



The genie is out of the bottle: Be careful what you wish for

Keynote address at joint Early Childhood Intervention Australia (ECIA) and International Society on Early Intervention (ISEI) Conference 2019.

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Abstract

Supporting parental choice and building parental choice-making capabilities have long been recognised as central features of best practice in early childhood intervention (ECI) services. On that basis, we should be welcoming that fact that the National Disability Insurance Scheme (NDIS) funding model is based upon parental choice and control. Although they were supposed to have the final say in family-centred practice, giving parents control of purchasing and choice of services takes empowerment to a different level. And the choices they are making have challenged the ECI sector's view of what constitutes best practice.

This presentation reports on some of the findings of a review of the impact of the introduction of the NDIS on best practice in ECI services, and explores the conditions needed by parents to make choices that are most likely to achieve the outcomes they want for their children, themselves and their families. The presentation concludes by considering the implications for ECI practitioners and the NDIS itself.





Introduction

At the previous ECIA National Conference in 2016, Sylvana Mahmic gave a powerful paper on the history of family centred practice in early childhood intervention (ECI) services (Mahmic, 2016). Speaking as a parent of a child with a disability and as a manager of an ECI service, she recounted how ECI practice was transformed in the 1990s through the adoption of family-centred practice. In this approach, ECI services sought to engage parents as partners, considered the needs of the whole family, and delivered services based on individual family goals and service plans. As a parent, Mahmic found this approach profoundly empowering, so she was dismayed as it began to be eroded when the Federal Government commenced funding ECI for the first time, through the Helping Children with Autism (HCWA) program (introduced in 2008) and the Better Start for Children with Disabilities (Better Start) program (introduced in 2011). Speaking as a manager of an ECI service, Mahmic describes what impact this had on her program:

This individual funding could only be spent on approved services that were predominantly allied health based. Our team transformed and became swollen with allied health staff, as the scheme favoured employment of these professionals who were seen to provide evidence-based intervention.

The role of educators in early childhood intervention was downplayed, as their services could only be approved under guidelines that they had to be delivered in partnership with allied health staff. ...

The funding was welcome as it enabled families to access supports; however, early intervention was now seen as a list of therapy services. Although children and families received more services, the focus on diagnosis, therapy and treatment took hold. A challenge to family-centred practice emerged, and the role of the family in their own early intervention experience was being eroded.

Therapy began to be conflated with early childhood intervention.

Transdisciplinary practice was a challenge to provide within the funding envelope, and the funding model incentivised families to favour centre-based visits as their funding would stretch further.

In our initial phone calls with families, we noticed more were requesting speech therapy or occupational therapy immediately. It became harder to explain the family-centred key worker model our organisation was offering – and its value. Some families came to us and were disappointed when they realised we did not work like their private therapist did. They were familiar with the model where the therapist conducts assessment, finds gaps and then addresses them directly themselves. Multiple therapy visits per week became increasingly common; some families had a number of therapists from the same discipline at the same time. The medical model was back (Mahmic, 2016).



The two funding programs that triggered these changes – the HCWA and Better Start programs – have now been absorbed into the new National Disability Insurance Scheme (NDIS), along with funding for ECI services. What impact is this having on ECI services? Are we still seeing the same effects observed by Mahmic?

Established by a federal Act of Parliament in 2013, the NDIS represents a fundamental shift in how disability support is delivered. Under the NDIS, participants can exercise **choice and control** by purchasing their supports directly from providers. It is a market-based system where government funding no longer goes directly to disability service providers, but instead to the client, who can choose the providers they want.

This shift involves changes in funding mechanisms, planning procedures, and parental decision-making that, in the short term at least, are proving hugely disruptive for the ECI sector. A particular concern is what impact these changes are having on the way ECI service are delivered, especially on the use of family-centred practice. States and Territories governments have received anecdotal evidence from NDIA early childhood partners and service providers that suggest that the transfer to the NDIS has resulted in a reduction in family-centred practice, and that there is a major risk that the NDIS as it is currently operating may be undermining best practice in early childhood intervention

In the light of this concern, the Victorian Department of Education and Training commissioned the Centre for Community Child Health (CCCH) to examine what effect the NDIS was having on the way ECI service are delivered, particularly in relation to the use of family-centred practice.

We have produced two reports. The first (Moore, 2019) is an extensive literature review of evidence that has accumulated over the last 10 years regarding two specific questions: What does recent evidence say about best practice in ECI? Is family-centred practice still considered best practice?

