



## Strengthening Supports for Children 0 – 8 years and their Families: A Literature Review

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### 1 Executive Summary

The Strengthening Supports for Children and Families 0-8 Years Strategy is to improve the way that the New South Wales (NSW) Department of Family and Community Services: Ageing, Disability and Home Care (ADHC) provide services to young children and their families (NSW Government, 2013b). Consistent with the international, national and state policy context and discourse, ADHC's strategy encourages the inclusion of young children with disabilities and their families in mainstream settings.

This report presents the findings of a systematic review of the literature on interventions provided in mainstream settings for children with disabilities aged 0 to 8 years and their families. Further, the focus of the review is on inclusion-based approaches to delivering services in mainstream settings.

The review examines the literature describing:

- best practice for promoting the inclusion of young children and their families
- benefits and outcomes of inclusion-based approaches
- key factors in the effective provision of inclusion-based approaches
- barriers and challenges to inclusion-based approaches.

## 1.1 Best practice for promoting the inclusion of young children and their families

As described in this section of the report, in Australia services for young children with disabilities and their families are in a state of evolution with increases in family-centred, participation-focused services in mainstream settings, albeit in tension with the introduction of individualised funding for targeted services. In the absence of a coherent national framework, services typically adopt a family-centred approach described in the literature according to the following principles:

- collaboration and partnerships between families and professionals
- viewing the whole family as the unit of service provision
- ensuring family choice in identifying priorities, goals and interventions
- taking a family strengths-based approach
- providing individualised family services
- providing culturally-appropriate services.

### 1.2 Benefits and outcomes of inclusion-based approaches

The literature describes the benefits and outcomes of inclusion-based approaches to: multidisciplinary interventions; discipline-specific family-centred practices; discipline-specific interventions in inclusive educational settings; discipline-specific interventions involving significant others; and inclusive parent, teacher and assistant education and information resource programs.

The findings indicate the following benefits and outcomes of inclusion-based approaches:

- children receiving multidisciplinary interventions made progress toward goals and, for those studies set in educational settings, increased peer acceptance and interactions
- where measured, multidisciplinary interventions also demonstrated benefits to families, typically developing peers, and educators
- family-centred interventions, delivered at home, were associated with increased parental satisfaction with the effectiveness of intervention
- interventions in inclusive educational settings increased children's interaction with peers and participation in activities as well as improving skills and functioning
- interventions involving significant others such as parents and siblings enabled children to achieve targeted functional communication and daily life activity goals
- interventions in inclusive educational settings or involving significant others also benefitted those significant others such as teachers through increased knowledge, and siblings and caregivers in terms of enhanced interaction and capacity to support the child with disability
- parent education programs that included parents of typically developing children achieved the best outcomes for children and parents when they included home visits and a focus on the individual needs of parents and children
- teacher and teacher assistant education achieved positive outcomes for both teachers and children with disability when in-classroom mentoring was provided to assist in translating strategies to the classroom in an inclusive manner
- an information resource package was able to assist parents to navigate both mainstream and specialist services, which was particularly appreciated as parents learned of their child's disability and first encountered the multiple service systems.

### 1.3 Key factors in the effective provision of inclusionbased approaches

Facilitators to inclusion-based intervention are:

- implementation of family-centred practice by teams
- ensuring fit with family priorities
- organisational change based on the adoption and support of policy objectives
- teamwork and preparation of professionals for transdisciplinary and consultation roles
- implementation of effective key worker roles
- addressing parent needs and parenting competence
- addressing influences on the perception of family-centred care and satisfaction.

# 1.4 Barriers and challenges to inclusion-based approaches

Challenges exist for families, professionals, services and systems in the implementation of inclusion-based, multidisciplinary, family-centred services. Key barriers to implementing inclusion-based interventions and attaining the optimum benefits and outcomes are:

- diverse and complex needs of individual families
- parent-professional relationships
- lack of coordination and role clarity
- lack of resources and continuity
- service gaps
- inadequacies in intervention design to achieve inclusion-based outcomes.

While there is little discussion in the literature about strategies for addressing these barriers and challenges, a number of recommendations have emerged from findings of studies reporting benefits and outcomes and key factors in the provision of inclusion-based approaches. These are outlined in the final section of the report.

# 1.5 Interventions provided in mainstream settings that are not inclusion-based

The literature describes a range of interventions delivered in mainstream settings (children's homes and mainstream preschools and schools) that were *not* inclusion-based. That is, children were segregated during the interventions, and in many cases the interventions appeared similar to those delivered in clinical settings rather than reflecting genuine integration into mainstream settings.

Generally these interventions were discipline-specific. Studies also tended to report outcomes in terms of norm-referenced test scores or developmental scales, sometimes with functional or inclusion-based goals. One recent empirical study suggests that in these approaches there is a mismatch between the concerns that parents note, the goals they set, and outcomes they observe, and those of therapists. Specifically, parents have a much greater focus on their children's participation and personal factors, while therapists focus on body functions and activity limitations.

#### 1.6 Conclusion and recommendations

On the basis of this review, we conclude that the small number of studies in any one area and their methodological weaknesses present limited evidence for the effectiveness of inclusion-based interventions for children aged 0-8 years with disability and their families. The evidence on multidisciplinary and family-centred interventions is particularly limited, despite studies describing these as the most common approaches in practice. This conclusion is, however, that there is limited evidence for effectiveness rather than evidence for limited effectiveness. The existing evidence **does** indicate the *potential* for these approaches to benefit children with disability, their families, educators

and others. There is a need to increase both the quality and depth of research in any given area to build this evidence, and to specifically compare approaches.

The literature provides little detail about the nature of interventions and other indicators of how to implement inclusion-based interventions. Evaluations of multidisciplinary and family-centred interventions in particular have tended to focus primarily on family outcomes such as parental satisfaction with interventions. The few measures of child outcomes with inclusion-based interventions have focused on attainment of specific goals rather than on inclusion or participation at home or in educational or community settings. The focus of much of the research and evaluation reported in the literature, even where inclusion-based approaches are employed, has been on developing skills in individual children, rather than on maximising their participation within mainstream settings. Further, there is little description of comprehensive interventions delivered in inclusive settings, nor evaluation of the effectiveness of partnerships or capacity building to enable mainstream services to be inclusive of young children with disability and their families. Nevertheless, the studies reviewed highlight which outcomes may be measured in future studies with stronger research designs. Such outcomes may further support the inclusion and social and educational participation of children with disabilities in mainstream settings.

Recommendations made in the report incorporate the key components in the effective provision of inclusion-based approaches and are suggested as pathways to addressing general barriers or challenges to their effective implementation. These recommendations are presented as guidelines/general principles for the implementation of inclusion-based approaches to meeting the needs of children aged 0-8 years with disability and their families that have emerged from the literature.

Recommended components of inclusion-based interventions are based on delivery of interventions in children's natural settings and involving people who are part of children's lives (e.g., parents, siblings, peers and educators). Recommendations are made for the development of teamwork and collaboration, in terms of both professionals from different disciplines working according to interdisciplinary and transdisciplinary models and professionals collaborating with parents, teachers and others in developing and implementing interventions.

Recommendations for inclusion-based, family-centred practices focus on strategies for addressing families' needs, concerns and priorities whilst also involving them as integral members of teams configured around their children. There are a number of specific recommendations made addressing delivery of inclusion-based approaches in preschool and school settings. This is followed by general suggestions for overcoming identified barriers to the implementation of inclusion-based approaches that include sections about organisational change and personnel preparation, and addressing the diverse

and complex needs of individual families, such as families with diverse cultural and linguistic backgrounds.

These recommendations may be useful to consider in the move towards provision of supports for children aged 0-8 years with disability and their families, aligned with current legislation and policy.

### 2 Introduction

### 2.1 Background

This report was commissioned by the New South Wales Department of Family and Community Services (FACS): Ageing, Disability and Home Care (ADHC).

It is intended to examine existing evidence for the philosophy underlying ADHC'S *Strengthening Supports for Children and Families 0-8 years Strategy*. This *0-8 Strategy* advocates that services to young children with disability and their families be delivered in mainstream settings and through collaboration between the disability sector and mainstream agencies (NSW Government, 2013b).

### 2.2 Purpose and focus of report

The purpose of this report is to present the findings of a review of the literature on the effectiveness of interventions provided in mainstream settings for children with disabilities aged 0 to 8 years and their families. Only studies reporting interventions delivered in mainstream settings are included. Further, a distinction is made between inclusion-based approaches designed to facilitate the inclusion of children with disabilities in the everyday activities and routines of mainstream settings and interventions delivered in mainstream settings that nevertheless segregate children with disability and their families (i.e., similar to those delivered in clinical settings).

Studies reporting on inclusion-based interventions are reviewed in the body of the text. Interventions delivered in mainstream settings that are *not* inclusion-based are included in a table.

### 2.3 Overview

Following a brief background statement, we present the literature in four main sections.

- Section 1: Summary: best practices for promoting inclusion of children and their families;
- Section 2: Systematic review: Benefits and outcomes of approaches common in inclusive settings;
- Section 3: Systematic review: Enablers and barriers to the implementation of inclusion-based approaches;
- Section 4: Table: Interventions provided in mainstream settings that were not inclusion-based.

We conclude with a summary of principles for implementing effective inclusive services.

A description of the approach used for the review is at **Appendix 1**.

Notes:

- Sections 2 to 4 of this report represent a systematic review of literature.
   Details of the approach from which the data were derived are reported in the Appendix.
- We precede lengthy sections with short summaries that encapsulate the major content. In all sections, we summarise relevant studies. In some sections, following the summary, we present details of a representative study to give readers the flavour of the papers that contribute to that section. Readers are always encouraged to access the full papers.

#### 2.4 Context

This review reflects a policy context and discourse that promote service delivery consistent with children with disabilities and their families in mainstream settings. Key documents highlighting this context and discourse are briefly and selectively outlined. They are arranged by scope: international, Australian national, and New South Wales.

#### 2.4.1 International context and discourse

The rights of children with disabilities have been enshrined in recent decades in a number of global policy documents. The *United Nations Convention on* the Rights of the Child (1989) specifies that children with disabilities have the right to enjoy a full life in conditions that promote self-reliance, and facilitate active participation in the community. This is accompanied by the right to support for accessing mainstream services that will promote social inclusion. Similarly, the United Nations Convention on the Rights of Persons with Disabilities (2006) includes the right of children with disabilities to have equal access with other children to participation in play, recreation and leisure. sporting activities, and cultural life. The impacts of a child's family context and other natural environments on participation in life situations is a major theme of the World Health Organization's (WHO) International Classification of Functioning, Disability and Health - Child and Youth version (ICF-CY; WHO, 2007). The ICF-CY emphasises the importance of clinicians, educators, policy makers, family members, and others in the community altering these environments to support the child's participation.

#### 2.4.2 Australian national context and discourse

Recent legislation and policy documents in Australia reflect the tenets of the global discourse. Under the *National Disability Insurance Scheme* (NDIS Act, 2013), people with disabilities and their families should receive the supports they need in order to participate in social and community life. This legislation also states that people with disabilities and their families should be supported to exercise choice in their goals and the planning and delivery of their supports. Individualised funding arrangements are intended to promote individualised support arrangements in which families have control over the services they receive and configure teams of professionals to meet the needs of the family and child. These funding arrangements will be bolstered by disability sector development at the state level designed to foster inclusion.

The National Disability Strategy 2010-2020 (Commonwealth of Australia, 2011) recognises that social inclusion and full participation cannot be

addressed by the specialist service system alone. Mainstream services (e.g., health services, schools and transport) must be accessible for people with disability. Various initiatives of the Council of Australian Governments (COAG) are designed to put in place universal supports that will benefit children with disabilities. The *National Early Childhood Development Strategy* (Commonwealth of Australia, 2009) includes a nested and integrated system of universal strategies, and targeted, intensive supports. The *Council of Australian Governments National Partnership Agreement on Early Childhood Education (2008)* aims to provide universal access to structured, play-based early childhood education with funding to target inequalities in outcomes by different disadvantaged groups. In New South Wales (NSW), the *Every Student, Every School: Learning and Support Framework* (NSW Government, 2012) includes increased professional learning and support for teachers and support staff to include students with disabilities in their classrooms, and links to other sectors around the transition to school.

#### 2.4.3 New South Wales context and discourse

Global and national policies pertaining to young children with disabilities and their families also are reflected at the state level in NSW. The NSW 2021 strategic plan (NSW Government, 2011) and Keep them Safe: A Shared Approach to Child Wellbeing (NSW Government, 2009) both set out goals for creating families and communities in which children are healthy and safe, and have a sense of belonging as well as opportunities to reach their full potential. Inherent in these goals is a commitment to prioritising the most vulnerable children and families. Stronger Together: The Second Phase 2011-2016 (NSW Government, 2010) is the NSW Department of Family and Community Services: Ageing, Disability and Home Care's plan for providing personcentred and family-centred assistance and solutions for people with disabilities and their families. With priority given to early childhood intervention, reform and implementation strategies target inclusion of 0- to 8year-old children with disabilities and their families in mainstream settings (Community Support Team Practice Package, NSW Government, 2013a; Strengthening Supports for Children and Families 0-8 years: Position Paper, NSW Government, 2013b).

As NSW transitions to the NDIS, there will be a shift from segregated supports provided via the specialist disability system to person-centred, family-centred approaches embedded in community-based family and social support networks. The focus of implementation will be on collaboration and coordination between specialist and mainstream services and on capacity building to enable genuine inclusion.

### 3 Definitions

The table below is a list terms, keywords and/or abbreviations used throughout this document.

Term	Definition
Discipline-specific	Interventions or services provided by a professional from one discipline, such as an occupational therapist, speech pathologist, physiotherapist, or psychologist.
Family-centred practice	An approach to the delivery of interventions and services to young children focusing on the expertise and needs of those children's families. Refer to "Best Practice in Inclusion-Based Approaches: Family-Centred Services" below for discussion of the principles of family-centred practice identified in the literature.
Inclusion-based services	Interventions or services that are: (i) provided in mainstream settings where all children are found commonly, such as home, preschool, day care, school and recreational or cultural facilities in the community; and (ii) embedded within everyday routines or activities including others naturally part of the setting (e.g., parents, siblings, peers/friends, extended family, educators/ instructors, and other community members).
Interdisciplinary	The direct provision of interventions and services by professionals of different disciplines working together, for example by conducting joint assessments and joint intervention sessions addressing different aspects of the same child or family need or goal.
Mainstream services	Interventions or services that are provided in settings where children are found commonly, such as home, preschool, day care, school and recreational or cultural facilities in the community. Note: Interventions or services provided in these settings are not inclusion-based, however, when they are not embedded within naturally occurring routines or activities, nor if children with disability and/or their parents are segregated.
Multidisciplinary	Interventions or services provided for a child and family by a range of professionals of different disciplines. Each professional provides interventions according to her specific discipline. Often little interaction among disciplines.
Transdisciplinary	The direct provision of interventions and services by one individual working across multiple disciplines. A therapist may work in a transdisciplinary role as a direct service provider or a consultant representing multiple disciplines. A therapy assistant may work in a transdisciplinary role as a technician providing direct

Term	Definition
	services on behalf of therapists representing multiple disciplines.
Universalism	A policy stance in which the default position is that all policies and the services should apply to the whole population. The emphasis is on the applicability of policy objectives to the whole population. Universalism is at odds with the targeted provision of specialised services for sectors of the population such as those with disabilities. Universalism therefore promotes integrated services.
ADHC	Ageing, Disability and Home Care
ASD	Autism spectrum disorders
COAG	Council of Australian Governments
DCD	Developmental coordination disorder
DVD	Digital video disc
ICF-CY	International Classification of Functioning Disability and Health, Children and Youth Version (World Health Organization [WHO], 2007)
IEP	Individual education plan
IFSP	Individual family service plan
KIT	Keeping It Together (D. Stewart et al., 2006)
MPOC	Measure of Process of Care (King, Rosenbaum, & King, 1995)
NDIS	National Disability Insurance Scheme
NSW	New South Wales
PPEY	Parents Plus Early Years
SSTP	Stepping Stones Triple P (Positive Parenting Program)
WHO	World Health Organization

# 4 Best practice for promoting the inclusion of young people and their families

The nature of interventions for young children with disability in Australia has gradually shifted from professional-driven, impairment-focused, and segregated to participation-focused, family-centred services (Sukkar, 2013). The multiplicity of national frameworks described above means there is no single coherent national framework to guide professionals in the delivery of effective interventions for young children with disability and their families. This policy context co-exists with a tension between supporting children in everyday settings and the introduction of targeted services "through an insurance model of individualised funding" (i.e., the NDIS; Sukkar, 2013, p. 99). Nonetheless, Sukkar (2013) stated that intervention services for young children with disability in Australia are typically working from "a philosophy of family-centred practice" (p.104). According to Sukkar (2013), the trend is toward transdisciplinary services involving key workers who deliver interventions in natural environments. These key workers are not necessarily therapists. They often are parents or early childhood staff.

