the benefits of early intervention for mitigating or preventing deterioration in a person’s functional capacity to undertake activities such as mobility, self-care or self-management?

ECIA would like to see a separation between early intervention and early childhood intervention. Early intervention is fundamentally different to early childhood intervention. Adult services that focus on early intervention are about someone who has grown and developed to a particular level of functionality, whereas early childhood intervention services are for children who functionality is constantly changing and the goal of the service is to improve functionality.

How can the support provided by families and other carers be made more sustainable by early intervention?

In early childhood intervention families as a whole are seen as the client, rather than the child in isolation. Strengthening carers and families is at the core of early childhood intervention. When considering the eligibility requirements of very young children, the needs of both the child and their family should be assessed, to identify if there are any additional circumstances that will impact on family well-being, and therefore the support available to the child. This will also ensure that the intervention is more sustainable.

Families with young children with a disability or developmental delay are vulnerable and deal with new, difficult and unexpected realities, involving grieving and processing changed expectations. All families have different capacities, skills and natural support networks to use in parenting children. Statistics demonstrate that vulnerable families are overly represented in having children with a disability or developmental delay.

Families at this stage require:

- Pre-diagnosis and post-diagnosis support;
• Information to enable them to make the best choices for their family; and,
• A sensitive, individualised approach to build their confidence and capacity in managing their child’s particular needs.

It is vital that the NDIS rules take this into account. Perhaps this may even involve separate categories and definitions to encompass the particular needs of young children and their families.

It is also important that the NDIS distinguishes between the care issues that a family has, and the programmatic issues. The more you build child and parent competencies, the more you are reducing the burden of care. While children and families will have care needs for equipment, respite, housing and so on, they will also need to be provided with an ECI service that is not just about narrowly defined care aspect. This is why ECIA firmly believes that if a key worker is allocated to all young children and their families who are eligible to receive support under an NDIS, the long term support will be more sustainable.

At a practical level, it is also important to recognise that no two families or carers are the same and many have specific needs of their own, whether that be a family with limited English who you may not think require an interpreter, to the family where one or more parents may have an intellectual disability themselves. This is why the Rules must articulate and provide adequate support to ensure that the Agency is engaged in family-centred practice.

How should the rules support innovative approaches to early intervention and balance this with the need to get the best outcomes for people with disability and for the scheme to be accountable and sustainable?

It is vital that the Rules support innovation, quality, continuous improvement, contemporary best practice and effectiveness. ECIA is keen to work with the parties involved regarding how best practice will be demonstrated and what evidence base will be drawn upon, particularly in relation to early childhood intervention. ECIA would like to reinforce that the importance of high quality and tested evidence cannot be underestimated, particularly given the NDIS’s move towards more individualized funding approaches. The NDIS presents a valuable opportunity to invest in expanding the body of knowledge regarding early childhood intervention best practice and explore new and innovative ways of service delivery. However, the Rules must prescribe innovative practice has a mandatory evaluation component. This will enable service providers to draw on, build upon and grow best practice models and research when developing, promoting and delivering their services to participants.

It is important that the Rules don’t just focus on the importance of engaging in best practice but also ‘how’ best practice is being implemented.

A recent example of how this has been recently done is through the National Health and Medical Research Council guide to the development, evaluation and implementation of clinical practice guidelines. This provides a model of sorts to judge an evidence base. It is also important that clinical wisdom should be considered in addition to research.
What criteria should be included in the rules to assist determining if an intervention strengthens the sustainability of informal support?

Strengthening the sustainability of informal support is at the core of what early childhood intervention is out to achieve and this has been articulated throughout our submission.

Appropriate outcomes measures that are used in early childhood intervention pre and post an intervention episode, to determine if the services offered are making a difference to families, that could include:

- The Family Quality of Life Survey is a measure of outcomes of service delivery. This survey measures the quality of life of a family having a family member with a disability;\(^\text{11}\)
- The Parental Stress Scale measures parent stress;\(^\text{12}\)
- The Family Quality of Life measure by Robin McWilliam (unpublished but is available);\(^\text{13}\) and,

The Measure of Engagement, Independence, and Social Relationships (MEISR) by McWilliam can also be used\(^\text{14}\).