The second paper (Arefadib & Moore, 2019) reports the results of a survey of planners, providers and families to understand what effect the NDIS is having on the way ECI services are delivered, particularly in relation to the use of family-centred practice.

The present paper does not report on all the findings of this survey (such as the significant implementation issues facing ECI services and the NDIA) but instead focuses on the specific issue of what impact having choice and control has upon the choices that parents of young children with developmental disabilities make.

Before addressing this question, we will briefly consider the findings of the literature review (Moore, 2019) regarding what recent evidence say about best practice in ECI and whether family-centred practice is still considered best practice.



What the evidence says

The first question addressed in the review concerned evidence regarding the overall aims of ECI: what are these services seeking to achieve and how to they go about it. A previous review of the evidence on this question (CCCH, 2011; Moore, 2012) reached the following conclusion:

Reviewing the rationale for ECI in the light of developmental research findings leads us to conclude that the aim of ECI is not so much to be the major agent of change through direct work with children, but to work with and through the children's caregivers to ensure that the children's everyday environments provide them with the opportunities and experiences that will enable them to develop the functional skills to participate meaningfully.

This same logic leads to the recognition that the learning environments that children experience outside the home are just as important for their development as their home environments.

Therefore, the learning environments provided by early childhood programs are properly regarded as being a major setting for early childhood intervention, not just as a desirable addition, and the task of ECI services is the same as in the home: to work with and through the early childhood staff to ensure that the early childhood environment provides them with the opportunities and experiences that will enable them to develop the functional skills to participate meaningfully in the same social and learning activities as the other children (CCCH, 2011).

The latest review (Moore, 2019) looked at the evidence published since that review and concluded:

The overall aim of ECI as identified in the previous review has continued to be endorsed by all experts. The central goal is 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 most learning takes place, not in therapy sessions. What children need are multiple opportunities to practice functional skills in everyday settings.

Here's a contemporary definition of early childhood intervention that exemplifies this consensus (Vargas-Barón et al., 2019):

ECI is a system of services that provides support to the families of children with developmental delays, disabilities, social-emotional difficulties, or children who may develop delays due to biological or environmental factors. Effective ECI systems are: (a) individualized; (b) intensive; (c) family-centred; (d) transdisciplinary or interdisciplinary; (e) team-based; (f) evidence-informed; and (g) outcomes-driven. ECI, a social and child rights model, replaces traditional approaches to service provision, such as the medical model. Whereas traditional deficit-focused approaches involve an "expert" providing the child with intervention services



typically delivered in a clinical setting, a contemporary ECI approach involves the provision of individualized, family-focused and child-centred services delivered in the least restrictive natural environment of the child. Rather than being “expert driven”, ECI service delivery is “family driven”. The family is a partner in the provision of services and makes all decisions regarding the child and family.



Regarding the second question addressed by the latest literature review – whether family-centred practice was still regarded as best practice – the review looked at the key best practice statements issued by peak bodies in early childhood and early childhood intervention since 2010. The most important of these has been the publication of national best practice statements for ECI services by Early Childhood Intervention Australia (ECIA) (2016). These guidelines identify eight key best practices in ECI:

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.



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.

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.
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.

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.

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.
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.

On the basis of a review of the evidence for each of these best practice principles, the current review (Moore, 2019) concluded:

The evidence also clearly supports the use of the eight best practice principles and family-centred practice in particular. There has been no challenge to these principles, only a deepening of our understanding of ways in which these best practices can be implemented. At the same time, the evidence indicates that these best practice principles are not always easy to observe consistently, and that we do not know to what extent they are being observed in practice

The review also looked at the evidence regarding effective ways of working with families. This evidence continues to highlight how much the effectiveness of ECI depends upon the quality of the relationships between service providers (including planners) and families, and the effectiveness of the



help-giving practices of ECI practitioners. The research also highlighted the importance of adopting a whole-of-family approach when planning and delivering ECI support services. It is also clear that ECI services need ways of identifying any psychosocial factors that may be compromising family functioning or parenting – unless addressed, these factors are likely to compromise the family’s ability to address the needs of the child with developmental disability.

With these findings in mind, we will now consider the specific issue of what impact having choice and control has upon the choices of parents of young children with developmental disabilities.

The genie is out of the bottle: giving parents control of purchasing

At the last national ECIA Conference, I gave a paper that contrasted two models of funding – the traditional block-grant funding model and the self-directed model that replaces it under the NDIS (Moore, 2016). I was interested in whether there was any evidence that either model was more compatible with best ECI practice. I concluded that neither model necessarily compromised or promoted best practice; we appeared to be swapping the virtues and vices of one system for the virtues and vices of another.

