

Literature review - Early psychological interventions for infants and toddlers with disabilities

Dr. Miri Keren¹

Shir Maayan Ziv²

Introduction

Developmental disabilities are a wide range of intellectual and physical delays and handicaps which interfere with typical development (Hsieh, 2008; Matson, Cooper, Malone, & Moskow, 2008; Mitchell & Hauser-Cram, 2008). These problems are pervasive and have a detrimental impact on the development of independent living skills, socialization and psychosocial adjustment, as well as school performance. One of the primary factors associated with these delays, which further compound and complicate normal development, are co-occurring problems such as social deficits, challenging behaviors, and psychopathology (depression, anxiety, chronic anger, poor self-esteem) (Agaliotis & Kalyva, 2008; Myrbakk & von Tetzchner, 2008; Ringdahl, Call, Mews, Boelter, & Christensen, 2008). Without proper diagnosis and treatment these difficulties tend to persist and intensify, and they can have a lifetime course (Lifshitz, Merrick, & Morad, 2008).

Well-grounded data indicates that comprehensive early intervention programs can, at minimum, help prevent the substantial decline in intellectual development that generally occurs across the early childhood period for children with developmental delays (Guralnick 2005). Moreover, both developmental and intervention studies have suggested that benefits to children's social and cognitive competence are the direct result of enhancing developmental influences on children's outcomes related to various components associated with parent-child interactions (e.g. socioemotional

¹ Child and Adolescent Psychiatrist

² MA, Developmental Psychologist

connectedness), family-orchestrated child experiences (e.g. community participation; inclusive preschool) and children's health and safety (e.g. preventive health) (Guralnick 2011). These three major areas of influence on child competencies are also influenced by the family's resources including the personal characteristics of the parents (e.g. coping style, mental and physical health) and material resources (e.g. financial resources, social support).

Although all the above are significant issues for children with special needs, but attention to the specific age range of the first five years is very scarce, which may reflect a concerning lack of awareness of the close link between mental health and brain development that is its peak in the first three years of life. It is true also on the long run, as these children, in later years, have been shown to be at risk for bullying and social exclusion and lack of social support (Lindsay & McPherson, 2012), leading to heightened risk of anxiety, depression and lower quality of life (Gini & Pozzoli 2009).

Co-morbidity is more the rule than not

To date, most of the focus has been on identifying symptoms of a primary disorder without focusing on comorbid disorders, that require therapeutic attention if one wants to improve the overall prognosis of the child. (Matson, Fodstad, & Mahan, 2009).

For example, in a study of 651 toddlers between the ages of 17- and 37-months with neurodevelopmental disorders, some 16% of them had significant eating and sleeping problems (Matson, Fodstad, & Mahan, 2009). This finding is consistent with data suggesting that neurodevelopmental disorders can affect the young child's general functioning (Goldman, Malow, Newman, Roof, & Dykens, 2009). Furthermore, these problems have been shown to persist without treatment (Lancioni, O'Reilly, & Basil, 1999). Also found in this study is that inattention/impulsivity and tantrums/ behavior problems were common (Matson, Fodstad, & Mahan, 2009). All these are obviously a major stressor for parents and impinge on their family relationships and functioning (Emerson, 2003; Kiernan & Alborz, 1995).

As presented above, children and adults with intellectual and other developmental disabilities are more likely to be diagnosed with a severe behavior disorder or mental health diagnosis than are their typically developing counterparts (Emerson, 2003). This dual diagnosis of cognitive and behavioral impairments places additional strain on parents and teachers (Baker, McIntyre, Blacher, Crnic, Edelbrock, & Low, 2003; McIntyre, Blacher, & Baker, 2006) and may be overlooked or underreported by health care providers (Levitan & Reiss, 1983). Furthermore, children with developmental disabilities and behavior or mental health disorders are at greater risk for difficulties in school; are more likely to be placed in out-of-home residential care; and, as adults, are more likely to have problems in the workplace (Borthwick-Duffy & Eyman, 1990; McIntyre, Blacher, & Baker, 2002; Taanila, Ebeling, Heikura, & Järvelin, 2003). Recent research using well-established measures has revealed that many of these behavioral problems emerge in various forms and are detectable even during the preschool years (3–5 years old). In general, young children with intellectual delays (IQ range 30–85) exhibit a range of internalizing and externalizing disorders to a much greater extent than a comparable group of children without delays, with approximately 25% of children with delays meeting criteria indicating a significant clinical concern (Baker, Blacher, Crnic, & Edelbrock, 2002; Baker et al., 2003). Stability of behavior problems between 3 and 4 years of age was also evident (Baker et al., 2003)