What criteria should be applied to determine ‘evidence-based’ assessment of the benefits of early intervention?

The NDIS needs to communicate best practice, so that when people are making choices about the types of service models and interventions they wish to access in a user pays environment, they are informed by the evidence. In relation to the evidence, ECIA would like to draw attention to the following sources of evidence on best practice, in particular the Centre for Community Child Health’s 2010 Early Childhood Intervention Literature Revised. This literature review is informing service delivery directions in all jurisdictions and should be central to informing reasonable and necessary supports for young children under the NDIS. Innovation builds on best practice. All services funded under an NDIS should be able to demonstrate best practice based on the Literature Review for example.

Early childhood intervention for children with a disability or developmental delay is not simply about ‘treating’ children\(^\text{15}\). In early childhood intervention the evidence demonstrates a move towards a

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\(^{13}\) McWilliam, R. (2005) Family Quality of Life (FaQOL), Vanderbilt University Medical Centre, [available online] http://www.siskin.org/downloads/FaQOLPaperQuestionnaire.pdf


trans-disciplinary key worker model, where interventions are based on routines and undertaken in natural environments predominantly by primary carers, with consultation and coaching from specialists\textsuperscript{16}. Communicating this model has been a challenge in ECI and while practice has shifted, many consumers are after a more traditional ‘therapy or medical model’ even though this may not be current best practice thinking. This appears to be the model currently reflected in the Act and other thinking regarding the NDIS. This can in part be attributed to the fact the evidence has not been broadly communicated and translated in meaningful ways. This shift in thinking must occur under an NDIS if we are to enable consumers and the community. The NDIS must be mindful of the medical, health, social, learning and development needs of participants.

**Participants’ Plans**

**Reasonable and necessary supports**

**Rules**

14. The methods or criteria for deciding which supports will be funded or provided. Clause (35 (1)(a)

15. The supports that will not be funded or provided under the NDIS. Clause 35(1)(b)

16. The supports that will not be funded or provided under the NDIS for certain participants. Clause 35(1)(c)

17. The methods or criteria for assessing the supports that will be funded may also include methods or criteria relating to the manner in which the supports are to be funded and by whom these supports will be provided. Clause 35(2); 35(3)

18. The methods or criteria for providing supports may also include methods on how to take in to account compensation payments. Clauses 35(4); 35(5)

**Questions**

*What methods or criteria should be used to determine those supports that would not be provided or funded by the NDIS, based on the criteria set out in clauses 34 and 35 of the Bill?*

ECIA believes that any supports that do not demonstrate best practice should not be able to be funded under an NDIS. This already occurs for the majority of block funded services in the current system. For


\textsuperscript{16} Centre for Community Child Health. (2010) Early childhood intervention reform project: Revised literature Review, DEECD, Melbourne.;

example, to be a funding ECI provider in Victoria, agencies have to demonstrate they meet the following best practice ECI features:

- **Family Centred Practices** that recognise and build on family strengths, increase confidence, and assist families to make informed choices and build family capacity to meet the needs of their children.
- **The provision of services in everyday family environments** to promote naturally occurring learning and development opportunities.
- **The provision of services in early childhood education and care settings** to promote sustainable inclusive learning and development opportunities, and build the confidence of ECEC staff to meet the needs of children with disabilities or developmental delays.
- **Responsiveness to the diversity of families**, including vulnerable families, families who identify as Aboriginal or Torres Strait Islander background, and those who are from cultural and linguistically diverse backgrounds.
- **The provision of information, support and resources in a collaborative, timely and effective manner.**
- **Maximising the use of universal and other targeted services** to support an integrated children’s services system that can respond to the needs of families of children who have a disability or developmental delay.
- **Use of a Key Worker approach** supported by a trans-disciplinary team that includes a range of suitable qualified specialists.  

It is vital that the Rules outline the parameters for each area of service delivery, such as early childhood intervention, respite, etc., that is based on best practice evidence.

