

Beyond inclusion: Towards a universal early childhood service system

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Abstract

Our current early childhood system of generic and specialist services has difficulty meeting the needs of all children. Generic services have particular difficulty meeting the needs of children who are vulnerable or at risk, who have behavioural or emotional problems, or have developmental disabilities and delays, and cannot easily access appropriate specialist support. At the same time, the specialist services have difficulty providing a comprehensive range of services to all children and families in need, and cannot easily arrange access for children and families to the generic services that they need. Alternative ways of co-ordinating and delivering services need to be explored.

This paper presents the rationale for moving towards a universal early childhood system of services. The different forms of service (universal, targeted and clinical) are described, and ways of co-ordinating and delivering these services are analysed. Evidence regarding the effectiveness of the various forms of system organisation is presented, and potential barriers to effective co-ordination outlined. The problems involved in catering for children and families with special needs within a universal system are addressed. Key issues considered include the need for effective ways of identifying child and family needs as early as possible, and of deploying specialist resources to support to them.

It is concluded that the future for early childhood intervention services involves seeking to go beyond inclusion, by exploring ways in which support to children and families can be delivered through a universal early childhood system of services.

In this paper, I will argue that the current general system of services for young children and their families, regardless of whether they have additional needs or not, does not support them as effectively as required and therefore needs to be redesigned. I will also argue that the system of specialist services for children with disabilities and their families is also unable to meet all their needs effectively and similarly should be rethought. I will suggest that part of the solution to both these problems lies in establishing a closer relationship between the two service systems. By integrating these systems, we will be able to go beyond inclusion to a deeper understanding of how truly meeting the needs of any particular child and family shows us the way to meeting the needs of all children and their families.

There are two reasons why we need to rethink the way we provide services to young children and their families. First, our current system is not able to meet all the needs of all children and families. Second, the system is not delivered in ways that make it easy for parents to access the supports they need.

The first weakness of the current system is that, partly as a result of the separation between generic and specialist early childhood services, it has great difficulty meeting all the needs of all children. On the one hand, generic services have difficulty meeting the needs of particular groups of children - especially those who are vulnerable or at risk, who have behavioural or

emotional problems, or have developmental disabilities and delays - and cannot easily access appropriate specialist support to help them in this task. On the other hand, the specialist services themselves have difficulty providing a comprehensive range of services to all children and families in need, and cannot easily arrange access for children and families to the generic services they need.

The second weakness of the current system is that it is not integrated or delivered in ways that make it easy for families of young children to access a range of services and supports according to their evolving needs. Instead, services tend to be funded and delivered in ways that reflect the administrative needs of government departments and the convenience of service providers. This is not a criticism of departments and service providers, but a recognition that the traditional way in which services have been administered and delivered – via separate departments with designated responsibilities (health, education, welfare etc.) and stand-alone service agencies operating from separate locations – is no longer capable of ensuring that families of young children receive the kind of fully integrated and easily accessible range of support services they now need. We need to think in terms of redesigning the service system from the bottom up, that is, of finding ways of supporting families of young children that are based on the needs and circumstances of these families rather than being determined by the needs of departments and service providers.

For these reasons, alternative ways of co-ordinating and delivering services need to be explored. Many national and state governments around the world have come to the same realisation and are now attempting to devise new ways of supporting young children and families, but none have yet found an effective way of integrating all the relevant services (Halpern, 2000).

Organising support services and systems

One way of approaching the question of how services are organised is to examine the different types of services and their underlying aims. Various types of services have been identified, each with distinct aims (Dunst et al., 1990; Huntington et al., 1994; Offord et al., 1999; Simeonsson, 1991, 1994; Simeonsson and Covington, 1994).

Dunst et al. (1990) distinguish between three modes of intervention - treatment, remediation, and promotion:

- *Treatment* involves the management and provision of care or help in order to eliminate or minimize the negative effects of a disorder, disease or problem. Treatment interventions focus on the remediation or amelioration of an aberration or its consequences.
- *Prevention* involves efforts to deter or forestall the occurrence of disorder, disease or problem. Preventive interventions occur prior to the onset of negative functioning and seek to reduce the incidence or prevalence of negative outcomes.
- *Promotion* involves efforts to enhance and optimize positive growth and functioning. Interventions focus on developing and enhancing people's competencies and capabilities.

Dunst et al. (1990) suggest that human services typically begin with a treatment focus and then evolve. Because successful treatment does not guarantee that the problem will not recur, service providers turn to remediation strategies to reduce the occurrence of the problem. And because successful prevention does not guarantee any strengthening of competencies or capabilities, providers eventually turn to promotion strategies.