The importance of early psychological interventions

National Academy of Sciences task force on the science of early development concluded that experiences during the first 3 years of life exert a powerful influence on future development (Bombard, Miller, Hayeems, Avard, & Knoppers, 2010). Mental retardation and most developmental disabilities are, by definition, disorders of the brain, and impact on the young child's responses to environmental stimuli and experiences (Andermann, Blancquaert, & Déry, 2010). Major literature reviews conclude that high-quality early intervention can influence the development of children with disabilities, with impressive effect sizes ranging from 0.40 to 0.75.^{21–24} Positive effects of early developmental

intervention have generally been shown for children with mental retardation and developmental disability, irrespective of etiology or severity (Bailey, Skinner, & Warren, 2005)

The Program for Infants and Toddlers with Disabilities (Part C of the Individuals with Disabilities Education Act of American legislation [IDEA]) provides funding to states to operate comprehensive statewide programs of early developmental intervention services for infants and toddlers (birth through age 2) with developmental delays and disabilities and for their families. Congress established the program in 1986 in recognition of "an urgent and substantial need" to: a) Enhance the development of infants and toddlers with disabilities. B) Reduce educational costs by minimizing the need for subsequent special education as a result of early Intervention. C) Minimize the likelihood of institutionalization and maximize independent living. D) Enhance the capacity of families to meet their children's needs. The federal law was grounded in a substantial body of research that demonstrated the power and necessity of providing intervention services to children with disabilities and developmental delays at young ages and to their families (Hebbeler, Spiker, Bailey, Scarborough, Mallik, Simeonsson, & Nelson, 2007).

Effects on the child and his or her family

The information presented above highlights the importance of early childhood intervention, but it lacks deficiency in addressing young children's mental states and the development of the young children's emotional development and coping.

An important theme for children with developmental disabilities is pain. Yamaguchi et al. (2014) suggest that pain intensity and pain anxiety may have strong associations with emotional and behavioral problems among children with CP. However, in studies reviewed there was little focus on how different levels of the Gross Motor Function Classification System functioning might influence youths' experiences of living with CP (Lindsay, 2016)

Furthermore, the high prevalence of challenging behavior and mental health problems among children with developmental disabilities attests to the importance of adopting a

socio-emotional perspective in examining children with developmental disabilities (Dykens, 2000; Schuengel & Janssen, 2006). Issues like affect regulation, social competences, and sense of autonomy may all be of significant importance to the adjustment of people with developmental disabilities to the everyday world (Schuengel & Janssen, 2006), and may matter even more for children with developmental disabilities than for typically developing children (Baker, Fenning, Crnic, Baker, & Blacher, 2007)

The effects on the lives of young children with developmental disabilities are many and varied. They affect his relationship with his parents and his peers, his mental state and his self-concept and more. We will discuss all of these in this review.

Parents

The needs of a family of children with CP and other developmental disabilities are different depending on the level of the child's functional ability (Wood, & Rosenbaum, 2000). Children with severe disabilities or highly dependent group, require additional health care resources, higher cost of medications, and are presented with more frequent medical problems than those with lower level of disabilities (Liptak et al., 2001). Previous studies showed that the family of children with CP who are severely disabled are more likely to have greater needs than family with less disabled children (Almasri, Palisano, Dunst, Chiarello, O'Neil, & Polansky, 2011; Bertule, & Vetra, 2014; Palisano, Almars, Chiarello, Orlin, Bagley, & Maggs, 2010).

