Independent Advisory Council
to the NDIS

Promoting best practice in Early Childhood Intervention in the NDIS

March 2020

Table of Contents

Purpose of the paper

The purpose of this paper is to advise the NDIA Board as to how refresh the Early Childhood Early Intervention Approach (ECEI) Approach deepening its understandings of the needs of children and families, so that young children disability and their families experience best practice early childhood intervention (ECI) to maximise their independence, and inclusion.

The paper will address key questions of:

- the nature of best practice and ways to harmonise best practice guidance for all children in the ECEI Pathway
- whether the ECEI as currently operating provides a framework for best practice Early Childhood Intervention (ECI) in ways that are sustainable for the NDIS
- whether there has been an erosion of best practice under the NDIS; and
- what best practice would look like in participant planning and budget.

Acronyms

ABA Applied Behavioural Analysis

ASD Autism Spectrum Disorder

ECI Early Childhood Intervention

ECEI Early Childhood Early Intervention

EIBI Early Intensive Behavioural Intervention

1. BACKGROUND

Context

The Early Intervention Foundation[1] endorses supporting children and young people as a social and economic priority demonstrating that stepping in early to provide evidence-based support for children can make a significant difference in children's lives and reduce demand for high-intensity and crisis services over time. Early intervention works by:

- preventing problems occurring in the first place
- tackling problems holistically and assertively when they first arise, before they get more difficult to resolve
- fostering the strengths and skills that ensure children and young people have the best opportunity to thrive and can participate in, and contribute to, their communities.[2]

Consistent with this framework, Early Childhood Intervention (ECI) is the term used in the disability community for a process of providing specialised support and services for infants and young children with disability and/or developmental delay, and their families, in order to promote development, well-being and community participation.[3] Replacing inconsistent state and territory provision, the NDIS built an Early Childhood Early Intervention (ECEI) Approach that is 'based on insurance principles, community inclusion, strengthening mainstream response and evidence-based practice, with the primary focus on the education and capacity building of families, delivered by skilled providers.[4]

S25 of the NDIS Act is the foundation of the ECEI Approach, enabling the NDIS to provide early intervention supports if satisfied that the early intervention will alleviate the impact of the person's impairment on their functional capacity, improve their functional capacity and strengthen the sustainability of informal supports including through building the capacity of the family. The aim is to develop nationally consistent practice to ensure that children receive timely support that is strengths-based, outcomes-focused and builds the capacity of the family to support the participation and inclusion of their child. Key to the approach is ensuring that any family concerned about the development of their child can access information, support, referral and short-term early intervention support where appropriate, and only those children who require longer term early intervention support become NDIS participants.

The NDIA response to very young children is currently an issue of prominence following criticism from parents and advocates of long wait times, challenges in navigating the system and inequitable access for families who experience multiple disadvantage such as families of Aboriginal and CALD background, families in rural and remote areas, families in which the

[1] https://www.eif.org.uk
[2] Teager, W, Fox, S and Stafford, N, *How Australia can invest early and return more: A new look at the $15b cost and opportunity.* Early Intervention Foundation, The Front Project and CoLab at the Telethon Kids Institute, Australia, 2019 P6
[3] Early Childhood Intervention Australia, (2016) National Guidelines for Best Practice Early Childhood Intervention p4
[4] NDIS submission to the Joint Standing Committee on the NDIS (2017) Inquiry into the Early Childhood Intervention Approach under the NDIS. Accessed https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/EarlyChildhood 15 Feb 2020

primary carer has a disability or requires complex mental health support and children in out-of-home care.[5] There have also been challenges from research and peak bodies that best practice knowledge and skills are being eroded under the NDIS[6] and concerns identified by NDIA actuarial analysis that the structure and process of the ECEI Pathway may have led to perverse practices with detriments to children, families and the NDIS.

There have also been challenges arising from debate as to whether the purpose of ECI is to 'fix' the child, promote the child's participation and inclusion or whether families should be able to expect progress in both spheres. These tensions are seen most clearly in relation to some voices around children with Autism Spectrum Disorder (ASD) and have implications related to who provides specialist support and the efficacy of clinical and natural settings.

[5] Arefadib, N. & Moore, T, (2019) *Realising the Potential: Early Childhood Intervention under the NDIS.* Prepared for the Victorian Department of Education and Training. Parkville, Victoria: Centre for Community Child Health, Murdock Children's Institute p3

[6] Arefadib, N. & Moore, T, (2019) p10

2. HARMONISING BEST PRACTICE FOR ALL CHILDREN IN ECEI

Synopsis

This section summarises the elements of early intervention that deliver optimal outcomes for children outlining:

- *the tension between general ECI practice guidance and that for children with ASD*
- *contemporary evidence in relation to delivering optimal outcomes in ECI*
- *contemporary evidence in relation to good practice in ECI for children with ASD in Australia and comparing it with contemporary evidence in NZ, UK, Scotland and US*
- *a comparison of broader ECI guidelines with those of ECI for children with ASD.*

The analysis concludes that:

1. *There is significant similarity between general practice guidance for ECI and that for children with ASD.*
    a. *Similarities relate to the importance of family-centred practice that is culturally appropriate, strengths-based, capacity building and outcomes-focused and delivered via a collaborative team approach*
    b. *Differences relate to the individualised nature and weight given to specialist versus capacity building focuses.*
2. *Australian guidance for children with ASD differs from guidance for children with ASD in UK, Scotland, US and NZ in its focus on:*
    a. *staff ratios and 'fixing the child' with less focus on working with the child, family and carers to respond to developmental needs in natural environments*
    b. *transition to opportunities for interaction with peers rather than on staff supporting parents and carers especially of very young children in the home, in child care and other natural settings*
    c. *in summary Australian guidance appears to prioritise expert intervention to get the child ready for participation where international guidance for children with ASD promotes the use of experts to guide parents and carers in natural settings.*

The IAC recommends the development of new practice guidelines for children with ASD to support best practice in ways that are sustainable for the NDIS.

Preliminary observations of the tensions

The growth in the number of children with Autism Spectrum Disorder (ASD) in general and those seeking access to the NDIS in particular is highlighted regularly in the media. Reports suggest significant tension between the NDIS and representatives of the autism sector in relation to access and the nature and intensity of early intervention required to assist children with ASD. There is however, more consensus than may be inferred from media reports. The consensus is based on the long-standing commitment to and experience of the ECI sector to supporting children with ASD to develop their potential. There is significant agreement on key

principles of the importance of family-centre practice that is culturally appropriate, strengths-based, capacity building and outcomes-focused and delivered via a collaborative team approach.

It is important to note however that in Australia and overseas there is no unified position within the ASD sector and people with autism are themselves beginning to contribute their views to the debate. Reframing Autism (RA),[7] an organisation run by people with autism for example, rejects views of autism as a disease or illness that is curable or treatable, reframing autism as a brain difference, fundamental to who autistic people are. RA seeks to change the lens through which Autism is seen to recognise its strength, value and beauty.

The current tension may be understood in the context of differences based on:

- *Level of maturity of the discussion*: ECI for children with ASD came into focus with the 2008 Federal Government funding of Helping Children with Autism Program that had a therapy approach to remediating deficits. Broader ECI (that includes support for children with ASD) has developed over 50 years and now promotes a more mature discussion.
- *Different framing of disability*: Some approaches for children with ASD are framed within a more medical approach focused on 'fixing' the child, while broader best practice ECI and other approaches for children ASD are based on the social model of disability and focus on optimising participation and inclusion.
- *Different approaches to intervention*: Some approaches for children with ASD prioritise skilled implementation of a carefully planned program and this weakens priority on parents as partners and inclusion in natural settings. Broader best practice ECI prioritises building the capacity of parents and carers to use every day interactions in natural settings to build capacity.
- *Different approaches to intensity*: In programs for children with ASD, intensity usually equates to hours of skilled intervention. New Zealand guidance for children with ASD however prioritises participation and development. It measures intensity as time when the child is focused on systematically planned, developmentally appropriate activities leading toward identified outcomes,[8] thereby identifying the appropriateness of parent and carer 'interventions' with the child in natural settings such as while shopping and in the bath. Broader best practice ECI does not specifically address the issue of intensity with guidance that practice must be consistent with family priorities, choices and life.
- *Some differences in approach to family-centred practice*: Whilst all approaches focus on the importance of working with families, approaches for children with ASD tend to view families as consumers who, with assistance, can choose among the various options identified and presented by the professional (family-focused model). Broader best practice ECI views families as equal partners, with intervention individualised, flexible and responsive to the family-identified needs of each child and family. Intervention

[7] https://www.reframingautism.com.au
[8] Ministries of Health and Education (2016) New Zealand Autism Spectrum Disorder Guideline (2nd edition), Wellington p90

focuses on strengthening and supporting family functioning with families as the ultimate decision-makers (family-centred approach).[9]

- *Different levels of evidence requirements for research*: ASD research appears more rigorous than research on which the broader best practice guidelines are based. For example, ASD research reported by NICE (Scotland)[10] differentiates 8 levels of evidence from high quality meta-analyses, systematic reviews of RCTs or RCTs with very low risk of bias at one end of the continuum and non-analytic studies e.g. case reports at the other. Expert opinion is placed at a lower level. Whilst the use of control group studies appears to provide a higher level of research rigour, many studies reporting RCTs measure different outcomes from those of broader ECI research (e.g. the achievement of milestones (that may / may not be amenable to the intervention), as against participation, inclusion and quality of life of the child and family). In addition, outcomes achieved via RCT may not be replicable in the messiness of real-life situations. Research underpinning broader ECI tends to report studies that use quasi-experimental or observational methods that are more replicable in the messiness of real-life. These interventions however are not randomised and so subject to bias because the subjects differ on a range of factors that impact on the outcomes measured.
- *Different questions* posed for ECI with different weight given to skills achieved by child, measures of participation and inclusion of child and family, and measures of family sustainability.

The paper will demonstrate that the similarities between broad based approaches to ECI and those for children with ASD are greater than the differences and that the development of a new guideline for ECI support for children with ASD, their families and carers will assist in ensuring that all children with disability are supported by best practice programs in ways that are sustainable for the NDIS.

Contemporary evidence to deliver optimal outcomes in ECI

The Victorian Department of Education and Training commissioned the Centre for Community Health (CCH) to undertake a literature review of recent evidence about best practice in ECI and whether family-centred practice is still considered best practice. The report *Realising the potential: A literature review of best practices in early childhood intervention services* (the Review) provides a rapid review of contemporary developments in policy, research and practice over the past decade that are of relevance for ECI services. “These include the increasing recognition of the importance of the early years, greater awareness of the importance of responsive caregiving, increasing focus on children with disabilities, changing ideas about disability, changing models of service delivery and changing ideas about evidence”.[11]

[9] Dunst, C, Johanson, C, Trivette, C and Hamby, D, (1991) Family-oriented and early intervention policies and practices: family-centred or not? *Exceptional children*, 58, 115-126, reported in Esp-Sherwindt, M, Family-centred practice: collaboration, competency and evidence (2008) *Support for learning,* v23, n3, p137

[10] National Collaborating Centre for Mental Health, The NICE Guideline on the management and support of children and young people on the autism spectrum, Clinical Guideline Number 170, commissioned by the National Institute for Health and Care Excellence.

[11] Moore, T (2019) *Realising the potential: A Literature review of best practices in early childhood intervention services* p9

In summary, the Review affirms the central role of ECI is to promote the capacity of caregivers to support the child's learning with inclusion and participation of children with disabilities and their families in community settings that serve typical children endorsed as the right of children and as best practice. A capacity building approach is a core underpinning of best practice, not just for children, but to facilitate families on a transformational journey from surviving to thriving, personally and as advocates for their children. Recent evidence supports the use of the eight practice principles and family-centred practice in particular and deepens the understanding of ways in which best practice can be implemented.

Elements of best practice to deliver optimal outcomes

The *central goal* of ECI remains "to promote the capacity of caregivers to support the child's learning. The logic of this is that children learn most in the environments in which they spend most of their time, not in specialist intervention sessions: what happens between formal sessions is when the learning takes place'. …. The other core plank of ECI services is the inclusion and participation of children with disabilities and their families in community settings that serve typically developing children. This approach continues to be endorsed both as the right of children with disabilities and as best practice. The enhancement of participation has been described as the ultimate outcome for health and educational interventions.'[12]

Research and parent reports over the period continue to endorse *family-centred practice*, demonstrating positive outcomes for the child, parent and family with the definition of King and Chiarello used to describe key features:

> *A family-centred approach is characterized by provider practices that convey dignity and respect to families, where information is exchanged so that informed decisions can be made, where there is responsiveness to the family priorities and choices, and where collaborative family-provider partnerships are considered to be fundamentally important. The key elements of family-centred practice include an emphasis on child and family strengths rather than deficits, facilitating family choice and control, and creating a therapeutic environment that optimizes the development of a collaborative family-provider relationship.* [13]

Capacity building practices: Acknowledging, supporting and building on family member strengths are defining characteristics of family-centred practice. They serve to maximise the child's learning and to strengthen the child's future by supporting families to guide their children to lives of participation and inclusion.

Culturally sensitive practice continued to be important to best practice with cultural competence viewed as a process not an endpoint.

Inclusion and participatory practice continue to be seen as central to best practice in ECI services. Research in the period identified the three defining features of high-quality inclusion as:

[12] Moore, T (2019) Ibid p3
[13] Moore, T (2019) Ibid p36

- *Access*: removing physical barriers, providing a wide range of activities and environments, and making necessary adaptations to create opportunities for optimal development and learning for individual children.
- *Participation*: using a range of instructional and intervention approaches to promote engagement in play and learning activities, and a sense of belonging for each child.
- *Supports*: creating an infrastructure of systems-level supports for implementing high-quality inclusion.[14]

Engaging the child in natural environments continues to be regarded as a central tenet of best practice with new tools developed to assess all aspects and intensity of family's concerns and priorities to plan targeted interventions embedded in daily routines and aligned to existing beliefs, values, hopes and practices already in place.

