

Centre for Community Child Health



From block funding to individual purchasing in early childhood intervention services:

Understanding the implications for service delivery and best practice

Tim Moore

Keynote address at 12th Biennial National Conference of Early Childhood Intervention Australia

Melbourne, 8 September 2016



Acknowledgements:

Thank you to Noushin Arefadib for valuable editorial comments on the final paper.

Suggested citation

Moore, T.G. (2016). From block funding to individual purchasing in early childhood intervention services: Understanding the implications for service delivery and best practice. Keynote presentation at 12th Biennial National Conference of Early Childhood Intervention Australia, Melbourne, 8th September.

<https://doi.org/10.25374/MCRI.7685945>

Prepared by:

Dr Tim Moore

Senior Research Fellow

Centre for Community Child Health

Murdoch Children's Research Institute

Phone: +61-3-9345 5040

Email: tim.moore@mcri.edu.au

The Centre for Community Child Health is a research group of the Murdoch Childrens Research Institute, a department of The Royal Children's Hospital, Melbourne, and an academic centre of the University of Melbourne.

Centre for Community Child Health

The Royal Children's Hospital Melbourne

50 Flemington Road, Parkville

Victoria 3052 Australia

Telephone +61 9345 6150

Email enquiries.ccch@rch.org.au

www.rch.org.au/ccch

Abstract

The advent of the National Disability Insurance Scheme involves a radical shift in the way the early childhood intervention services are funded. What impact (if any) will the shift from block funding to individual purchasing have on the way in which early childhood intervention services are delivered and on what services are delivered? This presentation explores the ways in which the two funding models either support or compromise best practice. The advent of the National Disability Insurance Scheme (NDIS) involves a radical shift to the way the early childhood intervention services are funded. What impact (if any) will the shift from block funding to individual purchasing have on the way in which early childhood intervention services are delivered and on what services are delivered? Does the individualised market-based funding model offer some real advantages over the previous funding model, or does it bring with it a new set of challenges to best practice?

After exploring these and other questions, the paper concludes that we may indeed be swapping the virtues and vices of one system for the virtues and vices of another. There is no perfect system for supporting best practice, but different systems can support or compromise best practice in different ways. The particular ways in which the market-based system can compromise best practice are explored, and ways of guarding against these are suggested.

Introduction

At the 2014 ECIA National Conference in Brisbane, Kerrie Delves and Paul Miller, from the Commonwealth Department of Social Services, gave a presentation on what the Department had learned from administering the *Helping Children with Autism* (HCWA) package and the *Better Start for Children with Disability* (Better Start) Initiative (Delves and Miller, 2014). Both the HCWA package, introduced in 2008, and the Better Start initiative, introduced in 2011, are individualised market-based approaches to funding early childhood intervention support for young children with developmental disabilities and their families.

As part of their presentation, Delves and Miller showed a table of the potential benefits of the market-based model over the traditional grants-based approach (see below). My intention is not to criticise the table or their conclusions, but to explore what it tells us.

Move to a market-based approach – potential benefits

Grants-based	Market-based
Block-funding	Individualised funding
Limited service types	Variety of services based on demand
Limited choice of provider	Choice between providers
One-size fits all	Tailored, based on individual need
Limited capacity/rationed services	Capacity for services to grow based on demand
Limited flexibility/responsiveness	Increased flexibility/responsiveness

Lessons from DSS' early intervention programmes (Delves & Miller, 2014)

Reproduced with permission of the authors

When looking at a table such as this, one can test how robust the logic is by seeing if it is possible to reverse the poles. What struck me about this table was that I could imagine a suitably reworded version of it in 20 years time, when the pendulum starts to swing back, listing problems with the market-based model and why we should shift to a block funding model. When this happens, as it surely will, it will suggest that such shifts involve swapping the vices and virtues of one system for the vices and virtues of another – and that there is no absolute best method or system.

The advent of the National Disability Insurance Scheme (NDIS) involves a radical shift to the way the early childhood intervention services are funded, and we need to know what effect this will have on services and families. What impact (if any) will the shift from block funding to individual purchasing have on the way in which early childhood intervention services are delivered and on what services are delivered? Does the individualised market-based funding model offer some real advantages over the previous funding model, or does it bring with it a new set of challenges to best practice? These are the questions explored in this paper.

The paper begins with a brief outline of basic assumptions about early childhood intervention (ECI) – its aims, key principles and practices – focusing particularly on the key role of relationships. It then explores a number of key questions about relationship-based ECI service delivery, focusing on the extent to which each funding model may promote or compromise best practice.

Basic assumptions about ECI

I recently heard the ECI field described as, ‘middle-aged’. This is deeply disquieting to those of us who have been involved since the field’s infancy and lived through its unruly adolescence. However, what it presumably indicates is that the field has reached a general consensus on its basic aims, principles and practices.

This appears to be the case. Regarding the *aims* of ECI, there is agreement that the overall aim of early childhood intervention is

... to ensure that the parents or other key caregivers are able to provide young children who have developmental disabilities with experiences and opportunities that help the children gain and use the functional skills they need to participate meaningfully in the key environments in their lives (Moore, 2012).

This way of framing the goals of ECI is consistent with that of many authorities, including the Workgroup on Principles and Practices in Natural Environments (2008a), Dunst and Trivette (2009), McWilliam (2014), Palisano et al. (2012), and Raver and Childress (2015a). For instance, in the US, the Workgroup on Principles and Practices in Natural Environments (2008a) state that (Part C) ‘early intervention builds upon and provides supports and resources to assist family members and caregivers to enhance children’s learning and development through everyday learning opportunities.’

The features of *best practice* are also well-established (DEC, 2014, 2015; Dunst and Trivette, 2009; ECIA, 2016; Moore, 2012, 2013a, 2013b; Workgroup on Principles and Practices in Natural Environments (2008b, 2008c). As stated by the Workgroup on Principles and Practices in Natural Environments (2008a), the key principles underpinning best practice in ECI are as follows:

1. Infants and toddlers learn best through everyday experiences and interactions with familiar people in familiar contexts.
2. All families, with the necessary supports and resources, can enhance their children’s learning and development.
3. The primary role of a service provider in early intervention is to work with and support family members and caregivers in children’s lives.
4. The early intervention process, from initial contacts through transition, must be dynamic and individualised to reflect the child’s and family members’ preferences, learning styles and cultural beliefs.
5. IFSP outcomes must be functional and based on children’s and families’ needs and family-identified priorities.
6. The family’s priorities, needs and interests are addressed most appropriately by a primary provider who represents and receives team and community support.
7. Interventions with young children and family members must be based on explicit principles, validated practices, best available research, and relevant laws and regulations.

In her keynote presentation at this conference, Mary McLean described the development and revision of recommended ECI practices by the DEC Division for Early Childhood (McLean, 2015, 2016), the nearest US equivalent to Early Childhood Intervention Australia (ECIA). These principles are reflected in the ECIA's *National Guidelines: Best Practice in Early Childhood Intervention* (ECIA, 2016), released this year. These are the first national statement on best practices in Australia, and ECIA is to be congratulated for this initiative. These guidelines identify eight key best practices in ECI:

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.
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.
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.
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.

The effective delivery of ECI services based on the above principles depends to a significant extent upon the nature of the relationships established between ECI practitioners and parents. The reason why relationships play such a central role lies in our neurobiology:

We are intensely social creatures, and our brains are shaped by relationships, for good or otherwise: It is clear that our brains are designed to respond to and be influenced by others. For good evolutionary reasons, ...we are wired to be social. (Lieberman, 2013).

Human services, such as ECI, are *relational* services, dependent to a much greater extent than other forms of service on the quality of the relationships between practitioners and parents (Ruch et al., 2010).

The reality is that the field of early intervention is a relationship-based discipline. Without a sound relationship with the child, the child's family and extended family, and other important people in the family's life, it is impossible to make meaningful changes in a child's development. (Raver & Childress, 2015b)

There is an extensive body of convergent evidence from a variety of sources to support these claims (Moore et al., 2012; Moore, 2015), including research on:

- The neurobiology of interpersonal relationships (Cozolino, 2010, 2014; Lieberman, 2013).
- Vulnerable families (Boag-Munroe & Evangelou, 2012; CCCH, 2010; Cortis et al., 2009).
- Psychotherapy efficacy (Cozolino, 2016; Duncan et al., 2010; Shore, 2012; Horvath et al., 2011; Norcross and Wampold, 2011; Sprenkle et al., 2009).
- Doctor-patient relationships (Nobile & Drotar, 2003; Roberts, 2004; Stewart et al., 1999; Sweeney et al., 1998).
- Family-centred practice (Bailey et al., 2011; Dunst et al. 1988, 2008; Dunst and Espe-Sherwindt, 2016; Dunst & Trivette, 2009; Raver and Childress, 2015; Trivette et al., 2010; Trute and Hiebert-Murphy, 2013) and the family partnership model (Davis and Day, 2010).
- Effective help-giving practices (Braun et al., 2007; Dunst & Trivette, 2007, 2009).