A dramatic shift in care responsibilities for families occurs with the corresponding increase in numbers of children with complex care needs living at home. Mothers as well as fathers provided a picture of intense parenting that worked best within a tag team scenario in which parents take turns carrying out the necessary duties related to caring for their child with complex care needs (Woodgate, Edwards, & Ripat, 2012). In this case, it is important to note that parents caring for children with a disability are at greater risk of poorer physical and psychological health than parents of children without disabilities (Dillon-Wallace, McDonagh, & Fordham, 2014; Gallagher & Whiteley, 2013; Singer, 2006) and experience higher rates of chronic stress, fatigue, chronic back pain and obesity,

depression, and chronic sleep problems (Bourke-Taylor, Howie, Law, & Pallant, 2012; Brehaut et al., 2004; Gallagher & Hannigan, 2014)

Like the children, there is a significant impact on parents' mental state in dealing with raising a child with physical or mental disabilities. Dealing with the diagnosis of illness or disability can be a struggle for parents. Parents must come to accept the realities of the changes that will occur. In doing so, many parents come to understand the importance of being an advocate for their child with complex care needs (Churchill, Villareale, Monaghan, Sharp, & Kieckhefer, 2010; Levine, 2005). In the process of advocating for their children, parents became assertive, working hard to get their children the services needed and making sure they are accepted in their society (Levine, 2005). Parents shared that they had to develop courage and learn to stand up for their child in difficult situations.

Research consistently shows that mothers of children with a disability have greater levels of depression compared with mothers of typically developing children, although the figures vary widely depending on the size of the sample and measure of depression (Bailey, Golden, Roberts, & Ford, 2007; Singer, 2006)

In an Australian study examining coping with mothers of children with special needs it was found that mothers of children with a disability in this study reported high rates of distress, depression, anxiety, and suicidality. There was a high perceived need for professional mental health support, which many did not access. Mothers reported common barriers that prevented them accessing support, and there was a strong preference for individual counselling. Mothers wanted mental health support at the time of their child's diagnosis and medical intervention (Gilson, Davis, Johnson, Gains, Reddihough, & Williams, 2018). Their results are consistent with those reported in the existing literature. For example, in a sample of 99 mothers of children with intellectual disability in Pakistan, 35% met criteria for anxiety and 45% for depression (Azeem et al., 2013). Furthermore, in Sweden, Olsson and Hwang (2001) found 45% of mothers of children with intellectual disability and 50% of mothers of children with ASD had depression. Although 75% of mothers perceived a need for support, 42% of those had

not attempted to access this. The main reported barrier to accessing support was caregiving responsibilities that made it difficult to schedule appointments. More accessible forms of treatment are needed for mothers of children with a disability. Another reason is the mother's belief that the problem was not severe enough, preferring to manage alone and thinking that nothing could help. These results indicate the need to increase mothers' knowledge about mental health problems and benefits of mental health treatment and the effect of their mental state on their child (Gilson et al., 2018). Additionally, most parents are also not comfortable to seek help because of social stigma (Vogel, Wester, & Larson, 2007), whereby these parents suffer from low self-esteem and are anxious of being judged negatively, which consequently became a barrier to treatment (Cantwell, Muldoon, & Gallagher, 2015). In a study examining parents' coping with highly dependent children with CP, parents reported that their need in explaining the child's condition to family members and other children was contented although challenging. However, the need in explaining the condition to strangers was not attained (Nordin, Azlin, Hui Shan, & Zanudin, 2019). There are parents who claimed that they initially felt ashamed, and this may be due to the concern of being rejected by the society due to the stigma associated with children with disability (McCabe, 2007).

The intense parenting also resulted in health challenges for parents. including parents experiencing physical problems and increased stress, anxiety, and depression. An especially troubling finding was that lack of sleep was among the most common health problem reported by all parents. Meltzer and Mindell note that caring for an individual with chronic illness often requires a significant amount of night care, resulting in significant sleep disruption and deprivation on top of the already physically draining tasks during the day (Meltzer, & Mindell, 2006)

Research has revealed that families of children with complex care needs have been willing to take on the case management role, despite its added exhaustion, as it gives them a sense of control. Families have reported, however, that coordination and planning is sometimes extreme and incredibly burdensome (Carnevale, Alexander, Davis, Rennick, & Troini, 2006; Hewetson, & Singh, 2009). Study detailing the experiences of parenting children with complex care needs found that parents experienced the case

manager role as intense, continuous, and energy consuming (Woodgate, Edwards, Ripat, Borton, & Rempel, 2015). Despite wanting to give up, parents sacrifice their emotional and physical well-being for the sake of their children and often refuse to withdraw from their caring tasks (Kars, Duijnste, Pool, Van Delden, & Grypdonck, 2008). Likewise, parents in this study were emotionally committed to their children and feared being separated from them while entrusting the care with others who they may view as lacking ability to provide the same level of care as they do (Woodgate, Edwards, Ripat, Borton, & Rempel, 2015).