On the surface, the NDIS seems to be in line with ECI best practices and family-centred practice in particular. It is based on the assumption that people with disabilities and their carers know best what outcomes they want to achieve and what their support needs are, and therefore can make better use of available funds. This could be regarded as the ultimate expression of family-centred practice. Moreover, there is a good case to be made for self-directed services or personal budgets: the rationale is that ‘by putting users at the heart of services, enabling them to become participants in the design and delivery, services will be more effective by mobilising millions of people as co-producers of the public goods they value’ (Leadbeater, 2004).

In the light of the research and other evidence re the impact of the NDIS on ECI best practice, I now think I underestimated the difference that having control of spending would have on parent choices. Although parents were supposed to have the final say in family-centred practice, having control of purchasing takes empowerment to a different level.

In a family-centred practice model, parents would be offered choices, but from a limited range – they could not choose a ‘bad’ option. For example, they were not offered centre-based therapy when home-based services were an option. Given full control of the money and with centre-based therapies on the menu, that is precisely what parents are choosing.

Parents should not be blamed for the choices they make in the early stages of involvement with ECI services and the NDIS.



Families of young children with developmental disabilities face particular challenges in making choices about the services they need. When families of young children with disabilities have the diagnosis confirmed and become eligible for ECI services, they are likely to be in a state of some distress and disorientation. They will be unfamiliar with the ECI service system and uncertain of their role in relation to professionals. They will also likely be lacking in confidence in their own abilities to help the child and tend to defer to the knowledge of professionals. Thus, at this point in time, they may not be well placed to be able to make informed decisions about the needs of the child or their own needs, or about what forms of service would best meet these needs, and it may be unreasonable and potentially harmful to expect them to be able to do so (Moore et al., 2019).

However, simply providing people with individualised funding is not sufficient to ensure they make choices that will lead to positive outcomes. As noted by Stephens and colleagues (2008):

By themselves, individual budgets entrench the ineffectiveness of the consumer model of care by encouraging users to ‘buy solutions’ rather than have an active stake in delivering (or ‘producing’) their own solutions.

Unless parents are properly supported through collaborative partnerships with professionals, they are at risk of choosing forms of support that fail to build their own capabilities to meet their child’s needs.

What parents are choosing and why

Our recent survey of planners, providers and families (Arefadib & Moore, 2019) gives us an insight into what ECI services parents are choosing under the NDIS and why. Here’s what we found:

What parents are choosing

- Parents are choosing therapy services for the child, as much therapy as they can get for the money they have – there is less demand for some professions that were traditionally part of ECI teams, especially teachers (early childhood/special education).
- Parents are choosing clinic-based services, and bearing the costs of travel themselves.
- Parents are choosing child-focused goals and not goals for themselves or their families.

What parents are not choosing

- Parents are not choosing key worker models.
- Parents are no longer opting to have service providers engage with other important people in the child and family’s life – because ECI providers charge for this.



- Parents are less likely to ask ECI providers for support with issues that affect parental or family functioning – again because they will be billed for this.

What factors are shaping parental choices

- Parents want to experiment, even when they know that what they are choosing is not the best option – this even applies to parents who had previously been getting a family-centred practice service.
- Paediatricians and others are sending parents to the NDIS with specific messages about what they should be asking for – the medical model privileges therapy services over other forms of service.
- Costs influence parents' decisions not to have home-based services (no dedicated funding line for travel) or keyworker models (ditto).
- Parents are not being informed of the full range of options – including family-centred practice and other best practices, keyworker models – there is inconsistent messaging from EC Partners in this regard.
- Parents are not being fully informed about how young children learn, especially the need to have multiple opportunities to practise functional skills in everyday environments.
- Parental choices are shaped by cognitive biases: they assume that more is better than less, and that what professionals can do is better than what they can learn to do.
- In a market-based system, there is a real danger that practitioners will collude with these initial assumptions and provide expert-driven services that fail to build parental competencies.
- Parental choices may be shaped by the (highly understandable) assumption that the child should be the focus of ECI efforts and not their own needs or those of the family.
- Parental choices are also shaped by the NDIS planning process: if parent goals are not included in the format, then it is far less likely that they will be included in the plan.
- Parental choice is also shaped by what professionals offer: professionals may collude with parental tendencies to regard them as experts, thereby encouraging parents to buy direct therapy services for the child rather than services that build their own ability to meet their child's needs.
- The tendency for ECI providers to offer therapy services under the NDIS may be due in part to what McWilliam (2015) has described as 'a sort of tribal regression toward the mean – people reverting to what they thought they were getting into when they entered the field.'
- What professionals offer is also shaped by the NDIS funding structure: it is more economically efficient for professionals to offer clinic-based services, and parents see this option as preferable because it saves money.
- Parental choices are shaped by the personal resources and skills of the parents themselves: those with more resources and greater power to advocate got services quicker and got more funding, while those with fewer resources – disadvantaged families, culturally and linguistically diverse



families, Aboriginal and Torres Strait Islander families – find the NDIS difficult to negotiate and got poorer service.