Overall, the evidence is clear: *how* services are delivered is as important as *what* is delivered:

The manner in which support is provided, offered, or procured influences whether the support has positive, neutral, or negative consequences (Dunst & Trivette, 2009)

Outcomes are not simply the result of advice (e.g. take drug X or play with your child) but are determined also by the ways in which advice is given (Davis & Day, 2010)

The evidence also indicates that the quality of the relationships between practitioners and parents are central to achieving the objectives of services (Bell & Smerdon, 2011; Braun et al., 2006; Greenhalgh et al., 2014; Moloney, 2016; Scott et al., 2007). As Greenhalgh and colleagues (2014) have argued of medical services,

Real evidence based medicine builds (ideally) on a strong interpersonal relationship between patient and clinician.

Bell and Smerdon (2011) use the term Deep Value to convey the importance of the practitioner-parent relationship:

Deep Value is a term ... that captures the value created when the human relationships between people delivering and people using public services are effective. We believe that there are real benefits in delivering public services in ways that put the one-to-one human relationship at the heart of service delivery. In these relationships, it is the practical transfer of knowledge that creates the conditions for progress, but it is the deeper qualities of the human bond that nourish confidence, inspire self-esteem, unlock potential, erode inequality and so have the power to transform. (Bell & Smerdon, 2011).

The more effective professionals are at engaging, communicating and forming partnerships with parents, the better child and family outcomes will be. In early childhood intervention services, successful engagement with parents leads to greater use of agreed strategies between home visits (Peterson et al., 2007). In medicine, engaging parents as partners leads to better outcomes (Sweeney et al., 1998), and effective communication results in greater adherence to recommended treatment plans and better health outcomes (Nobile & Drotar, 2003; Stewart et al., 1999).

Important as relationships are, they represent a necessary but not sufficient condition for effective outcomes. Relationships are best understood as the medium through which change evidence-based strategies are driven. The ultimate aim is to shape the environments in which children spend their time, which means shaping the way in which caregivers interact with their children and what opportunities they provide them.

~ ~ ~

With these aims, principles and practices in mind, we can consider the specific question of what impact (if any) will the shift from block funding to individual purchasing have on the way in which early childhood intervention services are delivered and on what services are delivered.

However, before we do so, there is one fundamental question that needs to be addressed:

Can a service delivery and funding model have an impact on the way in which services are delivered and received?

There is good evidence that, in general, people's behaviour and ideas about themselves are significantly affected by their immediate context or circumstances. Summarising this evidence, Sommers (2011) concludes that

To understand human nature, you must appreciate the power of situations. (Sommers, 2011)

In the case of ECI services, simply changing where services are delivered can have an impact. In a study of the effects of early intervention settings on the extent of parent involvement in early childhood intervention, Dunst and colleagues (2014) found that providing services entirely or partially outside a family's home was associated with minimal parent involvement compared with services delivered inside the home.¹

There is also evidence that people's values (and hence their behaviour) are shaped by public policy, especially policies that are highly visible and more proximal (as in the case of the NDIS and its impact on ECI services) (Crompton, 2010; Soss & Schram, 2007):

Values are also shaped by people's experience of public policies and of interacting with public and private institutions. For this reason, any piece of public policy will have both material impacts (the effect of the policy in directly changing the outside world) and cognitive impacts (the effect of the policy on citizen's values) (Crompton, 2010).

Policies can influence beliefs about what is possible, desirable, and normal (Soss & Schram, 2007).

Therefore, policies should be examined not just for likely material impacts, but also their 'cognitive' impacts – the effect a policy has on people's values. As George Lakoff (2009) argues, this means that we can legitimately ask:

What are a policy's empathetic consequences – how does it affect all that we are connected to?

Values are important because they shape people's behaviour – and practitioner's values, therefore, shape their practice (Crompton, 2010; Moore, 2016).

This evidence suggests that a service delivery and funding model – governing where services are delivered, how they are to be delivered, and how they are funded – *can* have an impact on the way in which services are delivered and received. Therefore, it is important to explore the impact that different funding and service models can have on the behaviour of those delivering or receiving services.

¹ However, the same study also found that more than half of the parents, regardless of setting or context, were not involved in their children's early intervention in a manner consistent with best practice, indicating that, while delivering services in the home increases the rate of meaningful parental involvement, it is no guarantee.

With this in mind, we will now consider specific issues that arise as a result of the shift from one model to the other, and ask what impact (if any) will this shift have on the way in which early childhood intervention services are delivered and on what services are delivered. Does one or other model better able to ensure that the aims, principles and practices outlined above will be observed?

The key questions to be addressed are:

- Is giving parents full control over funding a good idea?
- Does providing more choices lead to better choices and a greater sense of control?
- Does having control of the funding encourage the ‘purchasing fallacy’ – that what you buy is better than what you get for free or do for yourself?
- Does having control of a budget lead to better outcomes?
- Will a market-based system lead to services becoming less outcomes-focused and more service-focused?
- Will the need to ‘sell’ our services corrupt the process of providing unbiased information and lead to exaggerated claims of benefits?
- What impact does a market-based system have on the parent-professional relationship?
- What effect does a market-based system have on the family adaptation to having a child with a disability over time?
- What support do parents need and who should provide it?

The last three questions are particularly interesting because they address the ways in which the two funding models either support or compromise the all-important parent–practitioner relationship.

Block funding vs. individual purchasing: issues arising

Is giving parents full control over funding a good idea?

Individualised or personalised budgeting models for people with a disability have been widely adopted around the world (Fisher & Purcal, 2010; Pike et al., 2016). There is a good case to be made for these self-directed approaches (Leadbeater, 2004, Duffy, 2006). As championed by Leadbeater (2004), the rationale for personalisation 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.

This participative approach should deliver personalised, lasting solutions to people’s needs at lower cost than traditional, inflexible and top-down approaches (Leadbeater et al., 2008). Duffy (2010) describes this as a shift from a paternalistic model of service delivery (a ‘professional gift’ model) towards a model which treats people as citizens, not service users (a ‘citizenship-based’ model):

- *Professional gift model* - In this model the tax payers give money to the government, the government gives money to the professionals who turns that money into services that are offered to the needy person as a gift - that is, something that cannot be defined, shaped or controlled by the individual.

- *Citizenship-based model* - In this model the tax payers give money to the government, the government defines that money as an entitlement, and the individual (with their community) uses this entitlement to negotiate any professional support necessary.

This shift represents a transformational approach to public services (Leadbeater et al., 2008; Murray, 2010). Originally developed in the adult care services sector, this approach is now being piloted in children's services and in health care. If privatisation was the key focus of the 1980s, it has been claimed, then personalisation could be the key focus of the early 21st century (Murray, 2010). According to Murray (2010),

If we examine what families really need them we see that this help must be personalised. This is not just about financial control, it is more about respecting the very fabric of family life – their strengths, relationships and communities – building on the family's real well. Families do not want to do everything for themselves – but they want real relationships which are based on trust and enable the best solutions for their particular needs. (Murray, 2010)

Personal budgets are an international trend, with many countries experimenting with some form of individualised funding for people with disabilities (Pike et al., 2016). The UK *In Control* charity (Crosby, 2010; Crosby et al., 2012) has promoted personal budgets for children with disabilities and their families. They see these as depending upon the development of a new relationship between statutory agencies, services, and children with disabilities and their families. This new relationship is based on an approach which sees

- *The child and the family at the centre*: Families are the experts. They may need knowledge, skilled support and expertise from others to help with their child but it is essential to remember they hold the lead caring role and this should not be compromised by professional intervention.
- *The recognition of a family's 'real wealth'*: The child and the family have a range of existing resources that they can draw upon. They may simply need good support to enable them to recognise and utilise these resources.
- *A whole system*: All support needs a joined-up approach focused on strategic outcomes.
- *Clear and simple outcomes*: Outcomes agreed at the outset which set out simply and clearly what services will achieve for children, young people and families
- *A simple pathway*: A set of steps clearly identifying the process for how children and young people will be assessed, eligibility criteria, allocation of personal budgets and review (Crosby et al., 2012)

There are striking similarities between this approach and family-centred practice.

Reflections

While there is a strong logic to support giving parents of children with developmental disabilities direct control over the funding, we need to recognise that control of money alone is not inherently valuable in itself – it is a means to an end. The desired outcome is that the person / family feels in control of what is happening to them and makes the final decisions about how their needs are met.

