

# Challenges facing specialist and general human services: Identifying a way forward for specialist disability services

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## **Abstract**

The challenges currently facing specialist disability services need to be seen in the context of the difficulties being experienced by all human services in meeting the needs of children and their families. Reasons for this state of affairs include significant changes in families and family circumstances, and the problems the existing service system has in providing integrated services to families with complex needs. As a consequence, there are worsening developmental outcomes evident in adolescents and young adults, which have prompted renewed efforts to understand the factors that promote or undermine optimal functioning in children and families.

Specialist disability services are also having difficulty meeting all the needs of eligible children and adults, for many of the same reasons as other services. Children and adults with disabilities have many needs in common with those without disabilities, and the challenge is how to provide integrated services that meet both their specialist and more general needs.

This paper explores the implications for service delivery of this general situation, describing a series of key developments in specialist services that will help us address the current challenges. These include person-centred practice, family-centred practice, the use of natural learning environments, and person-centred planning. The implications for specialist disability services are outlined and a way forward proposed.

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## **INTRODUCTION**

This paper is in three parts. The first part involves ***looking back: what has changed and what have we learned?*** This includes social changes to families and to the circumstances in which they bring up children, the challenges facing services for young children and families, and the evidence of worsening developmental outcomes for young people. We will also look briefly at what we have learned from developmental research about the early years, before considering the implications of all this for services for children and families.

The second section focuses on ***children with disabilities and their families***: what we have learned about them and about ways of working with them.

The final section will involve us ***looking forward: what needs to change?*** What are the implications of all that we have considered for specialist disability services?

## LOOKING BACK: WHAT HAS CHANGED?

The challenges currently facing specialist disability services need to be seen in the broader context of social and economic change and the challenges that these pose for all human services. We also need to take account of recent key findings about child development and family functioning.

### Key social and economic changes:

The key changes that have occurred over the past two or three decades include:

- Significant changes in families and family circumstances over the past two or three decades.
- Difficulties that the existing service system has in providing integrated services to families with complex needs.
- Worsening developmental outcomes for adolescents and young adults, which have prompted renewed efforts to understand the factors that promote or undermine optimal functioning in children and families.

Each of these is considered in more detail below.

### Changes in families

Regarding **structure**, families have changed significantly over the past two or three decades - they are more varied in their structure, and more diverse culturally and ethnically:

- families are smaller
- childlessness is increasing
- mother's age at first birth is increasing
- more single parents
- more blended families
- more same sex couple families
- more shared custody arrangements.

Regarding **cultural and ethnic diversity**, there has been an ongoing influx of migrants and refugees from an ever-widening range of countries, ethnic groups and religions. This contributes to Australia becoming and less and less homogeneous society.

### Changes in family circumstances

The circumstances in which families are raising young children have also changed:

- more parents are working
- more mothers with babies are working
- more parents are doing shift work and working non-standard hours
- more parents are working longer hours
- more families are jobless
- more children are being raised in poverty.

Other key social changes include:

- There has been a partial erosion of traditional family and neighbourhood support networks, due to factors such as increased family mobility and the search for affordable housing.
- There has been an increase in the number of parents whose own experiences of being parented were compromised, and who therefore have difficulty parenting their own children.
- All these factors have contributed to an increase in the number of families with complex needs.
- These social changes have also contributed to an undermining of confidence among parents in their ability to raise their children well.
- There is no longer a social consensus about the right way to bring up children, or even that there is a single right way.
- Overall, parenting young children has become a more complex and more stressful business for many families.

### **Challenges currently facing services for children and families**

As a result of these and other factors, early childhood and family support services are struggling to meet the needs of young children and families. The main challenges and problems are as follows:

- First, the service system is having difficulty providing support to all families who are eligible.
- Second, services cannot meet all the needs of families that they do serve
  - no single service is capable of meeting the complex needs of many families
  - these unmet needs may loom larger in the lives of parents than the needs of the child with a developmental or mental health problem.
- Third, families have difficulty finding out about and accessing the services they need.
- Fourth, services are often not well integrated with one another and are therefore unable to provide cohesive support to families.
- Fifth, services have difficulty tailoring their services to meet the diverse needs of families.
- Sixth, services are typically treatment-oriented rather than prevention- or promotion-focused, and therefore cannot respond promptly to emerging child and family needs.
- Seventh, the service system does not maintain continuous contact with families of young children during the early years.
- Eighth, many families are isolated and lack supportive personal networks - extended family, friends or other families of young children.