Another common way of classifying types of prevention strategies is to distinguish between primary, secondary and tertiary prevention (Huntington et al., 1994; Simeonsson, 1991, 1994; Simeonsson and Covington, 1994, Statham, 1997):

- *Primary prevention:* The focus is on reducing the incidence (ie. the number of cases) of an identified problem or condition. In a complementary manner, it can also be defined as the primary promotion of health, development, and adaptation.
- *Secondary prevention:* The focus is on reducing the existing number of cases and lowering the prevalence of the manifested problems or condition in the population. From a promotion perspective, the emphasis is on the acquisition of compensatory skills and behaviour.
- *Tertiary prevention:* The aim is to reduce the expression of the sequelae and complications of the diagnosed or identified condition. Programs and services of this kind have a rehabilitative and remedial focus.

Evidence for the effectiveness of primary prevention programs has been summarised by Schorr (1991). Among the characteristics of effective prevention programs are

- They are interdisciplinary in nature
- They minimise bureaucratic boundaries
- They have a strong family and community orientation
- They ensure convenient and ready access to a wide array of services
- They promote relationships based on trust and respect
- They seek to personalize preventive services relative to the extent of risk

Another way of classifying services is described by Offord et al. (1999) who identify three models or service systems for addressing the developmental health needs of children and families: clinical, targeted and universal:

- *Clinical interventions:* The major characteristic of this type of program is that the family with a child who is perceived to have a disorder seeks help and are seen by some type of specialist or clinical service. In the past, the term "tertiary prevention" was used.
- *Targeted interventions:* The predominant characteristics of these interventions are that children and their families do not seek help, and certain children are singled out for the intervention, not necessarily because they already have a disorder but because they are at high risk for developing one. In the past, the term "secondary prevention" was used.
- *Universal interventions:* The cardinal characteristics of this type of program are that individual families (and their children) do not seek help and children are not singled out for the intervention. All children in a geographic area or setting (e.g., a school) receive the intervention. In the past, the term "primary prevention" was used.

When we combine the typologies outlined above, four service models can be distinguished according to their availability and focus:

- *Universal services* which are available everywhere and to everyone
- *Targetted / universal services* which are targetted to particular at-risk areas (eg. high poverty areas) but available to everyone in that area
- *Targetted / eligible services* which are targetted to particular at-risk groups and available only to those who meet certain specified criteria (eg. income level)

- *Clinical services* which are available to those who meet certain criteria (eg. children with disabilities) wherever they live

These service models are summarised in the following table:

	LOCATION	ELIGIBILITY
UNIVERSAL	Everywhere	Everyone
TARGETTED / UNIVERSAL	Selected groups or areas	Everyone
TARGETTED / ELIGIBLE	Selected groups or areas	Eligible individuals only
CLINICAL	Everywhere	Eligible individuals only

Traditional specialist early childhood intervention programs for young children with developmental disabilities fall into the fourth category, while programs for those at risk of developmental problems (such as the Head Start program in the US) fall into the third. What needs to be considered are the benefits to be gained from catering for both these groups along with all other children (including children from culturally and linguistically diverse backgrounds) through a single integrated universal system.

One major argument in favour of such an approach is that children with developmental problems have many needs in common with other children and should therefore be regarded as children above all, rather than always being thought of as children with disabilities or special needs. Similarly, families with children with special needs should be thought of as families first of all, rather than as special families. The underlying presumption should be that such families have universal needs that they share with all families, plus some additional needs unique to their particular subset of families. This is in contrast to thinking of them as a different class or type of family altogether, all of whose needs should be met through a specialist system of services.

Adopting this approach has important consequences for how supports and services are delivered. It means ensuring that families with additional needs have access to universal services, with additional specialist support added to the extent required. These adaptations or additional services can be short-term or long-term, depending on the chronicity of the needs. The alternative approach is to provide these families with specialist services first of all, later adding access to normal services where possible. This tends to result in families being 'captured' by specialist services and having much reduced access to mainstream services, even though the specialist services are often unable to meet all the needs of all families.

Thus, the aims of early childhood services for the community at large apply to all children, including those with special needs. In delivering early childhood services to special needs populations, the aim is to adapt or add such services as are necessary to meet these goals. An example of this add-on approach is given by McCroskey and Meezan (1998) in the context of child protection services. They describe a continuum of family and children services ranging from those likely needed by all families at some time, through to those only needed by families where relationships between parent and child have broken down entirely. Another example of this kind of approach, this time in the context of day care services, is reported by Statham (1997). She envisages a comprehensive and universally available service for young children and their families, created by greatly extending the role of mainstream services such as schools. While some children will have additional or specialist

needs, she argues that it should be possible to meet these from within such a universal service, without stigma attaching to either the services or the users.