The Review provides updated evidence to support the effectiveness of approaches that involve the use of naturalistic teaching strategies such as responsive care and teaching practices, interest based and self-directed practices and the use of everyday naturally occurring activities to provide children with multiple opportunities to practice functional skills as the means of ensuring the intensity of intervention required to achieve outcomes. The Executive Summary of *Realising the Potential* concludes however that 'it is not an either /or debate: both approaches (to change the child and to change the environment to support the child) may be needed under different circumstances.[15]

Collaborative teamwork practice continues to be endorsed as best practice by experts and families with transdisciplinary teamwork and keyworker models in which a primary service provider is backed by an interdisciplinary team favoured[16]. Families of children with disabilities often need to make use of a variety of professional services and this can be an added stress for mothers in particular. One study found that the psychological wellbeing of mothers was greatest when they had continuity of care from professionals, and steadily worsened as the number of professionals they were dealing with increased.[17]

An *outcomes-based approach* remains a central feature of ECI practice emphasising the importance of focusing on building children's functional skills, especially for children with functional impairments. The Review highlights the development and evaluation of functional, activity-focused therapy approaches that focus on family identified goals, analysis of factors within the child, task and environment that influence performance and the performance of functional tasks and activities. Research points to the need for outcome statements to increase participation from the skill developed, viewing increased participation as both and

[14] Moore, T (2019) Ibid, p39
[15] Moore, T (2019) Ibid, p4
[16] Transdisciplinary team practice means that families and professionals work together as a collaborative team sharing information, knowledge and skills across disciplinary boundaries with a key worker coordinating and doing most of the intervention
Interdisciplinary teams comprise parents and professionals from several disciplines who have formal channels of communication
In multidisciplinary teams, a range of professionals work independently with the child and have limited interaction with one another. Early Childhood Intervention Australia (2016) National Guidelines Best Practice in Early Childhood Intervention.
[17] Moore, T (2019) Ibid, p42

end in itself and a means to end of increased experiences that build social and other skills. A number of outcomes tools have been developed over the period.[18]

Assessment of the sector

The Review found that over the period, service sectors are generally moving to models consistent with family-centred care and that the greater focus on the importance of the early years reinforces the value and role of early intervention.

The Review affirmed that the Best Practices as described in the National Guidelines (at Appendix A) are consistent with corresponding statements in the US, Canada, Spain, Portugal and the UK[19] and that the overall aim of ECI as identified in the 2011 literature review conducted by the Centre for Community Child Health [20] has continued to be endorsed by all experts. The Review found however, that there is a research-to-practice gap, both in the delivery of family-centred practices and the application of up-to-date evidence-based strategies.' [21]

The Review reported that family-centred practice has been challenging to operationalise and implement consistently with parental expectations, lack of appropriate training and lack of managerial support identified as factors shortfall. The Review raised the issue of balance in relation to the role of parents: an over-reliance on parents' participation has the potential to undercut a sense of normalcy in families' lives and emphasise the child's disability.[22] The literature review noted research identifying factors that contribute to parent-professional partnerships including parents' preparedness to engage, their understanding of systems and services and the establishment of good rapport with the professional.[23]

The Review reported however that coaching has been demonstrated as an effective approach of engaging and empowering caregivers and increasing opportunities for children to practice and master skills. The period has seen the development of practice based coaching frameworks and practice guides to support early childhood practitioners to implement evidence-based teaching practices with fidelity.[24]

The Review drew attention to collaboration between Australia and NZ that is producing leading edge understandings and processes of family capacity building directed at empowering caregivers. Parent-to parent peer support is reported to have developed as a buffer to the early isolation and stress, starting parents of children with disability on a transformational journey from a 'surviving' mindset (just getting by) to a 'thriving' mindset in which parents feel supported by their peers and able to thrive, grow and flourish. Parents are reported working as peer workers, supporting other parents.[25]

[18] Moore, T (2019) Ibid, p45
[19] Moore, T (2019) Ibid, p33
[20] Centre for Community Child Health (2011), DEECD Early Childhood Intervention Reform Project: Revised Literature Review. Melbourne, Victoria: Department of Education and Early Childhood Development.
[21] Moore, T (2019) Ibid, p37
[22] Moore, T (2019) Op cit, p37
[23] Moore, T (2019) Op cit, p38
[24] Moore, T (2019) Op cit, p43
[25] Moore, T (2019) op cit. p50

Resources supporting inclusion and participatory practice in the home, community and ECI settings have deepened. The Review noted the evolution of systematic tiered strategies that support inclusion and blur the distinction between regular and special education.[26]

The Review reports that strategies for increasing children's participation in everyday learning activities developed in the period and include the use of activity schedules and lists, activity-based intervention, naturalistic instructional techniques and the Coaching in Context approach that aims to enhances functioning in everyday activities of children with autism and their families.[27]

The Review provides deeper insights into what is required to ensure that parents and care givers learn how to promote their children's functional skills, describing home programs as a mode of delivering services rather than an intervention in its own right. The Review also reports that delivery at home is not in itself a guarantee that the delivery focuses on building parent capacity to support their child but that parental involvement became minimal when services were provided outside the home.[28]

The research base supporting ECI service delivery has grown considerably over the decade with the publication of systematic reviews of evidence related to interventions for children with ASD, cerebral palsy, preterm infants, OT for young children with developmental disabilities and naturalistic instructional approaches in ECI. The Review draws attention to evidence-based strategies, performance checklists, practitioner practice guides and practice-based coaching as strategies to support the incorporation of new knowledge into practice. The use of quality indicators to measure service quality remains a challenge with the development of an evidence-informed decision-making framework promoted to help practitioners and families make decisions that balance practitioner experiences with family values.[29]

The Review also examined evidence related to best-practice in working with families of children with developmental delays and disabilities highlighting new knowledge that refines and strengthens practice. Elements include relationship-based practice, effective help-giving and whole of family approaches that take account of family circumstances and stresses on families. The importance of social support is reinforced with new developments in parent to parent peer support to buffer the early isolation and stress and start parents on a transformational journey from a 'surviving' mindset to embrace a 'thriving' mindset in which parents are supported by their peers and able to thrive, grow and flourish'.[30] Research in the period has also drawn attention to the heightened risk of children with disability experiencing violence and mistreatment.

Areas for resolution or improvement

The Review identifies key areas for resolution or improvement. These include the need to:

[26] Moore, T (2019) Op cit, p41
[27] Moore, T (2019) Op cit, p41
[28] Moore, T (2019) Op cit, p42
[29] Moore, T (2019) Op cit, p43
[30] Moore, T (2019) Op cit, p50

1. "address the tension between approaches that aim to meet the needs of people with disabilities by changing the person to fit in with the existing environments, or changing the environments to enable the person to participate more fully",[31] recognising that this is not an either/or debate and both may be needed at some times for some children.
2. identify necessary pre-conditions for self-managed funding so that parents can 'make productive decisions' and experience the benefits of self-directed funding.
3. consider the circumstances in which families are living, helping the most vulnerable to address the multiple environmental challenges they face and supporting parents and care givers to develop positive and responsive relationships with children with developmental delays and disabilities from as early an age as possible.
4. further align the ECI inclusion support practices with the National Early Years Learning Framework (EYLF) (COAG, 2009) based on the belief that children's lives are characterised by *belonging*, *being* and *becoming*. [32]
5. close the research-to-practice gap, both in the delivery of family-centred practices and the application of up-to-date evidence-based strategies.

Contemporary evidence to deliver optimal outcomes for children with ASD

Autism is the disability that attracts the most funding and research, in part attributable to its contribution to the increased prevalence rates of childhood disability. At November 2019, 29% of children 0-6 receiving NDIS ECEI supports had a diagnosis of Autism. Actuarial data from June 2018 indicates that participants (0-6) with ASD were more likely than most other disability groups to experience difficulties in six or more areas of development and are less likely to be able to make friends, to participate in community activities, and to feel welcomed or included when participating.

The call, by some sections of the ASD sector for higher levels of capacity building support led the NDIA to commission a report [33] to answer three questions about the provision of early intervention for children with autism. The three questions were:

- What is evidence-based/evidence-informed good practice for supports provided to children with autism and their families/usual carers — with a focus on the autism-specific elements?
- What characteristics or other factors would assist in deciding individualised levels of early childhood intervention support needed for a child with autism?
- What factors, including intervention outcomes would indicate a need for a modification, for example an increase or decrease to intensity and/or type of intervention, once an early intervention program has been in place and the recommended timeframe for review of outcomes.

[31] Moore, T (2019) Op cit, p31
[32] Moore, T (2019) Op cit, p41
[33] Roberts, J & Williams, K, (2016) Autism Spectrum Disorder: Evidence-based, evidence-informed good practice for supports provided to preschool children, their families and carers. Funded by the NDIA.

The resultant report contributed to understanding requirements for good practice guidance. However an updated good practice guideline has not been developed.

In order to determine the extent to which the Australian good practice guidance for children with ASD reflects the guidance provided in other jurisdictions, this section compares Australian guidance with guidance for good practice in New Zealand,[34] UK (NICE),[35] Scotland (SIGN)[36] and the US (National Standards Project of the National Autism Centre (NAC))[37] (at Appendix B). Comparison is made in relation to: underpinning principles, aims of intervention, approaches, questions of when to commence ECI, who should provide ECI and the most efficacious location in which to provide ECI, program requirements such as intensity, quality, delivery and evaluation and evidence-based program types.

Evidence-based programs for children with ASD are outlined in Appendix C.

Observations

Overall there is significant similarity between the Australian guide to good practice for children with ASD and guides from NZ, UK, Scotland and the US with explicit agreement in relation to the aims of ECI, requirements for evidence-based practice via multi-disciplinary teams and the efficacious nature of Early Intensive Behavioural Intervention (EIBI).

All guides indicate that ECI should commence as soon as the family is ready post diagnosis but the NZ guidance is explicit that services should be provided as soon as significant delay is noted rather than waiting until diagnosis.

All guides feature the importance of family-centred practice with NZ guidance explicit about the need to plan for sustainable family involvement. All guides describe similar aims of intervention related to the development of social communication and the minimisation of behaviours that challenge, to enhance learning and participation. The Scottish guidance (SIGN) is also explicit about the aim of adapting environments to compensate for skills not present. NZ Practice guidance is explicit that the emphasis of intervention is on enhancing participation rather than 'fixing' the child and this approach is also clear in the UK and Scottish guidance. The focus of the Australian practice guidance appears to prioritise 'fixing' the child.

All bar the Australian guidance emphasise the importance of skilled staff supporting parents and carers especially of very young children in the home, in child care and other settings in which children and their families can be found. Australian guidance on the other hand focuses on staff ratio requirements with a focus on transition to mainstream and opportunities for interaction with typical peers.

The NZ guidance directly tackles the challenges of natural settings for children with ASD. Acknowledging the importance of socially and physically structured environments for young

[34] Ministries of Health and Education (2016) New Zealand Autism Spectrum Disorder Guideline (2nd edition), Wellington

[35] National Collaborating Centre for Mental Health, The NICE Guideline on the management and support of children and young people on the autism spectrum, Clinical Guideline Number 170, commissioned by the National Institute for Health and Care Excellence.

[36] Scottish Intercollegiate Guidelines Network (SIGN). Assessment, diagnosis and interventions for autism spectrum disorders, Edinburgh: SIGN 2016 (SIGN publication no 145

[37] National Autism Centre (2015) National Standards Project, Phase 2, Addressing the need for evidence-based practice guidelines for autism spectrum disorder, Randolph Massachusetts

children with ASD, the guidance requires teachers to provide structure within these environments (e.g. by the use of visual supports) and for professionals to support parents and carers to structure environments for learning.

The UK guidance does not address issues of intensity. The Australian, Scottish and NZ guides see 15-25 hours/week as the required intensity of intervention to achieve outcomes with the NZ guidance explicit that this does not imply 15-25 hours/week of interaction with skilled professionals. Research is used to demonstrate that the quality of intervention is at least as important as its intensity and may include time engaged with parents and other carers who are incorporating the goals of the child into family routines and play.[38] Educational opportunity is measured by hours of engagement, defined as time when the child is focused on systematically planned, developmentally appropriate activities leading toward identified objectives. The guideline also recognises the value of naturalistic models in which engaged time is defined as time in which the child is interacting and responding during activities such as play sessions, reading or sharing, one to one parent-child time, time in an early childhood education setting where the child is engaged in goals related to his/her individual plan and activities such as shopping and bath time where there is a deliberate intention to practice skills or engage in interactions. [39]

All jurisdictions require ongoing evaluation of interventions with NZ and Scottish guidance highlighting the need to support parents to be involved in evaluation including the identification of criteria by which the intervention will be measured prior to commencement of the intervention.

The voice of adults with autism

Reframing Autism (RA) acknowledges that many therapies have the potential to be beneficial in helping Autistic[40] individuals to manage the challenges inherent in living in a world that is not oriented to Autistic neurology. This Australian voice of people with Autism endorses the use of therapies approached from a strengths-based, citizenship framework when utilised to support an Autistic individual to be their best 'Autistic self'.[41]

RA specifically rejects the use of any therapy or intervention that utilises a system of rewards and punishments to modify Autistic behaviour and train Autistic individuals to act and perform non-autistically, or which are intensive in nature. The use of Applied Behavioural Analysis (ABA) and Early Intensive Behavioural Intervention (EIBI) are specifically questioned noting that in Australia, many families are recommended ABA as the 'only' evidence-based, effective

[38] Ministries of Health and Education (2016) New Zealand Autism Spectrum Disorder Guideline (2nd edition), Wellington p89
[39] Ministries of Health and Education (2016) op cit, p90
[40] RA capitalises autism when referring to individuals who have ASD
[41] Reframing Autism, (2020) Therapies and Interventions including Early Intensive Behavioural Therapies (EIBIs) and Applied Behaviour Analysis (ABA): Position Statement. Accessed https://www.reframingautism.com.au/resources 15 February 2020

'treatment' or intervention for Autism[42] and that ABA is offered as a family's best hope of setting their child up for success and ordinary, independent life.[43]

RA rejects the use of ABA and EIBI treatments on the basis that these therapies:

- are not as effective with all people with Autism as claimed. [44]
- frame Autism as a disease to be cured or treated with the aim of decreasing Autistic symptomatology and rewarding and promoting the concealment or suppression of authentic Autistic self-expression.
- therapize the home in ways that detrimentally effect the mental health and quality of life outcomes not only for Autistic children, but for their whole family by sacrificing the sense of 'intactness' that is fundamental to an individual's feelings of self-worth, self-efficacy and self-determination.
- develop characteristics in autistic children that put them at even greater increased risk for emotional, physical and sexual abuse (because they promote dependence on prompts and rewards, reduce performance quality, lead to difficulty in generalising and promote unquestioning compliance and learned helplessness).
- are inherently tied to the medical model of disability, with the purpose of 'recovery of Autistic children who become 'indistinguishable from their peers' as a result of behavioural intervention. [45]
- are not evidence-based to improve well-being or to decrease mental illness or distress, or to increase self-determination, resilience, long term independence or communication, or to boost family quality of life outcomes. [46]
- may decrease well-being and increase mental illness including severe psychiatric distress like post-traumatic stress disorder,[47] with the Australian Autistic population experiencing a mental health crisis, with mortality rates 2.06 times that of the general population, and with suicide a leading cause of premature death.[48]
- are oversold to parents as 'cures' without due understanding of the significant risks associated with these interventions.

Comparison of 'Best' Practice in ECI with 'Good' Practice for ECI for children with ASD

It is important to note that the use of 'best practice' in the broader ECI and 'good practice' in ECI for children with ASD reflects different evidence requirements as described in Section 1.

[42] Lizard Centre. (2017). Applied Behaviour Analysis (ABA). Available at https://www.lizardcentre.com/.
Autism Partnership Australia. (2013). What is applied behaviour analysis? Available from http://www.autismpartnership.com.au/what_is_aba.