The rationale behind this is threefold. First, clients have a better understanding (than professionals) about what they need and how these needs can best be met. Therefore, client control of funding can mean that resources will be better directed and more efficiently used. Second, people suffer and outcomes are worse when they do not feel they have much control over their lives or what happens to them – this generates stress with worse outcomes for health and well-being. Third, participation both in decision-making and in intervening is empowering, and helps build parental capabilities.

Autonomy over money and how it is spent is a means of achieving these three goals of targeting, control, and participation. But whether or not this autonomy is an *effective* way of achieving these outcomes is an empirical question; it may well be effective for some people, especially more experienced or better resourced people, but could equally be a source of greater rather than lesser stress for others, and may lead to poor choices and inefficient use of resources, and fail to build parental competencies.

Moreover, it could be argued that the traditional block-funding funding approach can also produce positive outcomes for parents when the ECI service provider fully implements a family-centred approach. Such an approach is designed to focus on issues most salient to parents, allow them to make all final decisions about services, and build their competencies – the same outcomes claimed of the self-directed funding approach. Of course, if the ECI service provider fails to deliver family-centred practices, inferior outcomes result – parents will not feel in control, will not be able to participate, services will not be directed to the issues most important to parents, and parents will not become better able to meet the needs of the child and family.

What this analysis suggests is that both funding systems are able to produce positive or inferior outcomes. Therefore, it is not whether parents have control over money (or not) that is of most significance, but rather how well the funding method in place is suited to that particular family's circumstances and capabilities, and how appropriately they are supported during decision-making processes.

Does providing more choices lead to better choices and a greater sense of control?

The assumption that providing more choices will lead to better choices has been challenged (Brown & Brown, 2009; Dickinson et al., 2014; Mol, 2008; Peters et al., 2013; Stephens et al., 2008). In an analysis of health-related policies, Peters and colleagues (2013) note that

A key underlying assumption underlying many policies is that more choice, more information, and more autonomy will produce better decisions and outcomes as well as greater comfort with those decisions and outcomes. A growing literature suggests that this assumption is problematic: it appears that foisting on individuals a wider swathe of options and information in an autonomy-rich environment can lead to less satisfaction, more anxiety, greater disengagement, and poorer decision making.

Stephens and colleagues (2008) also warn about the dangers of giving clients unfettered choice about what to do with the money. While clients often know best what priorities they have and how money allocated to them should be spent, there is also a risk of leaving them isolated if all we offer is a budget and nothing more. What clients want are long-term partnerships with professionals with whom they can co-produce plans and interventions, and these are not so easily the product of individual budgets (Stephens et al., 2008).

Annemarie Mol (2008) argues that good care has little to do with 'patient choice' and that creating more opportunities for patient choice will not improve health care. Although it is possible to treat people who seek professional help as customers or citizens, Mol argues that what she calls the logic of choice can actually lead to poor care: 'It can shift the weight of everything that goes wrong on to the shoulders of the patient-chooser'. She contrasts the logic of choice (in which people are assumed to be able to act as autonomous rational individuals in making decisive choices) with the logic of care (in which people are seen as embedded in relationships with professionals and others, and make – and continuously revise – decisions collaboratively). Mol argues that good care is not a matter of making carefully considered individual choices but something that grows out of collaborative and continuing attempts by practitioners and patients to match knowledge and strategies to the patients' complex lives.

In considering choice as an aspect of quality of life for people with intellectual disabilities, Brown and Brown (2009) point out that,

even though choice is valued as a right and entitlement, when it is applied to the real lives of people it may not *necessarily* lead directly to improved quality of life, happiness, or even the best course of action.

Thus, as is the case with control of funding, providing unfettered choice does not necessarily equate to good choices and positive outcomes.

In addition to these considerations, there are ethical challenges to be addressed in supporting client choices (Brown and Brown, 2009; Dickinson et al., 2014; Stevens et al., 2011). Providing families with choices can lead to ethical problems for practitioners, as when parents choose a form of intervention that is ill-advised or even harmful:

Whatever the choices put forward by the individual, they must be recognized by frontline personnel and family members as valid perceptions, and respect must be accorded to the decisions involved. However, respect does not always mean acquiescing or supporting the decision. Some decisions are simply ill-advised, and skilled judgment is required to know when and when not, to support a decision. (Brown and Brown, 2009)

Thus, an unthinking acceptance of the choices made by families can amount to an abdication of professional responsibility (McMahon, 2010). As noted by Dickinson and colleagues (2014), if individuals become more involved in making decisions about the services that they receive, it becomes less clear who is accountable for the outcomes of those services. If governments step back from accountability for outcomes, users of services have to assume this responsibility and bear the risks of their own choices (Clarke et al., 2006). The problem is that people vary in their ability to handle such responsibility:

The capacity to act as an expert consumer will be unequally distributed between people with disabilities, and concerns about the potential for self-directed support to magnify existing inequalities have been expressed. (Dickinson et al., 2014)

To a greater or lesser extent, families need support in articulating their needs and identifying the kinds of services that are best able to meet those needs. This is best delivered through a collaborative partnership with an experienced practitioner who is able to provide the level of scaffolded support the particular family requires. Families also need to be protected from having to make choices when there are too many options and/or when they lack a good understanding of what the various options involve.

Reflections

Providing more choices does not always lead to better choices. Too much choice can be just as paralyzing as too little choice. What matters are the *conditions under which choices are provided* – the range of options available, how well informed the families are about the options, and the availability of support that is tailored to each family's unique capabilities and circumstances.

How does this apply to our two funding models? In the case of the market-based model, there is clearly a danger that parents could be faced with too many choices and/or provided with too little information and support in making decisions. Under such circumstances, those with fewer resources will be particularly disadvantaged. In the case of the block-funding model, there is a danger that parents will be given too few

choices, and/or not given meaningful opportunities to choose. In both cases, special steps need to be taken to ensure that conditions that optimise sound decision-making and promote a sense of control.

Does having control of funding encourage the ‘purchasing fallacy’ – that what you buy is better than what you can get for free or do for yourself?

We are all subject to prevailing tendencies to believe that more is better, that what we buy is better than what we can get for free or do for ourselves, and that what we pay more for is better than less expensive options. This is true in the case of families of children with disabilities who assume, for instance, that more sustained and intense direct therapy for their children is better than less (Novak, 2012). Parents who are new to ECI services and unsure of their own capabilities are also more likely to think that professionals can meet their child’s needs more effectively than they can.

Is this an equal issue for both funding models? The purchasing fallacy has always played a role in the early childhood intervention sector: those who could afford to do so have often preferred to buy therapy services for their children rather than use the services provided by publicly funded agencies. Moreover, even under the block-funding model, parents tend to assume that more is better, and that what the professional can do with their child is better than what they can do. If the professionals collude with these assumptions, then they will end up providing more direct services to the child and failing to build parental competencies.

What about the individual purchasing model? If parents have control of the money, then the purchasing fallacy may play a major role in shaping their service choices. As Stephens et al. (2008) point out,

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.

Parents may learn over time that this is not the best strategy, but in the meantime, valuable time and money can be wasted.

This analysis suggests that, while having control of funding may exacerbate the tendency for parents to buy direct services rather than seek to build their own capabilities, this tendency can also play a role in shaping parental choices under traditional block funding models. In both cases, guarding against the purchasing fallacy takes the same form: practitioners need to keep in mind the goal of building parental capabilities, respectfully challenge parental assumptions that professionals can meet their child’s needs more effectively than they can, and help build the parents’ ability to meet the needs of their child and family.

Does having control of a budget lead to better outcomes?

There have been numerous studies of the effects of personalised budgets for adults with disabilities, and some on the benefits for families of older children with disabilities. However, there has been relatively little research into the effects of such budgets on very young children with developmental disabilities and delays.

Evidence regarding personalised budgets for adults with disabilities

There have been a number of evaluations of personalised budgets with adults, including case studies of personalised budgets as a way of providing better support to people at times of crisis or vulnerability (Keilty, 2014), reviews of evidence regarding personalised budgets for adults needing social care (Manthorpe et al., 2011), and review of self-management strategies for adults with health problems (Da Silva, 2011). Australian studies suggest that individualised and self-managed funding can significantly enhance the choice, dignity,

control and empowerment of adults who have a disability, their families and carers, as well as improving their wellbeing, independence, resilience and social participation (Fisher & Purcal, 2010; Fisher et al., 2010; Gendera et al., 2011 Pearson & Hill, 2012).

Evidence regarding personalised budgets for children with disabilities

In the UK, there have been evaluations of pilot programs of Individual Budgets for Families with Disabled Children, mostly involving older children rather than those involved in early intervention services. These studies have looked at the impact of the individual budgets program (Prabhakar et al., 2011; Prabhakar & Thom, 2012) and on family outcomes and impacts (Johnson et al., 2011; Johnson & Thom, 2012). A summary report of these evaluations (Thom & Prabhakar, 2011) suggested that the individual budget programs clearly demonstrates an increased sense of choice and control, improved access to social care services, shifts in the types of service that families used, greater satisfaction with the services they received, and some flow through benefits for improved wellbeing.