**Are there any issues that are not covered by these proposed topics for determining reasonable and necessary supports that should be?**

When thinking about reasonable and necessary supports for young children and their families it is important to have a thorough understanding of what early childhood intervention encompasses. Early childhood intervention can provide learning opportunities and developmental programming; routines based interventions, support for inclusion, family support, service planning and coordination, assistance and support to access services such as kindergarten and child care. Services are tailored to meet the individual needs of the child and their family and are focused on supporting the child in their natural environments and in their everyday experiences and activities.

These components of support need to be reflected in the criteria for reasonable and necessary support. This could be done through adding in reference to: the importance of maximizing children’s development; supporting their capacity to engage in play and developmental tasks; enhancing their inclusion in mainstream services; and, providing families with the opportunity to support their child’s developmental opportunities. These supports need to be explicitly accounted for in the NDIS

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17 Victorian Government tender for ECIS places - February 2013. (not publicly available)
description of reasonable and necessary support for young children with developmental delays or disabilities. As previously discussed, using the ICF-CY will assist in this process.

ECIA would like to see it guaranteed that young children and their families receive trans-disciplinary support under an NDIS as this will ensure service coordination. One option could be the allocation of predetermined packages for young children, such as the key worker model described throughout this submission, delivered by registered providers; this could then be supplemented by client/family directed components. This would then ensure that all young children are receiving best practice support. This approach would allow for flexibility within the plan to provide responsive services that the family requires. It is important that reasonable and necessary supports that are determined are not overly prescriptive on amounts of sessions and therapy types. The needs of young children emerge and change and whilst well covered under the umbrella of early childhood intervention, should not be sliced up into a specific number of sessions of a particular type of therapy.

Management of Plans

**Rules**

19. Criteria for determining whether a participant managing a matter would present an unreasonable risk to the participant. Clause 44(3)

20. Particular matters within a participant’s plan that must not be managed by the participant. Clause 44(2)(b)

21. Circumstances which would require a review of a participant’s plan to be automatically triggered. Clause 48(6)

**Questions**

*What criteria should be used by the Agency in deciding whether there is an unreasonable risk for the participant in self-managing funding?*

In the case of young children, age will be a factor if the child is seen as the participant. This is why viewing the family as the participant is important. Family functioning should be assessed, along with how to best include the voice of the child where relevant. Other criteria that could also be used could encompass: the literacy skills of the family; the intellectual capacity of care givers; access to information; and so on. A key worker would also have the capacity to mitigate much of the risk, working in partnership with the family.

Families who have come into the system via a child protection authority for example may need additional assistance with selecting services for their child. If rigorous quality assurance and provider registration processes are established, then vulnerable families will not be taken advantage of.

*What flexibility should a person have in making changes to their support arrangements without requiring a review of the plan?*
Family circumstances change and evolve. This is why we support the allocation of a key worker to all families of young children who can support flexibility and plan evolution as required. Families would be able to work with the Agency to select a key worker that meets the needs of their child and family.

It is important that in determining the reasonable and necessary supports for a child and their family plans are flexible enough for changes in circumstances. It is important that the process for relatively minor changes in plans can be made easily (perhaps online or over the telephone) and that this process of making changes does not become a barrier for the child and family accessing the supports they need.

**What circumstances should trigger an automatic review of a person’s plan?**

Yearly or biennial review may not be appropriate for children. For example the difference between a newborn baby’s functioning compared with that of a two year old is significant. The needs of young children need to be constantly reassessed. The NDIS planning process needs to recognise that the child is developing and changing and that services will need to have high levels of flexibility to accommodate this.

This is why the allocation of funds to a key worker model to all young children in the NDIS would be ideal, as it will provide children and their family’s access to a trans-disciplinary team of professionals and an agency that can evolve and change the service based on a team approach to continual assessment.

**What matters within a participant’s plan must not be managed by the participant?**

This would need to be considered on an individual basis, based on the strengths and interests of the family, along with the known risks.