[43] Grasswill, H. (2014). Hope for autistic teens: How Applied Behaviour Analysis helped Ian Rogerson's son Jack overturn bleak prognosis. Australian Story. Available from https://www.abc.net.au/news/2014-10-06/jacks- high-school-graduation-gives-hope-to-autistic-teens/5790032. Reported in Reframing Autism, (2020) p1-2

[44] Reichow, B., Hume, K., Barton, E. E., & Boyd, B. A. (2018). Early intensive behavorial intervention (EIBI) for increasing functional behaviors and skills in young children with autism spectrum disorders (ASD). Cochrane Database of Systematic Reviews, Issue 5. Art. No.: CD009260. doi: 10.1002/14651858.CD009260.pub3

[45] https://www.autismpartnership.com/recovery-autism

[46] Reframing Autism, (2020) p4

[47] Kuperferstein 2018, 2019

[48] Reframing Autism, (2020), p5

Table 1 Comparison of Australian National Guidelines for best practice in ECI with Australian practice guide for children with ASD

Australian National Guidelines: Best Practice in ECI	Australian Guide to good practice in supporting children with ASD
Family-centred, strengths-based practice	Family-centred, strengths-based practice is a core principle Roberts & Williams[49] use a definition of family-centred practice that is similar to the National Best Practice Guidelines. Family-centred appears to have less prominence in ASD literature because of the expert nature of intervention but the aim of intervention is the same and there is clear acknowledgement that intervention must account for family values and preferences.
Culturally responsive practice	Culturally responsive practice is a core underpinning principle.
Inclusive and participatory practice	ECI for children with ASD aims to improve social communication and minimise 'behaviours that challenge,'[50] to enhance learning and participation. Focus is on transition toward the mainstream to provide opportunities for interaction with typical peers.
Engaging the child in natural environments	Engaging in natural environments has less priority because intervention favours highly skilled and well-trained professionals adhering closely to individually planned programs.[51] This is challenging in the messiness of natural environments and requires support for parents and carers to structure environments for learning. The National Autism Centre (NAC) however lists naturalistic teaching (strategies used to teach children skills in their home, school and community) as an evidence-based approach that may be especially useful in early years. Parent training and peer training are also identified as evidence-based intervention.
Collaborative teamwork practice	Collaborative multi-disciplinary teams are a core principle.
Capacity building practice	Parent training and development is an element of good practice with the important recognition that at the time the child is diagnosed,

[49] Roberts, J & Williams, K, (2016) op cit

[50] Behaviours that challenge is a contested term. Also known as 'behaviours of concern' defined as "Culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities" (Emerson, 1995). Accessed https://www.autismwestmidlands.org.uk/wp-content/uploads/2017/11/Autism-and-behaviours-of-concern.pdf 12 February 2020

[51] Roberts, J & Williams, K, (2016), p81

Australian National Guidelines: Best Practice in ECI	Australian Guide to good practice in supporting children with ASD
	parents know least about autism, about child's strengths and difficulties and services but are required to select services.
Evidence-base, standards, accountability and practice	Skilled implementation of a carefully planned program suggests a focus on fixing the child. This may compete with practice principles related to inclusive practice in natural environments.
Outcomes-based approach	Outcomes-based approach is a core principle.

The table identifies the significant similarity between the two sets of principles and provides the basis for a more integrated set of best practice guidelines in ECI. With nuanced variations, both sets of practice guides agree on the importance of family-centre practice that is culturally appropriate, strengths-based, capacity building and outcomes-focused and delivered via a collaborative team approach.

Tension between the two sets rests in the individualised nature and weight given to skilled implementation of a carefully planned program that weakens the priority given to parents as partners and to inclusion in natural environments.

A new guideline for ECI support for children with ASD

In order to manage these tensions and move toward a more integrated set of best practice guidelines, it is proposed to develop a new guideline for ECI support for children with ASD. Whilst there have been two major Australian reviews of evidence and best practice related to children with ASD,[52] their purpose was to identify the evidence, not develop guidelines and hence a new guideline would be timely in supporting good practice for children with ASD under the NDIS. The development of a new guideline is not a new idea in the NDIS and has support from the Australian Autism CRC,[53] suggesting an opportunity for collaboration.

Acknowledging the 10-year investment made by the Howard Government into Autism Specialist Centres and drawing on UK (NICE) and Scotland (SIGN) and NZ guidance developed in 2016, a new guideline will include the development of an evidence map and additional work to translate this information to the respective audiences – planners, participants, practitioners, etc.

A cost-effective approach to production of a new guideline would be to:

- Establish a guideline group involving all relevant stakeholders and a technical team

[52] Prior, M and Roberts, J (2012) and Roberts, J and Williams, K, (2016)
[53] https://www.autismcrc.com.au . Autism CRC describes itself as 'the world's first national cooperative research centre focused on autism across the lifespan'.

- Appraise these documents for quality (but the expectation is that they will meet all requirements)
- Cross reference the recommendations from the two guidelines to identify any inconsistency that would need to be followed up
- Update the literature searches to capture any new evidence published since the earlier searches were conducted (from 2016, maybe 2015)
- Generate new guideline with recommendations

The guidelines will include the development of an evidence map that would identify for each question/potential intervention:

- What works and what is the strength of the evidence supporting this finding
- The emerging evidence in the market, identifying innovation that is delivering good outcomes
- Where there is really strong evidence – what is required to get this into practice (e.g. do we have the knowledge of barriers, enablers and implementation processes or do we need to do further research to identify them)
- Where there is not really strong evidence – what is the best type of research to fill this evidence gap (e.g. trials, analysis of large registry data, etc)
- Where there is no evidence – what is the best type of research to start with (e.g. feasibility studies, pilot studies, development of interventions, qualitative studies to explore issues, etc).

3. FACTORS THAT IMPACT ON EFFECTIVENESS

Synopsis

This section reports on evidence in relation to effectiveness of intervention related to characteristics of the intervention and characteristics of the child and family. The section concludes with a discussion of peer support as an emerging field.

The analysis concludes that:

- *whilst evidence tables in the Scotland and the UK sought to identify evidence of the impact of child, family and intervention variables on the efficacy of intervention, no evidence was found.*
- *Peer support is an emerging field with early suggestions of impact on the effectiveness of ECI.*

To enhance outcomes for children and families and understand the efficacy of intervention, it is important to understand the impact of factors related to the nature and intensity of intervention and factors related to the characteristics of the child and the family. Research underpinning the National Guidelines for Best Practice Guide in ECI does not appear to seek to address these questions. Evidence tables underpinning guidance for good practice in ECI for children with ASD in some jurisdictions seek to answer these questions.

Factors related to the intervention

Of the jurisdictions reviewed, the Scottish evidence (SIGN) specifically sought to identify the impact of different models of service deliver on outcomes in children with ASD. Specifically, the review sought to explore issues related to:

- ASD-specific service versus general service
- Multi-disciplinary service/ agency versus single agency
- Clinically integrated pathway compared to single service
- Single day assessment clinics.[54]

The UK evidence (NICE) sought to identify the impact of key components of service delivery on outcomes, namely:

- Intensity of the intervention
- Duration of the intervention
- Length of follow up
- Program components [55]

No evidence was found addressing any of these issues.

[54] Scottish Intercollegiate Guidelines Network (SIGN). p61
[55] National Collaborating Centre for Mental Health, The NICE Guideline RQ 4.1.3 p182

The major international reviews do not address questions pertinent to contemporary Australian inquiry such as evidence related to effectiveness of intervention depending on delivery by a highly skilled professional, a therapy aide or embedded in the child's daily routines. However, the efficacy of naturalistic teaching strategies, parent training and peer training as evidence-based approved interventions demonstrates that delivery by parents and carers in natural settings delivers outcomes for children with ASD.[56] This is further strengthened by effectiveness of approaches based on applied behaviour analysis (ABA) (such as Early Intensive Behavioural Intervention (EIBI)) that support individualised instruction in the home and community as well as the clinic.[57] An outline of evidence-based approved programs for children with ASD is provided at Appendix C.

Factors related to the child and the family

In relation to the impact of child and family characteristics on outcomes, Roberts and Williams[58] report that these questions are not addressed in any detail in any of the reviews used to inform her report, making it difficult to predict which children will respond well to intervention and an individual approach is recommended. The Roberts Report then goes on to report that:

- Children with greater baseline cognitive skills and higher adaptive behaviour scores at baseline have better outcomes from early intensive applied behaviour analysis (ABA)-based interventions (Agency for Healthcare Research and Quality (AHRQ)).
- Younger children have better outcomes from early intensive ABA-based interventions (AHRQ).
- For young children (aged less than 2) a potential modifier of treatment efficacy includes baseline levels of object interest (AHRQ).
- Very young children may be particularly responsive to naturalistic behavioural interventions as these children are less likely to have established patterns of maladaptive behaviour (Schreibman et al., 2015).[59]
- Among these very young children, Schreibman et al. (2015) reported reduced dependence on prompts, more natural sounding language, habituation to real world distractions and improved adult-child social interactions resulting from naturalistic behavioural interventions.[60]

The UK review of evidence (NICE) specifically sought to answer questions of whether the engagement with or effectiveness of interventions aimed at the core features of autism was effective for 'looked-after children' (children in out of home care), immigrant groups and children with regression in skills'[61] and whether the effectiveness of interventions aimed at the core features of autism is moderated by:

- the nature and severity of the condition

[56] National Autism Centre (2015) National Standards Project p53
[57] National Autism Centre (2015) National Standards Project p47
[58] Roberts, J & Williams, K, (2016), p32
[59] Schreibman, L. Dawson, D, Stahmer, A.C., Landa, R, Rogers, S.J., McGee, G., Halladay, A, (2015) Naturalistic Developmental Behavioural Interventions: Empirically validated treatments for Autism Spectrum Disorder, *Journal of Autism and Developmental Disorder,* 1-18
[60] Roberts, J & Williams, K, (2016), p32
[61] National Collaborating Centre for Mental Health, The NICE Guideline RQ 4.1.1 p182

- the presence of coexisting conditions (including, mental and behaviour, neurodevelopmental, medical or genetic, and functional problems and disorders)
- age
- gender
- the presence of sensory differences
- IQ
- language level
- family/carer contextual factors (for example, socioeconomic status, parental education, parental mental health, sibling with special educational needs)? [62]

No evidence was reported relating to any of the above-mentioned questions.

Peer support

Peer support is an emerging field with early suggestions of impact on the effectiveness of ECI. There is no suggestion that research on peer support in any way approximates the nature of evidence used in international guides to good practice, however emerging evidence from practice encourages consideration of this low-cost strategy.

Moore reports on new developments in parent to parent peer support to buffer early isolation and stress. [63] Other research demonstrates that peer support increases social belonging, facilitates learning from the experience of others and supports the acquisition of practical knowledge that families can use to enhance outcomes for their children.[64]

Work by Janson and Mahmic [65] that uses intentional and manualised training from Peer Facilitators has produced outcomes for the child, the family and the individual. Grounded in Positive Psychology and focusing on children's and families' strengths, the peer led capacity building program enables parents to formulate goals and scaffold their learning by trialling strategies to achieve their goals. Program evaluation demonstrated that the program assisted parents to create clearer and more sustainable goals, grow pathways thoughts and instil greater agency. Parent participants learnt how to use their unique strengths to support their child's outcomes and resulted in the development of a peer workforce, a mechanism to train Peer Facilitators and as a vehicle to keep parents learning together after the program finished. A Parent-Professional Statement,[66] developed by parents for parents is an example of the deep capacity enhancing impact of peer facilitators empowering families to be powerful agents of change for their children and work in respectful and honest relationships with professionals. Appendices D and E showcase family friendly graphics by Mahmic and Janson[67] that demonstrate that breadth and depth of evaluated strategies [68] to empower families.

[62] National Collaborating Centre for Mental Health, The NICE Guideline RQ 4.1.2 p182
[63] Moore, T (2019) Op cit, p50
[64] Janson, A and Mahmic, S, Embedding positive psychology and flourish thinking in peer support networks for parents raising children with disability: A game changer,
[65] Janson, A and Mahmic, S, p24
[66] https://plumtree.org.au/the-parent-professional-relationship-statement
[67] Janson, A, Theory of Change, available from annick@egl.ac.nz
[68] Moore, T., Fong, M., and Rushton, S (2018), Evaluation of Plumtree Children's Services *Now and Next* Program. *Prepared by Plumtree Children's Services.* Parkville, Victoria, Centre for Community Child Health, Murdoch Children's Research Institute. Accessed at https://plumtree.org.au/wp-content/uploads/Now-and-Next-evaluation-Murdoch-Childrens-Research-Institute.pdf 25 January 2020

4. THE OPERATION OF THE ECEI APPROACH

Synopsis

This section addresses the question of whether the current operation of the ECEI Approach provides a framework for best practice ECI in ways that are sustainable for the NDIS.

The section summarises:

- *actuarial data in relation to the operation of the ECEI gateway and Scheme access, and for ECEI participants with an approved plan, the section reviews budgets, utilisation and exits.*
- *research and expert opinion in relation to the impact of NDIA policy and practice on the experience of children and their families.*
- *workforce challenges.*

The analysis concludes that:

- *the practice in the ECEI Pathway is very different from that planned and modelled by the NDIA with key differences related to:*
  - *proportion of children who enter the Scheme under s25 early intervention requirements as against s24 disability requirements*
  - *proportion of children with an individualised plan in the specialist therapy market*
  - *the performance of ECEI Partners*
  - *the proportion of exits*
  - *equity in planning and planning implementation as seen in the size of plans, plan utilisation and rates of self-management.*
- *the ECEI Approach lacks a structured vision and framework for implementation and hence is perceived solely as gateway NDIS funding.*
- *planning is deficit-based and child-focused (rather than strengths-based and family-focused).*
- *The short time frame for planning and high turnover of staff reduces effective support for decision-making and potentially undermines optimal outcomes for children.*
- *Services are increasingly centre based or delivered in offices of sole practitioner therapists resulting in duplication and lack of coordination.*
- *ECI is conflated with therapy yet a broad workforce could include early childhood educators, developmental educators, peer workers and therapy assistants, thus easing pressures on demand for therapists while promoting a more holistic approach.*

Challenges in the delivery of the ECEI Approach

The ECEI Approach was planned to be more than a gateway into the NDIS for children. Implemented by ECEI Partners with variable experience related to early childhood, the aim of the ECEI Approach was to ensure that any parent concerned about their child's development could be supported with information, referral and short-term early intervention support where

appropriate, and only those children who require longer term early intervention support would become NDIS participants. Actuarial data however demonstrates that the ECEI design has been compromised during implementation resulting in fewer children moving to inclusive support in mainstream settings. Instead, children enter the Scheme to get support and there is no clear narrative and strategy to celebrate the success of not needing the NDIS and thereby exiting the Scheme.