This new perspective of how early childhood services should be delivered leads in turn to a change in how we define early childhood intervention. The definition of early childhood intervention and its goals provided by Shonkoff and Meisels (2000) in their authoritative *Handbook of Early Childhood Intervention* (2nd.Ed.) is as follows:

'Early childhood intervention consists of multidisciplinary services provided to children from birth to 5 years of age to promote child health and well-being, enhance emerging competencies, minimize developmental delays, remediate existing or emerging disabilities, prevent functional deterioration, and promote adaptive parenting and overall family functioning.' (Meisels and Shonkoff, 2000, p. xvii)

This definition differs from that given in the first edition of the *Handbook* (Meisels and Shonkoff, 1990) in which the target population was 'developmentally vulnerable or disabled children ... and their families' (Shonkoff and Meisels, 1990, p. xvi), rather than all children.

A similar call for a broader definition of the target population comes from Erickson and Kurz-Riemer (2000) who see early childhood intervention as encompassing not only programs for children with disabilities, but also programs aimed at infants and toddlers who are considered to be at risk due to some condition of birth or circumstance (e.g., premature infants, children in poverty, infants born to parents who are chemically dependent or mentally ill), and even child care programs:

'The grouping together of such a broad array of so-called early intervention services is supported by the striking convergence of findings from studies of various populations - children with disabilities, so-called high-risk children and families, and children in the general population. The factors associated with positive child outcomes, and strategies for helping families promote those good outcomes, appear to be much the same across varied groups and settings.'

Catering for all children through a single system implies a dramatically changed relationship between specialist and mainstream services. Just how big a change can be understood when we examine the full range of early childhood intervention service systems. On the basis of a study of nine different early childhood intervention service systems across three US states, Harbin and colleagues (Harbin and West, 1998; Harbin, McWilliam and Gallagher, 2000) identified a continuum of six qualitatively different models for organising early childhood intervention services:

- *Single, stand-alone programs* operating autonomously and without links to other programs
- *Network of programs* largely operating autonomously but beginning to coordinate their services
- *Loosely-coupled coordinated system*, with primary coordination of services between two or more programs within an otherwise networked system
- *Moderately-coupled coordinated system*, with a lead agency or core group of agencies coordinating planning and service delivery among a multiagency group
- *Strongly-coupled coordinated system*, with leadership and decision-making shared among a multiagency group which delivers services cooperatively
- *Comprehensive system for all children*, provided through a local interagency coordinating council composed of a broad array of child and family services

This continuum of service models varies not only in the degree of coordination but also in the populations served and the nature of the services provided: at one extreme, stand-alone programs cater only for children with disabilities and provide a relatively narrow range of disability-focused services, while, at the other extreme, the comprehensive system caters for all children and provides a wide range of specialized and natural community programs and resources. This model is based on a philosophy that all children and families belong to the community, and thus it is the community's responsibility to support and facilitate the development of all children and support all families in this task.

Comprehensive universal service systems have a number of important potential benefits for vulnerable families (Statham, 1997) and families of children with developmental disabilities (Harbin and West, 1998; Harbin, McWilliam and Gallagher, 2000). Statham (1997) cites UK studies suggesting that family centres which offered a wide range of services and which had an open door policy were particularly successful in attracting large numbers of vulnerable families. These families used facilities that were open to anyone in the community (such as toy libraries and coffee mornings) but were then prepared to take advantage of the more specialised help the centres also offered.

On the basis of their US research, Harbin and her colleagues (Harbin and West, 1998; Harbin, McWilliam and Gallagher, 2000) identified a number of ways in which comprehensive universal services could benefit families of children with developmental disabilities:

- First, children in need of additional help can be identified and receive specialist services as soon as possible (early identification)
- Second, because all children receive services, developmental problems can be minimized or avoided (prevention)
- Third, stigma for receiving service is eliminated, because it is viewed as natural the community to take advantage of resources; there is nothing wrong with the help-seekers, help is their right and to their advantage.
- Fourth, this model makes it easier to access natural settings, resources, and activities.

Furthermore, the studies conducted by Harbin and her colleagues (Harbin and West, 1998; Harbin, McWilliam and Gallagher, 2000) indicate that comprehensive service systems achieve better results:

‘In general, the more comprehensive and cohesive the system, the better the results for children and families. The more cohesive the system, the broader the array of services and the better the linkages among programs in the public sector, as well between the public and private sectors. In cohesive service system models, staff tend to use practices more frequently that are identified as desirable by experts in the field (e.g., family-centered and inclusion). Conversely, the service delivery models that were generally associated with less positive results (e.g., not meeting needs of children and families and families frustrated by the system) were usually more insular, having a narrower array of services and weaker linkages with other programs and resources. These programs did not employ nationally recognized best practices in their policy and procedures and were often described as more bureaucratic and rigid.’ (Harbin, McWilliam and Gallagher, 2000, pp. 403-4)