- Ninth, the early childhood field is undervalued and underfunded, and has difficulty attracting and retaining staff.
- Tenth, many people working with children and families have not had opportunities to learn about recent early childhood research findings.
- Finally, many people working with children and families have not been trained in ways of working with families.

Some of these problems are specific to the early childhood services system, but many are applicable to services for other age groups as well. In addition, there are some more general systemic issues that undermine the effectiveness of early childhood and other human services:

- Government departments, research disciplines and service sectors tend to work in 'silos' – that is, they plan, fund and deliver services independently of one another. This is despite strong evidence for the benefits of a coordinated approach to service delivery.
- The early childhood sector does not present a united front - there is a tendency for particular service types to seek their own preservation at the expense of working collectively towards better outcomes for children and families through improvements in the overall system.
- Responsibility for provision of services to young children and their families is spread across three levels of government - federal, state, and local - with different planning processes and funding priorities.
- Governments are more concerned about promoting general economic growth than reducing economic disparities. This is despite evidence that wider social inequalities are linked with poorer developmental outcomes.
- Governments spend a disproportionate amount on services for adults and the aged, in comparison to the very young, despite the greater developmental importance of the early years and the greater likelihood of young children living in poverty.

### **Concern about worsening developmental outcomes**

Another important consideration is the evidence of worsening (or unacceptably high) developmental outcomes for adolescents and young adults in most developed nations, including Australia. These outcomes cover the full range of health and well being, as follows:

- *Mental health* - eg. depression, suicide, drug dependence
- *Physical health* - eg. obesity, diabetes, heart disease
- *Academic achievement* - eg. literacy levels, retention rates, educational outcomes
- *Social adjustment* - eg. employment, juvenile crime.

This phenomenon has been dubbed ‘modernity’s paradox’ (Keating and Hertzman, 1999):

‘A puzzling paradox confronts observers of modern society. We are witnesses to a dramatic expansion of market-based economies whose capacity for wealth generation is awesome in comparison to both the distant and the recent past. At the same time, there is a growing perception of substantial threats to the health and well-being of today’s children and youth in the very societies that benefit most from this abundance.’

The developmental pathways that lead to each of these outcomes can be traced back to early childhood, leading to a growing interest in forms of early intervention.

All the poor developmental outcomes identified have associated social and financial costs that cumulatively represent a considerable drain on societal resources

### **New understandings about child development and family functioning**

In addition to the three factors so far mentioned – changes in families and family circumstances, challenges faced by human services, and worsening developmental outcomes – we need to look briefly at recent findings about child development and family functioning. We have learned a huge amount about these in recent years, but we will focus on just two key findings here.

■ ***First, both child development and family functioning are shaped by the ongoing interplay among sources of vulnerability or risk and sources of resilience or protection***

- These are multiplicative rather than additive in their effects.
- Exposure to adverse conditions does not inevitably damage individuals or thwart development.
- Risk and protective factors tend to be pervasive – a person confronting adversity in one context is also likely to be facing it in others as well.
- Behaviour or experiences at one age predispose to the occurrence of risk or protective factors at a late age.

The implication of these findings is that we need a coordinated systemic strategy to minimise child, family and community risk factors, and to promote protective factors in the lives of young children and their families.

■ ***Second, personal support networks have major effects on the well-being of children and families***

- Parents with adequate social support networks are less likely to have low birth weight babies, to abuse their children, or to have mental or physical health problems.

- Social support mostly influences child functioning by strengthening parents' ability to raise their children effectively.
- Informal support has a greater influence on the personal functioning of parents than formal support.
- Whether professional support is as effective as informal social support depends upon the nature of the relationship with the professionals - the more the professionals are seen as part of the family's informal network, the more effective they will be.