Actuarial data

Recent actuarial analysis found that:

1. The practice in the ECEI Pathway is very different from that planned and modelled so that children 0-6 now:
    a. make up 14% of all Scheme participants, being 60% higher than originally modelled
    b. are more likely to enter under disability criteria (s24) as against early intervention criteria (s25).
2. More children in the ECEI Pathway are progressing through to funded supports than expected, with results varying considerably by ECEI partner.
    a. Those partners that have had long term experience in delivering ECI for children with disability have the highest rates of exits to mainstream supports.
3. The number of access decisions for children aged 0 to 6 has increased considerably over the last two quarters (2019/20 Q1 & Q2) with:
    a. approximately 96% of ECEI participants found eligible to enter the Scheme as at 31 December 2019 and these eligibility rates have remained broadly consistent over time.
    b. ECEI participants becoming an increasing proportion of all Scheme participants, from 13% in 2018/19 Q4 to 15% in 2019/20 Q2.
    c. Some of this increase may be due to implementation of the Agency's July 2019 remediation plan to resolve ECEI wait times and backlogs, including the provision of standardised interim plans for eligible participants who are expected to have wait times greater than 50 days for an approved plan.
4. The proportion of ECEI participants entering the Scheme under early intervention requirements (s25) has changed from 83% of participants in the Scheme for 4+ years to 55% for participants in the Scheme for 0-1 year. Currently:
    a. only 20% of children with autism enter the Scheme under s25 but
    b. an increasing proportion of children with other disability types enter the Scheme under s25 criteria.
5. In the last 12 months there has been a significant decrease in both ECEI and all Scheme non-mortality exit rates due to a temporary pause (between Feb 2019 and Dec 2019) on participant eligibility reassessments and associated work by Partners to provide supported exits from the Scheme.
6. Plan utilisation rates for ECEI participants are lowest in their first year in the Scheme. This could suggest a need for increased decision support at the outset to assist families to understand how best to use their budget to achieve their goals.

7. ECEI participants have the highest rate of self-management. At 2019/20 Q2, 50% of ECEI participants were either partially or full self-managed compared to 31% of all Scheme participants, enabling access to unregistered providers.
    a. ECEI participants with autism have the highest rate of self-management in 2019/20 Q2, with 42% being fully self-managed.
8. Parents/carers of children 0-6 are very likely to perceive that the NDIS has helped them with their child's development and access to specialist services, but are less likely to perceive that the NDIS has improved how their child fits into family (75% after year 2) and community life (63% after year 2).
    a. Supporting children through the family and community is one of the principles of best practice in early childhood intervention.

In relation to equity in plans:

1. Access is broadly in line with population expectations except for children in CALD families but there are inequities in the size of plans, plan utilisation and rates of self-management.
2. Notable inequities include:
    a. Plans of Aboriginal children have lower average committed supports, plan utilisation and are less likely to be self-managed than those of non-Aboriginal children.
    b. Access for children from CALD backgrounds is lower than expected (although gap between expected and actual lower than for any other CALD cohort in the NDIS). They have similar level of committed supports to those of non-CALD participants, with higher utilisation but they are slightly less likely to self-manage.
    c. Plans for children in remote areas have higher committed supports (includes loadings) but plan utilisation and use of self-management are lower.
    d. Socio-economic status, with increasing level of socio-economic advantage associated with higher average annualised committed supports, plan utilisation and self-management, consistent across age groups, level of function, gender and disability type.

Research and expert opinion

Leaders in the ECI field report that the introduction of the NDIS has led to an erosion of best practice. With pressures to reduce wait times, all focus of ECEI Partners has been on hastening children's entry into the Scheme. A shortage of skilled workforce to deliver ECI services has also presented challenges.

The lack of clear options for support outside the NDIS is a major incentive for making children in the ECEI Pathway, participants. State and territory governments withdrew from services that would have provided tier 2 support for this cohort, handing the funds to the NDIA in transition. There have not however been ILC grants that might provide the tier 2 support anticipated. ECEI Partners have a small amount of funds to provide short term direct support but actuarial data shows variable use of these resources. In addition, ECEI Partners cover

large geographical areas (20 contracts nationally) and as a result, connection to local communities is lost, especially when the NDIA does not require data collection in relation to their work connecting to local communities.

Genuine community concern for children not likely to become NDIS participants was reported in a 2018 report by ECIA NSW/ACT.[69] Whilst the longer-term responsibility for children and their families who are at risk, who may not access an ECEI Partner or mainstream services rests with state and territory governments, the plans for the ECEI Pathway included the responsibility of ECEI Partners to be accessible and available to facilitate their path to mainstream and community supports.

The fact that the implementation of the ECEI Approach is very different from that planned suggests that the ECEI Approach lacks a clear vision and framework for implementation and as a result the Approach is viewed as a Gateway Model and its role limited to a question of funding with a focus on reducing time frames. NDIA policy [70] identifies six roles of the ECEI Partners including information gathering, community connections, initial supports, access request, plan development and plan handover and implementation. The original vision included multiple pathways which recognised the importance of supporting the development of children and the capacity of families, the importance of a whole of government approach with early intervention as part of a network of Partners working within family and community settings and a marketplace of providers delivering best practice outcomes for children and families has not been implemented.

In reviewing the impact of the NDIS on ECI services, Arefadib and Moore identify the positive impact of multiple entry points and referral pathways into the NDIS, reporting that now more families are accessing ECI services than under previous state and territory arrangements. [71] Concerns are reported however, that there has been a decrease in the number of very young children (below 2 years) and that access appears inequitable with an under-representation of disadvantaged families including those of ATSI and CALD backgrounds and those who have difficulty in navigating complex NDIS systems. In addition, long wait lists and a shortage of providers in some areas were identified as issues of concern.[72]

Minister Roberts responded to these concerns in June 2019 with a plan to resolve delays and backlogs in accessing ECI supports for children with disability. The plan was successful in reducing wait times but had the unintended effect of increasing the number of participants with approved plans (some of whom would otherwise have been supported to use mainstream supports) and reducing the number of participants exiting the Scheme because of the temporary pause (between February and December 2019) in eligibility reassessments and the associated work by Partners to provide supported exits from the Scheme.

Arefadib and Moore also identify the lack of decision support as a key challenge in the operation of the ECEI Approach. Evidence from literature, survey and interview drew the

[69] Early Childhood Intervention Australia NSW/ACT (2018) Position Paper: Gaps in services for children age 0-6 with developmental delay and disability. Accessed https://www.ecia.org.au/Representation/Position-Statements 15 February 2020
[70] NDIS Partners in the Community Program – Round Three – Statement of Requirement.
[71] Arefadib, N. & Moore, T, (2019), p73
[72] Arefadib, N. & Moore, T, (2019) p72-3

researchers to the conclusion that in the early stages, parents are not sufficiently well informed or have a clear enough understanding of the needs of the child and family to make good choices. They proposed a range of conditions needed for parents to make productive choices including access to unbiased and accurate information and support from an experienced and skilled planner, neither of which could be guaranteed in the current operation of the ECEI Approach.[73]

Other challenges that may potentially undermine the efficacy of ECI and the ECEI Approach include the short time frame allowed for planning, the high turnover and inexperience of some staff from Partner Organisations and the insufficient focus on family capacity building.

Impact of NDIS on best possible outcomes

Comparison of practice under the NDIS with best practice guidance highlights some of the challenges in delivering best practice ECI in the NDIS. The best practice guidance is divided into 4 quality areas, discussed below.

[73]Arefadib, N. & Moore, T, (2019), p5

Table 2 Impact of NDIS on practice in ECI

Area of best practice	Reality in the NDIS	Consequences	Recommendations
Family: Family-centred, strengths-based, culturally responsive practice	Families are in very different places on their 'disability journey'. They seek different things and require personalised support. Participant plans and budgets are 'child focused, therapy driven and disability framed'.[74] The planning process and plans do not take a whole of family approach with NDIS requiring outcomes only pertain to the child.[75] Capacity building for families must compete with capacity building for child. Planning meetings focus on child' s deficits. Capacity building conflated with therapy. Plans only include Capacity Building Daily Living	Plans do not take a whole of family approach Plans do not include outcomes for caregivers or the family unit Families with 2 children with approved plans find no synergy between the plans Families taking strengths-based approach are penalised by less funding in the plan Families rewarded for exaggerating challenges by increased funding in the plan Families only purchase therapy Families do not build their capacity Children use services that do not reflect family-centred practice	Audit and amend NDIA process to require that they facilitate outcomes that are: – Family-centred, – strengths-based and – build the capacity of both the child and the family Include capacity building for families in stated supports

[74] Moore, T, (2019) The Impact of the National Disability Insurance Scheme on early childhood intervention services for young children with developmental disabilities and delays, p1
[75] Arefadib, N. & Moore, T, (2019), p62

Area of best practice	Reality in the NDIS	Consequences	Recommendations
	Price Guide[76] inhibits use of therapy assistants preventing parents from directly hiring final year therapy students to assist their child to practice skills and participate in natural environments.		
Inclusion: inclusive and participatory practice; engaging the child in natural environments	Funding for therapists to travel to build the capacity of family and carers at day care, preschool and other community settings reduces the quantity of direct therapy Plans do not include any core support that may be required to ensure child is included in family activities	Families prioritise direct work with child over building their capacity and that of carers. Family and carers do not learn how to support child in developmental enhancing ways. Services increasingly delivered in office of sole practitioner therapists. Family and carers hand over responsibility to 'expert' staff. Families do not understand the critical importance of their role.	Incentivise ECI practice in natural environments by: – differentiating funding for travel from funding for direct intervention – providing the funding for travel in stated supports. Require providers to report on location of service and if in non-natural settings, to provide a plan that demonstrates how support will be transitioned to natural settings Increase flexibility in plans

[76] Changes in the Price Guide require therapy assistants to be supervised by the child's therapist. Without this supervision, there is no insurance cover.

Area of best practice	Reality in the NDIS	Consequences	Recommendations
			Include core support to facilitate inclusion in family activities
Teamwork: collaborative teamwork practice; capacity-building practice (keyworker backed by a transdisciplinary team considered best practice)	Delivery of services in a market-based system means: – a focus on billable hours so that the only services delivered are those paid for by the participant – non-direct work with a child is minimised – co-operation is diminished as previous colleagues are now competitors Cost of collaboration significant – discussion between 3 therapists working with child may be the equivalent to 3 hours of direct intervention with the child. Families view more intervention by skilled professionals as better than less. Capacity building with families and care givers to support their child in natural settings is not prioritised Role of peer support seldom recognised	Services increasingly delivered by sole practitioner therapists working in isolation. Families do not prioritise high cost of collaboration Therapists work in silos duplicating and even contradicting each other Families value direct work with child more than building their own capacity Families lack a vision of hope, participation, inclusion Families look to 'experts' for support rather than sharing knowledge gained from lived experience.	Use registration requirements and operational guidelines to require providers to demonstrate a multi-disciplinary approach (as was used in Helping Children with Autism Program) Provide capacity building for families in stated supports, separate to capacity building for children

Area of best practice	Reality in the NDIS	Consequences	Recommendations
Universal principles: evidence-based, standards, accountability and practice; outcomes-based approach	ECI is different in different parts of Australia There is a research-to-practice gap, both in the delivery of family-centred practices and the application of up-to-date evidence-based strategies.[77] Parents report that the current system is not working well for them.[78] Participant plans do not include outcomes for families. Meaning of choice and control uncertain. Parents choose services based on what health professionals advise (usually in a medical model) and proximity to home [79] Families 'don't know what they don't know'. Unlikely to have heard of family-centred practice but know about individual therapy.	Many providers do not use evidence-based practice. Families find the NDIS stressful Parents of newly diagnosed children are not sufficiently well informed or have a clear enough understanding of the needs of their child and their family to make good choices. [81] Families do not develop a vision of hope, relationships and inclusion.	Bridge the research-to-practice gap Develop outcomes for families and carers in participant plan Develop effective decision-support for families including: – Unbiased and accurate information – Peer support – Support from experienced and skilled planner Consider making family capacity building as a pre-requisite for self-management. Contribute to the evidence base in ECI by evaluating innovative approaches.

[77] Arefadib, N. & Moore, T, (2019), p26
[78] Gavidia-Payne, S, (2019) Australia's National Disability Insurance Scheme: Promises, potentials and challenges. Paper p[resented at International Society on Early Intervention Conference, 2019, Sydney 25-28 June, reported in Moore, T, The impact of the NDIS.
[79] Moore Impact of the NDIS on ECI services (article)
[81] Arefadib, N. & Moore, T, (2019), p28

Area of best practice	Reality in the NDIS	Consequences	Recommendations
	They understand an expert model and may not realise the importance of building their capacity and that of other carer givers. Families do not have access to unbiased and accurate information and support from an experienced and skilled planner. [80]		As market steward, shape markets that are not yet well developed e.g. - developing connectedness between ECI providers and their communities - encouraging the sector to develop communities of practice as a strategy of continuous improvement.

[80] Arefadib, N. & Moore, T, (2019), p5

Workforce

As noted earlier, under the Federal Government Helping Children with Autism and Better Start Programs, ECI became conflated with therapy and today, the ECI workforce in Australia is perceived to be comprised of allied health practitioners, especially occupational therapists, physiotherapists and speech pathologists. This creates a serious challenge because it overlooks staff with other qualifications and experience that have traditionally made a significant contribution to young children and their families in the context of early childhood intervention and early childhood more broadly. Given the national shortage of therapists, diversifying the workforce beyond therapy could offer a viable solution to workforce challenges arising out of the NDIS.

Arefadib and Moore document the significant challenges related to recruiting an adequately trained, qualified and experienced workforce with a good working knowledge of ECI. This situation is exacerbated in rural and remote Australia. As a result, it is not uncommon for planners and providers to recruit staff who are either new graduates or those with experience in early childhood education (not ECI). [82] In its submission to the 2011 Productivity Commission Inquiry into the Early Childhood Development Workforce, the sector peak, Early Childhood Intervention Australia[83] noted the high training needs of new graduates and workers without disability backgrounds leading to large practical and financial impact within both smaller organisations and those in geographically remote areas.

Given the workforce shortages and the critical importance of working with children in natural settings, it is vital to ensure that therapy staff are used where required and staff with other qualifications and experience are also used. Early childhood educators, special educators, developmental educators, peer workers and therapy assistants are some of the groups that receive little attention in workforce discussions and yet whose contribution could be an important part of an overall broadening of the pool of workers in the NDIS context. Each group is at a different stage of readiness and may need a strategic approach in order to be incorporated into the NDIS however, they all have a complementary role to play in assisting children and their families to reach their goals of independence, participation and inclusion which are the ultimate outcomes of the NDIS.