This has very real benefits for families of young children with developmental disabilities:

‘The most comprehensive and coordinated services for disabled children and their families tended to occur in the community that had designed a comprehensive system for all young children and families. It appears from this review that within this

broader system it was easier to match the needs of children with the available resources and programs. This broader system seemed to bring greater knowledge to all those involved with service delivery, thus improving their ability to identify and use an array of community resources. Conversely, the greater the fragmentation of services, the more difficult the task identifying resources to meet the individual needs children and their families.' (Harbin, McWilliam and Gallagher, 2000, p. 408)

Towards a more integrated service system

If we accept the argument that a more integrated service system is required, how can this be achieved? For services and service systems to be effective, they must be based on a shared understanding of

- what the ultimate aims are, ie. what long-term outcomes are being sought
- how these are to be achieved, ie., what the underlying 'theory of change' is
- how progress towards the long-term outcomes will be measured, ie., what indicators or markers of development or functioning will serve as short-term goals

There do not appear to be shared understandings across early childhood and family services on any of these three points:

- *Long-term outcomes:* A clear vision of the long-term outcomes being sought by child and family services has not been articulated. Even within early childhood intervention services, there are ambiguities about what child and / or family outcomes we are seeking, and whether these are short term or long term
- *Rationale or theory of change:* It has become increasingly apparent that one of the features of effective services or service systems is that there is a clearly articulated and widely shared understanding of the rationale or 'theory of change', that is, of how the services being provided achieve the desired outcomes (Davis, Martin, Kosky and O'Hanlon, 2000; Halpern, 2000; Schorr, 1997). Many individual services and interventions are based on clear rationales and theories of change, but there are no models of how all of these link with one another. Thus, there is no overall model of how a whole system of child and family services might work together to achieve shared long-term outcomes.
- *Monitoring children's well-being:* Schorr (1997) has proposed that we need a system of collecting data to document the effects of intentional interventions on the well-being of children, families, and communities. This means identifying a set of short-term indicators of developmental health and well-being that are known to be associated with the desired long-term outcomes. A number of projects seeking to identify such a set of indicators are currently being undertaken. An international study group is working on development of appropriate indicators to measure the well-being of children beyond survival (Andrews and Ben-Arieh, 1999; Ben-Arieh et al., 2001).

Another major initiative is being undertaken in Canada. In their 1999 report *Reversing the Real Brain Drain: Final Report of the Early Years Study*, McCain and Mustard (1999) recommended the development of a new outcome measure for the early childhood years, and work has been undertaken since to develop an Early Development Index based on the concept of readiness to learn as it is reflected in a child's preparedness for school (Janus and Offord, 2000).

Creating a more integrated system of child and family services therefore requires the development of a better shared understanding of what we are collectively trying to achieve,

how these goals are to be achieved, and how we can monitor progress towards these goals. In addition, creating a more integrated system requires breaking down barriers between different services, and overcoming bureaucratic restrictions.

Addressing the need for a more comprehensive and integrated system of child care provision in the UK, Statham (1997) has argued that this can be only achieved if some of the traditional distinctions can be broken down:

‘In order to move to a more integrated system, it will be important to break down the current fragmentation of early childhood services into care, education, play, health, family support (including the promotion of equal opportunities for women) and child protection, and consider how the different functions can be met in a more coordinated way within an overall policy and framework for service to young children.’ (p. 2)

Achieving true interdepartmental and interagency coordination has proved difficult to achieve in practice. Harbin and McNulty (1990) have identified six dimensions that influence the extent and quality of interagency service coordination:

- history of and climate for cooperative service delivery
- availability of fiscal and personnel resources to support coordination
- policies that support coordination
- leadership and the involvement of key people from relevant constituencies
- an informal and formal process for communication and decision-making
- an administrative structure and mechanisms to facilitate coordination

Harbin (1996) lists a number of barriers to interagency coordination that have been identified, including

- agency rigidity
- lack of leadership and involvement from high level decision makers
- protection of boundaries
- competition for financial resources
- conflicting state and federal policies

Harbin (1996) reports the results of US studies of interagency coordination showing that, even when coordination efforts were relatively successful, problems still arose because agencies were different from one another in many crucial aspects, including mission, target population, administrative structure, approach to decision making, level of authority over providers, degree of formality, specificity of policies, geographic jurisdictions, professional backgrounds, terminology, philosophy of agency, experience with innovation, and resources. These aspects combine in an interactive way and result in each agency having a unique way of working which is qualitatively and fundamentally different from other agencies. Inevitably, when they attempt to work together, there are culture clashes and misunderstandings.