The implication of these findings is that one of the key ways in which we can promote family functioning is to help them develop or strengthen their personal support networks.

### **Implications of these factors for human services**

- We cannot adequately fund all the individual intervention programs that we know to be effective.
- Instead we need to address the common underlying factors that lead to children and families having problems that require intervention.
- We need to provide support at all levels of the ecological system.
- We need to build stronger personal and community support networks for all families of young children.
- We need a more integrated community-based infrastructure geared to the needs of families with young children.
- We need an early childhood and family support system able to cater for the diversity of child and family needs and circumstances, including those with additional needs.
- We need services that are truly integrated (not just better linked or coordinated), easy to access, and responsive to emerging child and family needs.
- We need a philosophy and way of delivering services that is common to all forms and levels of service.

With this general picture in mind of the changed social conditions and the service challenges these pose, we will now look specifically at families of children with disabilities.

### **CHILDREN WITH DISABILITIES AND THEIR FAMILIES**

In this section of the paper, we will explore what have we learned about the families of children with disabilities and about the most effective ways of working with them.

## New understandings about families of children with developmental disabilities

The most fruitful insights gained in recent years into families of children with developmental disabilities concern their reactions to having a child with a disability and the ways in which they adapt. Three particular findings will be considered first: the management of nonfinite loss, families that transcend disability, and family adaptation and the establishment of routines.

- **Non-finite loss.** Nonfinite loss is grief that is ongoing and changing as life continually falls short of expectations. Bruce and Schultz (2001) argue that the grieving and therapeutic processes for dealing with nonfinite loss (eg. disability, chronic illness) differ from finite loss (eg. death). They describe therapeutic techniques to build grieving people's competence to become more emotionally resilient — to acknowledge and legitimize their feelings and adapt to nonfinite loss.
- **Transcending disability.** Some families ultimately report that they are better off for having a child with a disability. This means that they have gone beyond mere acceptance of having a child with a disability, which has usually been seen by professionals as the ideal end state of the grieving process. Instead, they have reached a state where they recognise that, while this was not an experience or a challenge that they would have sought for themselves or would wish on anyone else, it has made them stronger as individuals and as a family.
- **Family adaptation / establishing family routines.** One of the most studied aspects of families of children with disabilities has been their capacity to manage the demands, strains, and stresses associated with childhood disability. This focus is understandable, given the demands of childhood disability. However, so exclusive a focus on crises, stress, and psychological reactions also perpetuated the notion 'that a family with a child who has a disability is a family with a disability' (Glidden, 1993).

The past decade has seen a call to broaden research perspectives on families of children with disabilities to include adaptation and adjustment. Although there is a continuing interest in family stresses associated with childhood disabilities, there is also increasing recognition that families of children with problems are faced with the same tasks as are families with typically developing children. According to Gallimore, Bernheimer and Weisner (1999), knowing what families do in crisis or how they handle emotional costs of dealing with childhood disability are necessary but not sufficient indicators of their functioning. We also need to conceptualize and research how families construct and sustain unremarkable times - the times of family life between episodes of crises and problems, when there is established routine, balance, homeostasis, and equilibrium. It is the established routines of families and how they are created and sustained that are more important for families.

Finally, there is a fourth insight regarding children with disabilities and their families that has become increasingly apparent in recent years:

- ***Children with developmental disabilities have the same core needs as other children, and families of children with disabilities have the same core needs as other families.***

They also have additional needs, but these tend to become the principle focus to the exclusion of those needs they share with other children and families (Moore, 2001). This is unfortunate, because it can lead to the neglect of the broader needs of children with disabilities and their families, so that they miss out on other support services they might need as well as the normal experiences open to all other children and families.

### **New understandings about ways of working with families of children with developmental disabilities**

Our ideas about how professionals can best help children with disabilities and their families have evolved steadily over the past couple of decades. We will focus on seven areas (which overlap to some extent) in which there have been significant developments in research and practice.