Issues like affect regulation, social competences, and sense of autonomy may all be of significant importance to the adjustment of people with ID to the everyday world (Sigman et al., 1999; Schuengel & Janssen, 2006), and may matter even more for children with ID than for typically developing children (Baker, Fenning, Crnic, Baker, & Blacher, 2007). Empirical studies support the understanding that the parent-child relationship is the primary context in which these constructs develop (Schuengel, de Schipper, Sterkenburg, & Kef, 2013) Groh et al., 2017 showed in their meta-analysis that early secure attachment is associated with children's socio-emotional adjustment, social competence and externalizing problems. Moreover, the findings underscored the across-the-board significance of all insecure attachment patterns for social competence. One of the tenets of attachment theory is that the formation of the parent-child relationship involves the processes of building cognitive representation of past experience with this parent (Bowlby, 1982). Children with intellectual disability, by definition, have cognitive deficits, and therefore it is not taken for granted that these children are able to form an attachment representation (Bretherton, 1990; Egeland & Carlson, 2004). Studies on attachment and intellectual disability indicate that many of the children exhibit secure attachment relationships to their mothers. Relatively to findings from studies of typically developing children, however, the intellectual disability population showed an elevated rate of attachment insecurity and disorganization (Feniger-Schaal, & Joels, 2018).

Peers-

Relationships with peers hold considerable developmental significance, influencing domains that include the socialization of aggression, the development of prosocial behaviors in general, and the formation of self-concepts (Bates, 1975; Garvey, 1986; Howes, Rubin, Ross, & French, 1988). These same issues are also highly relevant to young children with intellectual delays, as the developmental pathways, processes, and significance are likely to be similar to those of typically developing children (Guralnick, 1999). Clearly, experiencing social isolation from peers during the preschool years as a consequence of behavior problems is likely to place any child on a developmental trajectory that further heightens the risk of mental health difficulties emerging over time (Rubin, 1993). But children with intellectual delays confront even greater problems with respect to social isolation from their peers, resulting in an even greater threat to their long-term mental health. In particular, the extent to which behavior problems identified in young children with intellectual delays represent problems in regulating emotions (Guralnick, 2006).

Direct observations of the peer interactions of preschool-age children with intellectual delays in community programs reveal that not playing with peers is strongly associated with higher levels of behavior problems as rated by teachers (Guralnick, 2006). These emotion-regulation problems are especially apparent when children attempt to enter play with others. Not only are children with intellectual delays more intrusive and disruptive during peer group entry attempts than are comparable groups of children without delays, but they also use fewer emotionregulation strategies (Kopp, Baker, & Brown, 1992; Guralnick, 2006; Wilson, 1999)

Observations of young children with intellectual delays during interactions with peers reveal a pattern of social interaction that is likely to have contributed to these peer relationship and friendship difficulties. Most apparent is the absence of appropriate social strategies children use to achieve their interpersonal goals, such as gaining entry into playgroups, sustaining play sequences with peers in the face of the many changing demands that inevitably occur, and resolving conflicts that are frequent occurrences in the play of all children (Guralnick, 1999). For example, during conflicts, children with delays display numerous negative interactions, often become non-responsive, and rarely

utilize strategies considered to be conciliatory (Guralnick et al., 1998). Moreover, their social bids are less successful, suggesting poorly chosen or poorly timed social strategies (Guralnick & Groom, 1987a; 1987b).

Living with disability in developing countries, , may be an additional risk factor for those young children with developmental disabilities, as the inadequate provision of services for empowering people with disabilities with low socioeconomic status might reinforce the negative social attitudes concerning disability (Lang, Kett, Groce, & Trani, 2011). In some cultures, a child's disability is connected with embarrassment and shame (Al-Aoufi, Al-Zyoud, & Shahminan, 2012), and many children are hidden from society or exposed to rejection, abuse, and humiliation (Burton, Sayrafi, & Srour, 2013). The stigma of disability can strongly affect the children and their family members in terms of their health, emotions, behavior, and social life (Saca-Hazboun & Glennon, 2011).