According to Murray (2009, 2010), families of children with report that the personalised approach gives them a range of benefits, including a sense of being valued, a positive view of their disabled child, ability to respond to the fluctuating needs of illness and impairment, transparency and greater understanding of what services and support costs, opportunities to try things out to see what works best, and control over how the money allocated to them is spent.

The logic informing the move to allow people with disabilities to direct their own service budgets is principally focused on the *care services* required by *older people* with disabilities. The primary focus of ECI services is not the care needs of young children, but their need for experiences, opportunities and supports that will promote their functional skills. The suitability of the self-directed budget model for achieving these particular ECI aims has not been tested – what we need to know more about are the conditions necessary for parents to be able to learn to manage such budgets.

Will a market-based system lead to services becoming less outcomes-focused and more service-focused?

How we define early childhood intervention matters. Dunst (2012) argues that, in the US, ECI was originally defined in terms of '*the kinds of activities that were intentionally used with young children to produce desired outcomes and consequences.*' The federal ECI legislation introduced in the United States in 1986 redefined ECI in terms of the *type and frequency of professional services* provided young children and their families, rather than the experiences, activities, and learning opportunities used to influence infant and toddler behaviour and development.

Does that matter? I have argued elsewhere (Moore, 2012) that it does – the professional services are a means to an end, not an end in itself, and to help keep the end in mind at all times we should define early childhood intervention in terms of the *outcomes* we are trying to achieve rather than the *services* we provide. Family service plans that are framed in terms of the service to be provided (eg. weekly visits by a therapist) are more likely to count themselves as being successful when the particular services have been delivered as planned, regardless of whether they were successful in enhancing child and family functioning. Service plans that are framed in terms of outcomes desired by the family (eg. specific improvements in child functioning or family capabilities) are more likely to be flexible in the form of service being provided and to achieve the outcomes in question.

Moreover, framing ECI as a form of professional service can compromise best practice. Dunst (2012) claims that defining early childhood intervention in terms of the provision of professional services has led to less attention on identifying the key characteristics of learning experiences and opportunities needed by children

with developmental disabilities, and on how these are provided. It has also resulted in professionals more often providing services directly to children without meaningfully involving the family in the interventions.

However, these problems are not exclusive to a market-based system, and can also arise under block-based funding models. A focus on outcomes is not guaranteed under either funding model. Whatever the model, practitioners and policy makers should always keep the end in mind, focusing on the outcomes that families want for their children and providing services that are explicitly designed to achieve those outcomes. To ensure that this happens, ECI practitioners and services need to use planning and evaluation protocols that are framed around child and family outcomes, with the actual services able to change quickly if they are not helping the family achieve their outcomes, or if the outcomes themselves change. Similarly, the NDIS should require that the plans approved for NDIS funding should be outcomes-focused rather than framed in terms of services to be provided.

Will the need to 'sell' our services corrupt the process of providing unbiased information and lead practitioners to exaggerate the benefits of their services?

Market-based systems involve greater insecurity for providers. Instead of funding being available up front, providers will only be paid after the service has been provided. If services are not seen as desirable (by would-be purchasers) or do not satisfy those who choose them, there will be less money coming in. This makes it harder for agencies to guarantee ongoing employment for practitioners, and increases the likelihood that they will be employed on short-term contracts.

This can place pressure on providers to market their service in a way that will maximise the number of people who choose them. There are benefits and dangers in such marketing endeavours. The benefits are that it will encourage providers to make it more explicit to families what exactly they offer and how it can support families. The danger is that providers will exaggerate the potential benefits of their service, making claims of improvements that they cannot guarantee.

Is this different for block-based funding? Block-based funding model is not exempt from this tendency. In the traditional service environment, services compete for customers, sometimes on the basis of providing particular forms of treatment claimed to be superior to other forms of treatment. However, the commercial demands of the market-based funding model places greater pressure upon service providers to sell their wares, and therefore increases the likelihood that they will promise more than they can achieve. It also increases the likelihood that they will provide services in ways that are more cost-effective for themselves but not for the parents (eg. providing clinic-based rather than home-based services).

All market-based systems have this problem and therefore need regulations to guard against false advertising and quality assurance mechanisms to ensure that services are providing best practice. These have not yet been developed for the NDIS, but will undoubtedly be needed before long. This would be a welcome development for the ECI sector, bringing it in line with other service sectors such as child care and aged services.

What impact does a market-based system have on parent-professional relationship?

Stephens and colleagues (2008) make the strong claim that

‘...neither markets nor centralised bureaucracies are effective models for delivering public services based on relationships. Market logic applies to narrow deliverables, but misses out the crucial dimension that allows doctors to heal, teachers to teach, and carers to care: the relationship with

patient, pupil or client. Centralised bureaucracies, public and private, find it equally hard to grasp these essentials.

Chapman (2004) is another who doubts the effectiveness of market-based systems to deliver relationship-based services:

One can 'deliver' a parcel or a pizza, but not health or education. All public services require the 'customer' to be an active agent in the 'production' of the required outcomes. Education and health care initiatives simply fail if the intended recipients are unwilling or unable to engage in a constructive way; they are outcomes that are co-produced by citizens.

Similarly, Stephens et al. (2008) argue that

... service users don't usually regard themselves as customers: they want long-term partnerships with professionals, and these are not so easily the product of individual budgets.

Are these critiques justified?

A market-based system inevitably heightens both practitioner and parental awareness of the cost of services – the practitioner keen to 'make a sale' and the parent wanting to budget sensibly. There is some evidence that a heightened focus on the cost of things can shift our values or behaviour, or disrupt services. According to Crompton (2010), experimental studies show that, when you put people in situations where there is a strong focus on financial success, they are more likely to show 'lower empathy, more manipulative tendencies, a higher preference for social inequality and hierarchy, greater prejudice towards people who are different, and less concern about environmental problems.' Other experiments demonstrate that priming people's awareness of money leads them to be less helpful (Burgoyne and Lea, 2006; Vohs et al., 2006), reflecting the empirical evidence that the extrinsic goal of financial success is almost perfectly opposed to the intrinsic goal of community feeling.

If you 'prime' people to think of money rather than more neutral concepts, they adopt a self-sufficient orientation in which they prefer to be free of dependency and dependents, so that they are less likely to ask for or to offer help (Vohs, et al., 2006).

But these are experimental studies, not real life. While practitioners in market-based systems are very likely to be more aware of costs, this does not necessarily make them any less empathetic or able to engage parents as partners. In the NDIS model, there are hourly rates for professional services, which will mean practitioners will have to learn to manage their time efficiently. However, this will not necessarily make them any less attentive to parents during the time they are with them.

This suggests that, despite the ways in which explicitly financial transactions can shape relationships between provider and client, relationship-based practice is not *necessarily* compromised by a market-based funding model. As argued earlier, delivering effective human services depends greatly upon the quality of the relationships involved. This is true whatever the funding model used. Under the NDIS, it will be as important as it ever was for practitioners to work on their relationship skills and to build effective partnerships with families.

What effect does a market-based system have on the family adaptation to having a child with a disability over time?

A family's adaptation to having a child with a disability emerges over many years and takes many forms. As Landsman (2005, 2009) has shown, mothers of children with disabilities may begin by subscribing to the medical model of disability, one in which the disability is seen as being in the body or mind of the child, and therefore as something to be 'cured'. However, over time, they often gravitate towards a social mode, one in which the barriers to a high quality of life are not within the child but rather the product of environments that do not make accommodations to enable the child to participate meaningfully. The changes that mothers experience on this journey include embracing the exceptional qualities of the child as the essence of who they are, or even reassessing the very concept of normality itself (Landsman, 2005).

Many other studies and accounts of the impact on families of having a child with a disability have shown that some families go well beyond mere 'acceptance' of the child, and consider themselves changed for the better (eg. Corman, 2009; Dykens, 2005, 2006; Flaherty and Glidden, 2000; Hastings and Taunt, 2000; Kausar et al., 2003; King et al., 2006; Schwartz, 2003; Solomon, 2011). However, there is no way we can fast track parental adaptation to having a child with a disability – this is a deeply emotional transformation that each parent needs to go through at their own pace. What we can do is provide the conditions for parents to develop their capacity to meet the needs of the child and family, and to build a positive narrative about their family's journey.

Can a market-based system achieve this just as well as a block-funded system? Both systems face the same challenge: how to respond to and address the immediate short-term needs of the family while simultaneously keeping in mind the long term goal in mind. There does not seem to be any reason why a market-based funding system cannot do this just as well as a block-funded system.