In Canada where the approach to funding and provision of early childhood intervention is similar to that in Australia, Underwood and Frankel (2012) described the evolution of a systems approach at the provincial level in which community sites and agencies collaborate to provide services based on local community and family needs, including coordination of services and resources for parents. These sites provide a link between teams of professionals and early childhood education settings and support the integration of services into these settings designed to support children with disabilities and their families. However, the lack of a coherent national policy results in geographically-based inequities in access to services.

For very young children, inclusive practices must be family-centred. Several papers were identified that presented principles of family-centred practice for 0- to 8-year-old children with disabilities and their families. While there seems to be an emerging agreement about these principles, Epley, Summers and Turnbull (2010) pointed to the need for consensus on key components and the development of key indicators to support the implementation of genuine family-centred practices.

In a systematic review of current conceptualisations of family-centred practice, Epley et al. (2010) included 63 relevant papers published between 1996 and 2007. They identified five broad principles: (i) collaboration between families and professionals; (ii) viewing the family as the unit of service provision; (iii) family choice regarding priorities, goals and interventions; (iv) a family strengths-based approach; and (v) individualised family services. Weiss and Theadore (2011) added as (vi) the principle of culturally-appropriate service provision. Crais, Roy and Free (2006) called for regular documentation in particular about "which practices are (and are not) used and how families and professionals view these practices" (p. 376), particularly where families'

cultural, linguistic or ethnic backgrounds are different to those of the professionals in the service.

### 4.1 Partnerships between families and professionals

#### Families are crucial to evaluation and intervention

### Partnerships require honesty, trust, respect, open communication and cultural sensitivity

The principle of collaboration between families and professionals is the most widely-accepted principle of family-centred practice. Epley et al. (2010) found that 90% of definitions of family-centred practice included the family-professional relationship. Examples of behaviours constituting this principle include: information sharing, honesty, mutual trust, respectfulness, and being positive. On the part of professionals, cultural sensitivity, flexibility, active listening, and other "help giving" practices (p. 276) also were commonly included in the definitions.

Examples: Arango (2011) described family-centred practice as a partnership where families and professionals work together to make decisions in the best interests of the child. She stated that this relationship requires trust, respect for each other's contributions, and open communication. The author added that the context of family-centred interventions should be the family home and community settings. Specific to intervention for children under 3 with diagnosed or suspected autism spectrum disorders (ASD), Smith and Dillenbeck (2006) emphasised the expertise families bring to evaluation and intervention teams. They considered families as essential guides to the teams of professionals.

### 4.2 The whole family is the client

### High quality of family life is the goal

Epley et al. (2010) argued that assessments, Individual Family Service Plans (IFSPs) and interventions "must focus on the concerns and needs of the entire family" (p. 273). This means viewing the family holistically, and focusing on family outcomes (e.g., family quality of life.) Hjorngaard (2011) reminded professionals that families should not be expected to "conform" to prescribed interventions.

Example: Speaking specifically to intervention for children aged under 3 with diagnosed or suspected ASD, Smith and Dillenbeck (2006) listed these essential elements: understanding families' routines and embedding interventions into everyday routines; focussing across disciplines on engagement, independence and social relationships rather than on discipline-specific goals; home visits providing emotional, material and informational supports; regular evaluations of progress and plans; and planning for transitions to school.

### 4.3 Family priorities for goals and interventions

The extent of family input in family-centred practice varies widely in the literature

Input to goals is one of the most common characteristics of familycentred interventions

These goals form the basis for evaluation of outcomes

Input to the characteristics of interventions is another common trait of family-centred practice

The third principle of family-centred intervention is ensuring that family priorities are reflected in goals and that family members have genuine input into decisions about interventions. Families also should be in control of information that pertains to their members. Epley et al. (2010) noted differences in the extent of family choice, ranging from ultimate choice to some involvement. Collaboration in identifying goals and interventions was the most common example of family choice. Hjorngaard (2011) indicated that, in a genuinely family-centred approach, each family's value system and views about their child's disability form the platform for service delivery. Each family decides on the purposes and objectives of intervention and these form the basis for evaluating outcomes (Hjorngaard, 2011).

Example: Based on interviews with stakeholders, focus groups with staff and a review of four existing service models, Weatherill, Bahn, and Cooper (2012) developed the Bespoke Collaborative Consulting Transdisciplinary Model. Underpinned by the values and assumptions of family-centred practice, the child's and family's needs, priorities, and preferences were the focus. Individualised outcomes address needs in home and community settings, namely increasing the child's participation in daily life and building family capacity as required. A transdisciplinary team including therapists, social and family supports, parents and the child (if able), school professionals and other experts share information and expertise to attain desired outcomes. The authors recommended that therapists work with therapy assistants to facilitate integration and participation in school and other community settings. This change to traditional therapist roles increases the likelihood of positive outcomes for children and their families. Weatherill et al. (2012) also discussed facilitators and barriers to effective inclusion-based service delivery. We review those below.

### 4.4 Taking a family strengths-based approach

Interventions taking a strengths-based approach recognise and build on family members' capabilities and competencies rather than focussing on problems

Epley et al. (2010) found that individualised family services was the principle least often described explicitly in literature about family-centred practice. Fewer than half of all definitions described matching services to "the needs and resources of each individual family" (p. 276). There was infrequent mention of parent support groups, parent education, service co-ordination, respite care, counselling, or support with meetings and specialist appointments.

### 4.5 Culturally appropriate service provision

Family-centred care takes into account sociocultural expectations for development and participation

Therapists should aim to empower clients and families such that they no longer require services

Families have a responsibility to engage in services and this requires therapists to engage families in culturally-appropriate ways

Family-centred care demands taking into account each family's socioculturalrelated expectations for development and participation. Weiss and Theadore (2011) addressed the significance of this in relation to speech pathologists' interventions, particularly for social communication disorders, however their advice applies across disciplines.

Weiss and Theadore (2011) highlighted that social communication does not develop independently of other developmental systems. Further, conversations are the essence of social communication and are guided by cultural values and norms. They argued that the involvement of families in services provides the best opportunity to address social communication disorders. Not only is this approach best practice and consistent with familycentred practice and services delivered in mainstream environments, it also is necessary given the high numbers of children who would benefit from early intervention and the delays in identifying them. Indeed, Weiss and Theadore suggested that families have a responsibility to be involved in service provision and therapists should aim to empower clients and families such that they no longer require services. To achieve this, therapists must engage families in culturally-appropriate ways, recognising that the roles and responsibilities of family members and therapists in early intervention may differ between families and therapists. A number of therapist behaviours can help to engage families from diverse backgrounds: open-ended enquiries about activities in which families are involved and that could provide

opportunities for learning; enquiries about families' expectations for involvement in services; and avoiding stereotyping families based on group impressions.

### 5 Benefits and outcomes of inclusionbased approaches

Thirty five studies were identified investigating benefits and outcomes of inclusion-based interventions for young children and families. These approaches to intervention can be divided into five categories:

- multidisciplinary or interdisciplinary interventions
- discipline-specific ,family-centred practices
- discipline-specific interventions delivered in inclusive educational settings or involving significant others
- inclusive education for parents and others and information resource programs.

Each category is introduced with an outline of the key features; these are followed by key findings, benefits, and outcomes. The key findings begin with an indication of the number of studies reviewed in each category and the scope of those studies. Conclusions regarding benefits and outcomes are limited by the quality and depth of research. Readers are referred to individual papers for further detail regarding specific interventions, findings and major limitations.

# 5.1 Effectiveness of multidisciplinary/interdisciplinary interventions

Key findings, benefits and outcomes:

- 10 publications, two of which reported different components of the same study
- 3 studies were across multiple environments, 5 based in childcare or educational settings, and 1 in children's homes
- Children made progress toward goals / across functional skill areas, and participation and peer acceptance and interaction in educational settings
- Limited evidence for effectiveness of inclusion-based, multidisciplinary interventions with methodological limitations making it difficult to interpret findings of some studies
- Existing evidence provides positive indications of the impact of multidisciplinary interventions

### 5.1.1 Systematic review of early interventions for children with physical disabilities

Ziviani, Feeney, Rodger, and Watter (2010) included 10 papers published 1992-2007. (Two papers reported on the same intervention; 9 of 10 papers reported on multidisciplinary programs.) Family related outcomes were measured more frequently than child related outcomes. Child related outcomes focussed on developmental gains and individual goals. Outcome

measures used most commonly were: *Measure of Process of Care* (MPOC; King et al., 1995), *Client Satisfaction Questionnaire* (Larsen, Attkisson, Hargreaves, & Nguyen, 1979), and *Goal Attainment Scaling* (Kiresuk, Lund, & Larsen, 1982). Services were generally family-centred 'to at least a moderate extent' and parents were satisfied. Only one study (Quah, 1997) of facilitated integration into a mainstream preschool measured inclusion, and then using author-developed scales of preschool peer interactions and acceptance. Following the 9-month intervention, parents rated ~ 50% of children as having interactions with peers much of the time and ~ 70% of those as highly positive. The use of different measures and methodological limitations restricted further analysis across studies.

### 5.1.2 Practices to support inclusion in childcare centres and preschools

Cross, Traub, Hutter-Pishgahi, and Shelton (2004) investigated programming for 7 children with significant disabilities. Physiotherapy, occupational therapy, speech pathology and psychology were provided within classroom routines. Therapists supported educators and parents to work toward children's goals, usually via demonstration of interventions. Subsequently, teachers and parents implemented the interventions during daily routines. Therapists occasionally withdrew children or worked with them individually in the classroom when intense, direct, individual intervention was required to teach skills. Interventions were guided by an Individual Family Service Plan (IFSP) or Individual Education Plan (IEP) that outlined functional goals for individual children, such as independent eating, toileting, and making choices. All children were reported to make progress toward their goals.

### 5.1.3 Large scale (N = 637) effectiveness study

Greenwald, Siegel, and Greenwald (2006) reported that 97% of children progressed in two or more skill areas. A team comprising an occupational therapist, physiotherapist, speech pathologist, psychologist, early childhood special educator and therapy assistants visited children and their families in one or more settings: home, childcare centre, preschool or playgroup. Therapists worked together to conduct an interdisciplinary assessments. Coordinators helped families develop IFSPs. Therapists made joint visits to the home or educational setting, working within individual family routines to promote functioning and participation. Therapists sometimes worked with children individually or in small groups that also included typically-developing peers. Interdisciplinary teams also conducted parent education programs. The authors provided an example of a speech pathologist and occupational therapist working together to address the feeding needs of a child (i.e., positioning, sensory-motor and relationship issues) and enhance parent child interaction during meal times.

### 5.1.4 Outcomes associated with IFSPs or IEPs

Duby (2007) reviewed literature about the benefits of teams comprising a speech pathologist, occupational therapist, physiotherapist, psychologist and social worker conducting home visits for 0- to 3-year-old children. Little description was provided about how interventions were implemented but

improvements were reported in all domains of functioning. Similarly, *Chevignard, Toure, Brugel, Poirier, and Laurent-Vannier (2010)* reported that on-going visits by a multi-disciplinary team to the home, preschool or school classroom enhanced the social and educational outcomes of 268 children with acquired brain injury. Like Cross et al. (2004), Chevignard et al. (2010) attempted to evaluate the impacts of these interventions on inclusion and children's participation in their natural environments. They concluded, from descriptive analyses, that interventions facilitated the participation of children in their educational settings. In addition to improved outcomes for children, authors also reported parental satisfaction with children's progress (Cross et al., 2004; Greenwald et al., 2006) and improved family functioning (Duby, 2007).

### 5.1.5 Inclusive childcare or preschool

Stahmer and colleagues (Stahmer & Carter, 2005; Stahmer, Ingersoll, & Koegel, 2004) investigated the impact of at least 6 months attendance in an inclusive childcare program with children aged 18-30 months diagnosed with autism spectrum disorders. The childcare program was 5 days a week in halfday sessions for the children with ASD and full-day sessions for the typically developing peers. The program comprised early childhood and special education teachers in a 1:3 ratio with children; they incorporated a range of evidence-based instruction methods. The program also included consultative support from speech pathologists and occupational therapists. Additionally, children with ASD were provided 30 minutes of 1:1 instruction 4 days per week, and a 2-hour weekly home or community visit with a teacher to encourage generalisation and support parents to deliver at least 10 hours/week of naturalistic intervention. Additionally a parent support group enabled parents to access a resource library. Stahmer and colleagues reported that the children with ASD (N = 20) improved significantly in intellectual and adaptive functioning as measured on standardised assessments (Stahmer et al., 2004), and that the peers (N = 23) showed no signs of disadvantage but rather developed further age-appropriate communication skills (Stahmer & Carter, 2005). For the children with ASD significant improvements were also observed in functional communication, social interaction, and play skills (Stahmer et al., 2004), but these were measured on scales developed by the author and there was also no control group from which to identify expected development trajectories.

Jolivette, McCormick, McLaren, and Steed (2009) investigated the impact of an inclusive preschool on the frequency of naturally occurring opportunities for choice making for 23 children with disabilities and 19 typically developing peers. A speech pathologist, physiotherapist and occupational therapist were based at the preschool and collaborated with educators and assistants in planning and implementing interventions in the inclusive classrooms. Interventions designed to increase opportunities for children with disabilities to make choices were embedded within activities chosen by the children and usually included other children. Therapists supported educators and assistants to implement interventions by demonstrating these during regular classroom routines. Only one therapist at a time worked in a classroom.

Based on covert observations during free play, the authors reported naturally occurring opportunities to make choices that reinforced individual children's goals. However, there were no pre- or post-intervention measures or control groups that enabled the authors to conclude that these opportunities for choice making were the result of interventions. The authors commented that it was difficult to compare their results with frequencies of opportunities for choice making reported in the literature as most previous research had been conducted in segregated settings.

Yeo, Neihart, Tang, Chong, and Huan (2011) conducted a qualitative study with parents, teachers, principals, and therapists of 9 children with mild disabilities who had been involved in interdisciplinary interventions in two preschools in Singapore. A team comprising a psychologist, occupational therapist, and learning support teacher visited the preschool-kindergarten while a paediatrician and speech language therapist were available at the hospital clinic. The therapy comprised six sessions of approximately 50 minutes each. Presence of specialists in the classroom was graded from pullout to in-class support. Assistance from a learning support teacher was provided for the classroom teacher for an additional four maintenance visits. The findings of this study were similar to those of a mixed methods study of the transition from an early childhood development program to kindergarten ("prep school"; Walker et al., 2012). In both, qualitative data revealed benefits including socialisation opportunities, skills and confidence in communication and peer interactions, and academic learning. Teachers in each study reported gaining new skills. Therapists in the study by Yeo and colleagues reported benefitting from experiencing the realities of the classroom. In both studies, classmates were reported to benefit from an increased understanding and acceptance of children with different needs, and from learning to compromise and work together. Unfortunately, details about the nature of the support were not provided in either study.