In a similar analysis, Hanft and Feinberg (1997) suggest that one of the barriers to effective interdepartmental or interagency service coordination is that different models of service adopt different positions on the questions of how best to provide service, and can end up competing rather than collaborating. This is because

‘... the underlying assumptions for why and how to provide services within medical / rehabilitative, special education, and early intervention systems often differ dramatically and result in competing, rather than collaborative, interagency action among early childhood stakeholders:

~ The traditional medical / rehabilitative model typically features a fairly intensive

frequency of intervention with reliance on professionally delivered services in a formal setting to alleviate the impact of disability.

- ~ A special education model assumes that eligible students can benefit from an adapted curriculum and specialized instruction in order to learn.
- ~ A family-centered early intervention model mandates family-generated outcomes with services delivered in natural environments (eg, home, child care, and other community settings).

Advocates of each of these systems often argue passionately about the merits of their point of view. Each perspective embraces a belief system, resulting in recommendations for child-specific intervention that often have more to do with the culture and tradition of the specific setting than an objective, authentic analysis of child needs and family desires. Unfortunately, as families and practitioners move from one system to another, bewilderment and distrust toward the new program and its unspoken assumptions often occurs, particularly when care changes so dramatically from one setting to another. For example, frequent "hands-on" therapy is often expected by families when they transition to local early intervention program from a medical setting, regardless of what the identified outcomes are for the child.' (p. 28)

Schorr (1997) argues that it is bureaucratic rules and regulations that constitute a major barrier to developing a truly integrated and flexible system of services. She discusses the 'tensions that arise when *government gets in government's way* – when efforts to pursue the public interest are thwarted in a collision with rules and regulations that no longer serve a useful purpose, or whose useful purpose is overshadowed by how much they interfere with getting the job done' (p. 69). Schorr acknowledges that all rules and red tape were originally put in place for a good reason – to control corruption and patronage, to protect agencies and staff, to protect clients, or to allocate funds to particular groups. However, these rules have unintended consequences:

- Rules to assure equity can undermine responsiveness
- Rules to assure quality can also undermine responsiveness
- Controls meant to protect against wrongdoing interfere with discretion
- The accumulation of rules can lead to paralysis
- Rules that stem from hyper-categorization interfere with coherence and prevention
- Under prevailing rules, accountability is almost always at odds with achieving the mission

Schorr considers possible solutions to the bureaucracy problem:

- *Devolution to states and districts*: This does not work because it does not reduce the number of bureaucrats or lessen the influence of special interests or reduce paperwork: 'Shuffling administrative and fiscal responsibilities among various levels of government will not improve outcomes unless bureaucracies themselves are reconstructed to support what works' (p. 87)
- *Service integration and collaboration*: 'The fragmentation of service caused by bureaucratization and specialization is probably the single most obvious obstacle to delivering effective services and supports for families most in need of outside help' (p. 87). However, purely local attempts at service integration have not been able to solve the problem of fragmentation: 'They cannot overcome the complexity of existing finance streams and administrative practices, the sheer insufficiency of needed services, the absence of informal supports, and the isolation of the service sector from the community or economic conditions that created many of the needs for services' (p. 88). What are needed are not so much efforts to integrate services as new social policies.

- *Privatisation and entrepreneurship:* Privatisation is meant to reduce the costs, size and scope of government. Although this may work for some forms of service (eg. rubbish collection or road repairs), it does not necessarily work for services designed to strengthen families. Contracting out of human services can simply lead to the replacement of a government monopoly with a non-government one, as well as the employment of less experienced staff under poorer employment conditions. Market forces do nothing to make agencies and service providers more responsive and effective with clients.
- *Taming bureaucracies and renewing the public sector:* We need a new model of human service that relies less on rules and more on discretion, judgment and creativity.

Despite the difficulties of implementation, Schorr sees the last of these as the only solution and describes a number of successful efforts in the US to deliver unbureaucratic services. In a similar vein, Edgar (2001) has called for a revision of role of the central bureaucracy in Australian governments, and even proposed that all bureaucrats be given sabbaticals to be spent in direct service provision.

Interagency cooperation requires that agencies work together over time to achieve greater consensus about service models and greater consistency on each of the service aspects identified by Harbin (1996). According to Harbin (1996), what is required is the establishment of an interagency entity that understands the differences between agencies but is committed to a broader agenda. The success of such an entity depends upon

- development of a shared mission and vision
- involvement of all key people
- provision of leadership and facilitation
- development of a structure and process for joint planning
- existence of a positive climate for coordination
- shared knowledge of policies and politics
- resources to facilitate coordination
- shared information about best practices
- successful management of the change process

Achieving all these conditions is not easy. As a result, most service systems are not truly coordinated or integrated. Of current services in the U.S. for disadvantaged families of young children, Halpern (2000) comments thus:

‘Not a single state or city has developed a coherent system of birth-to-3 services or has provided adequate funding for the services that are available. In fact, services for birth-to-3 poor children do not so much constitute a system as a patchwork of categorical purposes and programs. Few of the numerous comprehensive community initiatives sprouting up in urban areas around the country include concrete plans to develop or strengthen early childhood intervention services.’ (p. 362)

Halpern (2000) describes ongoing challenge of developing service systems that are comprehensive, continuous or seamless, and provide a continuum of services:

- Comprehensive services – based on the principle that vulnerable families have multiple needs and that services, individually or in conjunction, should be able to address all of them as required
- Continuous or ‘seamless’ services from birth to 5 years – based on the principle that there should be no gaps in service from the time children are born to the time they enter

school, and services to particular families should evolve in relation to their changing support needs

- Continuum of local services – based on the principle that, at any time, there should be a variety of types of service available to young families (eg. a core of non-specialised services backed up by specialist services)

A fourth challenge identified by Halpern (1999) is that of achieving greater coherence in terms of the system of service delivery. At present, he suggests, 'early childhood intervention is not a system but consists of multiple, overlapping systems with different, sometimes competing, priorities' (p. 383)

In the Australian context, the need for new models of interagency collaboration to improve access to services for families of young children has been championed by Vimpani (1996). He proposes that re-organising the system would include the following steps:

- the organising focus for primary care services needs to shift from a regional or statewide model to a neighbourhood level.
- the total range of primary care services - government, non-government, private for profit - needs to be involved in restructuring.
- the restructuring needs to be done in conjunction with members of the local community.
- the principles of primary care should be 'something for everyone and more for those in special need'.
- the network of primary care services should be backed up by a range of more specialised support services which serve a number of neighbourhoods.

This network of services should involve a wide array of prevention, treatment and support services, delivered in an atmosphere of mutual respect, which focus where possible on the whole family and aim to achieve improved outcomes for children and families. These include

- primary health care services - including health visiting, general practice (acute illness care), immunisation, health monitoring of young children
- emotional and practical support for families
- participatory case management for helping children and families with special needs
- early childhood educational experiences
- child care / respite care
- faith communities
- community spaces for meeting - schools, faith communities, neighbourhood centres
- safe recreational areas
- adult education, including literacy training
- job training and employment services
- transport services
- flexible operating hours for many services
- information and referral

Children and families with additional needs

The argument so far is that early childhood and family services do not form a coherent system and need to be drastically recast in order to provide families with the supports they need to be able to raise their children effectively in our contemporary world. What does this imply for children with additional needs? Can they and their families be appropriately supported through some form of comprehensive universal service?

In approaching these questions, the first and most important point to note is how much children with disabilities and their families have in common with other children and families. With regard to the commonalities between children, the Committee on Integrating the Science of Early Childhood Development (Shonkoff and Phillips, 2000) report that research in developmental psychobiology emphasises the continuity that exists between typical and atypical variability in human characteristics. One of the important emerging insights of molecular genetics is that many psychological difficulties arise not from single-gene mutations, but instead from extreme variations on a biological continuum that includes normal variants of the same characteristics. There is, in other words, a very broad range of individual differences in which the boundaries between the normative and the atypical are matters of degree rather than quality. This means that, in studying the growth of typical children, researchers gain insight into the developmental dynamics of atypicality and that, conversely, efforts to understand the challenges of children with developmental disorders yield insights into normative growth.

This has implications for the kinds of services we provide for young children with special needs:

‘Inevitable tensions between the generic and idiosyncratic characteristics of children and families create a complex agenda for the early childhood field. All children, with or without biological or environmental vulnerabilities, do best when they are reared in a nurturing environment that responds to their individuality and invests in their well-being. All families, regardless of their material resources, depend upon informal social supports and varying levels of professional service. Thus, despite the challenges of special needs, the general principles of development apply to all children and families across the broad array of early childhood service systems.’ (Shonkoff and Phillips, 2000, p. 371)

A related point is that many of the strategies that are effective with non-disabled children are also effective with children with developmental problems (Moore, 2001). Thus, there is convergent evidence of an important principle regarding children with disabilities: We should regard children with disabilities as being children first of all, and as having the same needs as other children plus some additional needs. Evidence to support this principle comes from studies of language development (Kaiser and Hester, 1996), parent-child and teacher-child interactions (Mahoney et al., 1998; Mahoney and Wheeden, 1999), longitudinal studies of preschool curricula (Weikart, 1998) and curricula for young children even with severe disabilities (Klein, Chen and Haney, 2000). The principles on which this curriculum is based and the strategies recommended are immediately recognisable as those that characterise sensitive parenting of any child, only more consciously and deliberately applied.