What support do parents need and who should provide it?

The early years of the parent's long journey as parents of a child with a disability are challenging because most know so little about what they or their child needs and therefore what they should buy with the funds available. When families of young children with disabilities have the diagnosis confirmed and become eligible for ECI services, they are likely to be in a state of some distress and disorientation. They will be unfamiliar with the ECI service system and uncertain of their role in relation to professionals. They will also likely to be lacking in confidence in their own abilities to help the child, and tend to defer to the knowledge of professionals.

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

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

In a market-based funding model, there are three key areas that families of young children with disabilities need support in:

- deciding what their needs and priorities are,
- choosing appropriate services or strategies to address these needs, and
- managing the budgets to purchase these services

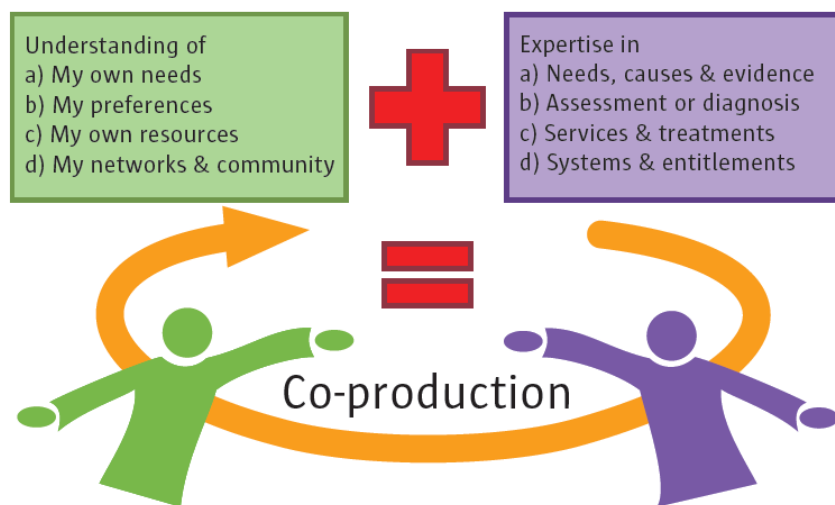
The first two of these support areas – helping parents decide their needs and priorities, and helping them choose appropriate services or strategies to address their needs – have always been key features of family-centred practice, but their importance is highlighted in a market-based funding model because of budget implications.

The challenges faced by parents in the early stages of their journey are illustrated by an Australian study by Grant and colleagues (2016) of the intervention decision-making processes and information preferences of parents of children with autism spectrum disorders. When a child is diagnosed with autism, parents are faced with the task of choosing from many different intervention options. To find information about the options available, parents turn to a number of different sources, with the Internet being the primary source. The parents in this study reported being overwhelmed by the sheer volume of information available, and their preferences for information varied according to their stage in the journey post diagnosis. These parents resorted to a 'trial and error' approach to choosing interventions, with their confidence increasing as they became more familiar with their child's condition, and had opportunities to explore numerous information sources about their child's diagnosis.

In another Australian study, Johnston and colleagues (2013) examined how the internet could be used as a conduit to build the capacity of families who have young children with disabilities to enable them to make effective decisions about intervention and support. They found that the majority of parents were confident in using the internet, but a significant minority were not. For such parents, websites needed to be interactive and as jargon free as possible. Information also needed to be available in multiple forms and in multiple languages.

The transition to an individualised funding model for young children with disabilities (and their families) demands that parents and/or carers be able to advocate effectively for their children and make informed choices about services and support. To do this, parents need access to information on best practice in early childhood intervention which is both easily obtainable and in a form which is meaningful to them. This kind of information does not appear to be currently available (Grant et al., 2016). However, what ECI services can provide is a key worker or case manager who is skilled and knowledgeable about early childhood intervention and who can assist them in navigating the system and in coordinating services. As Johnston and colleagues (2013) have shown, parents value such support highly.

The third of the areas of support – helping parents learn to manage budgets – is a new aspect of ECI work, and one that practitioners need to develop skills and strategies. In helping parents build budget management and resource deployment skills, professionals are in the curious position of helping parents learn how to employ and manage them – but this is how partnership relationships develop, each party both training and learning from the other. The best model for helping parents with these tasks is a partnership relationship based on principles of co-production, as depicted in this model (Murray, 2010)



Fair Start: A Personalised Pathway for disabled children and their families (Murray, 2010).

IMPLICATIONS

We have considered a number of specific issues that arise in the context of the shift from a block-based funding model to a market-based model. In each case, we have asked what impact (if any) this shift will have on the *way* in which early childhood intervention services are delivered and on *what* services are delivered.

Here are some of the implications arising from this analysis.

Best practice. The NDIS needs to identify what best practices must be followed by the ECI services it funds. The ECIA's *National Guidelines: Best Practice in Early Childhood Intervention* (ECIA, 2016) is the obvious reference point. We also need to develop ways of monitoring how services are delivered and what impact they are having, and not solely rely on the competitive market to weed out services that are less effective.

Provision of support for best practice. The ECI sector needs detailed guidance on what best practice looks like in practice. We could learn much from how these matters have been handled in the UK.

The introduction of the UK Children and Families Act in 2014 led to changes in services for children and young people with disabilities. The purpose of these changes are to give children and young people a stronger voice in the services they receive and to produce better outcomes by integrating the provision of services from different areas of government across the period from birth to 25 years. There is an economic rationale for these reforms: if young adults with disabilities are able to achieve greater independence and participation in their early years, they will be less dependent on life-long services and more able to make their own contribution. This is also part of the rationale underpinning the NDIS.

What is significant is that the introduction of these changes in the UK has been supported by extensive guidance (UK Departments of Health and Education, 2015). The implementation process has included a number of measures to support both the adoption of the new planning process and to ensure that families have sufficient information about the changes. As one such initiative, the Council for Disabled Children has been funded to provide a network of independent supports for families to provide advice on how to benefit from the new approach (Council for Disabled Children, 2014). This kind of guidance is urgently needed by the ECI services working within the NDIS.

Communicating with parents. ECI services need to be purposeful and transparent about the aim of building parental capacity to identify what they want, be partners with professionals, manage money etc. We need new descriptions of what ECI services offer, explicitly stating the outcomes sought (building parental capacities) and the way in which they will work (partnerships with parents)

Support for parents. The NDIS model will work best for parents whose personal resources and circumstances allow them to be clear about their goals (and what works for them), and can effectively manage and navigate funds and services. For those who lack these resources (or are in challenging circumstances), other forms of funding and supports will be needed.

In their capacity to parent children with (and without) disabilities, parents follow a normal distribution, from those who can manage self-directed funding brilliantly to those who cannot manage at all. We need a range of options to cater for this spectrum, always keeping in mind the goal – to build the capacity of the family (and ultimately the people with disabilities themselves) to manage their own lives – which is precisely what the NDIS is designed to do

Training. Given the importance of the practitioner-parent relationship in ensuring the success of help, training in the development of the necessary skills should be considered a priority for ECI practitioners. The development of what psychotherapists call a therapeutic alliance is ‘a skill and/or capacity that therapist can and should be trained to develop just as they are trained to attend to other aspects of their practice’ (Horvath et al., 2011).

CONCLUSIONS

In my opening remarks, I raised the question of whether the switch from a block-funding model to a market-based model involves swapping the vices and virtues of one system for the vices and virtues of another – and that there is no absolutely best funding method or system.

Overall, my analysis suggests that this is indeed the case. There is nothing in either service model that guarantees best practice or that prevents it, but the different systems can support or compromise best practice in different ways. But what does this mean for the NDIS, the market-based system that now governs how ECI services are delivered?

What the NDIS funds and the *way* in which the funding is distributed must serve the overall purpose of early childhood intervention: **to ensure that the parents or other key caregivers are able to help the children gain and use the functional skills they need to participate meaningfully in the key environments in their lives.** *What* services are delivered must be proven to be effective in achieving this aim. *How* services are delivered must also be based on what is known about effective ways of delivering support.

Most importantly, the system of distribution must do no harm, eg. it should avoid adding to family stress. Instead, funds should be distributed in ways that ensure that families are provided with all the information and support they need to make informed choices, are provided with options to meet their personal circumstances and preferences, and are helped to become competent and confident managers of funds.