Early Childhood Educators are the main workforce group that work with all young children and their families. They already play an important role in supporting young children with delays and disabilities in mainstream early childhood settings through supporting their inclusion and participation. The early childhood sector's experience and commitment is exemplified in their joint position statement with Early Childhood Intervention Australia on the Inclusion of Children with Disabilities in Education and Care.[84] Educators have also played a role in early childhood intervention systems across the country to varying degrees, working within teams to provide a holistic approach to child development and family support. Early childhood special educators

[82] Arefadib, N. & Moore, T, (2019), p2

[83] Early Childhood Intervention Australia (2011), submission to the Productivity Commission's study into the Early Childhood Development Workforce https://www.pc.gov.au/inquiries?collection=productivity-commission-sub-web&f.Inquiry%7CT=early+childhood+development&query=ECIA Accessed 25 January 2020

[84] http://www.earlychildhoodaustralia.org.au/our-work/inclusion-resources/

are teachers who have post graduate qualifications or experience working with young children and their role is to adapt the environment and resources to support learning and development as well as support transition to primary school. Developmental Educators, trained at Flinders University, South Australia and widely used in that state are 'highly skilled multi-disciplinary disability specialists with expertise in fostering skills, independence and quality of life of individuals with developmental disability. They have a practical approach and work holistically across the lifespan to address issues which may affect the function, independence and social inclusion of individuals with disability, their families and carers.[85]

Peer workers are an emerging group that could help to address workforce shortages. When trained and supported, their lived experience offers valuable insights in building capacity of families. Peer workers can be used to lead group programs, work on an individual basis with families to build their capacity and as therapy assistants (thereby representing substantial cost reductions over sole use of traditional allied health professionals and educators). Peer workers enable providers to deliver supports and services that are complimentary to those offered by other professionals and which may have previously have been unavailable in those organisations.

Peer workers at one early intervention organisation in Sydney provide a growing range of complementary services including the Circle of Security Early Intervention Parenting Program, NDIS First Plan Readiness workshops, a quarterly interest group for parents with children with autism as well as the *Now and Next* Program that has been provided in multiple community languages.[86]

Therapy assistants are a further group that should be encouraged into the NDIS workforce. The NDIA Price Catalogue recognises the therapy assistant role but they are not readily available or widely used. Research into the shortage of therapists in rural and regional Australia led to a study that demonstrates that 'appropriately supported, local therapy facilitators provide a flexible workforce adjunct that expands the reach of therapists into rural and remote communities and enhances service access for children and their families'.[87] Therapy assistants could also provide focused developmental support for children in natural settings where intensity and frequency of support is needed to help fulfil goals under the supervision of therapists This could be a better way to utilise the specialist knowledge of therapists and such approaches have been used in the medical field. Partnerships between tertiary institutions and providers are needed to demonstrate efficacious use of therapy assistants and to support the development of this workforce.

[85] Developmental Educators Australia Inc, (2018) Submission to the Productivity Commission: National Disability Agreement Review, Accessed https://www.pc.gov.au/__data/assets/pdf_file/0019/231742/sub064-disability-agreement.pdf 12 February 2020

[86] Heyworth, M, Families as peer workers in early childhood intervention organisations A project of the Innovative Workforce Fund implemented with the assistance of funding provided by the Australian Government Department of Social Services. Accessed https://workforce.nds.org.au/project/families-peer-workers-early-childhood-intervention-organisations/ 25 January 2020

[87] Dew, A., Bulkeley, K., Veitch, C., Bundy, A., Lincoln, M., Glenn, H., ... & Brentnall, J. (2014). Local therapy facilitators working with children with developmental delay in rural and remote areas of western New South Wales, Australia: the 'Outback' service delivery model. *Australian Journal of Social Issues*, *49*(3), 309-328.

5. BEST PRACTICE APPROACH TO PLANNING TO INFORM PARTICIPANT BUDGET

Synopsis

This section summarises expert opinion in relation to:

- *the planning process*
- *current participant budgets*
- *features of a participant budget that facilitate best practice support*
- *the role of peer support, provider requirements, quality assurance, the ILC and market development to support quality outcomes for children 0-6 and their families.*

The analysis concludes with the identification of additional elements to promote effective planning and participant budgets including:

- *features to be promoted in the planning process*
- *family capacity building, therapy/educator travel and low-cost resources to be safeguarded as stated supports*
- *peer support has an important strategy to build family capacity*
- *strategies to promote the use of multi-disciplinary teams*
- *an enhanced role for the Quality and Safeguards Commission*
- *targeted ILC investment for this cohort and*
- *an NDIA role as market steward to improve practice.*

Planning

A review of evidence-based processes by Moore et al found that *how* services are delivered is as important as *what* is delivered, and the quality of relationships between practitioners and parents is central to delivering the objectives of services. [88] ECEI Partners have an important role to play in building the confidence and capacity of parents new to disability as they progress to the access and planning processes.

There is significant evidence that NDIS planning processes are deficit-based, child-focused and rush families to decisions at a time when they are insufficiently informed about their child's disability, its impact on their child, the purpose and processes of ECI, the NDIS and mainstream and community services to make informed decisions. The fact that families of children 0-6 report that the NDIS has assisted them with their child's development and with access to specialist services, but perceive the NDIS to have been less helpful in assisting the child to fit into family and community life (core principles of a family-centred approach) demonstrates that planning, plan implementation and service activity have not suffficeintly focused on the priorities of families.

[88] Moore, T, et al (2016), op cit. p2

Best practice planning would be family-centred, strengths-based, build the capacity of the family, be facilitated by a person trusted by the family and knowledgeable about the system and take place at the pace of the family.

Current budget for participants 0-6

Recent actuarial data demonstrate

- The changes in average plan budgets for ECEI participants by level of function are:
  - High LOF: committed supports reduce by time in Scheme. This may be due to early intervention supports reducing support need over time.
  - Medium LOF: committed supports are highest after 1 year in the Scheme, and reduce thereafter
  - Low LOF: committed supports generally increase the longer participants are in the Scheme.
- Capacity building supports make up 90% of budgets for ECEI participants who have just entered the Scheme, reducing to 61% for participants who have been in the Scheme for 4 years or more.
- Plan utilisation rates for ECEI participants are lowest in their first year in the Scheme, peak at year 2-3 and reduce thereafter. This could suggest that utilisation rates decrease for participants once they transition out of ECEI.

Table 2 outlined challenges in current NDIS practice that makes parents 'choose' between building their own capacity and direct intervention with their child; makes it very expensive to provide supports in children's natural settings; and reduces the opportunity to employ final year therapy students as therapy assistants. Good practice in a participant plan should clearly incentivise best practice support.

Features of a desirable individual participant plan and budget

A family-centred participant budget for young children that considers the needs of the family as well as the child would provide a cost-effective approach because children can only thrive in well supported families.

Stated supports

To promote best practice, it is proposed that features that are universally agreed to be best practice in the delivery of ECI are prioritised by the NDIA in transparent ways that communicate expectations to families and providers. The NDIA approach to prioritisation of supports is to describe them as 'stated supports', in order to ensure the supports are used for their desired purpose and to ensure funding for these supports is not absorbed in meeting immediate and pressing needs.

Hence, a desirable participant budget structured to facilitate best practice includes family capacity building, therapy travel and a small amount for resources in stated supports.

Family capacity building

All stakeholders agree on the critical nature of family capacity building to enable the parents, grandparents and other key family members to develop the insights and skills to make decisions that maximise opportunities for their child. This includes, but is not limited to, developing a vision, understanding their child's disability and the impact of the disability on their child, understanding the purpose and opportunities of early childhood intervention, understanding 'the system', how to use funding flexibly to achieve their goals, develop partnerships with professionals, monitor progress toward outcomes for their child and pace and monitor their plan funding and much more. Family capacity building can also assist families to the understand the direct and indirect elements of support for their child and family to thrive.

Differentiating family capacity building from capacity building for the child in stated supports, overcomes the challenges that arise when family capacity building is in competition with direct work with the child. It also demonstrates to families that family capacity building is very important.

Family capacity building could be provided in plans using a tiered approach, requiring key evidence-based capacity building in the first plan and providing flexible family capacity building in second and subsequent plans, not just for children in the 0-6 cohort, but for children and young people up to age 18.

Therapy / educator travel

Best practice requires intervention with a child to take place in natural settings including the home, childcare, preschool etc. This is in recognition that most learning takes place outside direct sessions with a child and hence the child's development is maximised when parents, carers and all who engage with the child do so in capacity enhancing ways.

Differentiating therapy travel from capacity building and placing it in stated supports ensures support in natural settings does not have to compete with the quantum of direct intervention, removing another obstacle to the use of best practice. Professional reports required for plan review should ask where the intervention took place and with whom the professional worked. Where intervention took place outside natural settings, the professional should be required to justify the use of a non-natural setting and provide a transition plan as to how the intervention will be transitioned to natural settings.

Low cost resources

Many children require and benefit from low cost items such key word sight cards, picture books that include key word sight cards, adapted pencils and paint holders, special pencil grips, special seating cushions, seating supports and straps to enable a child to use a swing safely,

a mini trampoline etc. Whilst these items are low cost for the NDIS, cost can be a barrier to acquisition for a family on a tight budget.

Differentiating low cost resources as stated supports demonstrates that the NDIA understands these additional costs that families face and proactively encourages their use.

It is recommended that this is a small budget item (e.g. $500) and parents can use the money flexibly with very low-key reporting.

Flexible supports

The remainder of participant budget should be available for flexible use. This will reduce the current over-emphasis with therapy with family capacity building an essential precursor to understanding how to get best value from their budget to maximise their child's development.

In recognition of the additional challenges experienced by families of children with disability, the budget would also include supports that reflect family judgement as to what is necessary to sustain family care, remain in or return to work and build informal support.

Consideration should be given as to how to support increased flexibility while simultaneously requiring family capacity building to support good decision-making. Family capacity building is an essential safeguard for the family and the Scheme. Ensuring families have unbiased information necessary for informed decision-making mitigates the risk that parents will 'buy the wrong things' in a flexible budget. The use of stated supports as described above further mitigates risks to the child, the family and the Scheme.

In order to promote parent growth and development toward self-direction and self-management, it is recommended that all plans for children 0-6 include at least a small amount of self-managed funds. Experience of a small self-managed program for young children in NSW [89] found that all families used the funding judiciously and developed the skills and confidence for further self-management.

Peer support

Significant value can be derived when intentionally structured participant budgets are complemented by the availability of peer support that has been demonstrated to enhance family quality of life, family functioning and family satisfaction and have a buffering effect on family stress.[90] Peer support built on consistent messages of hope and possibility for a positive future, assists families to build a bridge from the stresses of their earliest concern for their child's development to expectations of a good life, friendship, belonging, purpose, independence, and inclusion. Evidence-based peer support programs have also been shown to enable parents to identify, pursue and achieve goals for their child, their family and themselves.[91]

[89] Plumtree, https://plumtree.org.au
[90] Moore, T (2019) p50
[91] Janson, A and Mahmic, S,

Provider requirements

All stakeholders agree on the value of multi-disciplinary teams with Arefadib and Moore [92] identifying the key worker approach as best practice. The growth of sole trader therapy providers coupled with the market approach to billable hours challenge collaboration because parents prioritise direct support over 'paying for specialists to talk'.

In addition, non-direct activities such as coordination, reports and engagement with other systems are little understood by families who are reluctant to authorise payment for these activities that do contribute to quality support.

The FACSIA use of Operational Guidelines to facilitate collaboration was noted in section 4. The NDIA could make multi-disciplinary teams a requirement in a similar way.

Quality assurance

The sector must look to the Quality and Safeguards Commission to require and monitor for good practice. Areas for Quality and Safeguards attention identified by Arefadib and Moore Review[93] includes:

- promoting the use of evidence-based professional development
- mandating or incentivising the registration of all ECI providers working with NDIS participants aged 0-6
- supporting the development of:
    - a National Service Delivery Framework for ECI providers similar to the Early Years Learning Framework and
    - a National Quality Framework for ECI Providers

What else is required to achieve best practice?

ILC Investment is an important contributor to child and family capacity building and wellbeing but the approach currently appears scatter gun, uncoordinated and families are not well informed about the availability of avenues of support. It was noted earlier however that there appears to have been no ILC investment targeted at the ECEI cohort. It is however the responsibility of the NDIA to share information systematically so that families know what has been funded and is available in an area.

The NDIA has a role as market steward to shape markets that are not yet well developed. Two areas in which the NDIA could contribute to improved practice include:

- developing the connectedness between ECI providers and their communities to facilitate inclusion support in mainstream services and ensure participants are connected to everyday opportunities
- encouraging the sector to develop communities of practice to support ECI providers to reflect on their practice as a strategy of continuous improvement.

[92] Arefadib, N. & Moore, T, (2019), p64
[93] Arefadib, N. & Moore, T, (2019), p92-3

The table below highlights some of the strategies recommended in the Arefadib and Moore Review [94] that would contribute to strengthening evidence-based processes in the ECEI Pathway and in individual participant packages.

Table 3 Recommendations and strategies to promote best practice

Recommendation	Strategies	Responsible
Promote the use of family-centred practice in ECI under the NDIS	Ensure ongoing training on family-centred practice to all ECI services and Partner Organisations	Q&S Commission
	Monitor for family-centred practice all ECI services and Partner Organisations	Q&S Commission
	Provide pre-planning sessions to families, including discussion of the importance of family-centre practice	ECI Partners
	Adopt a whole-of-family approach to what is included in all ECI plans	NDIA and EC Partners
	Adopt a strengths-based approach to planning meetings and NDIS plans	NDIA and EC Partners
	Allow families to review their draft plan before it is sent to the NDIA for endorsement/approval	NDIA and EC Partners
	When families have more than one child eligible for NDIS, Plans should be considered together and inter- dependent	NDIA and EC Partners
	Make parental/caregiver capacity building a central goal of the NDIS	NDIA, EC Partners and ECI providers
	Introduce peer support groups for families receiving ECI NDIA and EC Partners	NDIA and EC Partners
	Promote the use of tools such as the M-POC21 to continually evaluate the degree to which family-centeredness	Q&S Commission, NDIA and EC Partners
Prioritise conditions needed for parents to	Strengthen the skills of all EC Partners to provide families with essential information about family-centred practices and other key elements of best practice	NDIA & Partners

[94] Arefadib, N. & Moore, T, (2019), p85-88

Recommendation	Strategies	Responsible
exercise informed choice and control	Provide families with easily accessible and culturally appropriate information and introductory support about the NDIS	NDIA, Partners & Providers
	Refocus planning on the need to build parental capacity	NDIA & Partners
	Provide specific funding for a keyworker to support vulnerable and disadvantaged families	NDIA
	here required, provide specific funding for interpreters to facilitate meaningful engagement between families and ECI providers	NDIA
	Provide information and additional support to families regarding how to navigate the NDIS Portal. Special consideration must be given to families who are not literate, computer-literate, and who do not speak English as a first language	NDIA & EC Partners
	Provide families with accessible and easy to follow information regarding how to self-manage (if this is what they choose), and where to seek support or additional information	NDIA & EC Partners
	Ensure that parents/carers are not only given information about the ECI services, but also ways in which ECI services function – the rationale for working with and through parents, and the key features of family-centred practice	NDIA & EC Partners
	Consider implementing a graduated model of choice NDIA and control	NDIA, Partners & Providers
	Support parents to build their capacity to make choices NDIA, EC Partners based upon family values and circumstances as well as and ECI providers evidence-based practices	NDIA, Partners & Providers
Align NDIA planning and funding with the values and purpose of ECI	Create a separate line item for service provider travel	NDIA
	Promote engagement with children in their natural NDIA environments	NDIA
	Provide incentives for service providers to work in a collaborative and interdisciplinary manner	NDIA

Recommendation	Strategies	Responsible
Review the way in which the NDIS supports families of young children	Consider introducing a graduated model of choice and control in the early years of NDIS, modifying the current pathway to provide greater support for parental decision-making at the beginning of their NDIS journey	NDIA

6. DISCUSSION

The paper has shown that it is possible to build on the substantial consensus that exists to harmonise best practice for all children in the ECEI Pathway but that substantial work is required to refocus the ECEI Pathway to reflect the original design of the ECEI Approach. Resolution of tension about whether the purpose of ECI is to 'fix' the child or change the environment to welcome the child is fundamental for the delivery of high quality ECI supports. Families can never be asked to choose between two elements essential for their child's future.