### 5.2 Discipline-specific, family-centred practice

Key findings, benefits and outcomes:

- 2 studies, one systematic review and one qualitative, both from occupational therapy
- Family-centred practices was delivered most readily in family homes
- Home-based interventions were associated with increased parental satisfaction
- Therapists working in schools reported difficulties with implementing family-centred practices

### 5.2.1 Occupational therapy incorporating family-centred practices and inclusive interventions

Kingsley and Mailloux (2013) published a systematic review comprising eight papers published 2002-2012. Five reported on studies in which families participated in interventions embedded in family routines and activities. The most commonly used outcome measure was parent questionnaires, with few measures of child outcomes. The family-related outcomes indicated increased parental satisfaction with the intervention when family-centred practices were

implemented. Three papers reported studies in which family-centred interventions took place in combinations of home and community-based settings, and home and centre-based settings. One study (Love et al., 2005) reported better outcomes for combined home and centre-based interventions than for interventions delivered in either setting alone. On the whole, few outcome measures were reported and Kingsley and Mailloux (2013) concluded, overall, that therapists conducted limited evaluation of the outcomes of their family-centred practices. Limited detail about interventions and methodological differences among studies restricted further analysis.

Through interviews with occupational therapists *Fingerhut et al. (2013)* identified a continuum of family-centred practices that differed according to the setting in which they were delivered. Occupational therapists working in family homes described their practice as family-centred and, when compared with therapists working in educational settings, reported more collaboration with parents and more emphasis on family concerns, priorities and outcomes. When occupational therapists worked in homes, parents were involved in decision making; interventions were based on whole family needs and concerns; goals and interventions were integrated into family routines; and family members collaborated in interventions. Outcomes reported for familycentred practices in the home setting included: enhanced skills or behaviours of children that enabled greater independence and participation in family life. and enhanced parental empowerment and quality of life. In contrast, occupational therapists working in schools found it difficult to implement family-centred practices. When compared to occupational therapists working in family homes, however, occupational therapists based in schools reported far less communication with parents. Nonetheless, they identified the importance of: parents being part of the team, carryover of goals and interventions in the home, and considering the child's functioning across settings.

# 5.3 Discipline-specific interventions in mainstream educational settings

Key findings, benefits and outcomes:

- 10 studies employing combinations of capacity-building and collaboration with educators, therapy and teaching assistants, peers, parents and the broader community
- Following intervention, children displayed:
  - increased interactions with peers and decreases in segregated activities and undesirable behaviours
  - o increased participation in educational activities and play
  - improved basic skills and functioning
  - broader benefits, such as development of friendships
- Teachers reported increased knowledge and confidence in using support strategies in the classroom

### 5.3.1 Speech pathology

Hunt, Soto, Maier, Liboiron, and Bae (2004) evaluated the collaboration between a speech pathologist and early childhood teachers, teacher's assistants and parents of three children with multiple disabilities in three inclusive preschools. The speech pathologist worked as part of a team that developed, implemented, and reviewed support plans to facilitate participation in classroom activities and decrease dependence on individual supports. The team identified a learning and social profile for each child that included strengths and support needs. They then developed educational. communication and social supports: modified curricula, adapted materials, low tech communication boards, small group interaction, and buddy systems. Support plans identified team members responsible for implementing each support and included a rating scale for evaluating the extent to which each was implemented. Support plans were reviewed at monthly team meetings. Child outcomes were evaluated via systematic observation using the Interaction and Engagement Scale developed by Hunt and colleagues, and via team focus groups. All supports were implemented by the 6-month point. The children displayed reductions in: non-engagement in classroom activities, time alone, and working individually with the teacher's assistant. They displayed increases in: interactions with peers, and initiation of interactions that were reciprocated by teachers and peers. The team reported the development of friendships with peers, increased functional communication with the support of communication boards, and active participation in all educational and play activities.

Similarly, Paradice, Bailey-Wood, Davies, and Solomon (2007) described a collaboration between speech pathologists, teachers, therapy assistants and parents across six inclusive schools in the UK. The project was jointly supported by the government agencies separately responsible for education and the employment of speech pathologists and therapy assistants. Speech pathologists and therapy assistants visited schools regularly over two school terms. During these visits they provided observations, assessments. discussion of children, teacher and parent education; they participated in monthly team meetings with parents and school staff. Teachers determined the content and timing of training they received. Principals of participating schools released teachers from their classrooms for meetings and training. On pre-and-post-test teacher questionnaires: 88% reported gains in confidence for developing IEPs and using techniques in the classroom; 85% indicated that the children they worked with had benefited from the intervention. Few post-intervention parent questionnaires were returned, so it was not possible to draw conclusions about their perceptions of the intervention. Another limitation of the study was the lack of direct measures of child outcomes.

Nelson (2010) described an intervention in which speech pathologists worked with special and general educators in a mainstream school in a low-income, inner city region in the United States. The language instruction ("writing lab") was based on BACKDROP principles (balance, authentic audience, constructive learning, keep it simple, dynamic, research-based reflective

practice, ownership by the student, and patience) and involved mini lessons to develop skills that were implemented immediately. The school had a speech pathologist but while she continued to provide her usual services during this intervention, a speech pathology researcher-clinician assisted by a speech pathology graduate research assistant implemented the writing lab. All facilitators interacted with all students, but the speech pathologist had a particular role in mediating the experiences for students with special needs (four students across three classes in this study, one each with ASD, cognitive impairment, learning disability, and a fluency disorder). This study focused on differences in characteristics of written language across the year and between African American and European American students and did not include any control or comparison group. Therefore interpretations on the attribution of outcomes are limited. However the project did demonstrate that speech pathology and educational staff were able to implement this instruction in an inclusive manner, benefitting students both with and without disabilities.

Toth (2009) investigated the use of sign language as a communication tool for hearing children aged 0-6 years with communication difficulties and developmental delays (e.g., autism, Down syndrome, and learning /intellectual disability). The "Bridge of Signs" program was developed in conjunction with the Deaf communities in Canada in two versions, an English-ASL (American Sign Language) version and a French-LSQ (Langue des Signes Québécoise [Quebec Sign Language]) version. After being introduced to the sign language via a DVD, teachers, resource assistants and/or parents worked creatively with each child to practice and incorporate the signs in everyday routines. The program was launched via a training conference and participants gathered for a second training conference to exchange ideas and experiences. In total, hands-on assistance was provided by the research team for 3 months, with email, phone and video support for an additional 3 months. The engagement of the Deaf communities also resulted in the voluntary support of adults with hearing impairments. The benefit to hearing children varied, seemingly dependent on maturity rather than disability. Daily use of signs for 10-15 minutes and including parents, siblings, and grandparents, led to beginning recognition and application of signs. Even where children's communication did not improve, they increased their capacity to anticipate activities when those around them incorporated the signs. Children aged 3 and over, and those with Down syndrome (of whom three of four were female) showed the greatest benefit. Those with the greatest cognitive impairment required the greatest intensity of one-to-one work including, specifically for children with autism, the need for concrete, real-life presentations rather than the use of the DVD materials. Finally, in a number of cases the program led to the voluntary introduction of signs for all in an educational or community setting (e.g., church), particularly when those around the child with disability included adults with hearing impairments as expert consultants.

### 5.3.2 Developmental Coordination Disorder (DCD)

Missiuna et al. (2012) described an emergent model for supporting children to participate in inclusive education without individualised intervention. The

model involves three steps. The focus of the first step (universal design for learning) was on building educators' understanding of developmental differences and teaching motor-based skills to all children. In the second step (differentiated instruction), educators and therapists collaboratively designed activities, products and evaluation methods (e.g., written vs. oral) for the small group of children with DCD. In the third step, educators and therapists analysed the demands of motor tasks and environmental factors that facilitated or hindered performance with the intent to minimise difficulties. Strategies that improved a child's performance could be incorporated into a child's IEP. The overall focus of the model was on building capacity in educators and parents to manage challenges facing children with DCD in the classroom. The "emphasis [is] on building relationships and on the knowledge translation that occurs when therapists collaborate with teachers in context" (p. 45). As yet the model has not been evaluated. However the authors described positive teacher reports about knowledge translation and outcomes for children involved in similar models in the UK.

Bazyk et al. (2009) evaluated an occupational therapy service for twelve 5- to 8-year-old children with motor difficulties in two inclusive classrooms. An occupational therapist spent 2 days per week in the classrooms over 7 months (average of 28 sessions /child). Interventions were based on IEP goals linked explicitly to the curriculum and embedded within classroom activities. The authors reported that the majority (64%) of the therapist's time was spent in indirect service: collaborative consultation with educational staff and parents to evaluate children's progress and develop home and classroom programs; training for teachers and teacher's assistants about promoting participation in classroom activities; and planning and preparing classroom materials. The latter included procuring materials, such as easels, to be incorporated into the classroom for all children, and therapy materials, such as tongs, that would be stored in the classroom and made available to the children with disabilities at the teacher's discretion. The other 36% of the therapist's time was spent in direct services, mainly group and some individual interventions. These focused on skills required for particular classroom activities, included programming to achieve generalization, and usually involved typically developing peers. Standardised tools were used to assess outcomes for fine motor skills relevant to writing (Peabody Developmental Motor Scales-2, Visual Motor Integration Test) and literacy (Observation Survey of Early Literacy Achievement, Approximations to Text). Children with disabilities made statistically significant improvements in fine motor and literacy outcomes but the authors did not relate these back to the children's IEPs.

Sugden and Chambers (2007) reported on a study combining intervention and ongoing monitoring of change with children aged 7-9 years. Based on an individual profile of strengths and weaknesses developed from each child's Movement ABC assessment results, the research team (who had academic backgrounds in psychology and education) provided guidelines to parents and teachers to address agreed priorities. Each of 31 children was provided 7 weeks of intervention delivered by a teacher, and 7 weeks delivered by a

parent, in random order. Interventions were individualised, used an eclectic approach and included weekly guidance on abilities to work on, activities to target those abilities, and suggestions for teaching. The idea was to have the parent or teacher build activities into daily routines that were of optimal difficulty and addressed similar requirements. Children's performance improved, more on balance than on ball skills or manual dexterity, but selfesteem did not improve consistently. Improvements were maintained for at 7-week follow up. Monitoring for a further 2 years revealed three profiles. For 14/26 children gains were relatively permanent, for a subgroup of 8 children initial improvements were not maintained, and for the remaining children, there was neither gain from the initial intervention nor any later change. The authors recommended one-on-one intervention for those children.

### 5.3.3 Fine motor impairments

Bayona, McDougall, Tucker, Nichols, and Mandich (2006) evaluated a schoolbased occupational therapy service for 23 children (5- to 8-years) with fine motor difficulties. This service was based on a consultation model with five to ten visits over one school year. Occupational therapists consulted with teachers regarding: the assessment of individual children, (observations in the classroom); identification of goals and appropriate activities, strategies, devices, and environmental/task modifications. The therapists met with teachers and parents to discuss intervention strategies, monitor the children's functioning and provide further consultation as required. The majority of therapists (86%) utilised some direct therapy with individual children. Child outcomes were measured using the Vineland Adaptive Behaviour Scales -Classroom Version and the School Function Assessment Version 3.0. The consultative process was also evaluated using tools developed by the authors for this study, a client satisfaction questionnaire and the School-Based Occupational Therapy Questionnaire. Children achieved improvements in written communication and in use of school-related materials. By the end of the year, teachers had increased their use of task and environmental modification and teaching/learning strategies (from 26% pre intervention to 70% post intervention). Therapists and teachers indicated by survey that the interventions had been moderately successful while parents were mostly satisfied.

#### 5.3.4 Autism

Thiemann and Goldstein (2004) evaluated an intervention in which pairs of peers matched with 5 children with autism or Asperger's syndrome (i.e., triads) engaged in five, 30-minute training sessions before or after school to learn five social skills (look-wait-listen, answer questions, keep talking, say something nice, start talking). The second part of the intervention involved the trainer working with each triad in brief sessions 3-4 times per week during activities in their classrooms. These activities included academic tasks, simple board games, or activities designed by the trainer to match current classroom themes and learning objectives. In a multiple baseline design, one facilitative social skill was taught at a time, with the trainer introducing both the peers and target child to the skill and generating written text prompts, followed by monitoring the peers' application of facilitative skills. Prior to the study the five

target children (all boys aged 6 years, 8 months to 9 years, 1 month) were able to interact with peers with variable and occasionally high rates of initiation and contingent response. Skills increase was mixed, and was generally maintained after the conclusion of the interventions through ongoing use of the written text prompts. The combined intervention increased the length of conversations and turn-taking within each triad. Untrained peers in the class reported increased playground interactions, greater enjoyment of play and higher friendship ratings of the target children. However, there was no control, so it is not clear to what extent this may be attributed to greater familiarity with the target child, teacher awareness of the study goals, desire to please the researcher, or other effects.

Stichter, Randolph, Kay, and Gage (2009) tested the effectiveness of manipulating the structural antecedents to adaptive prosocial behaviours (i.e., curricular and environmental variables) with 7-8-year-old children with diagnoses on the autism spectrum. The three students in this multiple baseline design study received most of their education in general classroom settings, with some pull out to special education resource rooms and inclassroom paraprofessional support. After establishing baseline behaviour rates, individualised antecedents (e.g., the structure of the activity) were identified for each student and each target educational setting (small and large group work with peers, independent seated work, and transitions between classrooms with peers). The intervention was then carried out with educators implementing the antecedent manipulations identified as ideal for each student in each context, with prompting from the researchers as necessary so as to ensure fidelity to treatment. Finally, maintenance probes were collected for each student in which the educators' permission was sought for data collection, but no prompting or support was provided. All children were able to increase the percentage of time they engaged on task to close to, or exceeding, that of their typically developing peers, while increasing the rate of prosocial interactions and/or decreasing the rate of undesirable behaviours according to individual targets. Effects were maintained at follow-up when educators were not prompted. All interventions were built into the school routine and teachers found the structural antecedent analysis easier than a functional analysis in which there is a need to identify the purpose fulfilled by the child's undesirable behaviour.

# 5.4 Discipline-specific interventions involving significant others in the home and other settings

Key findings, benefits and outcomes

- 7 studies, including 1 systematic review and 2 studies investigating training siblings
- Involving siblings to promote communication development:
  - led to increases in some areas of communication directly targeted by intervention, which were maintained, but with few measures of generalisation
  - appeared to improve interactions between siblings and benefit both siblings

- Involving parents and preschool assistants to facilitate performance of daily life activities:
  - increased caregivers' engagement in sharing the lead of interventions sessions, teaching strategies used with the child, and focus on the child with the therapist
  - increased knowledge of support strategies for preschool assistants

### 5.4.1 Positive behaviour support

Snell, Voorhees, and Chen (2005), conducted a systematic review of studies investigating team processes and support strategies. Across 111 studies, a significant minority of assessments or intervention occurred at least once in inclusive settings: home environments, 15-17%; general education classrooms, 8-10%; school environments beyond the classroom, 8-9%; and other community settings, 6-7%. The authors surmised that the best practice (i.e., natural settings and typical intervention agents [e.g., parents, teachers]) was, overall, not common. Setting, intervention agent, assessment, and type of intervention were inter-related. Studies in natural settings were more likely to involve parents and teachers, but other people in the children's lives (e.g., siblings) were rarely included. Studies in natural settings were also more likely to use functional behaviour assessment either independently or with functional analysis, and those in natural settings and/or employing functional behaviour assessment were in turn more apt to use a larger number of strategies in interventions. Only two thirds of strategies involved modifying antecedents to behaviour, and strategies like lifestyle changes, peermediated interventions, and self-management were not common. Teaching children replacement skills was more likely to be used as a strategy in natural settings, but was only employed in about half of the studies.