NDIS DOCUMENTS

- Buckmaster, L. (2016). **The National Disability Insurance Scheme: a quick guide**. Canberra, ACT: Parliamentary Library (Australia).
http://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/rp/rp1617/Quick_Guides/DisabilityInsuranceScheme
- NDIS (2014). **Operational Guideline – Access – Early Intervention Requirements (v 2.1)**.
https://myplace.ndis.gov.au/ndisstorefront/html/sites/default/files/documents/access_early_intervention_requirements3.pdf

REFERENCES

- Bailey, D.B., Raspa, M., Humphreys, B.P. & Sam, A.M. (2011). Promoting family outcomes in early intervention. In J.M. Kauffman and D.P. Hallahan (Eds.). **Handbook of Special Education**. London and New York: Routledge.
- Bell, K. and Smerdon, M. (2011). **Deep Value: A literature review of the role of effective relationships in public services**. London, UK: Community Links.
http://www.community-links.org/uploads/documents/Deep_Value.pdf
- Boag-Munroe, G. and Evangelou, M. (2012). From hard to reach to how to reach: A systematic review of the literature on hard-to-reach families. **Research Papers in Education**, **27** (2), 209-239.
- Braun, D., Davis, H. and Mansfield, P. (2006). **How Helping Works: towards a shared model of process**. London, UK: Parentline Plus.
<http://www.parentlineplus.org.uk/index.php?id=81&backPID=80&policyreports=95>
- Brown I. & Brown R. I. (2009). Choice as an aspect of quality of life for people with intellectual disabilities. **Journal of Policy and Practice in Intellectual Disabilities**, **6**, 11–18. doi: 10.1111/j.1741-1130.2008.00198.x
- Burgoyne, C.B. and Lea, S.E.G. (2006). Money is material. **Science**, **314**, 1091-1092.
- Chapman, J. (2004). **System failure: Why governments must learn to think differently (2nd Ed.)**. London, UK: Demos. <http://www.demos.co.uk/files/systemfailure2.pdf>
- Centre for Community Child Health (2010). **Engaging marginalised and vulnerable families**. CCCH Policy Brief No. 18. Parkville, Victoria: Centre for Community Child Health, The Royal Children’s Hospital.
http://www.rch.org.au/emplibrary/ccch/PB18_Vulnerable_families.pdf
- Corman, M.K. (2009). The positives of caregiving: Mothers’ experiences caregiving for a child with autism. **Families in Society**, **90** (4), 439-445.
DOI: 10.1606/1044-3894.3923
- Cortis, N., Katz, I. & Patulny, R. (2009). **Engaging hard-to-reach families and children**, *Occasional Paper No. 25*. Canberra, ACT: Department of Families, Housing, Community Services and Indigenous Affairs.
<http://www.fahcsia.gov.au/about/publicationsarticles/research/occasional/Documents/op26/op26.pdf>

- Cozolino, L. (2010). **The Neuroscience of Psychotherapy: Healing the Social Brain (2nd Ed.)**. New York: W.W. Norton.
- Cozolino, L. (2014). **The Neuroscience of Human Relationships: Attachment and the Developing Social Brain**. New York: W.W. Norton.
- Crompton, T. (2010). **Common Cause: The Case for Working with our Cultural Values**. Woking, UK: WWF-UK with Climate Outreach Information Network, Campaign to Protect Rural England, Friends of the Earth, and Oxfam.
http://assets.wwf.org.uk/downloads/common_cause_report.pdf?_ga=1.262925323.68876108.1470013635
- Crosby, N. (2010). **Personalisation: Children, young people and families**. Wythall, West Midlands: In Control.
<http://www.in-control.org.uk/media/15332/children%20briefing%20paper%201.pdf>
- Crosby, N., Kelly, G., Lazarus, C., Macintyre, L. and Sibthorp, K. (2012). **Building a new relationship with children, young people and families**. In Control Briefing 1. Wythall, West Midlands: In Control.
<http://www.in-control.org.uk/media/120711/building%20a%20new%20relationship%20final.pdf>
- Council for Disabled Children (2014). **Independent Support**. London, UK: Council for Disabled Children.
<http://councilfordisabledchildren.org.uk/independent-support/introducing-independent-support>
- Da Silva, D. (2011). **Helping people help themselves: A review of the evidence considering whether it is worthwhile to support self-management**. London, UK: The Health Foundation.
<http://www.health.org.uk/publications/evidence-helping-people-help-themselves/>
- Davis, H. and Day, C. (2010). **Working In Partnership: The Family Partnership Model**. London, UK: Pearson.
- Delves, K. and Miller, P. (2014). Disability funding in an individualised, market-based environment: Lessons from the Department of Social Services' early intervention programmes. Paper presented at 11th ECIA National Conference, Brisbane, August.
- Dickinson, H., Needham, C. and Sullivan, H. (2014). Individual funding for disability support: What are the implications for accountability? **Australian Journal of Public Administration**, **73** (4), 417–425.
doi: 10.1111/1467-8500.12106
- Division for Early Childhood (2014). **DEC Recommended Practices in Early Intervention / Early Childhood Special Education**. Los Angeles, California: Division for Early Childhood, Council for Exceptional Children. http://dec.membershipsoftware.org/files/DEC_RPs_%205-1-14.pdf
- Division for Early Childhood (2015). **DEC Recommended Practices: Enhancing Services for Young Children with Disabilities and Their Families**. Los Angeles, California: Division for Early Childhood.
- Duffy, S. (2006). The implications of individual budgets. **Journal of Integrated Care**, **14** (2), 3–10. DOI.
<http://dx.doi.org/10.1108/14769018200600012>
- Duffy, S. (2010). **The Future of Personalisation: Implications for Welfare Reform**. Sheffield, UK: Centre for Welfare Reform.
<http://www.centreforwelfarereform.org/uploads/attachment/225/futureofpersonalisation.pdf>

- Duffy, S. (2013). **Designing NDIS: An International Perspective on Individual Funding Systems**. Sheffield, UK Centre for Welfare Reform.
<http://www.centreforwelfarereform.org/uploads/attachment/360/designing-ndis.pdf>
- Duncan, B. L., Miller, S. D., Wampold, B. E., & Hubble, M. A. (Eds.) (2010). **The heart and soul of change: Delivering what works (2nd Ed.)**. Washington, DC: American Psychological Association.
- Dunst, C.J. (2012). Parapatric speciation in the evolution of early intervention for infants and toddlers with disabilities and their families. **Topics in Early Childhood Special Education**, **31** (4), 208-215.
- Dunst, C.J., Bruder, M.B. and Espe-Sherwindt, M. (2014). Family capacity-building in early childhood intervention: Do context and setting matter? **School-Community Journal**, **24** (1), 37-48.
- Dunst, C.J. and Espe-Sherwindt, M. (2016). Family-centered practices in early childhood intervention. In B. Reichow, B. Boyd, E. Barton & S. L. Odom, (Eds.), **Handbook of Early Childhood Special Education**. New York: Springer.
- Dunst, C.J. & Trivette, C.M. (1996). Empowerment, effective helping practices and family-centered care. **Pediatric Nursing**, **22**(4), 334-337.
- Dunst, C.J. & Trivette, C.M. (2009). Capacity-building family-systems intervention practices. **Journal of Family Social Work**, **12** (2), 119–143.
- Dunst, C.J., Trivette, C.M. & Deal, A.G. (1988). **Enabling and Empowering Families: Principles and Guidelines for Practice**. Cambridge, Massachusetts: Brookline Books.
- Dunst, C. J., Trivette, C. M., & Hamby, D. W. (2007). Meta-analysis of family centered helping practices research. **Mental Retardation and Developmental Disabilities Research Reviews**, **13** (4), 370–378.
- Dunst, C.J., Trivette, C.M. and Hamby, D.W. (2008). **Research Synthesis and Meta-Analysis of Studies of Family-Centered Practices**. Asheville, North Carolina: Winterberry Press.
- Dykens, E.M. (2005). Happiness, well-being, and character strengths: Outcomes for families and siblings of persons with mental retardation. **Mental Retardation**, **43** (5), 360-364.
- Dykens, E. M. (2006). Toward a positive psychology of mental retardation. **American Journal of Orthopsychiatry**, **76** (2), 185–193.
- Early Childhood Intervention Australia (2016). **National Guidelines: Best Practice in Early Childhood Intervention**. Sydney, NSW: Early Childhood Intervention Australia.
<http://www.ecia.org.au/resources/best-practice-guidelines/national-guidelines-for-best-practice>
- Ensher, G. and Clark, D.A. (2011). **Relationship-Centered Practices in Early Childhood: Working with Families, Infants, and Young Children at Risk**. Baltimore, Maryland: Paul H. Brookes.
- Fisher, K.R., Gleeson, R., Edwards, R., Purcal, C., Sitek, T., Dinning, B., Laragy, C., D'aegher, L. and Thompson, D. (2010). **Effectiveness of Individual Funding Approaches for Disability Support**. FaHCSIA Occasional Paper no 29. Canberra, ACT: Australian Government Department of Families, Housing, Community Services and Indigenous Affairs.