- What parents chose was also affected by where they live: major shortages of service providers in rural and remote areas meant that some parents have very little choice or not choice at all.

Helping parents choose

It is clear that way that the NDIS is currently structured and funded is having a profound impact on what ECI services parents are choosing, as well as what forms of services ECI providers are offering. It is also clear that best practice has been compromised in the process.

What can we do to help parents of young children with developmental disabilities and delays make choices that are in the best interests of their child and family? Our suggestions are based on what we have learned:

- Avoid giving parents too many options to choose from – rather than being empowering, having too many options can be disempowering.
- Avoid giving parents too few options to choose from – parents in rural and remote areas have many fewer service options, and may not be able to make a meaningful choice at all.
- Avoid asking parents to make decisions about matters that are too complex to understand immediately – expecting parents to know what they want and need at the beginning of their journey is unrealistic and potentially harmful.
- Provide parents with access to independent sources of informed advice about how children with developmental disabilities learn and what constitutes best practice in ECI.
- Ensure that parents receive help from professionals skilled in engagement and goal setting – authentic engagement, motivational interviewing, evidence-informed decision-making.
- Protect parents from misinformation – there needs to be regulations against false advertising.
- Protect parents against professional incompetence or outright fraudulence – there needs to be better regulatory oversight of the sector.
- For those parents with fewer resources, additional help needs to be provided – e.g. interpreters, culturally-sensitive information materials, advocacy services.

There are also some specific counselling and coaching strategies we can use when working directly with parents:

- Help parents understand that they do not have to be perfect – sometimes more can be achieved by not trying so hard to do everything at once.
- Help parents learn from failure – they can expect to fail some of the time, and need to take each failure as a learning opportunity.



- Help parents be outcome focused – gaining access to services is not an outcome, but a means to an end, and it helps to keep the outcome in mind at all times.
- Help parents be specific about what they want for the child and family – this makes it much easier to know when they have achieved what they wanted.
- Help parents be realistic – help them set achievable goals for themselves and the child.
- Acknowledge parents' long term hopes and goals as well as realistic short-term targets. As Rhonda Galbally (2016) has noted:

Choice and control is central to the NDIS – it means that, for the first time, people with disabilities can be in the driver's seat of their own lives. But in order for choice and control to become more than a mantra, people need a vision and aspiration for what is possible, and encouragement and support to realise those aspirations.

- Use other parents to help parents articulate their hopes (long term goals) and identify short-term goals (e.g. Plumtree's Now and Next program) (Heyworth et al., 2017; Moore et al., 2018)
- Use an evidence-informed decision-making framework (Moore, 2018) to help parents make better informed and more family-compatible choices – evidence-informed decision-making is a skilled process that reconciles evidence-based and relationship-based practices.

The difficulties that parents face in making choices are compounded when professionals disagree on what approaches are most effective. In a report for the Australian Government on the evidence for early childhood intervention, KPMG (2011) noted that there were two contrasting approaches to ECI described in the literature:

- One focuses primarily on the child's disability or developmental delay and seeks to ameliorate the effect of these through direct work with the child.
- The other approach focuses on the natural environments in which the child lives and seeks to promote the child's ability to participate.

These two approaches lead to very different ways of providing services that parents may find hard to choose between. While the consensus in the ECI literature favours the second approach as more effective and as having a more powerful rationale for young children, the allure of the first approach is enduring. This is especially so when combined with strong claims about evidence-based programs and their proven efficacy. Such claims can make parents feel that they have no choice but to go with whatever program is deemed most effective, regardless of the financial or personal cost.

However, the choice of the most appropriate intervention approach should never be determined by evidence alone, but also needs to include consideration of the outcomes the parents want to achieve and the impact of the intervention on family members and quality of life. The NDIS currently lacks an evidence-informed decision-making framework to help parents make choices that are clearly focused on the outcomes they want to achieve and that take account of their family's values, circumstances and capabilities.