All parents want to minimise the impact of their child's disability (or emerging challenges). Parents of a premature baby told that the brain damage, visible on the ultrasound, may be 'clinically silent' in the context of brain plasticity, will put all their effort into 'fixing' their child, using therapy to build neural pathways to subvert the brain injury. Parents of a baby with Down Syndrome will similarly seek to maximise the baby's capacity to become as independent. Parents of a 2-year-old newly diagnosed with ASD will want to reduce behaviours that challenge and replace them with 'normal' social interaction. They will find it hard to imagine how this can be done without a highly skilled practitioner working individually with their child.

If the ECEI Pathway and ECI services are to provide parents with evidence-based ECI, it is vital that we move beyond either/or debates to recognise that families want some direct intervention to help their child meet developmental milestones and some help to participate and be included. Evidence that families perceive the NDIS to have been less helpful than desired in assisting their child to fit into family and community life (core principles of a family-centred approach) demonstrates significant work is required to support children to thrive in well support families and communities. The key is to understand the nature of direct intervention that works best with which children under what circumstances.

All guidance affirms that ECI should be strengths-based and outcomes-focused, build the capacity of parents and carers and be delivered through multi-disciplinary teams. The similarities of practice requirements are greater than the differences and this lays the foundation for the development of more integrated practice guidelines for all children with disability. The paper highlighted a number of nuanced differences between Australian good practice guidance for children with ASD and those of UK, Scotland, US and NZ. Further analysis with particular reference to NZ practice will be important to enable children with ASD and their families to receive evidence-based support delivered in ways that are sustainable.

Whilst the NDIA affirms the Guidelines for Best Practice in ECI, the paper outlined practices in the ECEI Pathway that impede the delivery of best practice support. The development of the ECEI Pathway, targeted to families of very young children was a positive step, but this paper has provided evidence that the ECEI Pathway has not been implemented as planned and must be strengthened to reflect the unique features of the early years and support family-centred practice.

The fact that more children have been pulled into a disability pathway rather than facilitated to inclusion support in mainstream settings, that the practice of ECEI Partners varies according to their level of previous ECI experience, the fact that participant Aboriginality ethnicity,

geographic location and socio-economic status impact on experience (or not) of the NDIS are strong indicators of the need for remedial action to refocus the ECEI Pathway to that intended.

Recent evidence reviews reaffirm the efficacy of family-centred practice for children with all disability types, including children with ASD, but family-centred practice in the NDIS is undermined by the lack of attention to supporting families and building their capacity. Family-centred practice requires strategies to enable families to feel supported but research[95] tells us that many families of young children do not feel supported under the NDIS. Family-centred practice acknowledges the value of family judgement but planning conversations seldom genuinely consider the child in the context of his or her specific family and seldom respect family judgement as to what is necessary to sustain family care, remain in or return to work and build informal support. Participant plans in the ECEI Pathway are child plans and do not identify goals and supports for families.

Best practice guidance emphasises a strengths-based approach but the requirement to provide deficit-based reports undermines this practice.

Family capacity building is perhaps the core ingredient in shaping a positive future of hope and possibility, but NDIS practice makes parents feel like they 'rob' their child of direct intervention to fund their own capacity building. In addition, capacity building initiatives aimed at families of very young children, including those that use peer support are not widespread. The paper canvassed options for building the capacity of families with supports in participant plans to enable the purchase of capacity building services and the use of peer networks and a peer workforce.

The lack of effective decision-support is another challenge identified in the paper. Without appropriate time to work at the family's pace and for the child's/family's needs to be fully understood and other services outside the NDIS to be included where necessary, the ECEI Approach will be undermined. Effective decision support is essential for without it, most parents are likely to believe that more hours of direct therapy are better than less hours, that a therapist with university training has a more important role to play in enhancing their child's development than they do. They may also fail to see the way in which their children will grow and develop when surrounded by other normally developing children in natural settings.

Families 'don't know what they don't know' and effective decision support on the ECEI Pathway provides a safeguard to ensure that parents choose efficacious supports. Effective decision supports requires access to unbiased information, an experienced planner and peer support to enable families to recognise their key role in making decisions and building a positive future for their child.

Other features of the NDIS that inhibit the delivery of best practice include features of pricing that preference clinic-based intervention rather than the use of natural environments and a failure to take action to promote teamwork and collaboration even in the manner of FACSIA Operational Guidelines under the Federal ECI Programs.

[95] Gavidia-Payne, S, (2019) op cit.

7. THE WAY FORWARD

In order to facilitate the use of best practice in ECI and the ECI Pathway to enable parents of children 0-6 to have quality early intervention that enables choice and control, the IAC recommends that the NDIA:

1. *Refocuses the ECEI Pathway* to:
    a. provide information, support, referral and short-term early intervention support where appropriate to children whose families are concerned for their development, and only those children who require longer term early intervention become NDIS participants
    b. ensure planning is family-centred, strengths-based, builds the capacity of the family, is facilitated by a person trusted by the family and knowledgeable about the system and take place at the pace of the family
    c. ensure strong transition planning for children going to school
    d. ensure equity in plan allocation, utilisation and access to self-management for children of Aboriginal and CALD backgrounds, who live outside metropolitan centres and who are from families of lower socio-economic status.

2. *Provides more effective decision-support* including
    a. ensuring the provision of:
        i. unbiased and accurate information
        ii. peer support
        iii. support from an experienced and skilled planner
    b. adjusting NDIA Access and Planning processes to work at the family's pace and with enough time for the child's/family's needs to be fully understood and other services outside the NDIS to be included where necessary
    c. auditing and amending NDIA and ECI Partner processes to require that they facilitate outcomes that are:
        i. family-centred
        ii. strengths-based
        iii. capacity building
        iv. culturally responsive

3. *Promotes the use of family-centred practice in ECI* including enhanced emphasis on:
    a. a family-centred approach
        i. Audit and amend NDIA processes to require they facilitate outcomes that are family-centred, strengths-based and build capacity of the child and family
        ii. Adopt a whole of family approach to what is included in ECI plans
        iii. when parents have more than one child eligible for the NDIS, plans should be considered together and inter-dependant
        iv. When a participant child has a parent who is a participant, plans should be considered together and inter-dependant
    b. family capacity building

i. Refocus planning to include family capacity building
ii. Use a tired approach to family capacity building
iii. Strengthen the use of peer support for families
iv. Include family-capacity building as a stated support in all plans

c. use of natural settings
    i. Place provider travel in stated supports thereby differentiating funding for travel from funding for direct intervention
    ii. Require providers to report on location of service and if in non-natural settings, to provide a plan that demonstrates how support will be transitioned to natural settings
    iii. Include core support that may be required to enable the participant to fully participate in family and community
d. strengths-based
    i. Adopt a strengths-based approach to planning meetings and requirements for participant reports and participant plans
    ii. Respects family judgement about what is required to sustain family care, remain in or return to work and build informal support
e. multi-disciplinary teams
    i. Use registration requirements and operational guidelines to require providers to demonstrate a multidisciplinary approach
f. reaching out to families who face multiple disadvantages
    i. Provide specific funding for key worker support
    ii. Where required, provide specific funding for interpreters to facilitate meaningful engagement between families and ECI providers
g. participant budgets that support best practice including
    i. family capacity building, therapy/educator travel and a small amount for resources placed in stated supports
    ii. All budgets including a small amount of self-managed funds
h. supports the family to thrive including supports that reflect family judgement as to what is necessary to sustain family care, remain in or return to work and build informal support.

4. Building on NZ Practice, *develops new guidelines and evidence map for children with ASD*. This will also address the tension between approaches that aim to change the person to fit in with the existing environments, or change the environments to enable the person to participate more fully", recognising that this is not an either/or debate and both may be needed at some times for some children. [96]

5. *Enhances practice* by
    a. closing the research-to-practice gap, both in the delivery of family-centred practices and the application of up-to-date evidence-based strategies.
    b. strengthening the emphasis on participation and inclusion by working to ensure ECI practice is better aligned with the National Early Years Learning

[96] Moore, T (2019) Op cit, p57

Framework (EYLF) (COAG, 2009) based on the belief that children's lives are characterised by *belonging*, *being* and *becoming*.[97]

c. contributing to the evidence-base in ECI by evaluating innovative approaches.
d. promoting market development through
    i. developing the connectedness between ECI providers and their communities to facilitate inclusion support in mainstream services and ensure participants are connected to everyday opportunities
    ii. encouraging the sector to develop communities of practice to support ECI providers to reflect on their practice as a strategy of continuous improvement.

6. Promotes discussion related to *workforce development in ECI*, ensuring that
    a. therapy staff are used judiciously where required and
    b. complementary workforces such early childhood educators, special educators, developmental educators, peer workers and therapy assistants are developed and deployed.

[97] Moore, T (2019) Op cit, p41

8. BIBLIOGRAPHY

Arefadib, N. & Moore, T, (2019) *Realising the Potential: Early Childhood Intervention under the NDIS.* Prepared for the Victorian Department of Education and Training. Parkville, Victoria: Centre for Community Child Health, Murdock Children's Institute

Autism Partnership Australia. (2013). What is applied behaviour analysis? Available from http://www.autismpartnership.com.au/what_is_aba.

Centre for Community Child Health (2016), Supporting the roadmap for reform: evidence-informed practice.

Centre for Community Child Health (2011), DEECD Early Childhood Intervention Reform Project: Revised Literature Review. Melbourne, Victoria: Department of Education and Early Childhood Development.

Developmental Educators Australia Inc, (2018) Submission to the Productivity Commission: National Disability Agreement Review, Accessed https://www.pc.gov.au/__data/assets/pdf_file/0019/231742/sub064-disability-agreement.pdf 12 February 2020

Dept of Families, Housing, Community Services and Indigenous Affairs, (2009) *Early Intervention Service Provider Panel Operational Guidelines, Part A- revised August 2009*

Dew, A., Bulkeley, K., Veitch, C., Bundy, A., Lincoln, M., Glenn, H., ... & Brentnall, J. (2014). Local therapy facilitators working with children with developmental delay in rural and remote areas of western New South Wales, Australia: the 'Outback' service delivery model. *Australian Journal of Social Issues*, *49*(3), 309-328.

Dunst, C, Johanson, C, Trivette, C and Hamby, D, (1991) Family-oriented and early intervention policies and practices: family-centred or not? *Exceptional children*, 58, 115-126, reported in Esp-Sherwindt, M, Family-centred practice: collaboration, competency and evidence (2008) *Support for learning,* v23, n3,

Early Childhood Intervention Australia NSW/ACT (2018) Position Paper: Gaps in services for children age 0-6 with developmental delay and disability. Accessed https://www.ecia.org.au/Representation/Position-Statements 15 February 2020

Early Childhood Intervention Australia, (2016) National Guidelines for Best Practice Early Childhood Intervention

Early Childhood Intervention Australia (2011), submission to the Productivity Commission's study into the Early Childhood Development Workforce https://www.pc.gov.au/inquiries?collection=productivity-commission-sub-web&f.Inquiry%7CT=early+childhood+development&query=ECIA Accessed 25 January 2020

Espe-Sherwindt, M (2008) Family-centred practice: collaboration, competency and evidence, *Support for Learning,* v8, No 23, p136-141

Gavidia-Payne, S, (2019) Australia's National Disability Insurance Scheme: Promises, potentials and challenges. Paper presented at International Society on Early Intervention Conference, 2019, Sydney 25-28 June reported in Moore, T, (2019) The impact of the NDIS.

Grasswill, H. (2014). Hope for autistic teens: How Applied Behaviour Analysis helped Ian Rogerson's son Jack overturn bleak prognosis. Australian Story. Available from https://www.abc.net.au/news/2014-10-06/jacks- high-school-graduation-gives-hope-to-autistic-teens/5790032. Reported in Reframing Autism, (2020) p1-2

Hayworth, M, Families as peer workers in early childhood intervention organisations A project of the Innovative Workforce Fund implemented with the assistance of funding provided by the Australian Government Department of Social Services. Accessed https://workforce.nds.org.au/project/families-peer-workers-early-childhood-intervention-organisations/ 25 January 2020

KPMG, (2011) Reviewing the evidence on the effectiveness of early childhood intervention, Report to the Department of Families, Housing, Community Services and Indigenous Affairs

Lizard Centre. (2017). Applied Behaviour Analysis (ABA). Available at https://www.lizardcentre.com/.

Mahmic, S Family-centred practice: are we there yet? Pauline McGregor address, National Early Childhood Intervention Australia Conference, Melbourne 2016

Janson, A, Theory of Change, available from annick@egl.ac.nz

Kupferstein, H. (2018). Evidence of increase PTSD symptoms in autistics exposed to applied behavior analysis. Advances in Autism, 4(1), 19-29. doi: 10.1108/AIA-08-2017-0016.