- ***Key features of effective professional support services***

Enough research has now been conducted on the provision of services to families of children with disabilities for the key features of effective programs to be identified. For instance, a review of UK research (Sloper, 1999) on what forms of service are most effective identified the following features:

- ***Providing families with a key worker*** – parents find specialist support more helpful and manageable when it is provided through and coordinated by a key worker representing a transdisciplinary team rather than a string of different workers or services.
- ***Training workers in basic counselling skills*** – effective work with parents requires good relationship or counselling skills, and services are most effective when professionals have received some training in these skills.
- ***Parent partnership service delivery models*** – support is most effective when the specialist service providers work with parents as partners.

- ***Elements of effective help-giving***

On the basis of a number of studies they have conducted on the characteristics and effects of help-giving behaviours, Dunst and Trivett (1996) conclude that there are three elements of effective help-giving:

- **Technical knowledge and skills.** This refers to the help-giver's specialist knowledge and skills. High quality technical knowledge and skills result in the implementation of appropriate educational, therapeutic and medical interventions. Help which is technically of a high quality but which does not incorporate the other two elements can have positive outcomes in one area (eg. in the child's health) but negative outcomes in others (eg. parental resentment and disempowerment as a result of the manner in which the services are delivered).
- **Help-giver behaviours and attributions.** Help-giver behaviours which positively influence psychological well-being include good listening, empathy and warmth. Help-giver attributions that have positive outcomes include beliefs in the person or family's competences and capabilities. Positive help-giver behaviours and attributions result in (a) greater parental satisfaction with and acceptance of helping, and (b) greater psychological and emotional well-being. Help-giving behaviours and attributions are a necessary but not sufficient condition for strengthening family competencies and developing new capabilities. To achieve that, the third element of effective helpgiving is necessary.
- **Participatory involvement.** This entails the recipients of help being offered information about intervention options, sharing decision making, and being directly involved in acting on decisions. Effective participatory involvement results in (a) parents feeling more in control, and (b) strengthening of parental competencies.

All three elements need to be present for helpgiving to be truly effective. The second and third components provide value-added benefits, but cannot be faked:

'Research indicates that help receivers are especially able to "see through" helpgivers who act as if they care but don't, and helpgivers that give the impression that help receivers have meaningful choices and decisions when they do not.' (Dunst and Trivette, 1996, p. 337)

Another perspective regarding the features of effective caregiving is offered by King, King and Rosenbaum (1996). They reviewed the medical and rehabilitation services literature in search of the key interpersonal aspects of care associated with positive outcomes (ie. client satisfaction with service, client adherence to therapeutic or medical regimens, and reduction in levels of client stress and worry). Three key interpersonal aspects of care-giving were identified:

- **information exchange** – communication is bidirectional, and service providers solicit information as well as provide information.
- **respectful and supportive care** – service providers interact with clients in ways that make them feel respected and supported.
- **partnership / enabling** – service providers work collaboratively in partnership with clients.

While the emphases are different, the essential features of these key features of effective caregiving are the same as those identified by Dunst and Trivette (1996).

## ■ **Reconceptualising expertise**

As we have seen, one of the key elements of effective care-giving is technical knowledge and skills (Dunst and Trivette, 1996). Children and people with disabilities need support from professionals who are experts in their fields and whose knowledge and skills can be trusted. However, it is now recognised that this is only one form of expertise – parents and people with disabilities also possess a form of expertise which is equally valuable.

The expertise of professionals is of a general form: they know about the development of children in general, the impact that disabilities can have on development, and kinds of strategies that can be used to improve children's functioning. The expertise of parents is of a specific form: they know their particular child better than anyone else, as well as the circumstances in which the child lives, the functional challenges facing the child, and the resources available to the child and family. These two forms of expertise are complementary, and need to be shared and integrated for best results.