A corollary of this principle is that the kinds of experiences that are beneficial for normally developing children, especially social experiences, are important for children with disabilities as well. This includes opportunities to attend mainstream early childhood services. There is clear evidence for the effectiveness of inclusion for young children with disabilities in such settings (Bailey, McWilliam, Buysse and Wesley, 1998; Bricker, 1995; Buysse and Bailey, 1993; Guralnick, 2000, 2001a; Odom and Diamond, 1998). However, successful inclusion is not easy to achieve: we still have not implemented everything we know and are still

struggling to find ways to 'reallocate existing resources and generate new ones to assure access to specialists, materials, and time necessary for inclusive and integrated curricula' (Mallory, 1998). In addition, the goal of universal access to inclusive programs is far from being realized, and there is not yet a widespread understanding among professionals and the general public of the possibilities of such programs (Guralnick, 2001b).

The point is that, although child-environment interactions that promote learning for typically developing children are *appropriate* for children with disabilities, they are not *sufficient* (Mallory, 1998; Wolery, 1998, 2000). Children with special needs require purposeful intervention, because their disabilities and delays often make them dependent upon others, interfere with them learning well on their own, produce slower development, and disrupt their interactions with others.

Thus, while children with disabilities can (and should) have many of their needs met in mainstream settings, such experiences will only be of benefit to them if they and their mainstream service providers are given sufficient appropriate specialist support. In addition, they may also need other services that specialist early childhood intervention agencies provide. This is the conclusion reached by Bailey, McWilliam, Buysse and Wesley (1998):

'In our opinion, placement in inclusive settings should be a goal for all children with disabilities. The legal, moral, rational, and empirical arguments provide a consistent and compelling foundation which supports this position. However, we temper our recommendation with the caveat that inclusive settings also should be of high quality, able to address the special needs of children, and consistent with parent goals and priorities.' (p. 36)

Families of children with special needs

Just as children with special needs should be regarded as children first, so families with special needs should be thought of as families first of all, rather than NESB families or families of children with a disability. The underlying presumption should be that such families have universal needs that they share with all families, plus some additional needs unique to their particular subset of families. This is in contrast to thinking of them as a different classes or types of families altogether, all of whose needs should be met through different specialist systems of services.

The universal needs of families include affordable housing, secure employment, high quality child care, personal support networks, and supportive communities. Families of children with disabilities have these same needs. Research and practice (Guralnick, 1998) suggest that they are likely to have significant additional needs for

- information about their children's health and development
- support for the interpersonal and family distress that can result from having a child with a disability
- additional resource needs resulting from having a child with a disability, and
- threats to the parents' confidence in their ability to meet their child's needs.

Focusing on the universal needs of families has important consequences for how supports and services are delivered. It means ensuring that families with additional needs get access to universal services, with additional specialist support added to the extent required. The alternative approach is to provide these families with specialist services first of all, adding access to normal services where possible. This tends to result in families being 'captured' by specialist services and having much reduced access to mainstream services, even though the specialist services are often unable to meet all the needs of all families.

Despite the arguments for adopting a universal approach to service delivery, there are some risks attached to this approach. One is that the additional needs of children and families will not be recognized. This is not just a problem for service providers and the service system – it is also a problem for parents themselves:

'How do parents know when their children might need more help than they can provide them? How do they come to recognize that they should seek out the assistance of a professional for evaluation and possible treatment? How do they choose the best intervention when presented with many options? These are difficult questions that few parents are completely prepared to answer.' (García Coll and Magnuson, 2000, p. 102)

As well as the risk of failing to identify when children and families need help, there is also the danger that even the system may not be able to provide the help required. Statham (1997) has argued that, in order to prevent this, it will be necessary to have effective systems for

- identifying children and families with additional needs
- establishing the nature and extent of the services they require, and
- deploying specialist resources to support them within mainstream services.

Identifying children with additional needs requires some way of monitoring children's development. This can be done through a population-based screening model, such as that described by Meisels and Atkins-Burnett (2000), or through scales completed by parents (Squires, 1996). Some proven parent scales that have been developed include *Child Development Inventory* (Ireton, 1992), *Parents' Evaluation of Developmental Status (PEDS)* (Glascoe, 1997, 1998); *Child Health Questionnaire (CHQ)* (Landgraf et al., 1996), the *Ages and Stages Questionnaire (ASQ)* (Bricker and Squires, 1999), and the *Communication and Symbolic Behavior Scales Development Profile (CSBS DP)* (Wetherby and Prizant, 2001).

Once children and families with additional needs have been identified, the next step is to establish the nature and extent of the services they require. For the system to be able to do this in a consistent and equitable fashion, it is necessary that agreement be reached as to what the desired outcomes of service are. However, shifts in service philosophy and practice have been accompanied by changes in how we conceptualise what outcomes we are seeking for children and families (Moore, 1996; Bailey et al., 1998). The result is that there may no longer be a clear consensus in the early childhood intervention field as to what the desired outcomes are.