Kupferstein, H. (2019). Why caregivers discontinue applied behavior analysis (ABA) and choose communication- based autism interventions. Advances in Autism. doi: 10.1108/AIA-02-2019-0004

Ministries of Health and Education (2016) New Zealand Autism Spectrum Disorder Guideline (2nd edition), Wellington

Moore, T (2019) *Realising the potential: A Literature review of best practices in early childhood intervention services,* Prepared for the Victorian Department of Education and Training. Parkville Victoria, Centre for Community Health, Murdoch Children's Research Institute

Moore, T, (2019) The Impact of the National Disability Insurance Scheme on early childhood intervention services for young children with developmental disabilities and delays

Moore, T, Forster, J and Bull, K (2019) Supporting parental choice: the impact of a funding model, in Acar, S, Hix-Small, H and McLaughlin, T, International Perspectives on Early Intervention. Young Exceptional Children Monograph Series 18. Arlington Virginia. Division of Early Childhood, Council for Exceptional Children

Moore, T., Fong, M., and Rushton, S (2018), Evaluation of Plumtree Children's Services *Now and Next* Program. *Prepared by Plumtree Children's Services.* Parkville, Victoria, Centre for Community Child Health, Murdoch Children's Research Institute. Accessed at https://plumtree.org.au/wp-content/uploads/Now-and-Next-evaluation-Murdoch-Childrens-Research-Institute.pdf 25 January 2020

Moore (2018) *Strengthening evidence use in practice: An Evidence-based decision-making framework.* Melbourne, Berry Street Childhood Institute

Moore, T, et al (2016) Supporting the roadmap for reform: evidence-informed practice, Centre for Community Child Health, Murdock Children's Research Institute

National Autism Centre (2015) National Standards Project, Phase 2, Addressing the need for evidence-based practice guidelines for autism spectrum disorder, Randolph Massachusetts

National Collaborating Centre for Mental Health, The NICE Guideline on the management and support of children and young people on the autism spectrum, Clinical Guideline Number 170, commissioned by the National Institute for Health and Care Excellence.

Reframing Autism, (2020) Therapies and Interventions including Early Intensive Behavioural Therapies (EIBIs) and Applied Behaviour Analysis (ABA): Position Statement. Accessed https://www.reframingautism.com.au/resources 15 February 2020

Reichow, B., Hume, K., Barton, E. E., & Boyd, B. A. (2018). Early intensive behavorial intervention (EIBI) for increasing functional behaviors and skills in young children with autism spectrum disorders (ASD). Cochrane Database of Systematic Reviews, Issue 5. Art. No.: CD009260. doi: 10.1002/14651858.CD009260.pub3

Roberts, J & Williams, K, (2016) Autism Spectrum Disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers. Report funded by the National Disability Insurance Agency

Prior, M and Roberts, J (2012) Early intervention for children with autism spectrum disorders: Guideline for good practice, 2012, Accessed at https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/early-intervention-for-children-with-autism-spectrum-disorders-guidelines-for-good-practice-2012 21 January 2020

Prior, M and Roberts, J, Rodger, S, and Williams, K, (2011) A review of the research to identify the most effective models of practice in early intervention for children with autism spectrum disorders. Accessed at https://www.dss.gov.au/sites/default/files/documents/10_2014/review_of_the_research_report_2011_0.pdf 21 January 2020

Schreibman, L. Dawson, D, Stahmer, A.C., Landa, R, Rogers, S.J., McGee, G., Halladay, A, (2015) Naturalistic Developmental Behavioural Interventions: Empirically validated treatments for Autism Spectrum Disorder, *Journal of Autism and Developmental Disorder,* 1-18

Scottish Intercollegiate Guidelines Network (SIGN). Assessment, diagnosis and interventions for autism spectrum disorders, Edinburgh: SIGN 2016 (SIGN publication no 145.

Shkedy, G., Skjedy, D., & Sandoval-Norton, A. H. (2019). Treating self-injurious behaviors in autism spectrum disorder. Cogent Psychology, 6. doi: 10.1080/23311908.2019.1682766

Teager, W, Fox, S and Stafford, N, *How Australia can invest early and return more: A new look at the $15b cost and opportunity.* Early Intervention Foundation, The Front Project and CoLab at the Telethon Kids Institute, Australia, 2019.

Appendix A: Key Best practices in Early Childhood Intervention

QUALITY AREA 1: FAMILY

1. Family-Centred and Strengths-Based Practice: is a set of values, skills, behaviours and knowledge that recognises the central role of families in children's lives. Family-centred practice is a way of thinking and acting that ensures that professionals and families work in partnership and that family life, and family priorities and choices, drive what happens in planning and intervention. Family-centred practice builds on family strengths and assists families to develop their own networks of resources – both informal and formal.

2. Culturally Responsive Practice: creates welcoming and culturally inclusive environments where all families are encouraged to participate in and contribute to children's learning and development. Practitioners are knowledgeable and respectful of diversity and provide services and supports in flexible ways that are responsive to each family's cultural, ethnic, racial, language and socioeconomic characteristics.

QUALITY AREA 2: INCLUSION

3. Inclusive and Participatory Practice: recognises that every child regardless of their needs has the right to participate fully in their family and community life and to have the same choices, opportunities and experiences as other children. All children need to feel accepted and to have a real sense of belonging. Children with disability and/or developmental delay may require additional support to enable them to participate meaningfully in their families, community and early childhood settings.

4. Engaging the Child in Natural Environments: promotes children's inclusion through participation in daily routines, at home, in the community, and in early childhood settings. These natural learning environments contain many opportunities for all children to engage, participate, learn and practise skills, thus strengthening their sense of belonging.

QUALITY AREA 3: TEAMWORK

5. Collaborative Teamwork Practice: is where the family and professionals work together as a collaborative and integrated team around the child, communicating and sharing information, knowledge and skills, with one team member nominated as a key worker and main person working with the family.

6. Capacity-Building Practice: encompasses building the capacity of the child, family, professionals and community through coaching and collaborative team work. The goal is to build the knowledge, skills and abilities of the individuals who will spend the most time with the child in order to have as great an impact as possible on the child's learning and development.

QUALITY AREA 4: UNIVERSAL PRINCIPLES

7. Evidence Base, Standards, Accountability and Practice: ECI services comprise practitioners with appropriate expertise and qualifications who use intervention strategies that are grounded in research and sound clinical reasoning. Standards based on these ECI key best practices will ensure ECI practitioners and services are accountable to continuous improvement and high quality services.

8. Outcome Based Approach: focuses on outcomes that parents want for their child and family, and on identifying the skills needed to achieve these outcomes. ECI practitioners share their professional expertise and knowledge to enable families to make informed decisions. Outcomes focus on participation in meaningful activities in the home and community with outcomes measured and evaluated by ECI services from a child, family and community perspective.

Appendix B: Australian and international guides to evidence based/ evidence informed practice for support to preschool aged children with ASD and their families

Principles	Australia	NZ	NICE (UK)	SIGN (Scotland)
Underpinning principles	Evidence based Families require support Family centred Individual planning	Evidence based Families require support Family centred Individual planning Social inclusion Emphasis on participation and development rather than fixing the child	Government provision with equity Evidence based Families require support Family centred Individual planning	Family centred Individual planning to support decision-making
Aims of intervention	Social communication development Minimise behaviours that challenge Enhance learning and participation	Participation and development with spontaneous communication, socialisation and play goals as priority	Increase joint attention, engagement and reciprocal communication Anticipate and prevent behaviours that challenge	Promote development of skills Adapt environment to compensate when skills not present
Approaches	Environmental modification Building on opportunities Antecedent – behaviours – consequence Transition support	Best practice not achieved by teaching in isolated settings away from other children. Generalisation of learning crucial Problem minimisation and avoidance	Aim to increase parents', carers' and teachers' understanding of, and sensitivity and responsiveness to the child's patterns of communication and interaction Play based strategies with parents, carers and teachers	Promote development of skills Adapt environment to compensate when skills not present

Principles	Australia	NZ	NICE (UK)	SIGN (Scotland)
When	As soon as diagnosis is made and the family is ready	Services provided as soon as significant developmental need is identified	Information and support for decision making post diagnosis	Information and support for decision making post diagnosis
Who	Team approach including staff trained in autism and allied health professionals Staff: child ratios vary between 1:1 and 1:3 Professional development Parent training and development Peer interventions	Trained staff Multi- disciplinary teams Parents and carers	Highly skilled staff Multi- disciplinary teams Parents and carers	Personnel with appropriate skill and training
Where	No evidence one location superior to others. Programs should work toward inclusion in mainstream and provide opportunities for interaction with typical peers	In natural settings with support from skilled staff in how to provide structure and support for children in their natural settings	In natural settings	In natural settings
Interventions Program requirements	Intensity: 20 hours/week Quality: Comprehensive across all domains of learning with clearly stated and replicable process and content Delivery: With intensity and fidelity. May involve parents and carers	Intensity:15-25 hours per week Quality: incorporate person-centred planning, functional assessment, positive intervention strategies, multi-faceted interventions, focus on environment, meaningful outcomes, focus on ecological validity and systems level interventions.	Delivery: skilled professionals training parents and carers Evaluation ongoing	Intensity: EIBI approaches >15 hours/week PECS needs less intensity Delivery: skilled professional Evaluation: parents and carers encouraged to identify criteria by which

Principles	Australia	NZ	NICE (UK)	SIGN (Scotland)
	Evaluation: Evaluation ongoing	Delivery: Skilled professional working with family and carers. 'The high level of participation that is associated with effective outcomes does put considerable demands on parents' and is subject to joint decision making in a family centred approach Evaluation: parents and carers encouraged to identify criteria by which they will evaluate an intervention Evaluation ongoing		they will evaluate an intervention Evaluation ongoing
Evidence based Program types	Treatment and Education of Autistic and related communication handicapped children (TEACCH) and the Early Start Denver Model (ESDM) or a comprehensive intervention program. Parent training 'to increase the understanding of and sensitivity of and responsiveness to, the child's communication and interaction' Peer training	Interventions based on ABA including Early Intensive Behavioural Intervention (EIBI) should be considered for all children Interventions to be implemented across home, early childhood services, school & community settings Value of parent led support networks in helping parents deal with issues The most appropriate and efficacious programs for children with ASD employ a variety of practices, focus on	ABA programs are **not** routinely delivered in NHS and social care settings. Early intensive behavioural intervention programs (EIBI) PECs Social and communication programs Programs that use therapist modelling and video interaction feedback Parent training 'to increase the understanding of and sensitivity of and responsiveness to, the	Parent-mediated interventions should be considered to support family interaction with the child, promote development and increase parental satisfaction, empowerment and mental health. Interventions to consider include those that support: - communicative understanding and expressions such as PECS and the use of environmental visual supports

Principles	Australia	NZ	NICE (UK)	SIGN (Scotland)
	A list of EB strategies for preschool aged children at Roberts (2016) 26 *PECs* *Positive Behaviour Support* *Pivotal Response Training*	generalisation and systematic and ongoing evaluation of interventions (p87) Augmentative communication interventions Pivotal response training Positive Behaviour Support	child's communication and interaction'	- social communication programs - EIBI programs - OT to adapt environment, activities and routine in daily life
Other considerations	Key worker approach recommended		Key worker approach recommended	

Appendix C Evidence-based approved interventions for children with ASD

(from National Standards Project of the National Autism Centre, Massachusetts USA)

Intervention Target age range	Description	Skills increased – Behaviours decreased
Behaviour interventions Children and adolescents 3-21	The Behavioural Intervention category is comprised of interventions typically described as antecedent interventions and consequent interventions. Antecedent interventions involve the modification of situational events that typically precede the occurrence of a target behaviour. These alterations are made to increase the likelihood of success or reduce the likelihood of problems occurring. Consequent interventions involve making changes to the environment following the occurrence of a targeted behaviour. Many of the consequent interventions are designed to reduce problem behaviour and teach functional alternative behaviours or skills through the application of basic principles of behaviour change.	Skills increased: • higher cognitive functions • motor skills • academic, communication, interpersonal, learning readiness, personal responsibility, play, and self-regulation Behaviours decreased: • sensory or emotional regulation • problem behaviours • restricted, repetitive, non-functional patterns of behaviour, interests, or activity
Comprehensive Behavioural Treatment for Young Children (CBTYC) Children 0-9	CBTYC programs involve intensive early behavioural interventions that target a range of essential skills which define or are associated with ASD (e.g., communication, social, and pre-academic/academic skills, etc.). These interventions are often described as ABA (or applied behaviour analysis), EIBI (or Early Intensive Behavioural Intervention), or behavioural inclusive programs. CBTYC involves: • Intensive service delivery (typically 25-40 hours per week for 2-3 years) based on the principles of ABA • Data-based decision making that targets the defining symptoms of ASD • Typical interventions include the use of discrete trial teaching, incidental teaching, errorless learning, behavioural momentum,	Skills increased: • play • academic and learning readiness • communication, higher cognitive functions, interpersonal, and personal responsibility • motor skills Behaviours decreased: • general symptoms • problem behaviours

Intervention Target age range	Description	Skills increased – Behaviours decreased
	shaping, modelling and other interventions derived from ABA • Individualized instruction in various settings (e.g., home, community, inclusive, and self-contained classrooms) and small group instruction	
Language training Children 3-9	Language Training (Production) targets the ability of the individual with ASD to emit a verbal communication (i.e., functional use of spoken words) Language Training (Production) makes use of various strategies to elicit verbal communication from individuals with ASD. Language Training (Production) begins with appropriate assessment and identification of developmentally appropriate targets. Individualized programs often include strategies such as: • Modelling verbalizations for the individual with ASD to imitate • Various prompting procedures including verbal, visual, gestural prompts • Cue-Pause-Point • Using music as part of language training • Reinforcement for display of targeted verbal response	Skills increased: • interpersonal and play • communication
Modelling Children 3-18	The goal of modelling is to correctly demonstrate a target behaviour to the person learning the new skill, so that person can then imitate the model. Children can learn a great deal from observing the behaviour of parents, siblings, peers, and teachers, but they often need to be taught what behaviours should be imitated. There are two types of modelling — live and video modelling. Live modelling occurs when a person demonstrates the target behaviour in the presence of the child with ASD. When providing live modelling: • Clearly outline, in writing, the target behaviour to model. • Ensure all individuals modelling the target behaviour are doing so in a consistent manner. It may be helpful for	Skills increased: • higher cognitive functions • academic • communication, interpersonal, personal responsibility, and play Behaviours decreased: • problem behaviours • sensory or emotional regulation

Intervention Target age range	Description	Skills increased – Behaviours decreased
	parents/caregivers/therapists to practice together to make certain each person provides the same model. • Obtain the child's attention prior to modelling the target behaviour. • Develop a plan to fade or stop the use of modelling to encourage the child to independently display the target behaviour. Video modelling occurs when you pre-record a person demonstrating the target behaviour. Video modelling can be a great option for children /adolescents with an affinity for television shows, movies, or interest in seeing themselves on a monitor. Anyone who can correctly and independently perform the task can serve as a model — this includes the person with ASD. • Make sure your child is paying attention to and is interested in the video. • Point out the important steps/features to your child during the video. Be sure to make the best quality video possible. Remember, after the initial time invested in making the video, it is an easy-to-use teaching tool, and is cost- and time-effective (e.g., the same video clip can be used by multiple individuals any time).	
Naturalistic Teaching Strategies (NTS) Children 0-9	Naturalistic Teaching Strategies (NTS) are a compilation of strategies that are used to teach children skills in their home, school, and community. The basic concepts include using materials in the environment and naturally occurring activities as opportunities to increase adaptive skills. These strategies are primarily child-directed. When using NTS, consider the following guidelines: • Observe your child to find out what motivates him or her, and then structure teaching interactions around those interests. • Use materials your child is likely to encounter on a daily basis. For example, if you want to teach her to identify items that fall into the category "things you play with," you might use dolls, blocks, and cars that are available at home and at school.	Skills increased: • interpersonal and play • learning readiness • communication