Exactly what kind of knowledge and skills professionals need has been explored in a recent study by Bowers, Esmond, Lutz and Jacobson (2003). They examined what persons with disabilities think about the health care they receive, particularly how primary care providers facilitate or hinder quality care for persons with disabilities. The study involved interviews with adults with disabilities as well as parents of children with disabilities. They found that, for these groups, expertise had two primary dimensions:

- First, expertise is about **having knowledge** – facts and skills that includes but also extends beyond general medical knowledge about health and illness.
- Second, expertise is about **using knowledge** – being willing and able to deploy knowledge in the context of the patient's life. It also includes using knowledge collaboratively with patients in treatment decisions, integrating the knowledge and preferences of the persons with disabilities even when it is inconvenient or problematic to do so. Expertise only exists if the provider respects the patient, and provides opportunities for the patient or patient's representative to collaborate in decisions about care and treatment.

A further finding from this study is that there are **two main sources of expertise**:

- **Individual expertise** – what the individuals involved (ie. the providers and the patients) bring to the interaction.
- **Collaborative expertise** – what is developed through collaborative, reciprocal interactions between providers and patients over time.

## ■ **Reconceptualising parent / professional partnerships**

The reconceptualising of expertise has implications for the nature of the parent / professional relationship. Here too we have seen a steady shift in the power balance towards a much more equal sharing of responsibilities and decision-making. This trend is exemplified by the work of the Turnbells, themselves parents of a (now) young man with disabilities, at the Beach Centre in Kansas.

In a recent summary of their thinking, Turnbull, Turbiville and Turnbull (2000) describe three types of parent-professional power relationships:

- **Power-over relationships** are characterised by professionals exerting decision-making control over parents through perceived higher competence, professionalised communication, and control over environmental resources. Parent-professional partnerships have traditionally taken this form.
- **Power-with relationships** arise when collaborative decision-making is used among parents and professionals through perceived equal competence, contextual communication, and sharing of environmental resources. Family-centred partnerships are based on this form of power-sharing.
- **Power-through relationships** incorporate synergistic decision-making among family members, professionals, friends, and community citizens through perceived group competence, 'mind and heart' communication, and the creation of new and preferred environmental resources. Synergistic decision-making results in decisions and effects that are greater than the sum of the parts.

Power-through relationships result in **collective empowerment**, which is a process through which 'all participants (ie. professionals and families) increase their capacity and mastery over the resources needed to achieve mutually desired outcomes' (Turnbull et al., 2000, p. 641). The essence of the collective empowerment model is synergistic power, as opposed to monopolised power. Not only do all partners gain power, but the very nature of the power generated by the partnership is also transformed. Power is no longer simply about controlling events and processes, but is also about capacity building: participants gain in competence, abilities, resource acquisition, and capabilities, all without taking any power from others.

## ■ **Family-centred practice**

Family-centred practice involves a philosophy or set of values, as well as a number of principles and practices, and requires specific skills to be implemented well. It is based upon a collaborative partnership between parents and professionals based on a mutual recognition and valuing of their respective expertise, building on family strengths, and responding to family priorities (Dunst, 1995, 1997; Epps and Jackson, 2000; McBride, 1999; Rosenbaum, King, Law, King and Evans, 1998).

On the basis of discussions with fellow parents of young children with developmental disabilities, Viscardis (1998) defines the family centred approach as one that

‘... begins with the child’s and family’s strengths, needs and hopes, and results in a service plan which responds to the needs of the whole family. It involves education, support, direct services and self-help approaches. The role of the service provider is to support, encourage, and enhance the competence of parents in their role as caregivers.’

Despite family-centred practice being accepted as best practice in early childhood intervention services for a decade or more, there is often a considerable gap between the rhetoric of what professionals and services think and say they are doing and the reality of what they are actually providing.

### ■ ***Person-centred planning***

Perhaps the most significant development in the disability field in recent years has been the advent of person-centred planning (Holburn and Vietze, 2002; Kincaid, 1996). According to Kincaid (1996), person-centred planning is a collective process in which those involved with the (disabled) person seek to learn more about the person and his or her family, and plan a more positive future. There is a commitment to seeking five essential goals, outcomes, or valued accomplishments in the person’s life:

- being present and participating in community life
- gaining and maintaining satisfying relationships
- expressing preferences and making choices in everyday life
- having opportunities to fulfill respected roles and live with dignity
- continuing to develop personal competencies.