In a study among school aged Palestinian children, the children reported feeling insecure in peer and social interactions. They resorted to the family and religion for protection and support (Nahal, Axelsson, Imam, & Wigert, 2019). It is important to note that in the Arab Muslim culture, giving birth to a child with disability is often perceived as a punishment from God. But at the same time, the principles and practical suggestions in caring for the disabled and those in need are provided by the Qur'an and the Hadith (Al-Aoufi et al., 2012). A marked impact of negative social attitudes and stigma was observed on the children's psychosocial health, as they felt discriminated in every aspect of their daily life. The greater obstacle they faced was the strained social interaction with their peers and other people in society. This was reflected by showing anxiety and fear about peer prejudice at school, and by rejecting people's sympathy and prying questions. These difficulties produced feelings including embarrassment, secrecy, shame, exclusion, and abandonment (Nahal, Axelsson, Imam, & Wigert, 2019). Furthermore, the children in this study discussed the burdens of their physical appearance, incontinence, and mobility problems, as well as social prejudice, and restricted access to social activities (Nahal, Axelsson, Imam, & Wigert, 2019). These consequences were strongly associated with lowering their self-concept, which is similar to previous reports by authors in a variety of other settings (Fischer, Church, Lyons, & McPherson, 2015; Shields, Taylor, & Dodd,

2008). Also found in this study is that children reported fears of being seen as different to their Because of their physical disability (Nahal, Axelsson, Imam, & Wigert, 2019). Additionally, promoting the children's health and empowerment might be achieved by raising social awareness about the children's feelings toward the stigma of their incontinence, and by discussing these issues with the children and their families at young age (Fischer et al., 2015).

A qualitative systematic review that surveyed thirty-three articles involving 390 youth with CP, aged from 2 to 25 years, across six developed countries found that youth experienced social isolation and exclusion from peers (Lindsay, 2016), which can potentially threaten their biography and normalcy (e.g. self-image and confidence) and longer-term development if not addressed (Eccleston & Malleson 2003; Castle, Imms, & Howie, 2007). These findings are similar to other research suggesting that youth with CP place more emphasis on recreation and leisure, while their caregivers focus more on function and mobility (Gibson, Teachman, Wright, Fehlings, Young, & McKeever, 2011; Schiariti, Sauve, Klassen, O'Donnell, Cieza, & Mâsse, 2014). With this in mind, rehabilitation interventions for youth with CP need to address issues beyond mobility and function to enhance their participation, inclusion and well-being (Shikako-Thomas, Lach, Majnemer, Nimigon, Cameron, & Shevell, 2009). Clinicians should continue to encourage social participation to strengthen the social networks of youth with CP while recognizing that social support is strongly linked to improved health, social competence and self-management skills (Lindsay, Kingsnorth, Mcdougall, & Keating, 2014; Tong, Jones, Craig, & Singh-Grewal, 2012).

Children with physical and mental disabilities report about vulnerability and suffering due to social exclusion and stigma, indicate that caught in a state of existential, physical, and psychosocial stress, and in need of a great deal of support (Nahal, Axelsson, Imam, & Wigert, 2019)

in a study of 4-16 years children with CP from Canada, it was found that in general, children had a positive view of their abilities and described their strengths and facilitating factors, while their caregivers focused on the challenges their children encountered in

their everyday activities (Schiariti, et al., 2014). The gap between the Canadian and the Palestinian children's self-image may be explained by cultural and religious differences regarding the disability, as well as socio-economic factors. Additionally, the gap between the perspective of the children and their caregivers may be due, firstly, to the developmental stage of the child, resulting in a different expectation of ability from their caregiver. The majority of the children focused more on what is immediately relevant to them, their current abilities and supportive factors. In contrast, caregivers often reported being preoccupied by the future for their child, mainly how well their child would integrate into the community and become an independent adult. Secondly, the experience of growing up and living with a physical disability may affect a child's reporting. Children demonstrated an acceptance of their condition which influenced their perspective on functioning. Many children stated that 'they were born with CP' and that they had adapted and coped with the challenges; therefore, they did not see themselves as different from other children. The discordance between the perspectives of children and their caregivers has been shown in other studies (Dunn, Shields, Taylor, & Dodd, 2009; Shikako-Thomas et al., 2009). In keeping with the positive perspectives manifested by children interviewed in this study, studies have reported that people with significant functional problems do not necessarily report their quality of life as being low, showing that the perception of their overall well-being does not directly correlate with their functional challenges (Saigal, 2000; Saigal et al., 2000).