<u>Note:</u> Like Snell and colleagues, we found that most studies targeting behaviour difficulties were not conducted in mainstream settings, and very few were inclusive interventions. This is evidenced in the large number of studies on behaviour interventions conducted in mainstream settings but not demonstrating evidence of inclusion-based approaches. See Section 4. Even more were excluded from this review on the basis of not being based in mainstream settings.

### 5.4.2 Early intervention providers

Salisbury and Cushing (2013) investigated the impact on interactions with caregivers of experienced and well-supported therapists taking a triadic, rather than provider-led, approach. The triadic approach "emphasized collaborative practices, scaffolded teaching of the caregiver through coaching, and use[d] everyday routines and activities as contexts for intervention" (p. 30). The provider-led approach, on the other hand, "emphasized traditional direct instruction of the child and use of provider-determined activities" (p. 30). Six early intervention providers (occupational therapist, physiotherapist, speech pathologist or early childhood/special educators) worked individually with 17 infants and toddlers with developmental delay and their caregivers (predominantly mothers; 10 in the

triadic group, 7 in the provider-led group) to provide 71 video-recorded sessions (43 triadic and 28 provider-led) averaging 45 minutes in length and analysed in 30-second intervals. Differences were shown in elements of who was in the lead during a session, strategies employed, and the focus of the adults' attention. During triadic sessions caregivers more often shared with the provider in leading the activity, teaching the child and attending to their children rather than to the therapists. However, whether the therapist led less, spent more time setting the stage with the caregiver and less time teaching or focusing on the child remains to be investigated. Further, it is important to note that these American therapists were highly educated (masters or doctoral level) and had access to ongoing, employer-sponsored, continuing professional development. They were well-supported in the triadic approach at the organisational level, with participatory governance and research practices, regular team meetings and community of practice activities. DiCarlo and Reid (2004) used a multiple baseline single case design to evaluate the effectiveness of a preschool teacher/assistant- implemented program to increase pretend play between 2-year-olds with disability and typically developing peers. They found increases in independent initiation of play.

### 5.4.3 Speech pathology

Cannella-Malone, Fant, and Tullis (2010) evaluated the outcomes of an intervention to teach a 6-year-old girl with ASD to interact with her sibling. Approximately 10 sessions were conducted at the child's home. The therapist taught the child to use picture symbol cards (Boardmaker® Picture Communication Symbols) representing common words (e.g., food, toys, "yes", "no", "hi," "bye"). The sibling was taught how to respond. Three communicative behaviours were targeted during the intervention; greeting, requesting and responding. The child made modest increases in requesting and responding that were maintained one month after completion of intervention. There were no changes in greetings. Whilst the parent indicated in a questionnaire that the intervention had benefited both children and improved their interactions at home, there were no measures of generalisation to the school setting or with other peers.

Trent-Stainbrook, Kaiser, and Frey (2007) in a multiple baseline single case design study, evaluated the effects of a home-based intervention directed at three siblings aged 9-10 years for promoting the intentional communication of a younger sibling with Down syndrome aged 5-8 years. Twice weekly in 30-60 minute sessions the older siblings were trained to use responsive communication strategies using a pictorial manual, modelling, role play, discussion, and review of their video-recorded interactions with positive and corrective feedback. The older siblings learned the strategies quickly. The younger siblings slightly increased the number of "comments" (a range of verbal and non-verbal intentional communication acts) they made in response to sibling modelling and responsiveness but not the number of requests. Effects were generally maintained at after 1 month but did not generalise from play settings. Differences across the three dyads suggested that younger siblings required an amount of verbal communication at baseline to

benefit. Finally, the ratings of sibling interaction by blinded observers improved, but there were no measures of outcome outside of the observed brief interactions between the children.

Brookman-Frazee (2004) compared the effectiveness of a partnership model with therapist directed parent training for meeting family-selected goals. Participants were three 2-year-olds with autism spectrum disorder and little functional speech, and their parents. Therapists taught parents to implement strategies to increase communicative interactions and other activities within the context of ordinary routines at home. Parents who participated in the partnership model displayed reduced stress and increased confidence when interacting with their child compared with parents receiving a therapist-directed intervention. Children whose parents were in the partnership model displayed greater positive engagement with and response to their parents.

### 5.4.4 Physiotherapy

Ahl, Johansson, Granat, and Carlberg (2005) evaluated the effectiveness of an intervention based on functional goals on gross motor function for 14 children aged 0 to 5 years with cerebral palsy. Following a centre-based course for parents and preschool assistants, therapists conducted interventions over a 5 month period in the children's homes and at preschool. Most children received daily sessions. Goals for each child were identified collaboratively by the parent, preschool assistant and physiotherapist. Intervention incorporated parents and preschool assistants; however little detail was given about this aspect. Child outcomes were measured using goal attainment scaling, the Gross Motor Function Measure and the Pediatric Evaluation of Disability Inventory. Parents and preschool assistants completed the *Measure of Process of Care* (MPOC) questionnaire. The authors reported a significant change in gross motor function, sustained at 8 month follow up; 75% of goals were met completely; 20% were partially met. Parents reported improvements in self-care, mobility and social function and preschool assistants reported having more knowledge about how to support the children.

# 5.5 Parent, teacher/ assistant education and information resource packages

Key findings, benefits and outcomes:

- 8 papers, including 3 systematic reviews: 4 (including the 3 reviews) were about parent training to manage children's behaviours, 3 targeted communication and social interaction, and 2 were on a particular information package for parents
- Best outcomes achieved when parent education programs included home visits and a broad focus on individual needs of parents and children
- Parent education delivered exclusively in the home produced positive outcomes for children with disabilities and their parents
- Education of teachers and teachers' assistants, involving in-classroom mentoring resulted in increased knowledge and use of visual support strategies for children in the classroom

 Parent Information KIT (Keeping it Together) - a method for ensuring that families have necessary general information to advocate for their children with disability

### 5.5.1 Stepping Stones Triple P program (SSTP)

Many studies have examined the effectiveness of SSTP for teaching parents to promote children's development and manage problem behaviours. SSTP comprises a hierarchy of intensity of interventions from population screening and seminars through to extended group or individual programs. Adapted from Triple P (Positive Parenting Program) for typically developing children, SSTP is frequently delivered as a segregated group program for parents of children with disabilities (see Section 4 for recent examples). Here we describe only systematic reviews where parents of children without disabilities are included.

Outcomes of SSTP typically are evaluated with observational checklists and parent questionnaires with changes to children's behaviour and parent's implementation of strategies generating small to medium effects. *Einfeld, Tonge, and Clarke (2013)* reviewed two studies in which parents participated in two 2-hour group sessions yielding small reductions in children's behaviour problems and moderate improvements in parenting styles, which were maintained at 3-month follow up. However, at the same intensity, *Tellegen and Sanders (2013)* found moderate effects on children's behaviour but no significant effects on parent outcomes.

Larger effects on child behaviour and parenting styles have been achieved when implementation focused on the individual needs of parents and their children and included home visits (Tellegen & Sanders, 2013). *Einfeld et al.* (2012) reported significant reductions in behaviour problems, maintained at 12 months, as an outcome of working with families' individual needs in the home setting in low and middle income countries.

Einfeld et al. (2013) also reviewed studies evaluating other group parent programs that included individual sessions in the home. The Parents Plus Early Years (PPEY) program teaches parents to facilitate achievement of developmental and behavioural goals. The 12-week intervention includes 7 group sessions in which positive parenting and behaviour management strategies are discussed, and 5 individual sessions in the home to address specific issues and concerns. Sharry, Guerin, Griffin, and Drumm (2005) reported that PPEY was more effective for improving children's behaviour and reducing parental stress than clinic-based, therapist delivered interventions. PPEY effects were maintained at 5-month follow up.

The Incredible Years Parent Training program involves 11 group sessions interspersed with three individual sessions in the home. Einfeld et al. (2013) concluded that, while observational data indicated a decrease in negative parenting strategies, there were no measures of the impact of the program on family outcomes.

Einfeld et al. (2012) also reviewed research evidence for two parent training programs delivered in low and middle income countries. One parent education program was delivered in the home by local community workers trained by professionals. During home visits a broad range of issues were addressed, including self-care, language development, behaviour management, and motor development. Outcomes were measured by subjective worker reports of children's progress precluding rigorous evaluation of effectiveness. The second was of the *Portage home visiting program* for preschool children (Cameron, 1997). This program involves weekly home visits during which the professional and parents decide on skills that the child needs to acquire, and the professional demonstrates strategies for the parent to implement. The program had positive outcomes for both the children and parents who participated in the study.

Wetherby and Woods (2006) evaluated the effects of Early Social Interaction, a parent-implemented intervention built into daily routines, on the social communication outcomes of 2-year olds at risk of autism spectrum disorder. The focus of intervention is on individual social communication goals identified by parents. During home visits and an inclusive playgroup, family concerns about problem behaviours were addressed. Relative to a comparison group, participants in this program showed significantly better skills in interpreting social signals, frequency of communicating, and communicating for a variety of purposes.

### 5.5.2 Speech pathology

Wellington and Stackhouse (2011) presented a qualitative evaluation of a training for using visual supports for 5- to 7-year-old provided by a speech pathologist/assistant to teachers /assistants in seven mainstream schools. The training comprised a 2 ½ -hour group session, followed by six, weekly 2-hour mentoring sessions. Participants gained knowledge of (1) the impact of speech, communication, and language difficulties on access to the curriculum; (2) strategies to support children; and (3) greater confidence in using visual supports in the classroom. Classroom observations showed increases in the use of visual support strategies, which were for the most part maintained after 3 months, particularly in schools with higher incidence of students with special education needs or with English not being their first language. Most of the teachers and all of the assistants considered the mentoring the most important aspect of the intervention.

Two separate teams (D. Stewart et al., 2006; J. Stewart, Galvin, Froude, & Lentin, 2010) reported on a Canadian Parent Information KIT (Keeping it Together) targeting parents' support of their children, KIT was subsequently adapted for Australia and trialled in Victoria. KIT was designed to assist parents to manage information and advocate for their child as they navigated mainstream health and education services as well as specialist services. Parents reported increases in knowledge, confidence / empowerment, and satisfaction in advocating for their needs, accessing a range of services, and communicating with many professionals in different service systems. The studies indicated KIT should be distributed at the time of diagnosis. KIT

includes provision of general information, a factor that is consistently identified as low on the *Measure of Process of Care* (MPOC).

# 6 Key factors in the effective provision of inclusion-based approaches

Two papers focussed directly on facilitators to service delivery (Shannon, 2004; Ziviani, Darlington, Feeney, Rodger, & Watter, 2013). Many more identified pertinent factors among other findings. A number of these papers pertained to multidisciplinary interventions but provided little information on the nature of the intervention. The degree to which these studies were inclusion-based is therefore difficult to ascertain. Given the paucity of papers directly addressing factors in the effective provision of *inclusion-based approaches*, papers addressing factors in the provision of multidisciplinary and family-centred practices are also included here.

Together, the papers suggest a number of facilitators to best practice: ensuring fit with family priorities; organisational change based on the adoption and support of policy objectives; teamwork and preparation of professionals for transdisciplinary and consultation roles; implementation of effective key worker roles; addressing parent needs and parenting competence; and addressing factors influencing the perception of family-centred care and satisfaction with services.

### 6.1 Ensuring fit with family priorities

#### Key factors:

- Use family service plans
- Empower families by meeting their basic needs first, facilitating family-tofamily support, working to increase family self-esteem and confidence, and imparting skills for involvement in implementation of interventions
- Base interventions on the needs of children, their families and teachers, and in daily settings
- Collaboratively identify goals and decide on interventions
- Provide general information to families about community based supports and services
- Facilitate transition from preschool to school

#### 6.1.1 Barriers

Families experience direct barriers to accessing services when services are not in mainstream settings (i.e., lack of childcare, time, transport, and cost) (Resch et al., 2010; Serpentine, Tarnai, & Finke, 2011; Webster, Feiler, Webster, & Lovell, 2004; Ziviani et al., 2010). Families vary in time, organisational skills and motivation to utilise available resources (D. Stewart et al., 2006). They have individual priorities and approaches to confrontation when professionals are not meeting their needs (Shannon, 2004). Thus, professionals who prescribe intervention without negotiation, and families having to fit into a prescribed framework of service delivery, are serious

barriers to achieving positive outcomes (Dodd, Saggers, & Wildy, 2009, p. 179).

#### 6.1.2 Facilitators

Ziviani et al. (2013) identified several key factors that contribute to building relationships with families and shaping their attitudes and capabilities as they learn of their children's disabilities: service plans, flexible service delivery, a wide range of services, and early intervention. *Shannon (2004)* also identified empowering families as a key factor in effective service provision. Families are empowered when: their basic needs are met; family-to-family support is facilitated; they are provided with information; professionals work to increase their self-esteem and confidence; and they are taught skills to be involved in the implementation of early intervention tasks (Shannon, 2004).

Thus, a key facilitator of effective service provision is to base interventions on the needs of children, families and teachers, and provide them in everyday settings (Cross et al., 2004; Dunst, Trivette, & Hamby, 2007; Morgan & Long, 2012; Webster et al., 2004). The benefits of embedding interventions in routines and activities, including the school curriculum have been highlighted commonly in the literature (Chen, Klein, & Haney, 2007; Dunst, Trivette, & Masiello, 2011; Favazza et al., 2013; Kasari & Smith, 2013; Palisano et al., 2012; Pumpuang, Phuphaibul, Orathai, & Putdivarnichapong, 2012).

In a study investigating families' and professionals' perspectives on familycentred practices, Crais et al. (2006) found a significant gap between actual and ideal implementation of family-centred practices. The most frequently occurring practices included: identifying each child's strengths, identifying individual families' most important concerns, and collaboratively identifying goals and deciding on interventions. Infrequent but ideal practices associated with assessments included gathering background information about the child and family, and involving the family in assessments. In a similar study evaluating the extent to which family-centred practices are implemented by therapists, Darrah, Wiart, Magill-Evans, Ray, and Andersen (2012) reported that therapists collaborated with families in setting functional goals aimed at increasing the children's independence and participation in daily contexts. Therapists reported involving parents in individual program planning in educational settings. On the basis of their results, the authors identified a number of facilitators to the provision of family-centred services. These included provision of general information to families about community based supports and services, involvement of families in identifying therapy goals, and facilitation of transition from preschool to school for children with disabilities and their families.

### 6.2 Organisational support and policy objectives Key factors:

 Philosophical, funding, and infrastructure support for family-centred, multidisciplinary practices and continuing professional development

- Developing multidisciplinary, multi-agency plans for individual children; configuring teams around each child, with professionals being brought into teams as required
- Coordination of services
- Building multi-agency collaborations

The organisational adoption of, and support for, family-centred practice and universalism is a key factor in quality service provision (Darrah et al., 2012; Young, Temple, Davies, Parkinson, & Bolton, 2008). However, several authors concluded that the culture and structure of organisations are barriers when there is limited philosophical and funding support for family-centred, multidisciplinary practices, and professionals are required to work with large caseloads and a referral process that is not family-centred practice (Carter, Cummings, & Cooper, 2007; Fingerhut et al., 2013; Greenwald et al., 2006; Hingley-Jones & Allain, 2008). Dodd et al. (2009)noted a major barrier when professionals themselves do not embrace the philosophy and practices of family-centred practice. Further, Darrah et al. (2012) noted the absence of measurable indicators of family-centred services; thus evaluation of implementation is largely informal. However, Villeneuve et al. (2013) identified a lack of follow through despite indications that policies on the involvement of families and interprofessional collaboration was adopted in formal proceedings. Vehkakoski (2008) summarised the issues as stemming from a lack of focus on children's rights when planning for inclusive schooling, again despite an initial identification with policy objectives favouring mainstream schooling as a first option.