**How can the concept of ‘dignity in risk’ inform the development of these rules?**

We cannot underestimate the importance of the provision of high quality and evidence-based information. Informed choice and decision making needs to be taken into account when developing the Rules. The participant, or in the case of young children their families, should then be able to manage most of their plan unless they request assistance. Also, should a key worker model be adopted, they would play a role in supporting the family with plan management.

The dignity in risk issue has additional complexities when we are talking about a parent taking risks on behalf of their child. Whilst parents know their child best and have the rights to make choices about the supports they access, there needs to be acknowledgment that supports funded by the government should be supports that have an evidence base that leads to a positive outcome. Whilst there is dignity in risk the government should not be funding supports that are in themselves overly risky.
Information sharing

**Rules**

22. Prescribing State or Territory laws under which a person would not be required to provide information to the Agency. Clause 58(2)

23. Making provision for the Agency to disclose information in the public interest. Clause 66(2)

24. Making provision for the Agency’s CEO to disclose information to the head of a Commonwealth or State or Territory authority. Clause 67

**Questions**

*Under what circumstances would you consider it reasonable for the CEO of the Agency to disclose information to a Commonwealth or state or territory authority?*

*Are there any other protections for information that are not covered?*

*How do we strike the right balance between making sure people don’t have to repeat their story and personal information, and making sure people’s’ privacy is respected at all times?*

There needs to be a balance between respecting a child and family’s privacy, but also reinforcing the importance of the delivery of holistic wraparound services.

Unless there are extenuating circumstances, such as a child protection matter, participants (in early childhood intervention, the family or carer) should have to provide permission for their information to be communicated and for what purpose.

We cannot underestimate the significance of transitions, and important that time is provided for all of those involved in transition to engage in the process and to share materials and information, for example at the transition from early childhood intervention and ECEC, to school. Information needs to be shared so that stories aren’t told multiple times but families need to be engaged and aware of what information is being shared and why.

**Registered providers of support**

**Rules**

25. Criteria for registering or revoking the registration of a service provider to deliver supports or a class of supports, including whether compliance with safeguards or quality assurance standards and procedures or qualifications of employees is required. Clauses 70(1)(d); 72; 73(1)

26. Prescribing the consequences of registered providers failing to comply with the NDIS Act, regulations or rules. Clause 73(2)(a)
Questions

What would be appropriate criteria for registering a service provider to deliver different types of supports?

In relation to early childhood intervention, such as the previously discussed criteria currently used by the Victorian Government in engaging service providers that is based on best practice evidence should be used, as should demonstrated experience in delivering ECI. Experience and expertise in working with children and families is important to be a provider of services for children, and need to be specified separately to the registration process for adult providers.

Service providers should also have to meet quality measures that are relevant to the services that they are delivering. For early childhood intervention for example service providers should have to meet relevant prescribed safeguards and quality assurance standards and procedures.

How can the Scheme ensure that providers don’t have to go through a lot of red tape, while also ensuring that services are of a standard and quality to best support people with disability?

Good contracting processes and robust quality standards and registration processes are vital.

In ECIA’s opinion quality measures need to draw on more than the Disability Standards and standards relating to corporate governance and financial accountability. ECIA would like to see any standards draw also on recognized early childhood learning and development best practice, such as the National Quality Framework which includes the Early Years Learning Framework. An example of this is in NSW where the disability standards have been matched to the NQF for children’s services and gaps identified.

For not for profit organisations that are either registered as an association in their State and Territory jurisdiction, or a charitable entity registered with the Australian Charities and Not-for-Profit Commission, they should only have to provide information that is additional to that provided to these agencies. The purpose of organisations such as the ACNC was to reduce red tape for not-for-profit organisations, so it is hoped that the NDIS will not add additional and repetitive processes.

What registration information should the agency collect from registered providers of supports that will promote the policy objectives of the NDIS Act to enable people with disability to exercise choice and control?