Parent-child Relationship

Parenting a child with intellectual disability presents unique challenges, among which are the adjustments of parental expectations and hopes for their child, and coming to terms with, or "resolving", the feelings associated with the child's diagnosis. From the perspective of attachment theory (Marvin & Pianta, 1996), parental resolution is not only important for the parent's own wellbeing, but also has significant implications for the development of the child. This is because lack of resolution can interfere with the parent's capacity to respond sensitively and appropriately to the child's emotional signals (Feniger-Schaal, & Oppenheim, 2013). Most parents who receive a diagnosis of a serious developmental disability such as ID for their child experience strong emotional reactions,

including shock, sadness, despair, and confusion (Fortier & Wanlass, 1984). Receiving such diagnosis is a painful experience that shares many similarities with grief and mourning. Indeed, many have likened this experience to a metaphorical loss, as it were, of the hoped-for, typically developing child (Foley, 2006; Oppenheim, Dolev, Koren-Karie, Sher-Censor, Yirmiya, & Salomon, 2007). Parental sensitivity is the main mechanism thought to account for individual differences in children's attachment (Ainsworth, Blehar, Waters, & Wall, 1978). Parental sensitivity involves accurate reading of the child's emotional signals and prompt, flexible and appropriate responses, all within the context of a positive emotional climate (Ainsworth et al., 1978; Biringen & Robinson, 1991). Marvin and Pianta (1996) claimed that resolved parents, whose representations of the child are aligned with the child's functioning, are likely to be sensitive to the child's signals and to match their behavior to the child's strengths as well as the child's vulnerabilities (Marvin & Pianta, 1996). Conversely, unresolved parents' difficulties in revising their representations of the child in light of the diagnosis may limit their capacity to respond in a way that is appropriate to the child, hence, to be sensitive to their child. The mismatch between the perception of the child in the mind of the parent and the child in reality can interfere with the parents' capacity to read the child's signals correctly and respond appropriately (Feniger-Schaal, & Oppenheim, 2013).

In their role as guardians, parents discussed watching over their children to ensure their safety. While watching over their child and being present also helps create a trusting relationship between the parents and the child, it nonetheless involves parents missing out on relationships with family and friends (Woodgate et al., 2015). Other studies have shown that parents often temporarily restrict their social spheres and reject interactions with others during this time period of being there when nothing else can be done, in an attempt to further protect their child from physical danger, emotional stress, hostility, or invasive curiosity of onlookers (Levine, 2005).

Additional factors

Bourke et al. (2014) note that children with complex care needs necessitate direct costs on families that include extra medical attention, equipment, technology, devices,

medications, and specialized therapy services, as well additional costs such as costs related to modifications of the family home (Bourke-Taylor, Cotter, & Stephan, 2014). Moreover, parents assume tasks and responsibilities normally carried out by professionals who receive a salary for their work. Taken together, these findings suggest that additional financial assistance for parents of children with complex care needs is warranted. Professionals should also seek out parents' perspectives of what it means to them to be a "good" parent. As Hinds point out, professionals need to ask parents how they can help them to fulfill their role of the "good" parent and what they need to meet their child's needs (Hinds et al., 2009). Bearing in mind that parents' and children's needs change overtime, there should be regular assessments of needs to ensure families are receiving the appropriate services and supports (Alsem, Siebes, Gorter, Jongmans, Nijhuis, & Ketelaar, 2014).

Previous studies which assessed the needs of family of children with CP or disability have reported several main needs which include the need for information about the condition of their children, treatment options, presently available services and the services they may receive in the future. Additionally, these families require additional support, community services and financial aid for therapy and special equipment (Bertule, & Vetra, 2014; Palisano, Almars, Chiarello, Orlin, Bagley, & Maggs, 2010).