In an Australian study, *Ziviani*, *Darlington*, *Feeney*, *and Head (2011)* described variations in organisational adoption of approaches even under the same policy and funding provisions (in this case the *Early Intervention Initiative of Disability Services Queensland*) and where organisations had in common a mission to support children with physical disabilities and their families. Ziviani et al. (2011) engaged direct service staff including family support workers, occupational therapists, physiotherapists, social workers, and speech pathologists, along with some managers, in program logic workshops at their respective organisations. They found that the policy documents were broad and thus the nature of the programs delivered varied.

The broad objective for all programs was to enhance families' capacities for promoting children's development through information, education and support for families to deliver therapy programs at home. Participation of children and families at home and in the community was a long-term outcome of all services. However, services differed in scope, amount of reliance on the system, and provision of support and education to people and organisations beyond the child and family. Thus, while not directly evaluating the extent to which individual programs were inclusion-based or family-centred, this study identified varied interpretations of policies promoting family-centred early intervention in mainstream settings.

Several studies evaluated organisational change resulting from legislation and policies in Britain and the United States mandating inter-professional practices

with children with disabilities and their families (Abbott, Watson, & Townsley, 2005; Bush, 2005; Carter et al., 2007; Greenwald et al., 2006; Hingley-Jones & Allain, 2008). Abbott et al. (2005) evaluated services delivering structured. multidisciplinary, family-centred services to families of children with complex health care needs. Carter et al. (2007) evaluated services provided by professionals employed by different agencies. *Hingley-Jones and Allain* (2008) described the development of multidisciplinary, multi-agency plans with teams configured around each child. Bush (2005) described a service working with families to increase children's and families' community participation. A single therapy assistant provided physiotherapy, occupational therapy and speech pathology interventions in the child's home, preschool, school or recreational activity. Interviews and focus groups with families and professionals revealed improved implementation of services. Carter et al. (2007) concluded that families' needs are met more effectively when interventions are co-ordinated. Their evaluation also led to the development of "guidance plans" and "best practice statements" for the service (p. 532).

Hingley-Jones and Allain (2008) reported an increase in professionals sharing knowledge and skills and conducting joint visits to family homes and children's educational settings. Bush reported a greater number of children and families receiving services, as well as increased access for children and families to mainstream services such as preschool and leisure activities.

On the basis of their description of one centre's family-centred, interdisciplinary service for 0- to 3-year-old children, Greenwald et al. (2006) identified several facilitators to implementation at the organisational level. These included: strong, stable leadership and infrastructure support, particularly for information and communication technologies; and continuing professional development to bridge the "research to practice gap" and support staff to implement "highly specialised" inclusion-based, family-centred. multidisciplinary practice (p. 46). Targeting a similar group, Young et al. (2008) found that effective services viewed project funding that was intended to promote family-centred services as a catalyst for change rather than simply short-term funding for services to a population. Those services that adopted the policy agenda more broadly planned to sustain resources beyond the project funding, took strategic directions to build multi-agency collaborations, and embedded the activities in the organisation rather than keeping it a distinct project (Young et al., 2008). As a result, families benefitted from coordinated support and clear access pathways in which a universal tool was used to assess their needs and make the required referrals across services rather than individual assessments of eligibility for individual services.

Running counter to these findings however, in investigating the effectiveness with which services delivered a project intended to promote a universalism policy, *Young et al.* (2008) cautioned that a pure focus on universal, mainstream services may inadvertently result in reduced service quality and accessibility of specialist services for those families who need them. They identified this as a particular concern given the lack of evidence they found for effective mixing of universal and specialist services directed by families.

# 6.3 Teamwork and preparation of professionals for transdisciplinary and consultation roles

#### Key factors:

- Communication among team members, including teachers and parents
- Shared vision and team responsibility
- Development of the roles and skills of therapists to provide transdisciplinary consultation in addition to direct and indirect therapy
- Utilisation of therapy assistants who bring experience working in communities

Cross et al. (2004) identified facilitators to inclusion-based, multidisciplinary interventions provided within the everyday routines of preschool classrooms: communication among all team members; shared vision and team responsibility for IFSP/IEP goals; role release; and "reliance on and respect for the ideas, opinions and knowledge of parents, teachers and other team members" (p. 178). The important role of parents and teachers in intervention teams also has been emphasised by other authors (Gillette, 2006; Peplow & Carpenter, 2013). On the flip side, Walker et al. (2012) identified that difficulties with managing behaviours and adapting the curriculum impacted on the success of transition to school. Walker et al. also reported that these difficulties reinforced attitudes held by teachers with regard to including students with disabilities, and that those roles fell to aides and specialist support staff. Ziviani et al. (2013) identified that with larger and more complex caseloads, families were presenting with more goals than it was possible to address and therefore services must necessarily become more consultative.

Professionals may lack willingness to adopt new roles as required in multidisciplinary teams (Hingley-Jones & Allain, 2008), or lack experience on teams (Gallagher & Malone, 2005). Speaking to the issue of consultative services, Weatherill et al. (2012) noted issues regarding the preparation of organisations and therapists to deliver family-centred approaches in their project evaluation of school-based therapy services in a non-government organisation in Western Australia. They identified a place for developing the roles and skills of therapists to provide transdisciplinary consultation in addition to the direct and indirect therapy. The authors did not propose eliminating intensive programs, particularly for children and families facing major transitions. Rather, they sought to increase support for parents and significant others through mentoring, provision of resources, demonstration and training. They envisioned that family-centred approaches would be supported by therapy assistants who brought experience working in communities. In further support of teamwork and professional preparation, Ziviani et al. (2013) noted that high quality staff with skills to work in transdisciplinary roles could produce positive outcomes and compensate for staff shortages. On the other hand, Fingerhut et al. (2013) listed limited training in family-centred practices, attitudes about roles and perceived lack of time as barriers to family-centred practices.

#### 6.4 Implementation of effective key worker roles

Key factors:

- Working together with families to establish needs for services and support and set goals
- Co-ordinating and facilitating services to guide families through the 'services maze'
- Facilitating access to equipment, resources, and training that enables the child to participate at home and school
- Providing families with support with meetings, preparation of reports, and getting professionals together
- Providing families with ongoing emotional support

A nominated key worker for each child and family to co-ordinate and facilitate services both within and outside the organisation is key to success (Abbott et al., 2005; Carter et al., 2007; Young et al., 2008). Based on the results of parental questionnaires, Abbott et al. (2005) reported that the benefits included support for managing children's complex needs at home. Key workers facilitated access to equipment, resources, and training that enabled children to participate at home and in school. A "whole family" approach reportedly kept the team informed about the family's needs. Families reported an overall improvement in quality of life. They appreciated guidance through the "services maze", and with meetings, preparation of reports, and getting professionals together. Families identified the importance of ongoing emotional support from the key worker, for example through availability to discuss issues as they arose. The families in Abbott et al.'s study also expressed satisfaction with their child's participation in education and access to the curriculum. Most families reported that this approach made access to services easier: "it all seems to be glued together" (p. 234). Key workers brought in other professionals and arranged appointments for other services. Similarly, Young et al. (2008) identified key workers as a necessary but insufficient component – which organisations were, incidentally, reluctant to fund –in implementing the philosophy and model of Early Support in the United Kingdom.

Rodger, O'Keefe, Cook, & Jones, 2012 investigated one specific aspect of the key worker's role – setting goals with the family – as they piloted the implementation of their Family Goal Setting Tool in a multidisciplinary early childhood service in Queensland. They developed and introduced a tool that provided illustrated cards for a range of potential goals to include in Family and Team Plans. Parents sorted the cards into priority groupings (yes, maybe, no-not now) as part of their service planning session. The 77 cards comprised seven domains: (i) information, resources and support for parents/carers; (ii) inclusion of the child/family in community/participation; (iii) social relational support; (iv) daily living skills; (v) communication; (vi) gross motor/mobility; and (vii) play and early academic skills. By serving as prompts, the cards facilitated goal setting and reportedly reduced the anxiety parents felt when asked to generate goals. As a result, goal setting was consistently more family-centred, including the needs of the family beyond the child.

# 6.5 Addressing parents' needs and parenting competence

#### Key factors:

- Responding to the priorities and needs of families
- Focusing specifically on promoting parenting competence to reduce parent stress
- Exercising flexibility in how families' priorities and needs are addressed

Regardless of the intervention (Applied Behaviour Analysis or a family tutor model), most of the 15 families in Webster et al. (2004) evaluation stressed the value of flexibility for addressing the family's needs and assisting them to implement new strategies. The importance of addressing caregivers' needs and competence was quantified by Sarimski, Hintermair, and Lang (2013) who focussed on outcomes for parents. The authors used standardised questionnaires administered twice during one year at Time 1 and Time 2. Among a cohort of 125 caregivers of children receiving early intervention (0-3) services in Germany, those who perceived higher parenting competence reported less family-related stress and less parent-child stress. Parenting competence was in turn related to high general self-efficacy and higher satisfaction with early intervention services. Higher parent competence at Time 1 also predicted lower family-related stress at Time 2. Practical and emotional support were not predictive of stress at Time 2. Acknowledging that they found other child-related factors to be related to parent stress, they concluded that, "early intervention professionals (in Germany) should respond more to the priorities and needs of families and should focus more specifically on promoting parenting competence as major variable to reduce parent stress" (p. 371). There appears to be agreement in the literature that addressing the priorities, needs and competence of families, including children with disability, fosters positive outcomes for both (Dunst et al., 2007; Morgan & Long, 2012; Palisano et al., 2012; Peplow & Carpenter, 2013).

#### 6.6 Addressing influences on the perception of familycentred care and satisfaction

#### Key factors:

- Provision of respectful care
- Provision of frequent visits in the home for preschool aged children
- Involvement of as many team members as required
- Provision of general information about services and specific information about children's disabilities
- Focus on implementation of family-centred care by services provided in school settings
- Focus on provision of family-centred care for families in regional and rural areas
- Fostering 'working alliance' (feelings of mutual care between parties and collaboration toward a shared goal) in conjunction with family-centred practices

A number of studies (including: Raghavendra, Murchland, Bentley, Wake-Dyster, & Lyons, 2007; Wilkins et al., 2010) examined multidisciplinary services with a focus on families' satisfaction and/or measures of familycentred practice such as versions of the *Measure of Process of Care* (MPOC). Raghavendra et al. (2007) investigated the degree to which therapy, equipment, and family support services in one South Australian nongovernment organisation were perceived to be family-centred, analysing 169 caregivers' responses to the short form of the MPOC and 122 responses to the service provider form of the MPOC. Wilkins et al. (2010) analysed responses to the full MPOC from 165 parents / guardians of children with intellectual disability or global developmental delay who were referred to multidisciplinary early intervention (0-6) services from the Western Australian government provider. Across studies, caregivers and providers generally perceived services to be family-centred, particularly with regard to the provision of respectful care and least with regard to the provision of general information (Raghavendra et al., 2007; Wilkins et al., 2010). While there were differences between studies and disciplines, generally caregivers perceived better coordinated and comprehensive care for younger children and with the involvement of more team members or more frequent visits. The perceptions of families in metropolitan versus rural areas varied by service model and by aspect of family-centred care. Other factors associated with increases in aspects of family-centred care were increased provider experience, and providers in disciplines such as occupational therapy, family support staff, and psychology. Given the provision of general information is typically the lowest rated subscale of the MPOC, provision of a specific information-based intervention in Canada improved this aspect of family-centred care and also the subscale on enabling and partnership (D. Stewart et al., 2006), but this aspect was not measured when the intervention was adapted and delivered in Victoria. Australia.

These findings were mirrored in two later studies. *Hodgetts, Nicholas*, Zwaigenbaum, and McConnell (2013) also evaluated responses to the MPOC-20 from 152 parents and to the MPOC-SP from 146 professionals in a study about perceptions of family-centred care in the provision of services to children with autism spectrum disorders in Canada. Perceptions of familycentred care were generally positive, particularly with regard to provision of respectful care. Least satisfaction was expressed with regard to information sharing by professionals. Lack of information about services was a major source of stress for families. Differences in perceptions of family-centred care reflected child age; they were greater for preschool aged children receiving community-sector services at home than for school-aged children. Additional qualitative findings indicated a perception that there was little family-centred care in school settings. In another Australian study, Fordham, Gibson, and Bowes (2012) evaluated responses to the MPOC-56 from 130 families in a study about the provision of family-centred early intervention services. The authors found that only half of the families in their study were experiencing family-centred care, and that families living in regional towns experienced markedly less family-centred care than those living in cities. Consistent with the findings reported above (Hodgetts et al., 2013; Raghavendra et al., 2007), "families perceived respectful and supportive care to occur most often and providing general information to occur least often" (p. 651). Families who had a professional co-ordinating their child's services reported higher levels of family-centred care than others. Care co-ordination has been discussed in greater detail above. Services need to "do much more to meet families" information needs" (p. 651).

Finally, *Trute and Hiebert-Murphy (2007)* set out to identify relationships among satisfaction with services and feelings of mutual care and collaboration toward a shared goal and family-centred care. Working alliance was found to predict 42% of variance in satisfaction, and working alliance plus family-centred care predicted 57-60% of variance in satisfaction. While not replicated in other studies in this review, the findings suggest working alliance with families and family-centred practices both contribute to satisfaction.

### 7 Barriers and challenges to inclusionbased approaches

The papers reviewed highlighted that challenges exist for families, professionals, services and systems in the implementation of multidisciplinary, family-centred services. As with the identification of key factors above, few papers exclusively and explicitly addressed inclusion-based approaches but existing findings were consistent. The barriers and challenges identified were: (i) diverse and complex needs of individual families; (ii) parent-professional relationships; (iii) lack of coordination and role clarity; (iv) lack of resources and continuity; (v) service gaps; and (vi) inadequacies in intervention design to achieve inclusion-based outcomes.

### 7.1 Diverse and complex needs of individual families

Barriers and challenges:

- Language and cultural differences to service providers
- Socioeconomic disadvantage and low educational levels
- Family structure (single-parent household)
- Complex needs of very young children with significant disabilities and medical needs
- Availability of working families
- Transport issues limiting families access to services
- Families engaged with child protection services
- Parental (particularly maternal) stress and other personal stressors
- Parental expectations and family values
- Specific cultural barriers related to views about disability, interventions delivered in English, and program content and delivery

The diverse needs of individual families have been noted as a broad area contributing to barriers in effective service provision. Individual family characteristics such as language and cultural differences to service providers, low income and personal stressors, alter the ability of families to engage with

and benefit from services (Fingerhut et al., 2013; C. Grindle, Kovshoff. Hastings, & Remington, 2009). As *Dodd et al. (2009)* stated, "the everyday complexity of the lives of parents or their children may not always be appreciated by allied health and other professionals" and "the interpretation of what family-centred service means, i.e. truncated involvement in the treatment of their child under the direction of an expert" may be limiting and put pressure on families when there are "bigger things causing their reduced capacity to be involved" (p. 178). Professionals themselves have identified that they are limited by high workloads both in terms of numbers and the complexity of family needs: the additional needs of very young children referred for early intervention; the increasing numbers of children referred with very significant disabilities and medical needs; the numbers of working families who have limited availability, particularly for group interventions; and the complex needs of families from culturally and linguistically diverse backgrounds, with poor cognitive or coping skills, transport issues limiting access, or who are engaged with child protection services (Ziviani et al., 2013). These families require more liaison, more home visits, counselling, equipment, and respite services, which lead to concerns regarding reductions in 'hands-on' therapy time while waiting lists grow (Ziviani et al., 2013). Concurrently, families are perceived to be increasingly outspoken about their needs (Ziviani et al., 2013).