Implications

The NDIS is a visionary scheme whose introduction was widely supported by disabled individuals, families and stakeholders. While the policy shift to greater choice and control for people with disabilities is to be commended, the scale and complexity of the policy shift have been accompanied by a number of challenges for ECI services, as well as for families and carers of young children with developmental disabilities or delays.

The NDIS has been designed for adults with disabilities, and a majority of the funding is devoted to addressing their care needs. There are problems in applying this model to very young children with disabilities and their families – some changes have been made since the introduction of the scheme but many more are needed.

When we consider other human services sectors, such as aged care services, it is evident that when guidance about what to provide is limited, and regulatory oversight is poor, then a free-market system cannot be relied upon to deliver high quality services, and Royal Commissions are needed to begin sorting out the mess. Other sectors, such as early childhood services, do better because they have a national curriculum or service framework (e.g. the Early Years Learning Framework), backed by training resources (through early childhood associations), and a quality assurance mechanism (e.g. the Australian Children's Education and Care Quality Authority). The ECI sector under the NDIS has none of these, at least not in a fully developed form.

So what steps can be taken to improve matters for parents and ECI service providers under the NDIS?

In collaboration with the ECI sector, the NDIA could support the implementation of ECI best practice in a number of ways to:

- **provide policies and guidelines to support the core elements of ECI best practice.** These could be modelled on the practice guides for practitioners and families described by Dunst (2018) and available through the ECTA Center (<http://ectacenter.org/decrp>).
- **develop criteria for ensuring that registered services are committed to and able to deliver services based on these best practices.**
- **develop quality assurance and outcome measures.** This could include the requiring services to make regular use of evidence-informed checklists to ensure that services are actually being delivered in accordance with best practice
- **explore ways of providing fully independent advice specific to families of young children and the NDIS.**



- **ensure that parents are not only given information about the ECI services that are available to them, but also about the ways in which ECI services function** – the rationale for working with and through parents, and the key features of family-centred practice.

One way of doing this is to provide every parent with information about what constitutes best practice in ECI – e.g. ECIA Best Practice parent version (Early Childhood Intervention Australia WA/NT Alliance, 2017).

- **provide training to build the skills of early childhood partners to provide families with essential information about early childhood development and family-centred practices.**
- **help parents build their ability to make choices based upon family values and circumstances as well as evidence-based practices.**
- **make building parental capacity a central goal.** For parents to be able to exercise choice and control, they need to develop the skills to meet the needs of their child and family. Strategies for achieving this include the use of strength-building practices and parent coaching.

Conclusions

The arc of the moral universe is long, but it bends toward justice.

This was a favourite quote of President Obama.¹ What's meant by it was that, although it may seem at times that little progress is being made, justice will prevail in the end. The moral arc may appear to have taken a nosedive under Obama's successor, but that might be temporary, part of a pendulum effect that masks underlying progress.²

Those of us who have been on the ECI journey from its early beginnings and seen its steady trajectory towards parent empowerment via family-centred practice are dismayed at the way in which this trajectory appears to have been derailed so easily. However, we can never assume that the direction we have been moving will continue indefinitely and that family-centred practice represents the goal that everyone is moving towards. We also need to accept that the goal of truly family-centred practice has proved elusive in practice.

Does the challenge to family-centred practice we are observing under the NDIS represent a temporary set-back (two steps forward, one step back) or a major reversal? Does it represent the inevitable teething problems associated with such a major systems change, or is family-centred practice fatally compromised under a free-market system?

¹ Obama was quoting Martin Luther King who was in turn quoting 19th century clergyman Theodore Parker (1853)

² Stephen Pinker (2018) and Hans Rosling (2018) have sought to demonstrate that, despite appearances, the world is getting progressively better.



Until we can resolve the teething problems, we will not be able to tell, so our efforts need to be directed to fixing the problems. We need to tackle the fault lines in our own sector as well as revisiting/reasserting what best practice is and how it can best be supported.

Does the genie need to be put back in the bottle? No, but it does need to be trained to behave.

Do parents need to be careful what they wish for? I would not like to accuse any parent of being careless about what they wish for their child – the caring urge is much too powerful for that. Instead the onus is upon us – service providers, policy makers, funders as well as parents – to design a system that provides parents with the supports, information and funding mechanisms that enable them to make choices that are in the best interests of their child themselves and their family.

Given how rapidly best practice knowledge and skills are being eroded under the present system, this is a matter of urgency.



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