



ISSUES PAPER

**Drawn from discussions at the
Children, their Families and NDIS Forum,
November 2013**

**Joint Forum Partners –
National Disability Services,
Centre for Excellence in Child and Family Welfare,
Early Childhood Intervention Australia (Victorian Chapter)**

Background

In November 2012, National Disability Services, the Centre for Excellence in Child and Family Welfare and Early Childhood Intervention Australian Victorian Chapter hosted a three hour forum addressing Children, their Families and NDIS.

The aim of the forum was to engage representatives from Early Childhood Intervention services, children's disability services operating in the Barwon Region, relevant government staff and other stakeholders to:

- Consider the range of issues arising in relation to services for children and their families in the context of the NDIS
- Identify areas of concern; areas requiring further investigation, and valuable aspects of the existing service system which could be incorporated into NDIS
- Contribute to key recommendations compiled from Forum feedback and provide to NDIA, government, peak bodies and service providers to further inform relevant development work.

A summary report of the forum is available on the NDS website:

<http://www.nds.org.au/publications?s=VIC>

This paper summarises the key issues raised at the Forum, which were:

- Support for NDIS
- Need to retain family focus and trans disciplinary collaboration
- Empowerment of families
- Choice
- Outcomes
- Evidence
- Inclusion and universal services
- Appropriate expertise / workforce
- Transitions
- Safeguards and Quality Standards
- Funding, Accountability and Monitoring
- Cohorts with particular needs

Key Themes and Issues

Support for NDIS

The NDIS and additional investment in disability is strongly welcomed by many working in the disability and early intervention fields. However, forum participants identified an array of questions, concerns and issues in relation to development of the NDIS and children's services.

Need to retain family focus and trans disciplinary collaboration

There is a need to retain the current strong Victorian emphasis on family centered practice. Such practice is well supported by evidence demonstrating its efficacy. There is concern that the NDIS focus on individuals may lead to funding being directed to individual therapy for a child rather than support for the family. Examples were given of how such a market model can lead to a plethora of individual therapists, rather than use of the key worker model currently used in Victoria. There is a real question as to how NDIS will strike the balance between needs of families and needs of the individual child?

Furthermore the current service system supports collaboration between professionals and disciplines. What drivers can be used within an NDIS system to similarly encourage cross professional collaboration?

There is concern about where Early Childhood Intervention Services (ECIS) will fit within NDIS? Will they be shifted to operating as disability services rather than maintain their focus on being universal and inclusive services?

In addition to ECIS services the NDIS also needs to understand the explicit needs to children once they transition out of early childhood intervention until they are 18. Middle childhood and adolescence are key transition points for children and young people, and are a time when crucial neurological development is occurring.

Empowerment of Families

The empowerment of families is a key issue. Families need to navigate a complex system and face an array of options and choices. This is why all services for children and young people, funded under an NDIS, need to work from a strengths-based and family-centred approach. Service delivery must be about working in partnership with families as an extension of existing family support, that focusses on improving families' quality of life and support children to developing skills and abilities to fully participate in family and community life. Many Early Intervention services see their key role as one of empowering the parent so the parent can start empowering the child. This is undertaken through working with natural environments using a strengths based model, and building the capacity of the family within their daily routines and resources. The skills gained through this process are then used by the parents and ultimately the child right through life, and in their navigation of the system.

Good information and education for families is important, along with the valuable role of independent advocacy, and particularly advocacy dedicated to children and young people. Parents of newly diagnosed children are required to make an array of choices, and need very early and

timely support and information, both about the processes and options. What are the best ways of providing such information, to families already overburdened with demands? The need to empower parents with children in the school system was also highlighted, as many such parents experience a sense of 'lack of control' at this stage of their children's lives.

The extent of family support currently provided in Victoria needs to continue with the transition to NDIS. Support for families needs to be included in both the assessment and planning processes; and be available to families without diminishment of services to their child. It needs to be built into all therapists roles, with retention of the use of family support plans. In Family Centred Practice, it is not about giving families everything they want, but working as equal partners with professionals and then making the ultimate decisions.