Bagner and Graziano (2012) evaluated the impacts of family "risk factors" on the outcomes of parent training for families of 3- to 6-year-olds with developmental delays and problem behaviours: "socioeconomic disadvantage (poverty and maternal education), family structure (single-parent household), and maternal risk characteristics (minority status, lower intelligence, and maternal distress)" (p. 362). The authors found that the presence of risk factors significantly increased the likelihood that families did not complete the parent training program. In addition, they found a cumulative effect for risk factors. For families that did complete the program, this cumulative effect was associated with poorer treatment outcomes. Compared to families with no risk factors, parents with more risk factors reported less change in their child's behaviour problems and "displayed fewer improvements in parenting skills" (p. 368). Noting the limited uptake of parent training programs to begin with, Einfeld et al. (2013) identified a number of family characteristics influencing participation. These included: parental education level, socioeconomic status, expectations about program delivery and outcomes, family values, status of marital relationship and single parenthood (Einfeld et al., 2013). Further, Birkin, Anderson, Seymour, and Moore (2008) described cultural barriers to the participation of families in a parent training program in New Zealand. Participants from three ethnic groups were included: Maori or first people of New Zealand, Pacific People originating from a number of islands in the region, and Koreans. Different cultural discourses about disability were identified in this comment: "Children who are acknowledged as different are nurtured rather than pathologised within the [participants'] culture" (p. 112). The authors noted the importance of relationships with those providing the training, stating that "relationship-building must be attended to before interventions can be expected to 'take'" (p. 112). Programs conducted in

English were noted as a barrier for many families. A number of families who participated in Birkin et al.'s study expressed concerns about the content and delivery of programs, in particular possible anxiety provoked by group pressure and the requirement to be videotaped and receive feedback. These parents expressed a preference for the information to be shared with them by an Elder of their community. As previously mentioned, parents reported that the extent of demands from outside the home made it very difficult to undertake the extra commitments required by interventions. These findings may be of particular relevance to service accessibility for Aboriginal and Torres Strait Islander people. Limited cultural sensitivity and the absence of interpreters and interpreted resources are also barriers to service accessibility for families who have emigrated from countries where English is not widely spoken (Lindsay, King, Klassen, Esses, & Stachel, 2012).

#### 7.2 Parent-professional relationships

Findings, barriers and challenges:

- Lack of shared understandings about how professionals and parents can work together
- Professionals' limited understanding of families' circumstances, preferences and concerns
- Professionals judging families and attributing difficulty engaging as lack of motivation
- Professionals not adopting family-centred practices mean families lack information
- Discontinuity in parent-professional communication as children transition from preschool into school
- Organisations' and professionals' low expectations for school and community inclusion

Dodd et al. (2009) described limitations associated with parent-professional relationships, identifying a lack of shared understanding about how professionals and parents can work together as a major obstacle. Professionals' limited understanding of families' circumstances, preferences and concerns can underlie expectations that parents take on responsibility for implementing services while families differ markedly from each other in both capacity and preferences for this role (Dinnebeil, Pretti-Frontczak, & McLnerney, 2009; Dodd et al., 2009; Kargin, 2004). Similarly, Shannon (2004) noted that professionals were apt to pass judgment on families and attribute difficulty engaging as a lack of motivation on the families' part when they lacked the skills to address families' psychosocial issues and build relationships with families with different backgrounds and values to themselves, or were too busy with other families. An experience reported to be felt by parents in Resch et al.'s (2010) focus groups.

Professionals not adopting family-centred practices may result in families lacking needed information (Dodd et al., 2009; Fingerhut et al., 2013). The impact of discontinuity in parent-professional communication was highlighted in two qualitative studies involving detailed investigations of the transitions into and from preschool (Vehkakoski, 2008; Villeneuve et al., 2013).

Vehkakoski (2008) demonstrated that although inclusion was discussed as the first option in transition meetings regarding each of four Finnish children with cochlear implants, the children's eligibility for mainstream preschool and school settings was questioned in a way that required the child be proved deserving of a place based on their development. Combined with discussions about resourcing, this placed readiness for a mainstream placement with the child rather than obligating the educational system to provide accommodations for children with diverse needs. Further, the way in which these matters were discussed resulted in resource issues being accepted as fact without question of the commitment to the principle of inclusion. Given transition meetings were adult-centred and for the most part did not consider the child as a whole being with motivations and emotions, the child's voice and any focus on children's rights (a frame identified in the introduction to this report) was silenced in the discussion during transition meetings (Vehkakoski, 2008).

Villeneuve et al. (2013) added to this less-than-ideal perspective by following three Canadian children with developmental delays through the transition into school. They identified that the formal planning meetings demonstrated the involvement of parents and interprofessional collaboration, but that following this meeting there was limited communication with parents despite ongoing planning and decision making – at times against the agreements reached during the meeting. Each family experienced a "crisis" point as they transitioned from an individualised and family-centred system with frequent contact with providers into an education system where information, supports, and involvement in decision making were lacking. Despite all having older children in school, these parents felt ill equipped to navigate the special education support procedures and while advocating vigorously for their children's inclusion and their own involvement they did not know how to effectively support their children. Similar experiences of continual fights against low expectations for school and community inclusion fitting with human rights was reported by Resch et al. (2010) from focus groups including 40 primary carers of children with disabilities in the United States.

#### 7.3 Lack of coordination and role clarity

Barriers and challenges

- Lack of, or ineffective co-ordination of services
- Lack of shared understandings among professionals
- Lack of availability and clarity about the key worker role
- Key worker or care co-ordinator role not being taken up by professionals, being unofficial, or not recognised or supported by management

Lack of co-ordination of services was a barrier reported by families in a number of studies (Abbott et al., 2005; Carter et al., 2007; Hingley-Jones & Allain, 2008; Resch et al., 2010; Shannon, 2004). Ineffective co-ordination or integration of services had a number of impacts on children and families. These included: difficulty accessing needed services, exclusion of parents from multidisciplinary teams, difficulty gathering relevant professionals around

a child to provide services in school settings (particularly if the professionals were employed by different agencies), confusion about who is part of the team, and family stress that impacts on parent wellbeing (Abbott et al., 2005; Hingley-Jones & Allain, 2008; Resch et al., 2010; Shannon, 2004). Lack of coordination between disability supports and child protection services leads to increased child protection concerns for factors attributable to disability (Shannon, 2004). Professionals imposing middle class values on families living in depressed situations due to their children's disabilities, further generated general mistrust on the part of families towards professionals, thereby reducing utilisation of services (Shannon, 2004). For caregivers, a lack of coordination of services places pressure on the family in terms of time, difficulty filling this need, and the knock-on effects of lack of time, reduced ability to work and participate in activities with family and friends, and increased stress on family relationships and other family members (Resch et al., 2010; Webster et al., 2004). Other ways in which poor integration between different sectors presented a barrier to disability support services included conflicting advice between physicians with a 'wait and see' approach and early intervention approaches, and physicians' lack of knowledge of child development leading to dismissing families' concerns and labelling parents as over-involved or troublesome when concerns persisted (Resch et al., 2010; Shannon, 2004).

Lack of shared understandings among professionals and difficulties negotiating professional identities and role release were also identified as barriers to implementation (Hingley-Jones & Allain, 2008). Lack of clarity about the key worker role was a barrier to more effective service coordination, with few key workers perceived to actually co-ordinate services (Abbott et al., 2005). Also reported was limited availability to families of key workers, particularly on an on-going basis (Carter et al., 2007; Dodd et al., 2009; Hingley-Jones & Allain, 2008; Wilkins et al., 2010). Several authors reported that the key worker or care co-ordinator role was either not fully taken up by professionals or was unofficial and not recognised or supported by management (Carter et al., 2007; Hingley-Jones & Allain, 2008). In a study of the quality of early intervention services across Western Australia, the extent to which under-servicing of key worker services (and those of psychologist, physicians and psychologists) was due to parents not perceiving the need for services or parents experiencing or perceiving barriers to accessing those services (Wilkins et al., 2010).

#### 7.4 Lack of resources and continuity

Barriers and challenges:

- Accessing and sustaining adequate services: fragmentation of services
- Lack of continuity due to high staff turnover and recruitment and retention issues
- Funding restrictions and resource limitations
- Lack of time to address identified family needs and to plan services
- Lack of time for professionals to work together

Walker et al. (2012) identified that among 54 Australian caregivers of children with developmental delay (mostly ASD), the perceived adequacy of support was related to satisfaction. Conversely, as reported in another study (Webster et al., 2004), the pressures of finding and sustaining adequate supports compounded the pressures of raising a child with ASD.

Examining the outcomes and fidelity of occupational therapy services, Bayona et al. (2006) concluded that an insufficient number of school visits, with infrequent and inconsistent visits and insufficient follow up, were barriers to the effective implementation of inclusion-based interventions. These authors reported that teachers had insufficient time to meet with therapists and work on strategies. These barriers were compounded by parents not implementing interventions at home (Bayona et al., 2006). Similarly, Skarbrevik (2005) investigated the quality of educational supports to students in mainstream classes in Norway, finding that both the adequacy and equity of programs was related to the available financial resources and teaching materials as well as grade level, but not to rurality, physical barriers in the school environment, class size (already small in Norway), or severity of disability. However, greater social inclusion was associated with smaller class sizes in the elementary grades, and with less severe disability, but not with resourcing (Skarbrevik, 2005).

Both limitations in the availability of funding and restrictions in the uses to which available funding can be put were frequently cited as barriers to the provision of adequate and effective services. Little attention to the needs of families beyond the needs of their children with disabilities is a common shortfall that was linked by some to pressures to increase the delivery of billable services (Shannon, 2004), as was continually focussing on seeing children and families without allocating time for planning (Ziviani et al., 2013). Further, where funding was linked to the child rather than the service this was also reported to result in professionals making recommendations and withholding information so as to reduce referrals to other services with which they were in competition (Shannon, 2004). At the level of individual families, the cost of accessing services was often identified as a barrier. Further to this general issue, Shannon (2004) highlighted that by limiting the range of billable services (type, number, or duration), funding schemes may remove families and professionals from decision-making or require families to continually advocate for their needs, and that middle-income families may find themselves earning too much to qualify for service subsidies yet not enough to afford to pay for services. For non-government, not-for-profit services, fundraising to subsidise services to families was a time-consuming task and increasingly difficult in tight economic conditions (Ziviani et al., 2013).

Fragmentation of services, lack of resources within organisations, and lack of continuity because of high staff turnover present as persistent barriers (Abbott et al., 2005; Gallagher & Malone, 2005; Greenwald et al., 2006). In an Australian study, difficulties were identified with funding positions, recruiting and retaining staff – particularly in rural areas and for physiotherapists, given pay disparities between this work and other sectors and the lack of career

structure and support – and supporting less experienced staff (Ziviani et al., 2013). Part-time positions were identified as easier to fund and fill, but resulting in timetabling difficulties (Ziviani et al., 2013). Insufficient time for professionals to work together, for example through regular team meetings, was also reported as a common barrier (Cross et al., 2004; Gallagher & Malone, 2005), as was the lack of time to address the needs families identified (Ziviani et al., 2013).

#### 7.5 Service gaps

Barriers and challenges:

- IFSPs focusing primarily on developmental needs of the child with little focus on family issues
- Parents' concerns about children's safety, health needs and home modifications
- Support for financial issues
- Social and emotional support for families or their child with disability
- Limited access to respite facilities, leisure activities and connection to other families
- Lack of accessible housing and public transport
- Parents' lack of knowledge about equipment and assistive technology

A collection of papers identified that gaps in services and systems resulted in poor experiences of children and families with inclusion-based and family-centred services (Abbott et al., 2005; Ridgley & Hallam, 2006; Shahid, 2004), and parents feeling they only had one service option to address their children's needs (Serpentine et al., 2011). Gaps identified by Abbott et al. (2005) included: co-ordination of home modifications; support for financial issues, for example with claiming benefits entitlements; social and emotional support for families or children with disability to have a break or access leisure activities; and limited access to respite facilities.

Ridgley and Hallam (2006) identified similar issues in their study of rural, low income, American families of children with disabilities who were receiving two or more early intervention (0-3) services in the home. Identifying the challenges these families face, and comparing the needs they identified with those included in their IFSPs, the authors surmised that the plans primarily addressed issues related to the developmental needs of the child, many of which the parents did not indicate were concerns, and concerns the families shared in relation to parenting and meeting the developmental needs of their children. The plans rarely addressed family issues such as those identified by Abbott et al. (2005), safety concerns, and transport needs, in only one case touching on financial concerns. While informational needs were to some extent addressed in the plans, generally the plans did not address families' needs for social support including connection with other families. The plans also rarely addressed families' concerns about meeting their children's health needs.

In a survey of the parents of 28 children aged 3-14 with cerebral palsy, 10 occupational therapists and 7 physiotherapists found that the lack of

accessible housing and public transport in London, and perceived difficulty manoeuvring wheelchairs as well a lack of information about benefits was a barrier to the transition from a buggy to wheelchair and therefore independent mobility (Shahid, 2004). Further, while the therapists appeared to have a greater understanding of the issues, parents' lack of knowledge about how a wheelchair may meet their child's needs was a barrier to their seeking this transition.

## 7.6 Inadequacies in intervention design to achieve inclusion-based outcomes

Barriers and challenges

- Parent education interventions not including small group, active skills training
- Lack of attention to generalisation of skills to other settings and communication partners
- Paucity of research providing practice guidelines about implementation of interventions and programs

Studies of parent training interventions suggest that large group seminars that do not include active skills training, though they may be delivered in an inclusive manner with all parents, are possibly of insufficient intensity for parents to independently apply skills in practice (Griffin, Guerin, Sharry, & Drumm, 2010; Tellegen & Sanders, 2013). Conversely, a combination of group training and individual in-home sessions appears to accommodate different learning styles, address individual family needs, and allow the child to be included in the intervention (Griffin et al., 2010; Sharry et al., 2005). Inclusive group parent training that does incorporate skills training was also found to be limited by low levels of engagement of fathers since parenting is associated with mothers, and programs were often held during office hours (Sharry et al., 2005).

Cannella-Malone et al. (2010) implemented a home-based intervention on a one-to-one basis with the child and directly involved a sibling. They noted that a major barrier to achieving meaningful outcomes for the child was a lack of attention to generalisation of skills to other settings and with other peers. Finally, several authors noted the paucity of research providing practice guidelines and the need for more research evaluating programs (Chevignard et al., 2010; Gallagher & Malone, 2005).

# 8 Interventions provided in mainstream settings that are not inclusion-based

We identified a number of studies describing interventions delivered in children's homes, mainstream preschools, or mainstream schools that were *not* inclusion-based. That is, children were segregated during the interventions, and in many cases the interventions appear similar to those

delivered in clinical settings rather than reflecting genuine integration into mainstream settings. These studies are summarised in a table in **Appendix 2**.

Generally these interventions were discipline-specific. Such studies tended to report outcomes in terms of norm-referenced test scores or developmental scales, sometimes with functional or inclusion-based goals. Illustrating the significance of the outcome measures selected, rather than measuring the outcomes per se, Thomas-Stonell, Oddson, Robertson, and Rosenbaum (2009) compared the difficulties noted and gains anticipated and observed by the parents and speech pathologists of 218 Canadian children with communication impairment. At the start of therapy, both parents and therapists expressed concerns about the children's body functions and activity limitations, but parents were twice as likely as therapists to note concerns about the impact of children's communication impairments on participation and personal factors. Parents therefore hoped to see gains from therapy on these areas, while therapists expected gains and therefore set treatment goals most often in relation to body functions and activity limitations. While both parents and therapists noted fewer gains than expected in body functions, twice as many parents and seven times as many therapists noted gains in personal factors as expected. Finally, parents, who were initially more aware of participation restrictions and therefore hoping for change, also noted gains in participation twice as often as therapists.