Note that while this approach has been developed for people with disabilities – who are at risk of never achieving any of the above outcomes – it is applicable to any person with special needs. In fact, the outcomes can be seen as applying to everyone in society, regardless of age (children, adolescents, adults and elderly people), ability (those with and without disabilities), culture (those from mainstream cultures, and those from ethnic minorities) or socioeconomic status.

### ■ ***Natural learning environments***

One of the major recent developments in practice over the past decade has been the move away from centre-based and clinical models of service delivery in favour of exploiting the natural learning opportunities that occur in the course of family routines and community activities.

The rationale for this approach is that it is more normalising, places fewer extra demands upon families, and provides more practice opportunities for the child. As Hanft and Pilkington (2000) argue,

‘No infant or toddler needs physical, occupational, or speech therapy twice per week in order to grow and develop. What young children need is exposure to communication, mobility, play, gradual independence in activities of daily living, and nurturing interaction with family members, everyday, in their usual places and situations. Therapists, using their therapeutic expertise as the means to this end, can help young children and family members achieve their desired outcomes.’ (pp. 11-12)

It makes more sense to parents to use a natural learning environments approach.

‘Professionals kept asking me what my 'needs' were. I didn't know what to say. I finally told them, 'Look, I'm not sure what you're talking about. So let me just tell you what happens from the time I get up in the morning until I go to sleep at night. Maybe that will help’.

- parent quoted in Bernheimer, Gallimore and Kaufman (1993, p. 267)

Embedding learning opportunities in daily routines is preferable to asking parents to add activities to the already crowded family schedules. As Helen Featherstone pointed out, such demands can create major problems for parents:

‘Where is that fifteen minutes [to carry out the intervention plan] going to come from? What am I supposed to give up? Taking the kids to the park? Reading a bedtime story to my eldest? Washing the breakfast dishes? Sorting the laundry? Grading students' papers? Because there is no time in my life that hasn't been spoken for, and for every fifteen-minute activity that is added, one has to be taken away.’

- Featherstone (1981, p. 78)

## **LOOKING FORWARD: WHAT NEEDS TO CHANGE?**

In this final section, we look at the implications of what we have learned about the challenges facing human services in general and disability services in particular. It is apparent that specialist disability services are also having difficulty meeting all the needs of eligible children and adults, for many of the same reasons as other services. Recognising that children and adults with disabilities have many needs in common with those without disabilities, the challenge is how to provide integrated services that meet both their specialist and more general needs.

### **The way forward**

- The disability service system cannot resolve all its problems on its own – we must be part of efforts to reconfigure the general system of services to achieve better outcomes for all children and families. However, there are some steps that the disability service system can take to put its own house in order.

- We need to review the aims and purposes of disability services in the light of changing demands and circumstances, and new advances in the field – exactly what outcomes are we trying to achieve?
- In doing so, we must engage parents as partners in determining the aims and forms of support that will best help them meet their children's needs.
- We need to establish partnerships with mainstream early childhood and school services – working towards a truly inclusive model of service delivery.
- We need to establish partnerships with other child and family support services – working towards a truly comprehensive and coordinated system.
- We need to strengthen our ability to help parents and mainstream service providers use the natural learning opportunities that occur in daily routines to build children's functional skills.
- We need to ensure that parents develop strong personal networks, including support from other families of children with disabilities.
- We need to develop ways of making our services more flexible and more able to respond to the diverse needs and circumstances of families.
- We need to develop more sustained cross-sectoral training in the key skills needed for effective service delivery - core relationship skills, family centred practice, and discipline-specific technical skills.

## CONCLUSIONS

### *Looking back .... we can see that*

- much has changed in the world and in the circumstances in which families are raising children
- the service system that was once decently effective is now less consistently so, and needs to change
- we have learned much about children with disabilities and their families.

### *Looking forward .... we can see that*

- if we are to support children with disabilities and their families more effectively, we need to build much stronger partnerships with parents and with both mainstream and other specialist child and family services.
- we have an emerging set of principles and practices on which to base more integrated and holistic services.
- there is scope for specialist disability service providers to play a leading role in the development of new and more effective services for all children and families.

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