Another important aspect of empowerment is the ability for families to raise issues and have an independent complaint resolution process.

Choice

Choice is regarded as a positive tenant in the move to a NDIS. However what limitations should be put on choice for a family where the evidence does not support their choice of therapy or intervention? How does individual choice relate to the need for family support and community inclusion within the supports for a child?

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 practice¹. 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.

It is recognized that Early Intervention services need to significant improve their marketing and promotion of the benefits of an integrated and multidisciplinary key worker model, particularly given the relative ease of selecting a single therapist over a team package. Services need to focus on educating and engaging the broader community, including medical professionals such as pediatricians and GPs.

Outcomes

NDIS needs to work within an outcomes framework; one that reflects the social expectations for all children and families, and considers the best interest of children within the context of the broader human rights of the child. The NDIS needs to acknowledge Australia's obligations under the *Convention on the Rights of the Child*. Article 2 and Article 23 in particular focus on the needs of

¹ Centre for Community Child Health. (2010) Early childhood intervention reform project: Revised literature Review, DEECD, Melbourne.

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. We need to develop and support the environments around children that enable them to develop the functional skills they require in order to participate meaningfully in society, as children, young people and then as adults. This will require consideration of both the outcomes for the child and the family.

Outcomes have a crucial link to quality. Any standards that are developed under the NDIS need to recognize early childhood learning and development best practice, such as the National Quality Framework and 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. The Victorian Early Years Learning Framework, with its focus on outcomes for all children, rather than just children with disabilities, remains valuable. It is not just early childhood frameworks that need to be considered, it is also education frameworks that can be drawn up to ensure that the specific outcomes of school aged children are addressed.

The NDIS is a means to an end, and there needs to be a focus on this end in the development of all aspects of the NDIS, and all funding decisions. For example the concept of 'reasonable and necessary' supports being provided by the NDIS needs to be interpreted with a human rights lens, and against a clear outcomes framework for children.

Evidence

The development of a strong evidence basis relating to early intervention strategies will be critical given the NDIS social insurance model, and the need to demonstrate clear efficacy to justify financial investment. Yet at present we lack a substantial evidence base in relation to various therapy options. There will need to be substantial work to build such a base, and in the meantime, how will NDIS weight the evidence regarding particular interventions with the right of choice for a family?

There is a tension between requirements for evidence of efficacy and the need to allow for development of innovative responses. Both are important, and a balance needs to be achieved. Similarly, it will be important to achieve a balance in weighting between self-assessments and professional assessment. It was noted that the modern approach to evidence based practice takes into account all perspectives of what is working, and particularly the families' perspectives.

Concern was expressed that in a market environment, it will be those services with the most attractive packages and promotion that may be chosen by families rather than those with the strongest evidence base.

Inclusion and Universal Services

There is real concern about the interface between NDIS and universal services. There needs to be, under the NDIS, a mandated obligation for the inclusion of all children in universal services, particularly in early childhood education and care (ECEC), schools and health services.

In Victoria significant gains have been made in getting specialized services into universal services, such as childcare and schools, and this move needs to be supported and extended. It is noted that in

Victoria, ECIS is currently located within the Department of Education and Early Childhood Development, thus within an organisation with a universal focus.

The Local Area Coordinators will need to focus beyond a 'person-centred approach' when working with children and adopt a holistic approach to 'keeping life on track' and connected to community rather than 'sucked into disability vortex'.

The role of universal services such as schools, health services, or in the case of pre-school aged children, ECEC services is vital to ensuring that all children achieve adequate outcomes. 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 the draft Act and supplementary documentation do not articulate how universal services will be resourced and monitored to ensure the inclusion of all children. 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 Act. 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*.

There is also a need for NDIS systems to engage with other service systems that may be working with vulnerable families, including non-disability specific agencies.