In this study the need for information appears to be the most frequently reported (Nordin, Azlin, Hui Shan, & Zanudin, 2019), as highlighted by other studies (Bertule, & Vetra, 2014; Palisano et al., 2010; Tan, 2017). The participants of the study reported that they have needs in seeking various kinds of information regarding their child, but those needs were fulfilled mostly through the internet or parents of other children with CP. The participants claimed that the information received from the healthcare professionals was not conveyed in the way they desire, for example, the information was either difficult to understand or is inadequately provided in the primary healthcare center. Eventually, when all the needs in this aspect were satisfied, it was by the means of their own initiative. Over time, the parents become more knowledgeable regarding their child, aso their needs evolve (Kruijsen-Terpstra et al., 2016).

Early psychological interventions for infants and toddlers with physical and mental disabilities

The provision of comprehensive early intervention services and supports for children with established developmental delays continues to be a high priority in the United States and in virtually all other high resource countries throughout the world (Guralnick, 2017). Moreover, despite the unique challenges posed by lower- and middle-resource countries, the potential contributions of early intervention to children's development and to family well-being for vulnerable children in general are well-recognized by the international community (World Health Organization & UNICEF, 2012).

Parental intervention

Early developmental intervention is playing an increasingly prominent role in the field of intellectual disabilities. Early intervention is thought to enhance the development of young children already exhibiting intellectual delays, both by altering their developmental trajectories and by preventing secondary complications from occurring (Guralnick, 2005, 2017). The involvement of parents in early intervention (of any kind) for children with intellectual disabilities appears to be vital for children's positive development. Studies have shown that parenting interventions have positive effects on parents in regard to parenting styles, parental sensitive responsiveness, parental satisfaction, and inter-parental conflict over childrearing, which subsequently lead to significant improvements in children's behavior and their cognitive and social outcomes (Guralnick, 2017; Roux, Sofronoff, Sanders, 2013). In addition, studies have demonstrated that parental interventions contribute to increased parental confidence, in terms of their ability to carry out roles and responsibilities with respect to the child with ID (Guralnick, 2017).

The development of behavioral/emotional self-regulation and the ability to establish secure attachments and positive relationships with others during infancy and toddlerhood form the foundation for later social emotional competence and wellbeing (National Scientific Council on the Developing Child, 2004a). It is through interactions with others,

and especially with primary caregivers, that these foundational capacities and competencies emerge. This is true for all children, both typically developing and those with or at risk of disabilities (National Scientific Council on the Developing Child, 2004b, 2008; National Research Council and Institute of Medicine, 2000). Many young children at risk for disabilities or with identified disabilities develop social emotional competencies on an age-appropriate timeline. For others, deficits in physical, cognitive or communicative abilities may interfere with social emotional development, making early intervention to support effective caregiving practices even more critical (Powell, & Dunlap, 2010).

Family-centered approach

A family-centered approach has been well accepted in the field of early intervention from a philosophical and values-based perspective. Recent reviews and meta-analyses have provided documentation that when service delivery incorporates family-centered practices, outcomes for family and children are improved including parenting capabilities and positive child behavior and functioning (Dempsey & Keen, 2008; Dunst, Trivette and Hamby, 2006, 2007, 2008). Dunst, Trivette and Hamby (2006, 2007, 2008) classified family-centered practices as relational (clinical skills such as active listening, compassion, empathy, respect and beliefs regarding family member strengths and capabilities) or participatory (individualized, flexible, responsive to family priorities, providing informed choices and family involvement in achieving goals and outcomes) and found in their meta-analyses that participatory practices were most strongly linked with child outcomes including behavioral outcomes. Parents or other primary care providers are the key mediators of experience for infants and toddlers, and thus their influence is critical during this period of rapid development of foundational skills and competencies (Powell, & Dunlap, 2010).