- Fisher, K.R. and Purcal, C. (2010). Effectiveness of individual funding for disability support. **SPRC Newsletter**, No. 105 (July), 1, 4-7.
- Flaherty, E.M. and Glidden, L.M. (2000). Positive adjustment in parents rearing children with Down syndrome. **Early Education and Development**, 11 (4), 407-422.
- Genera, S., Fisher, K.R., Robinson, S., Clements, N. and Eastman, C. (2011). **Evaluation of the Self Directed Support Pilot Baseline Report**. SPRC Report 6/11, for the Department of Communities, Disability and Community Care Services Queensland, December 2010. Sydney, NSW: Social Policy Research Centre, University of New South Wales.
https://www.sprc.unsw.edu.au/media/SPRCFile/2011_6_2_SPRC_Report_Series_611.pdf
- Grant, N., Rodger, S., and Hoffmann, T. (2016). Intervention decision-making processes and information preferences of parents of children with autism spectrum disorders. **Child: Care, Health and Development**, 42 (1): 125-34. Epub 22nd October 2015. doi: [10.1111/cch.12296](https://doi.org/10.1111/cch.12296)
- Greenhalgh, T., Howick, J. and Maskrey, N. for the Evidence Based Medicine Renaissance Group (2014). Evidence based medicine: a movement in crisis? **British Medical Journal**, 348: g3725. doi: <http://dx.doi.org/10.1136/bmj.g3725>
- Hastings, R.P. and Taunt, H.M. (2002). Positive perceptions in families of children with developmental disabilities. **American Journal on Mental Retardation**, 107 (2), 116–127.
- Horvath, A.O., Del Re, A. C., Flückiger, C. and Symonds, D. (2011). Alliance in individual psychotherapy. **Psychotherapy**, 48 (1), 9–16. DOI: 10.1037/a0022186
- Johnson, R. and Thom, G. (2012). **Evaluation of the extended individual budget pilot programme for families with disabled children: the family journey one year on**. DoE Research Report DFE-RR232b. London, UK: Department of Education. <http://dera.ioe.ac.uk/15776/1/DFE-RR232b%20report.pdf>
- Johnson, R., Thom, G. and Prabhakar, M. (2011). **Individual Budgets for Families with Disabled Children. Final evaluation report: The family journey**. DfE Research Report DFE-RR145b. London, UK: Department for Education. <https://www.education.gov.uk/publications/eOrderingDownload/DFE-RR145b.pdf>
- Johnston, C., Tracey, D., Mahmic, S. and Papps, F.A. (2013). **Getting the best from DisabilityCare Australia: Families, Information and Decision Making**. Report of a Project undertaken for the Practical Design Fund, Department of Families, Housing, Community Services and Indigenous Affairs. Sydney, NSW: University of Western Sydney.
<https://myplace.ndis.gov.au/ndisstorefront/html/sites/default/files/documents/Johnston%20Tracey%20Papps%20and%20Mahmic%20PDF%20Report.docx>
- Kausar, S., Jevne, R.F. and Sobsey, D. (2003). Hope in families of children with developmental disabilities. **Journal of Developmental Disabilities**, 10 (1), 35-43.
- Keilty, T. (2014). **Self-Directed Support and Early Intervention**. Wythall, West Midlands: In Control.
<http://www.in-control.org.uk/media/167992/sds%20and%20early%20intervention%20final.pdf>
- King, G. A., Zwaigenbaum, L., King, S., Baxter, D., Rosenbaum, P. and Bates, A. (2006). A qualitative investigation of changes in the belief systems of families of children with autism or Down syndrome. **Child: Care, Health and Development**, 32 (3), 353-369.

- Lakoff, G. (2009). **The Political Mind: A Cognitive Scientist's Guide to your Brain and its Politics**. London: Penguin.
- Landsman, G. (2005). Mothers and models of disability. **Journal of Medical Humanities**, **26** (2/3), 121-139. DOI: 10.1007/s10912-005-2914-2
- Landsman, G. (2009). **Reconstructing Motherhood and Disability in the Age of Perfect Babies**. Routledge.
- Leadbeater, C. (2004). **Personalisation through Participation: A New Script for Public Services**. London, UK: Demos. <http://www.demos.co.uk/files/PersonalisationThroughParticipation.pdf>
- Leadbeater, C., Bartlett, J. and Gallagher, N. (2008). **Making it Personal**. London, UK: Demos. <http://www.demos.co.uk/publications/makingitpersonal>
- Lieberman, M.D. (2013). **Social: Why Our Brains are Wired to Connect**. Oxford, UK: Oxford University Press.
- McLean, M. (2015). A history of the DEC Recommended Practices Division for Early Childhood, In Division for Early Childhood, **DEC Recommended Practices: Enhancing Services for Young Children with Disabilities and Their Families**. Los Angeles, California: Division for Early Childhood.
- McLean, M. (2016). The DEC Recommended Practices: Advancing the Practice and Science of Early Childhood Intervention. Keynote presentation at 12th ECIA National Conference, Melbourne, 8th September.
- McConnell, D., Parakkal, M., Savage, A. and Rempel, G. (2015). Parent-mediated intervention: adherence and adverse effects. **Disability and Rehabilitation**, **37** (10): 864–872. DOI: 10.3109/09638288.2014.946157
- McMahon, L. (2010). Long-term complex relationships. In G. Ruch, D. Turney and A. Ward (Eds.). **Relationship-Based Social Work: Getting to the Heart of Practice**. London, UK: Jessica Kingsley.
- McWilliam, R.A. (2014). Future of early intervention with infants and toddlers for whom typical experiences are not effective. **Remedial and Special Education**, **36** (1), 33-38. doi:10.1177/0741932514554105
- Maio, G.R., Pakizeh, A., Cheung, W.Y. and Rees, K.R. (2009) Changing, priming, and acting on values: effects via motivational relations in a circular model. **Journal of Personality and Social Psychology**, **97** (4), 699-715.
- Manthorpe, J., Hindes, J., Martineau, S., Cornes, M., Ridley, J., Rosengard, A., Hunter, S., Little, S. & Gray, B. (2011). **Self Directed Support: A Review of the Barriers and Facilitators**. Edinburgh, Scotland: Scottish Government Social Research. <http://www.scotland.gov.uk/Resource/Doc/348067/0115948.pdf>
- Mol, A. (2008). **The logic of care: health and the problem of patient choice**. London, UK: Routledge.
- Moloney, L. (2016). **Defining and delivering effective counselling and psychotherapy**. CFCA Paper No. 38. Melbourne, Victoria: Child Family Community Australia information exchange, Australian Institute of Family Studies. <https://aifs.gov.au/cfca/publications/defining-and-delivering-effective-counselling-and-psychotherapy>

- Moore, T.G. (2012). Rethinking early childhood intervention services: Implications for policy and practice. Invited *Pauline McGregor Memorial Address* to the 10th Biennial National Early Childhood Intervention Australia (ECIA) Conference and 1st Asia-Pacific Early Childhood Intervention Conference 2012, 9th August, Perth, Western Australia.
http://www.rch.org.au/uploadedFiles/Main/Content/ccch/profdev/ECIA_National_Conference_2012.pdf
- Moore, T.G. (2013a). The NDIS and young children with developmental disabilities: Basic principles and major challenges. Invited presentation at Early Childhood Intervention - Future Opportunities forum hosted by Early Childhood Intervention Australia (Western Australia), Perth, 22nd October.
<https://www.rch.org.au/uploadedFiles/Main/Content/ccchdev/CCCH-Tim-Moore-WA-ECIS-NDIS-Forum-Paper.pdf>
- Moore, T.G. (2013). **Teamwork in early childhood intervention services: Recommended practices.** *NDIS Briefing paper*. Canberra, ACT: National Disability Insurance Scheme.
<https://www.rch.org.au/uploadedFiles/Main/Content/ccchdev/CCCH-Teamwork-in-ECI-Services-NDIS-version.pdf>
- Moore, T.G. (2016). **Towards a model of evidence-informed decision-making and service delivery.** *CCCH Working paper No. 5*. Parkville, Victoria: Centre for Community Child Health, Murdoch Childrens Research Institute. DOI: 10.13140/RG.2.1.3155.7367.
<http://www.rch.org.au/uploadedFiles/Main/Content/ccchdev/CCCH-Towards-a-model-of-evidence-informed-decision-making-and-service-delivery-Tim-Moore-May2016.pdf>
- Moore, T.G, McDonald, M., Sanjeevan, S. and Price, A. (2012). **Sustained home visiting for vulnerable families and children: A literature review of effective processes and strategies.** Parkville Victoria: Centre for Community Child Health, Murdoch Childrens Research Institute, The Royal Children's Hospital.
http://www.rch.org.au/uploadedFiles/Main/Content/ccch/resources_and_publications/Home_visiting_lit_review_RAH_processes_final.pdf
- Murray, P. (2010). **Fair Start: A Personalised Pathway for disabled children and their families.** Policy Paper 26.10.2010. Sheffield, UK: The Centre for Welfare Reform, and Birmingham, UK: University of Birmingham.
<http://www.birmingham.ac.uk/Documents/college-social-sciences/social-policy/HSMC/publications/2010/A-Fair-Start.pdf>
- National Disability Services (NDS) (2013). **The place for block funding in the NDIS.** *National Disability Services Policy Paper*. Deakin, ACT: National Disability Services.
- Neely-Barnes, S., Graff, J.C., Marcenko, M. and Weber, L. (2008). Family decision making: Benefits to persons with developmental disabilities and their family members. **Intellectual and Developmental Disabilities, 46** (2): 93-105. doi: 10.1352/0047-6765(2008)46[93:FDMBTP]2.0.CO;2.
- Nobile, C. and Drotar, D. (2003). Research on the quality of parent-provider communication in pediatric care: Implications and recommendations. **Journal of Developmental and Behavioral Pediatrics, 24** (4), 279-290.
- Norcross, J.C. & Wampold, B.E (2011). Evidence-based therapy relationships: research conclusions and clinical practices. **Psychotherapy, 48** (1), 98-102. doi: 10.1037/a0022161.