Intervention Target age range	Description	Skills increased – Behaviours decreased
	• Teach skills in a variety of situations and settings (such as the home and community) while using a variety of materials (e.g., teach numbers by using different items such as pieces of candy or silverware). • Provide consequences that are naturally found in the environment and have a direct relationship to the activity you are completing. For example, food might be a natural and direct reinforcer at lunch and toys might be a natural and direct reinforcer during "playtime." • Provide loosely structured teaching sessions that vary based on the child's interests for that day. For example, if you are teaching your child to request objects of different sizes, you may need to use dolls rather than teddy bears if she shows a greater interest in dolls that day. Different names have been given to the intervention strategies included in the NTS category. These include: focused stimulation, incidental teaching, milieu teaching, embedded teaching, responsive education, and prelinguistic milieu teaching.	
Parent Training Package Children and adolescents 0-18	The Parent Training Package refers to the elements of the interventions used in studies in which parents acted as therapist or received training to implement various strategies. Highlights parents' and caregivers' integral role in providing a therapeutic environment for their family members with ASD. Parent training can take many forms including: *In vivo* individual training; Group training; Support groups with an educational component; Training manuals Examples of skills parents learned to use include: • Strategies to develop imitation skills • Commenting on the child • Expectant waiting to elicit communication • Appropriate sleeping routines • Joint attention • Development of play date activities	Skills increased: • interpersonal and play Behaviours decreased: • general symptoms • problem behaviours • restricted, repetitive, non-functional behaviour, interests, or activity
Peer training package	Difficulty interacting appropriately with peers is a commonly reported characteristic of ASD.	Skills increased:

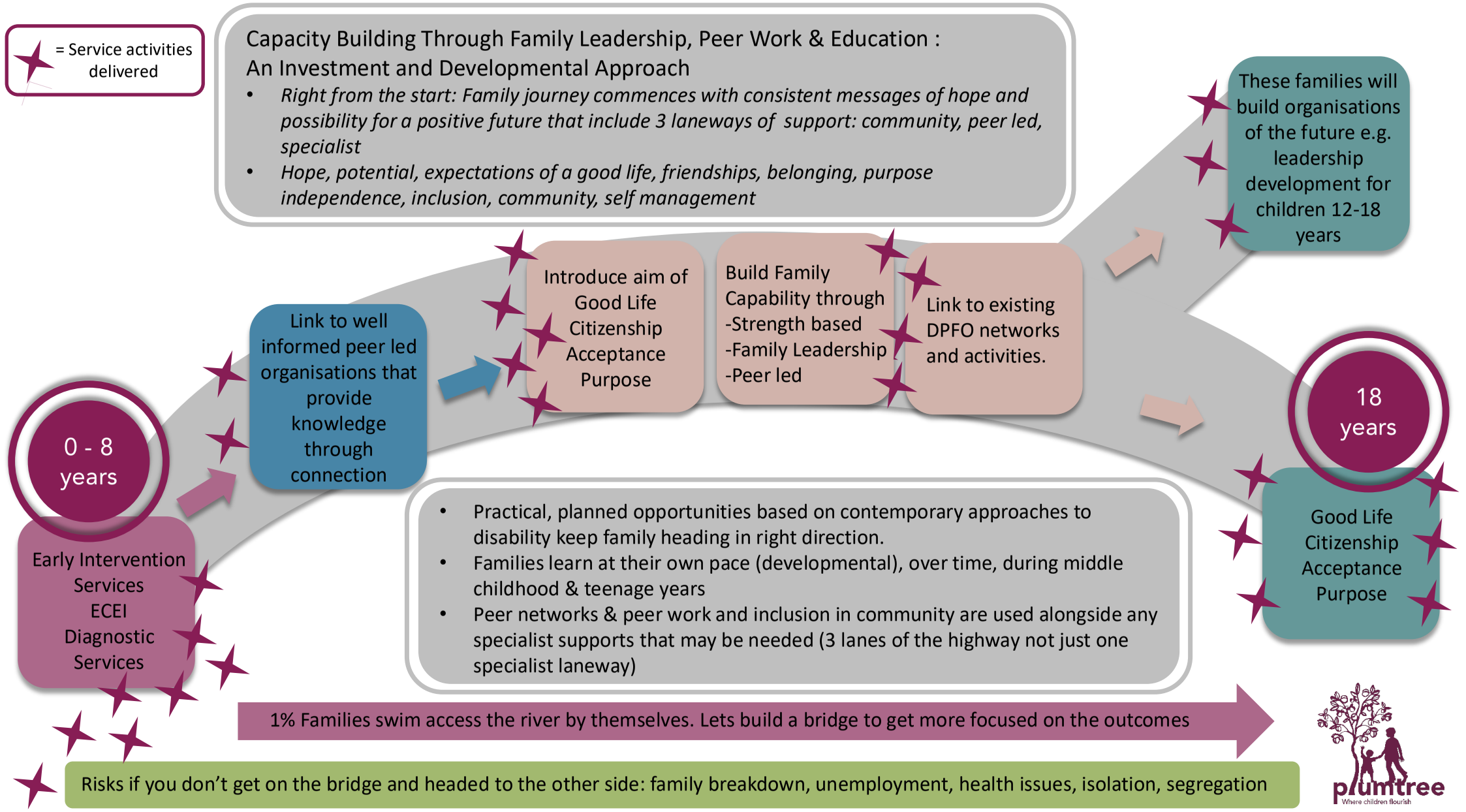
Intervention Target age range	Description	Skills increased – Behaviours decreased
Children 3-14	Further, children with ASD often rely on adults for prompting and guidance. Peer Training Packages facilitate skill growth for children with ASD by training peers on how to initiate and respond during social interactions with a child on the spectrum. These programs have been used in school and community settings. Factors to consider when designing a Peer Training Package including: • The age and skill level of the children (with and without ASD) should be similar. You should choose peers who are socially skilled, compliant, regularly available, willing to participate, and able to imitate a model. • The activities you include in the session should address the interests and preferences of both groups to ensure high motivation. • Teach the peers how to get the attention of the individual with ASD, facilitate sharing, provide help and affection, model appropriate play skills, and help organize play activities. • After training, have the peers interact with the individual with ASD in a structured setting during a familiar activity. This will allow the peers to practice their new skills in a comfortable environment. • The group instructor should use prompts and feedback to facilitate interactions. • Be sure to train in multiple settings and with multiple peers to increase the likelihood that all the children use their skills frequently. Different names of peer training programs include: Project LEAP, peer networks, circle of friends, buddy skills package, integrated play groups, peer initiation training, and peer-mediated social interaction training.	• learning readiness • communication and interpersonal Behaviours decreased: • restricted, repetitive, non-functional behaviour, interests, or activity
Pivotal Response treatment Children 3-9	Pivotal Response Treatment® focuses on targeting “pivotal” behaviours related to motivation to engage in social communication, self-initiation, self-management, and responsiveness to multiple cues. Key to the delivery of PRT® is parent involvement and implementation in the natural environment such as the home, community, and school setting. Pivotal Response Treatment® is also referred to as Pivotal Response Training®, Pivotal	Skills increased: • interpersonal • learning readiness • communication and play

Intervention Target age range	Description	Skills increased – Behaviours decreased
	Response Teaching® and the Natural Language Paradigm. Like Naturalistic Teaching Strategies, PRT® aims to teach children to respond to various teaching opportunities within their natural environment, and to increase independence from prompting. Motivation can be enhanced by increasing choice, making learning materials meaningful by: building a direct relationship between the target behaviour and the reinforcer; incorporating both new and mastered tasks into the day; and reinforcing reasonable attempts. • Self-initiation involves teaching children to take action in the world so they can be more independent. • Self-management involves teaching children to regulate their own behaviour by tracking their progress and accessing reinforcers for their successes. • Responding to multiple cues involves teaching children to respond to the diverse statements of others, or to different kinds of materials.	
Schedules children 3-9	Schedules can be used for children with ASD to increase their independence and allow them to plan for upcoming activities. A schedule simply identifies the activities that must be completed during a given time period and the order in which these activities should be completed. It is important for children and adolescents to possess prerequisite skills of picture identification (when using pictures) or reading (when using words/phrases) when considering use of schedules. Schedules: • Can be used once per day, multiple times per day, or once per week. • Are often used to help teach “first, then” concepts — such as, first complete your chores, then you can watch television. • Should be followed by access to preferred activities. You can gradually increase the number of activities required before giving your child access to preferred activities. • Can be presented in multiple formats. You can use pictures (real photos or	Skills increased: • self-regulation

Intervention Target age range	Description	Skills increased – Behaviours decreased
	Boardmaker®), written or typed schedules, 3-D objects, or personal digital assistance programs. The use of schedules may be as simple as: • Placing the pictures/texts on the board at the time of the activity • Pointing to the activity immediately prior to beginning each step or activity • Taking the picture off the board when the step or activity is completed • Placing the picture in a "done" container such as a bin, box, or pile	
Scripting Children and adolescents 3-14	Scripting occurs when an individual with ASD is provided guidance as to how to use language to initiate or respond in certain situations. These interventions involve developing a verbal and/or written script about a specific skill or situation which serves as a model for the child with ASD. Scripts are usually practiced repeatedly before the skill is used in the actual situation. Scripting consists of providing the child/adolescent with language to successfully complete an activity or interaction. • Ensure prerequisite skills are mastered. For example, the child should have necessary reading skills or be able to imitate a verbal model. • Scripting is typically used in conjunction with behavioural interventions such as reinforcement, modelling, and prompting. • Scripts can be useful in a variety of social situations in the school, home, and community setting. • Scripts should be faded as soon as possible to increase independence and spontaneity.	Skills increased: • play • communication and interpersonal
Story based interventions Children and adolescents 3-14	Story-based interventions identify a target behaviour and involve a written description of the situations under which specific behaviours are expected to occur. Most stories aim to increase perspective- taking skills and are written from an "I" or "some people"	Skills increased: • Communication and learning readiness

Intervention Target age range	Description	Skills increased – Behaviours decreased

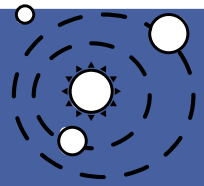
	perspective. The most well-known story-based intervention is Social StoriesTM.
	
	When using a story-based intervention, use written descriptions for:
	• The target behaviour
	• The situations in which the behaviour should occur
	• The likely outcome of performing the behaviour. This often includes a description of another person's perspective. Although the information included in the story will vary based on your child's cognitive and developmental level, some typical features include:
	  • Information about the "who/what/when/where/why" of the target behaviour
	  • Being written from an "I" or "some people" perspective with the goal of increasing perspective-taking skills
	  • Discussion or comprehension questions to make certain the child understands the main points
	  • Pictures to enhance comprehension of the skills
	
	Story-based interventions are often used with individuals who have acquired reading and comprehension skills, but may also be used with individuals with strong listening comprehension skills.
		• Interpersonal and self-regulation
		
		Behaviours decreased:
		
		• problem behaviours


= Service activities delivered
Capacity Building Through Family Leadership, Peer Work & Education :
An Investment and Developmental Approach
• Right from the start: Family journey commences with consistent messages of hope and possibility for a positive future that include 3 laneways of support: community, peer led, specialist
• Hope, potential, expectations of a good life, friendships, belonging, purpose independence, inclusion, community, self management
0 - 8 years
Early Intervention Services
ECEI
Diagnostic Services
Link to well informed peer led organisations that provide knowledge through connection
Introduce aim of Good Life
Citizenship
Acceptance
Purpose
Build Family Capability through
-Strength based
-Family Leadership
-Peer led
Link to existing DPFO networks and activities.
These families will build organisations of the future e.g. leadership development for children 12-18 years
18 years
Good Life
Citizenship
Acceptance
Purpose
• Practical, planned opportunities based on contemporary approaches to disability keep family heading in right direction.
• Families learn at their own pace (developmental), over time, during middle childhood & teenage years
• Peer networks & peer work and inclusion in community are used alongside any specialist supports that may be needed (3 lanes of the highway not just one specialist laneway)
1% Families swim access the river by themselves. Lets build a bridge to get more focused on the outcomes
Risks if you don't get on the bridge and headed to the other side: family breakdown, unemployment, health issues, isolation, segregation
plumtree
Where children flourish

Family Participation: Theory of Change

DEMONSTRATE OUTCOMES

Build family capability through participation



11.

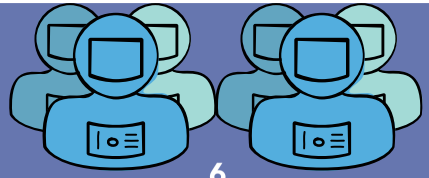
EVALUATE

Qualitative and quantitative evaluation of: family empowerment; families setting a vision for their child, family and self; achievement of goals; impact on agency, hope and wellbeing.

1. 2.

SUSTAIN

Collective benefit mindset

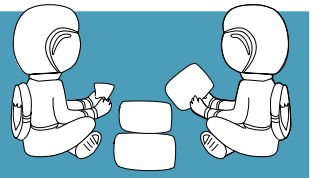


6.

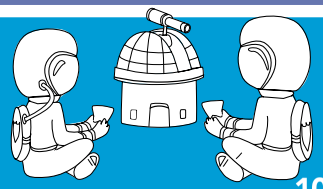
7.

EXPAND

Community of practice



Peer workforce



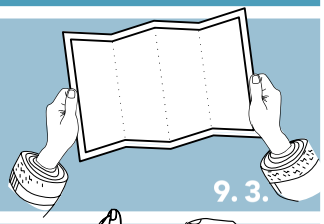
10.

Alumni peer network

5.

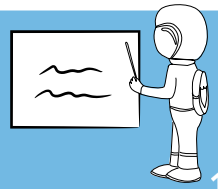
TRAIN

Professional development



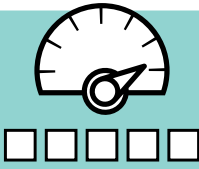
9. 3.

Peer worker training



12. 8.

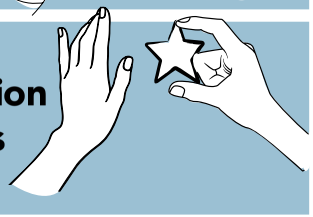
Family workshops



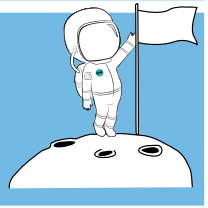
4.

ENGAGE

Early intervention professionals



Family leaders as peer workers



Families as participants

EVIDENCE BASE

Positive Psychology, Family Leadership, Strength-based Approach, Gamification and Family-Centered Practice.

The numbers in the illustration refer to research and publications building this Theory of Change.
Please turn over to access this body of research, or contact Dr. Annick Janson, Research Director of the project: annick@egl.ac.nz