A detailed exploration of approaches to identifying family needs and allocating resources is beyond the scope of this paper. Discussions of these issues can be found in Bailey and Simeonsson (1988), Darling (2000), Darling and Baxter (1996), Dunst, Trivette and Deal (1994), Krauss (2000), Krauss and Jacobs (1990), and Singer, Powers and Olson (1996).

Conclusions

What is needed is an overarching early childhood development policy and strategy that will address the needs of all children and families, including those with developmental disabilities. To facilitate the development of such a policy and strategy, Hertzman (2000) proposes that federal and state governments should offer to fund local early childhood development initiatives that fulfill the following principles:

- *Comprehensive*: Early childhood development programs must incorporate three basic components: early childhood education, child care and parenting / caregiving support.

- *Universally available and accessible:* All families should have the opportunity to participate in early childhood development programs. Such programs should be affordable, and no children should be excluded, regardless of aptitudes, abilities, disabilities or geographic location.
- *Integrated:* Integrated early childhood development programs should integrate existing programs across education, social services and health sectors. They should also combine programs and resources from federal, provincial and local governments.
- *Community-driven:* The design of early childhood development environments, the allocation of resources, and the delivery of programs should rest with intersectoral authorities in communities.
- *Quality:* Governments should establish standards of practice that reflect current knowledge and understanding of child development.
- *Accountability:* Early childhood development initiatives should be accountable to governments and the public in terms of finances, administration and performance. This will require ongoing monitoring and an outcome orientation. Local communities should be able to use outcome information to measure their progress and allocate resources.

In addition, a recurrent theme that emerges from the literature is the need for common philosophies and guidelines. If services are to work together effectively, they will need to establish a shared philosophy and operating guidelines, eg. family-centred practice. This is consistent with the principle that children with special needs and their families share many commonalities with all families and that services should be directed to all families.

Introducing system-wide changes in policy and practice is no simple matter. On the basis of their experience implementing early childhood policy in Ontario, Mustard, McCain and Bertrand (2000) identify a number of prerequisites for change:

- Political leadership and vision
- Financial incentives for both public and private sectors
- Federal-state cooperation
- Interdepartmental cooperation
- Public awareness campaign
- Time

Beyond inclusion

To summarise the case argued here:

- The current system of services for young children and their families does not support them as effectively as required and therefore needs to be redesigned from the bottom up
- The system of services for children with disabilities and their families is also unable to meet all their needs effectively and similarly should be rethought.
- There are common reasons for the deficiencies of the mainstream and specialist systems. First, the increasing complexity of the conditions under which families bring up children renders the old compartmentalised system of service delivery unable to provide the supports that families need in an easily accessible fashion. Second, the separation of specialist and mainstream services deprives both of learning opportunities and complementary skills that would enable them to cater for their respective (overlapping) clienteles more effectively.
- Universal service models provide a way in which a comprehensive range of services can be delivered in a more integrated and flexible fashion.

- With appropriate resourcing and support, universal service systems could also become more inclusive, catering for at least the some of the needs of children and families who are currently supported through specialist service systems.

What this implies is that we need to go beyond inclusion and to think about the broader needs of all children and families. Support for this line of argument is provided by Bailey, McWilliam, Buysse and Wesley (1998) who suggest that the concept of inclusion be subsumed under the broader goal of normalisation. They define normalisation as a philosophy that has as its primary goal 'the enablement of persons with disabilities and their families to live lives that, based on their own personal and cultural definitions, are as normal as possible' (p. 41). They suggest that focusing on normalisation rather than inclusion might have a number of implications for early childhood education and early childhood intervention:

- Inclusion in regular preschool might become part of a larger set of normalised experiences from which parents might choose
- Child assessment might focus on skills needed to function or participate in family-identified routines or activities
- Children might be taught skills in the contexts or settings in which parents feel they are most important
- Assessment might also include a focus on parent-identified goals in a variety of domains of family life
- Family support might focus on helping families achieve what they feel is a normalised life
- Quality of life for families and children might become a critical indicator of the effectiveness of early intervention

Similarly, within special education, there is a call for what are being called second-generation inclusive practices (Grenot-Scheyer, Fisher and Staub, 2000), based on a new vision of what is best for all students. This entails a radical transformation of the curriculum and of teaching practices, and an integration of the special and regular education systems. It is argued that the end result would be better outcomes for all children.

In the interests of all children and families, therefore, we need to go beyond inclusion, and seek a truly integrated system of services that is able to meet the needs of all children and their families more effectively. What we can learn by integrating specialist and mainstream services into a universal service system is a deeper understanding of how truly meeting the needs of any particular child and family can help us meet the needs of all children and their families more effectively.

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