Please refer to our response to the previous question regarding the criteria to assess the value of early intervention. These measures would provide suitable and evidence based data collection frameworks.
**What registration information should the agency collect from registered providers of supports that will build data for public evidence based decision making?**

While existing compliance, governance and financial data are important, it is also important that the public are aware of how they meet best practice evidence in their service delivery. Ongoing data collection on child and family outcomes for those who are accessing the registered service provider will be important, as will their relevant quality assurance ratings.

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**Children**

**Rules**

29. Criteria for appointing someone other than the person with parental responsibility to act on behalf of a child. Clause 74(6)(a)

30. Criteria for deciding whether a person managing the funding for supports would present an unreasonable risk to the participant (child). Clause 74(6)(b)

31. Criteria to use when making a determination as to whether a child is capable of making decisions. Clause 74(6)(c)

32. Criteria for determining who has parental responsibility when there is more than one potential person. Clause 75(4)

33. Prescribe other duties to support decision-making by the child or give appropriate weight to the views of the child. Clauses 76(4)(a); 76(4)(b)

**Questions**

**What criteria would a decision-maker need to take into account to appoint someone other than a parent to act on behalf of a child or young person?**

ECIA welcomes the separate section that refers explicitly to children. ECIA would like to see *UN Convention of the Rights of the Child* referred to in this section. Article 2 and Article 23 of the Convention in particular focus on the needs of children with a disability and it is vital that the Act, NDIS rules and also the universal service system adhere to the Convention of the Rights of the Child when operating under the NDIS.


This section of the Act could also provide Act definitions that are specific to children and their families, such as the definition of participant to encompass children aged 0-6 and their families for example.
This would be the criteria then that decision makers could take into account when determining child safety and decision making rights. In addition, other legislative requirements, such as child protection, guardianship and custody orders would also need to be adhered to.

**What criteria should be considered in deciding to exclude a child or young person under the age of 18 from being involved in decisions about the support they receive?**

This would need to be based on individual situations and that the main premise would be children are involved, unless it is deemed that they are unable to make or be involved in these decisions. It will be a developmental process as well, due to the age of the child over time and what you would expect from typical children determining their own lifestyles. The ICF-CY provides a useful framework to measure functionality and this can inform the child’s capacity to participate in decision making.

**What additional supports should be given to a decision-maker to ensure that a child or young person under the age of 18 is involved in decisions about the support they receive?**

Investing in independent advocacy is crucial, particularly in either supporting children and young people to be self-advocates or through the funding and appointment of independent advocates that have expertise in working with children and young people. Investment in robust and independent advocacy for participants will go a long way to ensuring the long-term success, sustainability and quality of the NDIS. It will enable continuous improvement and provide safeguards and a voice to vulnerable participants and their families. If independent advocacy is not funded either as part of or alongside the NDIS we will be doing considerable disservice to the integrity of the scheme.

It is important to be mindful that ECIA represents young children under school age, some of whom are newborns for example, and they have a specific set of circumstances and development at this age.

However, if children are unable to be involved in decision making due to age or level of functioning as determined by the ICF-CY, decision makers should also have to demonstrate how they have consulted with the child or young person, or taken the relevant evidence and expert opinion into account.

Decision makers should also be encouraged to ask children and young people how they feel about the process and their care, what are their likes, dislikes and impressions. Key workers will play a crucial role in this process.

**What additional supports should be given to a child or young person under the age of 18 to ensure that they are involved in decisions about the support they receive?**

ECIA would like to draw attention to the important of ensuring children’s involvement in decision making. The National Early Years Learning Framework (EYLF) talks about the importance of all children having a strong sense of ‘identity’ and we would encourage the Rules and the work of the Agency in plan development and management to draw on the outcomes detailed in the EYLF.
“Belonging, being and becoming are integral parts of identity…. When children participate collaboratively in everyday routines, events and experiences and have opportunities to contribute to decisions, they learn to live interdependently.”18

What additional supports should be given to a parent or guardian to ensure that a child or young person under the age of 18 is involved in decisions about the support they receive?

This is where the importance of the allocation of a key worker, who is able to work with both the child and their family, cannot be underestimated. A key worker will be able to support the parent or guardian to involve their young child, as best is possible, in decision making.