The table reports the nature of interventions delivered in mainstream settings and yet not inclusion-based that is reported in the literature. The purpose of including this table is to facilitate comparison of studies of this type with those of the interventions described above that are inclusion-based. While meeting the selection criteria with regard to being conducted in mainstream settings, these studies do not directly address the focus of this report on best practice for promoting inclusion, benefits and outcomes of inclusion-based interventions, and factors affecting the implementation of inclusion-based approaches. These papers are therefore not reviewed in detail as are those reported in the previous sections.

### 9 Conclusion and recommendations

In this report, we have reviewed research evidence for the effectiveness of interventions provided *in mainstream settings* for children with disabilities aged 0 to 8 years and their families.

The majority (almost two thirds) of studies that met the inclusion criteria reported on interventions delivered in mainstream settings that were not inclusion-based. There is a paucity of research reporting on/evaluating the effectiveness of inclusion-based approaches. Research is further limited in terms of quality and depth in any given area.

Studies of inclusion-based, team-based interventions provided little detail about *how* to implement these interventions. The research investigating

effectiveness of family-centred practices and team-based interventions has primarily measured family outcomes, such as parental satisfaction, rather than child outcomes. When child outcomes have been measured, these generally have been about attainment of specific skills rather than inclusion or participation at home or in educational or community settings.

The focus of the research has been on developing skills in individual children, rather than on maximising their participation within mainstream settings. The literature contains little description of comprehensive interventions delivered in inclusive settings. For example, there are only a few examples of curriculum, activity-, classroom- or school-based interventions. There is also little information about the effectiveness of interventions facilitating children's participation in inclusive preschool or school settings or in everyday family, community or recreational activities. Similarly, there is little description of the involvement of peers, siblings, teachers, or leaders of community-based recreational activities with young children who have disabilities. The perceptions of these significant others about interventions are also missing from the literature. To date there is limited research evaluating the effectiveness of partnerships or capacity building to enable education or community-based services to be inclusive of young children with disabilities.

Nonetheless, the existing evidence supports the *potential* for these practices to improve outcomes for children and families. Inclusion-based interventions have resulted in children making progress towards goals/across functional skill areas, improving peer acceptance and interaction and participation in educational settings. These interventions have also been associated with benefits for families, typically developing peers, siblings and educators. Home-based interventions in which family-centred practices are implemented seem to improve access to, and satisfaction with, services.

### 9.1 Recommendations for inclusion-based approaches

On the basis of the findings of the current review, more research is required documenting details about the implementation of inclusion-based interventions, in particular multidisciplinary and family-centred practices, and evaluating the impacts of these interventions on the inclusion and participation of children with disabilities. While there has been limited investigation of family-centred practices in school settings. *Epley et al. (2010)* have called for more such research. There is a need for more information about the frequency and duration of interventions required to bring about positive outcomes; the findings of this review have produced no guidelines regarding this component of services.

Despite the paucity of research providing practice guidelines about implementation of interventions and programs, it is possible to distil from the literature some general recommendations for the implementation of inclusion-based approaches.

Some guidelines/general principles for the implementation of inclusion-based approaches to meeting the needs of children aged 0-8 years with disability

and their families have emerged from the findings of studies that have reported benefits and positive outcomes, as well as key factors in the effective provision of these services. These guidelines include the following.

#### 9.1.1 Recommended components of inclusion-based interventions

- The aims of interventions should be to facilitate the inclusion and participation of children
- Interventions should be delivered in children's natural settings and involve the people who are part of the children's lives (e.g., parents, siblings, peers and educators)
- Interventions should be embedded within routines and activities in the home and classroom, utilising naturally occurring opportunities, and including activities chosen by the children
- Interventions should be based on the needs of children, families and their teachers
- Therapists need to support educators and parents to implement interventions – via demonstrations of interventions, practice with feedback and other strategies
- Interventions may also involve typically developing peers and siblings who can be taught to promote communication, social and other skills in children with disability
- Interventions should ensure generalisation of skills to other settings and other people
- Interventions should where possible also involve members of particular communities, such as members of the Deaf community in the use for example, of sign language
- Professionals should evaluate their practices by measuring progress towards functional goals on IFSPs/IEPs and/or measuring impacts of interventions on inclusion and children's participation, for example peer acceptance and interaction
- Interventions may involve some direct individual or small group work in order to teach children specific skills, however these should be based on inclusion outcomes and include typically developing peers
- Parents and teachers of children with disabilities can be included in education programs with parents and teachers of typically developing children.

### 9.1.2 Recommendations for the development of teamwork and collaboration

- Professionals need to collaborate with parents, teachers, teacher assistants and others in planning/developing, choosing and implementing interventions
- The development of teamwork appears to be a facilitator of inclusion-based approaches: professionals from different disciplines should work according to interdisciplinary and transdisciplinary models. As Hingley-Jones and Allain (2008) indicated, service providers need to collaborate effectively so that families are not inundated with a host of professionals and subjected to the stress caused by fragmented services

- IFSPs or IEPs should be developed for each child and their family, to guide team work for the professionals who are configured around a child. Each team member should be responsible for implementing plans
- Teams should have regular team meetings to monitor progress of implementation and develop solutions to barriers and challenges in implementation as they arise
- The utilisation of therapy assistants who bring experience working in communities facilitates implementation of collaborative and transdiciplinary implementation of inclusion-based approaches.

### 9.1.3 Recommendations for inclusion-based, family-centred practices

- Service providers need to ensure that services address and fit with family concerns and priorities
- Families should be full members of teams that form around their children involved in decision-making; in identifying goals and target behaviours, and deciding on intervention opportunities (activities and situations)
- Services need to address family outcomes as well as child outcomes, by addressing parents' needs and focusing on promoting parenting competence in order to reduce parental stress
- Professionals need to provide general information to families about community based supports and services
- Interventions are required to facilitate transition from preschool to school
- Co-ordination and facilitation of services is crucial (both across disciplines and organisations) for families of children with disabilities. The implementation of effective key worker roles is recommended to achieve this objective. Key workers should undertake a number of tasks, including: collaborating with families to identify needs for services and support and set goals; guide families' access to services; coordinate the involvement of other professionals and access to other services; facilitate access to equipment, resources, and training that enables the child to participate at home and school; provide families with support with meetings, preparation of reports, and ongoing emotional support
- Parent education programs need to include home visits and address individual needs of parents and children, and they can be delivered exclusively in the home
- Service providers need to ensure flexible service delivery, a wide range of available services, and early intervention. Professionals need to exercise flexibility in how families' priorities and needs are addressed and how input is provided to assist families to implement strategies.

### 9.1.4 Recommendations for the delivery of inclusion-based approaches in preschool and school settings

- Interventions should be embedded within preschool or school curricula
- Interventions can involve building the capacity of educators to include children with disabilities/teach skills to all children

- Professionals can collaborate with educators on specific support strategies/developing educational, communication and social supports. These may include: differentiation of curriculum, activities and materials; implementation of assistive technology, such as low tech communication boards; promotion of small group interaction; and implementing a buddy system. The implementation and effectiveness of such supports in facilitating inclusion should be evaluated
- Professionals can also collaborate with educators to analyse task and environmental demands and make modifications in preschool and school classrooms and in the environments beyond the classroom, in order to facilitate the participation and inclusion of children with disability
- Education programs for teachers and teacher assistants should be conducted at school, be specifically tailored to each school's needs, and involve in-classroom mentoring
- Parents should be included as part of teams delivering interventions in preschools or schools.

## 9.2 General suggestions for overcoming identified barriers

Several barriers exist to the implementation of inclusion-based services. These include: (i) the diverse and complex needs of individual families, (ii) difficulties in parent-professional relationships, (iii) lack of co-ordination of services and lack of role clarity, (iv) lack of resources and continuity, (v) service gaps, and (vi) inadequacies in intervention designs to achieve inclusion.

Presented below is a discussion of strategies for overcoming these barriers.

- (i) With regards the diverse and complex needs of individual families, professionals can develop an appreciation of the complex circumstances, preferences and concerns of individual families, and that these may influence individual families' capacity to participate in interventions. Professionals will need to be supported/given adequate time to build relationships with families and acquire skills for meeting the complex psychosocial needs of families. In addition, professionals need to be supported to build cultural sensitivity, and have access to interpreters and interpreted materials.
- (ii) With regard difficulties in parent-professional relationships, processes may need to be implemented that enable professionals and families to negotiate shared understandings about how they can work together. It appears to be important that professionals avoid automatically expecting families to assume responsibility for implementing interventions and avoid judging families who appear to have difficulties engaging with services as these may be due to broader circumstances. The adoption of familycentred practices, as discussed previously, is an important strategy for

- preventing potential and overcoming actual difficulties. Professionals can also support families to advocate for the child's inclusive education.
- (iii) With regards to the lack of co-ordination of services and lack of role clarity; recommendations discussed previously about the co-ordination and facilitation of services, apply to overcoming these particular barriers. Further, support is required at the organisational level for the key worker role. This role needs to be adequately funded and made available to families on an ongoing basis. Finally, as with parent-professional relationships, processes may need to be implemented that enable development of shared understandings among professionals from different disciplines about roles and ways of working within a transdisciplinary model.
- (iv) With regards to lack of resources and continuity, several recommendations are made in the literature pertaining to organisational change. These include the adoption of supportive policy, adequate funding, and infrastructure support for inclusion-based approaches. It is viewed as crucial that practices and activities supporting inclusion-based services are embedded in the organisation rather than viewed as distinct projects. Recommendations also include ensuring that professionals' caseloads and referral processes enable them to implement inclusionbased, family-centred interventions, and work as part of teams. Organisations have a role to play in supporting professionals, particularly if they work across agencies, to adopt the philosophy and practices of family-centred, team-based service provision. These include preparation for new transdisciplinary and consultation roles in addition to direct and indirect therapy. Access to continuing professional development is emphasised. Finally, organisations need to adopt measurable indicators of implementation of inclusion-based approaches, and there is a role for a peak body in supporting consistency in implementation across agencies of policies promoting inclusion-based services.
- (v) With regard to service gaps, there is a need for organisations to support professionals to take a broad, holistic focus on family needs/issues, so that they are able to assist families with accessing: home modifications, support with financial issues, social and emotional support, respite, housing, transport, and equipment for their child's participation and inclusion.
- (vi) Finally, inadequacies in intervention designs to achieve inclusion have been addressed in detail within recommendations for inclusion-based approaches outlined above.

Based on the literature reviewed in this report, we hope that these guidelines for inclusion-based interventions, and the suggestions for overcoming barriers to their effective implementation may be useful for managers, professionals,

families and other members of the community to consider in the move towards provision of supports for children 0-8 years with disability and their families that are aligned with current legislation and policy.

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Note: References not identified in the systematic review (i.e. background materials and secondary references) are indicated in this list with an asterix (\*).

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# 11 Appendix 1 – Approach to the systematic review

The primary data informing this report were gathered through a systematic review of the literature with database searches conducted from December 2013 to January 2014. The aims of the systematic review were to examine the existing evidence addressing three questions nominated by ADHC:

- 1. What are the benefits and outcomes for children with disability and their families when clinical supports are delivered and incorporated into the child's and family's mainstream settings?
- 2. What are the key factors and elements in the effective provision of clinical supports for children with disability and their families in mainstream settings?
- 3. What are some of the barriers/challenges to the effective provision of clinical supports to children with disability and their families in mainstream settings and how can these be overcome?

#### 11.1 Selection criteria

Publications that met the following criteria were included in the review:
(a) publication date between 1/1/2004 and 31/12/2013 inclusive; (b) English-language publication; (c) peer-reviewed full paper including journal articles or conference proceedings (full papers) reporting primary research material or reviewing and critiquing secondary sources from the peer-reviewed literature; (d) age of children in the range 0 to 8 years; (e) including children with disability, their families, educators and/or significant others in the community; (f) services provided in mainstream settings; and (g) services among the included interventions, those being therapy (speech pathology, occupational therapy, physiotherapy), psychology, behaviour support, dietetics, therapy support (by therapy assistants known by many titles) and/or case management. It was decided prior to starting the review to give strong preference to publications that described multidisciplinary, interdisciplinary and transdisciplinary approaches to service delivery.

### 11.2 Search procedures

To locate all publications that met the selection criteria, a search strategy was designed that favoured sensitivity over specificity (i.e., erred toward being sensitive to identify *all* of the relevant publications rather than specific to identify *only* the relevant publications). Searches were conducted in six databases: AMED, CINAHL, ERIC, Medline, PsycINFO, and Social Work Abstracts. Relevant papers from identified systematic reviews were also examined individually if appropriate and reported in the context of this review. Searches were conducted using keywords reflecting population, setting, intervention and approach, which were then combined to identify relevant publications. *Population keywords* included variants on disability, child, family, caregiver, teacher, and child care provider. Where available, database limiters

were used to include papers relating to children in the target age range. Setting keywords included variants on inclusion, mainstream, school, child day care, community, and home. Intervention keywords included variants on early intervention, prevention, therapy, and each of the disciplines identified in selection criterion (e). Approach keywords included variants on multidisciplinary, interdisciplinary, transdisciplinary, person-centred, family-centred and best practice. The actual search terms used were individualised to each database, mapped against the respective database subject headings and sub-headings where possible.

A total of 1809 unique abstracts were identified from the six databases. The flow of publications to reduce those to the papers cited in this report is illustrated in **Figure 1** and detailed below.

#### 11.3 Screening and analysis procedures

Results from the six databases were combined and duplicates removed. All titles and abstracts were then screened against the selection criteria by at least one of two report authors who were involved in abstract screening and data extraction (TDB and JB). Any publication not able to be clearly excluded based on the title and abstract was retrieved in full to gather further information to determine inclusion.

Initially both of the report authors involved in screening abstracts processed at least 100 abstracts each, including overlapping titles, before coming together to clarify interpretations of the inclusion criteria and check agreement on individual titles. Throughout the screening of the remaining abstracts these authors regularly discussed progress, resolving any uncertainties and identifying emerging themes. Any issues that could not be resolved between the two screening authors were discussed among the whole research team. Papers meeting the inclusion criteria (i.e., describing interventions of interest delivered to the target population in mainstream settings) were retrieved in full for analysis and reporting. Data was extracted including study design and methodology; approach to service delivery; participants; settings; outcome measures and results; and authors' conclusions and recommendations. Papers were analysed to identify if they reported inclusion-based approaches to intervention in mainstream settings. Papers reporting inclusion-based approaches (i.e., embedded within routines or activities and including significant others in children's lives) were "core papers" eligible for reporting in Section 5 if they described benefits and outcomes for children and families and Section 6 if they described key factors or barriers/challenges to effective implementation. Papers reporting interventions in mainstream settings that were not inclusion-based were briefly reported as "contrast papers" in Section 8. Finally, and in the absence of clear best practice emerging from the literature reporting benefits and outcomes, papers describing inclusion-based approaches but not directly addressing the questions in Sections 5 and 6 were reviewed to identify what the peer reviewed literature describes as best practice. These papers were selectively discussed in Section 4.