- Novak, I. (2012). Evidence to Practice Commentary: Is more therapy better? **Physical & Occupational Therapy In Pediatrics**, **32** (4), 383-387. DOI: [10.3109/01942638.2012.726894](https://doi.org/10.3109/01942638.2012.726894)
- Palisano, R.J., Chiarello, L.A., King, G.A., Novak, I., Stoner, T. & Fiss, A. (2012). Participation-based therapy for children with physical disabilities. **Disability & Rehabilitation**, **34** (12), 1041-52. DOI: 10.3109/09638288.2011.628740
- Pearson, J. and Hill, S. (2012). **Evaluation of Phase One: Self-managed Funding Initiative Final Report**. Submitted to Department for Communities and Social Inclusion. Adelaide, South Australia: Jenny Pearson & Associates Pty Ltd.
- Peters, E., Klein, W., Kaufman, A., Meilleur, L., & Dixon, A. (2013). More is not always better: Intuitions about effective public policy can lead to unintended consequences. **Social Issues and Policy Review**, **7** (1), 10.1111/j.1751-2409.2012.01045.x. <http://doi.org/10.1111/j.1751-2409.2012.01045.x>
- Peterson, C. A., Luze, G. L., Eshbaugh, E. M., Hyun-Joo, J. and Kantz, K. R. (2007). Enhancing parent-child interactions through home visiting: Promising practice or unfulfilled promise? **Journal of Early Intervention**, **29** (2), 119-135.
- Pike, B., O’Nolan, G. and Farragher, L. (2016). **Individualised budgeting for social care services for people with a disability: International approaches and evidence on financial sustainability**. Dublin, Ireland: Health Research Board. http://www.hrb.ie/uploads/tx_hrbpublications/Individualised_budgeting_for_social_care_2016.pdf
- Prabhakar, M., Thom, G. and Johnson, R. (2011). **Individual Budgets for Families with Disabled Children. Final Evaluation Report: The IB Process**. DfE Research Report DFE-RR145. London, UK: Department for Education. <https://www.education.gov.uk/publications/eOrderingDownload/DFE-RR145.pdf>
- Prabhakar, M. & Thom, G. (2012). **Evaluation of the extended individual budget pilot programme for families with disabled children: the extended packages**. DoE Research Report DFE-RR232. London, UK: Department of Education. <http://dera.ioe.ac.uk/15777/1/DFE-RR232%20Report.pdf>
- Raver, S.A. and Childress, D.C. (2015a). **Family-Centered Early Intervention: Supporting Infants and Toddlers in Natural Environments**. Baltimore, Maryland: Paul H. Brookes.
- Raver, S.A. and Childress, D.C. (2015b). Collaboration and teamwork with families and professionals. In S.A. Raver and D.C. Childress (2015). **Family-Centered Early Intervention: Supporting Infants and Toddlers in Natural Environments**. Baltimore, Maryland: Paul H. Brookes
- Roberts, C. (2004). ‘Only connect’: the centrality of doctor–patient relationships in primary care. **Family Practice**, **21** (3), 232–233. doi: 10.1093/fampra/cmh302
- Ruch, G., Turney, D. and Ward, A. (Eds.) (2010). **Relationship-Based Social Work: Getting to the Heart of Practice**. London, UK: Jessica Kingsley.
- Schore, A.N. (2012b). **The Science of the Art of Psychotherapy**. New York: W.W. Norton.
- Schwartz, C. (2003). Parents of children with chronic disabilities: The gratification of caregiving. **Families in Society**, **84** (4), 576-584

- Scott, D., Salvaron, M., Reimer, E., Nichols, S., Sivak, L. & Arney, F. (2007). **Positive Partnerships with Parents of Young Children**. West Perth, Western Australia: Australian Research Alliance for Children and Youth.
http://www.aracy.org.au/publicationDocuments/TOP_Positive_Partnerships_with_Parents_of_Young_Children_2007.pdf
- Solomon, A. (2013). **Far From The Tree: Parents, Children and the Search for Identity**. London, UK: Chatto and Windus.
- Sommers, S. (2011). **Situations Matter: Understanding How Context Transforms Your World**. New York: Riverhead Books.
- Soss, J. and Schram, S.F. (2007). A public transformed? Welfare reform as policy feedback. **American Political Science Review**, **101**, 111-127.
- Sprenkle, D. H., Davis, S. D. and Lebow, J. L. (2009). **Common factors in couple and family therapy: The overlooked foundation for effective practice**. New York, NY: Guilford Press.
- Stephens, L., Ryan-Collins, J. and Boyle, D. (2008). **Co-production: A manifesto for growing the core economy**. London, UK: new economics foundation (nef).
<http://www.neweconomics.org/gen/uploads/wyifkx552bjzvjkumj2zcnyq11072008194321.pdf>
- Stewart, M., Brown, J.B., Boon, H., Galajda, J., Meredith, L. and Sangster, M. (1999). Evidence on patient-doctor communication. **Cancer Prevention and Control**, **3** (1), 25-30.
- Sweeney, K.G., MacAuley, D. and Gray, D.P. (1998). Personal significance: the third dimension. **The Lancet**, **351** (9096), 134-136. doi:10.1016/S0140-6736(97)06316-2
- Thom, G. and Prabhakar, M. (2011). **Individual Budgets for Families with Disabled Children. Final evaluation report: Recommendations and implications**. DfE Research Report DFE-RR145e. London, UK: Department for Education. <https://www.education.gov.uk/publications/eOrderingDownload/DFE-RR145e.pdf>
- Trivette, C.M., Dunst, C.J. and Hamby, D.W. (2010). Influences of family-systems intervention practices on parent-child interactions and child development. **Topics in Early Childhood Special Education**, **30** (1), 3-19.
- UK Departments of Health and Education (2015). **Special educational needs and disability code of practice: 0 to 25 years. Statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities**. London, UK: Department of Education and Department of Health.
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf
- Vohs, K.D., Mead, N.L. and Goode, M.R. (2006). The psychological consequences of money. **Science**, **314** (5802), 1154-1156. DOI: 10.1126/science.1132491
- Workgroup on Principles and Practices in Natural Environments (2008a). **Agreed upon mission and key principles for providing early intervention services in natural environments**. Chapel Hill, North Carolina: National Early Childhood Technical Assistance Centre, Office of Special Education Programs,

US Department of Education.

http://ectacenter.org/~pdfs/topics/families/Finalmissionandprinciples3_11_08.pdf

Workgroup on Principles and Practices in Natural Environments (2008b). **Seven key principles: Looks like / doesn't look like.** Chapel Hill, North Carolina: National Early Childhood Technical Assistance Centre, Office of Special Education Programs, US Department of Education.

http://ectacenter.org/~pdfs/topics/families/Principles_LooksLike_DoesntLookLike3_11_08.pdf

Workgroup on Principles and Practices in Natural Environments (2008c). **Agreed upon practices for providing early intervention services in natural environments.** Chapel Hill, North Carolina: National Early Childhood Technical Assistance Centre, Office of Special Education Programs, US Department of Education.

http://www.nectac.org/~pdfs/topics/families/AgreedUponPractices_FinalDraft2_01_08.pdf

**Melbourne
Children's**

A world leader
in child and
adolescent
health



Centre for Community Child Health

The Royal Children's Hospital Melbourne
50 Flemington Road Parkville Victoria 3052 Australia
www.rch.org.au/ccch

The Centre for Community Child Health is a department of The Royal Children's Hospital
and a research group of Murdoch Children's Research Institute.