It is recognized that the universal service system will be supporting many people who are not eligible for NDIS packages, and there needs to be continued investment and development of this system to improve its response to people with disabilities. There also needs to be continued requirements on universal services to be accountable for their accessibility for children with a disability – there is concern that universal services may shift responsibility for people with disabilities to the NDIA funded services, especially for services for children aged 7 – 18.

The significance of community inclusion for children needs to be heavily weighted in decisions regarding 'reasonable and necessary'. An example was provided of the Better Start program funding therapy for a child, but not a car seat to transport child. It was argued that funding for a car may be more effective for community access than other uses of funding.

Appropriate Expertise / Workforce

The provision of services to children requires specialist knowledge, and it is important that the NDIA and local area coordinators (LACs) employ appropriate expertise. There needs to be people with knowledge and expertise to support the family appropriately, to know them and support them to make decisions around what they need and want to reflect where the child and family is at that time. It is vital that a number of LAC's have early childhood qualifications; this will inform a holistic approach.

The value of a skilled key worker or case managers was highlighted, along with their knowledge base regarding who has a trusting relationships with the family; the adaptations around having a child

with a disability; a good understanding of the family culture and good connection with the family. Implementation of effective strategies for the family often require such a relationship.

Workforce challenges will be an issue under an NDIS; including recruitment and retention of sufficient skilled workers; maintenance of specialist expertise; and provision of appropriate career paths.

Transitions

Transitions are a critical issue in the provision of early intervention and disability services to children. Participants discussed the transition from early intervention to school services; pediatric to adult services; and highlighted the challenges facing teenagers. There needs to be proactive preparation before such transitions, rather than interventions solely provided during or after transitions, wherever possible.

One point of transition is when the family moves between the medical and disability models, and require good support immediately prior to and upon diagnosis, with good education of the pediatric medical community and connections between hospital and the ECI services.

At present in Victoria children tend to be better supported in the early years of education, and then receive less support as they move through the system. By the time they are 16 some teenagers with disabilities are receiving minimal support. There are examples of parents relinquishing young people so they can obtain accommodation within the adult system. It is hoped that the the NDIS will address some of the current problems at transition points, and the diminution of service during the critical school and teenage years.

Safeguards and Quality Standards

There is support for strong safeguards, and use of an independent complaints system to improve service quality. Forum Participants welcomed the continuation of the roles of Community Visitors and the Disability Services Commissioner and the Critical Incidents Reporting framework operating in Victoria. Concern was expressed about what safeguards would exist for services which are self-managed and in private homes.

Support was expressed for an independent quality accreditation system, applicable to both nonprofit and private providers will be critical to assisting families in their choices. Such a system will need appropriate expertise in regard to services for children.

Quality measures need to draw on more than the Disability Standards and standards relating to corporate governance and financial accountability. Standards should also draw on recognized early childhood learning and development best practice, such as the National Quality Framework and 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.

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. There also needs to be robust and neutral dispute resolution process and complaints mechanisms.

Funding, Accountability and Monitoring

There are a range of infrastructure and services which will need to be block funded under NDIS. This includes: advice and advocacy; sector capacity building; some of the recreation and school holiday programs particularly for 7-18 year olds, as well as social inclusion and community development activities.

There is recognition of the need for clear accountability of services and monitoring under an NDIS, and many questions about the details of this remain.

Cohorts with particular needs

Concern was expressed for how children in a range of cohorts will be supported under NDIS, including:

- children with disability in foster and residential care
- indigenous children
- children from CALD and other marginalised groups (questions around funding for interpreters)
- rural and regional families (how realistic is the concept of choice?)
- will these families have 'choice'?
- children currently supported by specialist programs such as specialist Royal Children's Hospital; Family Choices for children with high medical needs

Note: The points articulated in this paper summarise the comments made at the Forum, and may not fully reflect the positions of the three organisations which convened the Forum: National Disability Services; Centre for Excellence in Child and Family Welfare; and Early Childhood Intervention Australia (Victorian Chapter).