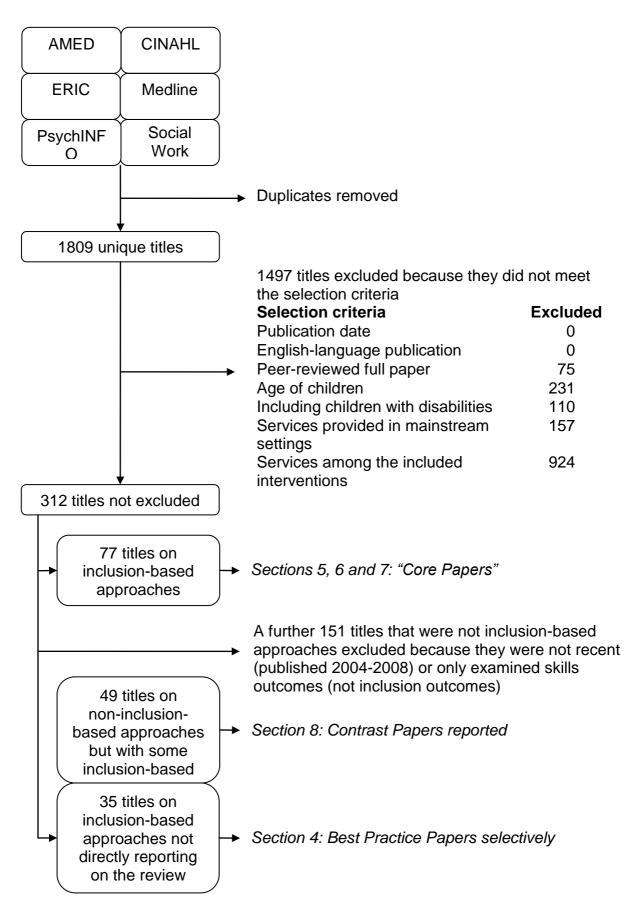


Figure 1: Flow of papers in the systematic review

# 12 Appendix 2 – Interventions provided in mainstream settings that are not inclusion-based

Nature of Intervention	Outcome Measures	Outcomes (numbers correspond right)	References
Parent-Mediated Interventions Individual programs in which the parent is trained, according to a consistent staged program, to support the child's skill development and to be warm and responsive to child-directed interactions and clear and consistent in parent-directed interactions. These may be combined with sessions to address parents' stress and issues associated with raising a child with a disability and behavioural issues.	Observations of Parent and Child Interactions  • Dyadic Parent-Child Interaction Coding System III  • Child's response to bids for joint attention  • Responsive parental communication rating  Child Behaviour and Child Development  • Child Behaviour Checklist  • Child Behavior Rating Scale  • Eyberg Child Behaviour Inventory  • Mullen Scales of Early Learning  • Scales of Independent Behavior-Revised  • Total number of communication turns  Parent Outcomes  • Depression Anxiety Stress Scale  • Maternal Behavior Rating Scale  • Parent Stress Index  • Parent Practices Scale  • Parent Problem Checklist  Satisfaction and Process Measures  • Satisfaction survey  • Semi-structured interview  Technical measures of website use and interactions	<ul> <li>Target parent behaviours improved in many cases (1,4,9,10), and were maintained (9), but in one study parent responsiveness toward their children increased only for parents classified as insightful of their child / relationship (8)</li> <li>Parent-mediated interventions resulted in increased practice of skills (2) and parents expressed satisfaction with coaching (3)</li> <li>There was a trend toward improved child behaviour / independence (5,7,9, 10), and parent stress (6,9), in small studies, but larger studies are needed</li> <li>Children displayed increases in the number of different concepts that they expressed following their parents being taught to implement targeted communication partner interaction strategy (6)</li> <li>Children with lower baseline language skills benefitted more, suggesting those with greater language skills may require different strategies to benefit (8)</li> <li>Online parent training was rated positively by parents (9)</li> </ul>	1. Colyvas, Sawyer, and Campbell (2010) 2. Dirks, Blauw-Hospers, Hulshof, and Hadders-Algra (2011) 3. Foster, Dunn, and Lawson (2013) 4. Galanter et al. (2012) 5. Karaaslan, Diken, and Mahoney (2013) 6. Kent-Walsh, Binger, and Hasham (2010) 7. Kierfeld, Ise, Hanisch, Görtz-Dorten, and Döpfner (2013) 8. Siller, Hutman, and Sigman (2013) 9. Wade, Oberjohn, Burkhardt, and Greenberg (2009) 10. Welterlin, Turner-Brown, Harris, Mesibov, and Delmolino (2012)

Nature of Intervention	Outcome Measures	Outcomes (numbers correspond right)	References
Behaviour Interventions A prescribed curriculum or program, often based on developmental progression, is delivered by the therapist (or in some cases trained volunteers) on a one-to-one basis with the child. Programs may be documented in a manual. Children are often seated at a table with the therapist in an environment designed to minimise distraction and with access only to the prescribed program materials.	Child Behaviour and Social Competence  • Adaptive Social Behavior Inventory  • Attention measure: Continuous Performance Test (CPT)  • Child Behavior Problem Checklist (CBCL/2-3)  • Flexibility measure: Wisconsin Card Sorting Test (WCST)  • Measure of interference control: Stroop test  • School Speech Questionnaire  • Working Memory Sentences (WMS)  Child Development  • Bayley Scales of Infant Development: Mental Development Scale, Developmental Language Scale  • Receptive and Expressive Language Scale-2 (REEL-2)  • WISC-R, Inverse Digits subtest	<ul> <li>Individualised interventions based on teachers' trial-based functional analyses of behaviour were effective to reduce problem behaviour and increase adaptive behaviour alternatives (1,5)</li> <li>Long term behavioural interventions in mainstream preschools and schools resulted in improvements in cognitive and adaptive behaviour functioning for children with autism (2,4) and particularly for children with intellectual disability (3)</li> <li>A 6-month, module-based intervention conducted in the home and preschool for children with selective mutism resulted in all speaking in preschool (7)</li> <li>Intensive behaviour treatment (IBT) for preschool aged children with ASD produced positive child outcomes, however because of methodological limitations there is limited support for intervention in a variety of settings (8)</li> <li>Teaching of self-regulation strategies over 16 sessions to children with ADHD, in conjunction with parent and teacher education about behaviour modification techniques, produced significant effects on attention and a number of cognitive tasks as well as improved parent and teacher ratings of task performance (6)</li> </ul>	1. Bloom, Lambert, Dayton, and Samaha (2013) 2. Eldevik, Hastings, Jahr, and Hughes (2012) 3. Eldevik, Jahr, Eikeseth, Hastings, and Hughes (2010) 4. C. F. Grindle et al. (2012) 5. Haley, Heick, and Luiselli (2010) 6. Miranda, Presentación, Siegenthaler, and Jara (2013) 7. Oerbeck, Johansen, Lundahl, and Kristensen (2012) 8. Odom, Hume, Boyd, and Stabel (2012)

Nature of Intervention	Outcome Measures	Outcomes (numbers correspond right)	References
Parent Education Groups Parent training programs were often based on a manual or prescribed curriculum with written group session outlines in checklist form. Parents	Outcome Measures  Child Behaviour and Child Development  Behavioral Pediatrics Feeding Assessment Scale  Behavior Intervention Rating Scale  Child Behaviour Checklist / Teacher Report Form  Conner's Parent / Teacher Rating Scales Revised	Outcomes (numbers correspond right)     Child behaviour/development improved (4,7), where parents completed and adhered to the intervention (2,3,10,12)     Interventions with parents as well as directly with children provided the best	<ol> <li>Case-Smith (2013)<sup>b</sup></li> <li>Fernandez, Butler, and Eyberg (2011)</li> <li>Ingersoll and Wainer</li> </ol>
were given information about child development and taught general skills for facilitating their child's development. Goals tend to be determined from developmental checklists. Home visits were aimed at teaching parents to implement these strategies at home.	<ul> <li>Conner's Parent / Teacher Rating Scales Revised</li> <li>Developmental Behaviour Checklist</li> <li>Difficult Behaviour Assessment Form</li> <li>Eyberg Child Behavior Inventory</li> <li>Goal Attainment Scaling (GAS)</li> <li>Peabody Picture Vocabulary Test</li> <li>Social-Communication Checklist</li> <li>Social Skills Rating System Parent/Teacher Form</li> <li>Target behaviour count (individualised)</li> <li>Unpublished Likert scales (parent reported importance, outcomes, and self-efficacy)</li> <li>Vineland Adaptive Behavior Scales-Expressive Language scale</li> <li>Parent Outcome</li> <li>Beck Depression Inventory</li> <li>Coping Styles Questionnaire</li> <li>Depression, Anxiety and Stress Scale</li> <li>General Health Questionnaire</li> <li>Observational checklist (individualised)</li> <li>Parenting Hassles Scale</li> <li>Parenting Sense of Competence Scale</li> <li>Parenting Stress Index Short Form</li> </ul> Family Empowerment and Efficacy	family and child outcomes (12)  Participation in the Triple P resulted in positive child and parent outcomes (4)  Participation of both parents resulted in enhanced outcomes for mothers when compared to mothers who participated alone, in terms of stress, confidence in managing their child's behaviour and overall ratings of their child's behaviour problems (5,6)  Parent attrition is significant and may be related to parent stress (2,10)  Parents were satisfied but desired more individual attention despite gains on both standardised and individualised measures (8)  Groups improved parent outcomes, including increasing the use of problemrather than emotion-focused coping strategies, by enabling informal support and empowerment (11)  Following Pivotal Response Training (7) and Parent Responsivity Training (9) preschool-aged children used more words and language in everyday	(2013) 4. Leung, Fan, and Sanders (2013) 5. Matson, Mahan, and LoVullo (2009) 6. May et al. (2013) 7. Minjarez, Williams, Mercier, and Hardan (2011) 8. Owen et al. (2012) 9. Paul, Campbell, Gilbert, and Tsiouri (2013) 10. Rinald and Mirenda (2012) 11. Samadi, McConkey, and Kelly (2013) 12. Springer and Reddy (2010)
	<ul> <li>Family Empowerment Scale Family Functioning</li> <li>Family Screening Form and Family Efficacy Scale</li> </ul>	situations, with effects maintained(9)	

Nature of Intervention	Outcome Measures	Outcomes (numbers correspond right)	References
Teacher Education A training package to develop mainstream classroom teachers' knowledge of disability they may encounter with children in their classrooms. The purpose of the training is to address basic knowledge in order to bridge the gap in understanding and terminology between health and educational professionals.	Knowledge  • Unpublished, training-specific knowledge questionnaire	Training increased basic knowledge and the improvements in knowledge were largely maintained	Rae, McKenzie, and Murray (2011)
Therapeutic Groups Group interventions conducted in community facilities and involving recreational activities, such as horse riding and ice skating. Groups are comprised only of children with disabilities.	<ul> <li>Parental satisfaction questionnaire (1)</li> <li>A systematic review (2) noted outcomes were recorded using various posture, balance and dynamic reach measures including standardised scales and measures from video and photographs</li> </ul>	<ul> <li>Ice skating lessons resulted in perceived improvements in balance and lower limb strength (1)</li> <li>Hippotherapy or therapeutic horseback riding resulted in improvements to the postural control and balance of children with cerebral palsy (2)</li> </ul>	<ol> <li>Fragala-Pinkham, Dumas, Boyce, Peters, and Haley (2009)</li> <li>Zadnikar and Kastrin (2011)<sup>b</sup></li> </ol>
Cognitive Skills-based Intervention The "Instrumental Enrichment Basic" program delivered on a one-to-one basis	<ul> <li>Raven Coloured Matrices</li> <li>Weschler Intelligence Scale for Children (WISC-R) sub-tests</li> </ul>	Variable outcomes in cognitive skills in children, attributed partly to the heterogeneity of the group studied	Kozulin et al. (2010)

Nature of Intervention	Outcome Measures	Outcomes (numbers correspond right)	References
Communication Interventions Interventions based on focused stimulation in which children are taught to comprehend or produce targeted articulation or language structures based on checklists of typical language development. The focus of intervention may be, for example, on modelling single word utterances and encouraging the child to imitate these. The next step in intervention is then to combine two words into an utterance. For children with more developed language skills, the focus is on the expression of more complex ideas verbally or using augmented communication.	Child Language / Communication Development  • Clinical Evaluation of Language Fundamentals – 4  • Communication and Symbolic Behavior Scales  • Expressive One-word Picture Vocabulary Test  • Illinois Test of Psycholinguistic Abilities  • Peabody Picture Vocabulary Test  • Preschool Language Scales – 3  • Reynell Developmental Language Scales  • Sequenced Inventory of Communication Development  • Systematic Analysis of Language Transcripts  Narrative and Complex Language Measures  • Coding of transcribed speech for linguistic complexity and story complexity  • Narrative Assessment Profile  • Functional Communication Measures  Child Development and Child Behaviour  • Battelle Developmental Inventory  • Mullen Scales of Early Learning  • Vineland Adaptive Behavior Scales	<ul> <li>Focused intervention led to improvements in performance on standardised measures of language and communication (1,9), and for many children in one study also on broader developmental indicators of function (9)</li> <li>Computer assisted intervention resulted in increased recognition of Picture Communication Symbols (2), however providing communication devices without ongoing collaboration with families results in negative outcomes (5)</li> <li>Achievement of communication goals on children's IEPs were similar for those receiving a speech and language therapy service via telepractice than for those receiving a direct intervention (3)</li> <li>The use of augmented communication with parent training led to increases in vocabulary (7)</li> <li>Children's abilities to express personal narratives using augmentative and alternative communication improved with structured intervention (8)</li> <li>Therapist delivered play-based intervention resulted in a significant increase in the number of words used by preschool age children (9)</li> </ul>	1. Cable and Domsch (2011) <sup>b</sup> 2. Fujisawa, Inoue, Yamana, and Hayashi (2011) 3. Gabel, Grogan-Johnson, Alvares, Bechstein, and Taylor (2013) 4. Joginder Singh, Iacono, and Gray (2011) 5. Lussier-Desrochers, Dionne, and Laforest (2011) 6. Paul et al. (2013) 7. Romski et al. (2010) 8. Soto, Solomon-Rice, and Caputo (2009) 9. Tsiouri, Simmons, and Paul (2012)

Nature of Intervention	Outcome Measures	Outcomes (numbers correspond right)	References
Aids to Daily Living			
Provision of commercially available adaptive equipment to support the everyday functioning of children with physical disability.	<ul> <li>Activity Performance</li> <li>Canadian Occupational Performance Measure, modified to measure activity performance</li> <li>Unpublished Home Activity Log Interview</li> <li>Family Outcomes</li> <li>Family Impact of Assistive Technology Scale (FIATS)</li> <li>Impact on Family Scale (IFS)</li> </ul>	<ul> <li>Supportive seating devices improved performance and satisfaction in seated self-care and play / school activities parents identified as priorities, with a non-significant trend for a small number of social / quiet recreation activities (1)</li> <li>The devices did not meet all needs and some children refused them (1,2)</li> <li>Family outcomes on the FIATS were significantly improved with the seating devices, but not IFS outcomes (2)</li> </ul>	1. Rigby, Ryan, and Campbell (2009) <sup>c</sup> 2. Ryan et al. (2009) <sup>c</sup>
Occupational Therapy An individually goal-directed, multimodal intervention developed in conjunction with parents and following visits to both home and school, for parents to administer at home with regular guidance and feedback. The program is adapted to address parents' priorities, and interventions may include child activities, environmental modifications, or the use of assistive devices.	<ul> <li>Motor Skills</li> <li>Bruininks-Oseretsky Test of Motor Proficiency 2</li> <li>Gross Motor Function Classification System</li> <li>Pediatric Evaluation of Disability Inventory</li> <li>Goal Attainment Scaling</li> <li>Occupational Performance and Participation</li> <li>Canadian Occupational Performance Measure</li> <li>Children's Assessment of Participation and Enjoyment</li> </ul>	<ul> <li>Goal-directed, functional therapy delivered in a preschool setting or within the context of daily activities resulted in improved motor function (1,2)</li> <li>Intervention resulted in moderate to large improvements in occupational performance and satisfaction, finemotor and manual coordination, and participation diversity and intensity. No such improvements were seen in body coordination, strength and agility, or enjoyment (3).</li> </ul>	1. Law et al. (2011) 2. Lowing, Bexelius, and Carlberg (2009) 3. Wuang, Ho, and Su (2013)