How can we best reflect the fact that as children and young people with disability get older, like all children and young people, they may want to have more say in what they do, and the care and support they receive?

This is why it is important to refer back to the Convention on the Rights of the Child, and also why developing best interests principles for children under the NDIS is a good idea. Mechanisms such as these will help reflect and guide the inclusion and empowerment of children and young people in decisions that affect their lives.

What is the best way for children and young people to be encouraged to express their views about the support that they receive?

Children need to be active participants in the supports they receive.

How can we best ensure that the views of children and young people under the age under 18 are regularly reviewed without being obtrusive?

In early childhood education and care environments, both parent and child surveys are sent out regularly as part of their accreditation process. Obviously the child surveys are more informal with feedback (such as a story written or picture drawn after an excursion to describe what they liked) for school aged children, or for very young children the National Early Years Learning Framework is all about following the child’s lead and interests in determining what experiences to put out or continue with. Any communication needs to be at the child’s level through facial expressions, key word signing, visuals and so on. Some resources on listening to children have been developed in the UK, including one on listening to children with a disability and it can be found here - http://www.ncb.org.uk/media/74024/listening_to_young_disabled_children.pdf.

Supporting decision-making

**Rules**

34. Criteria to be considered in deciding to appoint a nominee. Clause 88(6)(b)

35. Requirements and matters to consider in the appointment, suspension or cancellation of nominees. Clauses 93(a); 93(b)

36. Prescribing who must not be appointed as a nominee. Clause 88(6)(a)

37. Prescribing additional duties of nominees to support decision making by the participant personally or to give appropriate weight to the participant’s views. Clauses 80(4)(a); 80(4)(b)

**Note:** The NDIS rules will need to take account of differing arrangements for assisted or substituted decision making across State and Territory jurisdictions.

**Questions**

What criteria should guide the decision to appoint a nominee?

What criteria should be used to select an appropriate nominee?

How can a nominee demonstrate thorough knowledge and understanding of the participant’s wishes, goals and life aspirations?

How can we test that the decisions of a nominee are reasonably those the person would have made if they had the capacity to do so?

What should be in place to allow these arrangements to change?

Who should not be appointed as a nominee?

Other than duties to support decision making by the participant personally or to give appropriate weight to the participant’s views, what additional duties should be prescribed to nominees?

Should the appointment of nominees be for a fixed period or should there be a regular review of the arrangements to ensure the person with disability is satisfied with their nominee arrangements?

How can we ensure that the nominee arrangements continue to build the decision making capacity of people with a disability.

In the case of very young children it is generally their parent or guardian that makes decisions regarding their care, so it would be rare for a nominee to be appointed for a child, except in the circumstances where the parent may have limited functional capacity or if they were under state care and there was a court ordered legal guardian appointed, as described in the previous section. It is important that if a nominee is appointed for a child that the person know the child well, be able to communicate with the child and hopefully work with the child’s support network. We also need to
consider that if the client in an early childhood intervention context under the NDIS is both the child and their family then there may be a need for supported decision making in the case where a carer has a disability and is making decisions for the child.

**Compensation**

### Rules

38. The treatment of compensation payments in determining reasonable and necessary supports provided by the NDIS. Clause 35(4)(5)

39. Criteria for taking into account other amounts that a participant (or prospective participant) did not receive by way of compensation payments because they entered into an agreement to give up their right to compensation. Clause 35(5)

40. The Commonwealth, State or Territory laws to be set out in the NDIS rules that need to be considered in determining what if any, past NDIS payments can be recovered from a compensation payment made after the NDIS amounts were paid. Clause 106(5)(b)(iv)

### Question

*How should compensation payments for care and support be treated in working out how much care and support should be provided by the NDIS?*

ECIA has no additional comments in this area.

### Conclusion

ECIA values the ongoing opportunity to contribute to the discussions regarding the development and implementation of the NDIS. It is vital that the particular needs of young children with a disability and developmental delay and their families are reflected in the Rules, particularly given the life-long positive impact high quality ECI can have on the lives of children, their families and the community.

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