Relationship-focused intervention

A large body of research points to responsive, sensitive parent-child interactions as essential to promoting healthy social emotional development in infants and toddlers. While parental responsivity/sensitivity has been defined in a variety of ways, it generally

refers to interactions between infants/ young children and adult caregivers that are warm and accepting; responsive to the child's cues, initiations and lead; appropriate to the child's developmental level and interests; and mutually rewarding. In young children (< 2 years) with disabilities or at risk for developmental delays, parental responsiveness that is contingent (occurs promptly and in response to child behavior) and is appropriate and sensitive (matches the developmental level and mood of the child) is positively related to child social emotional outcomes including outcome measures taken more than two years after the initial responsiveness measures. Immediate child outcomes included increased positive affect and social responsivity; follow-up outcomes included increased prosocial problem-solving and decreased teacher-rated behavior problems (Trivette, 2007). Several meta-analyses have examined the characteristics of effective interventions for teaching responsive, sensitive parenting skills. Results indicate that interventions for teaching responsivity/sensitivity to parents are most effective when they a) are behaviorally oriented, relatively brief (<16 sessions) and highly focused; b) occur before 6-8 months of age; c) use video tape models and feedback; and d) emphasize caregiver awareness and attention to child's signals and behavior, accurate interpretation of child's intent to communicate and interact, and appropriate and prompt parent responsiveness to child's behavior (Powell, & Dunlap, 2010).

Another method of intervention relationship-focused intervention is Responsive Teaching. Responsive Teaching is a child development early intervention curriculum that was designed to be implemented by parents and other caregivers who spend significant amounts of time interacting with and caring for young children (Mahoney & MacDonald, 2007). Responsive Teaching was developed to help adults maximize the potential of each of their routine interactions with their children so that they support and enhance children's development and wellbeing. This curriculum encourages children to develop and use the 'pivotal behaviors' that are the foundations for developmental learning, such as social play, initiation, problem solving, joint attention, conversation, trust, cooperation, persistence and feelings of competence. The instructional strategies that are at the heart of Responsive Teaching are 'easy to remember' suggestions that adults can incorporate into daily routines with children. Responsive Teaching is designed to promote three

domains of developmental functioning. These include the following: Cognition; Communication; Social-emotional functioning (Herman, 2006).

These behavior problems of young children with intellectual and physical delays produce many of the same adverse effects found for older individuals (Guralnick, 2006). In particular, caregiver stress increases and, under the proper circumstances, can lead to a transactional process exacerbating both stress and behavior problems (Baker et al., 2003; Crnic, Hoffman, Gaze, & Edelbrock, 2004; Sameroff & Fiese, 2000). In addition, both parents and children often find themselves becoming more and more isolated from community activities and from individuals in their family and community (see Baker et al., 2003; Guralnick, 1997). Of importance, as described below, from the children's perspective this social isolation extends to relationships with their peers in a variety of forms (Guralnick, 2006).

Incredible Years Parent Training

Webster-Stratton and her colleagues have developed the Incredible Years Parent Training (IYPT) program (McIntyre, 2008). The IYPT program is one of two well-established psychosocial treatments for childhood conduct problems, as determined by the Division 12 (Clinical Psychology) task force of the American Psychological Association (Brestan & Eyberg, 1998). Although the IYPT has not been used with children who have developmental disabilities, other parent training programs have been employed with this population. Unlike parent training for families who have children with behavior problems, programs for children with developmental disabilities often target increasing children's adaptive behavior, self-help skills, language, or academic skills (Baker & Brightman, 2004). The IYPT emphasizes behavior management, limit setting, and reducing challenging behavior, as do other parent training programs (e.g., Plant & Sanders, 2007); however, this program also emphasizes developing positive relationships with children, especially through developmentally appropriate play and positive interactions (see Webster-Stratton, 2001). This intervention consists of 12-weekly 2.5-hour group sessions (8 to 12 participants per group) and included the topics of: play, praise, rewards, limit setting, and handling challenging behavior. Also, this

treatment program uses group discussion, viewing of videotape vignettes of parent–child interactions, role-playing, didactics, and weekly homework assignments (Webster-Stratton, 2000, 2001).

Results of a study examining children aged 2-5 with developmental delays and their parents found that the IYPT Program with developmental delay modifications is an acceptable intervention for use with parents who have young children with developmental delay or disabilities. Furthermore, results suggested that this program was successful in reducing negative and inappropriate parent–child interactions and child behavior problems relative to a usual care control group (McIntyre, 2008).

Conclusion

Research in the last decade has continued to strengthen our confidence that well-established developmental (both developmental and emotional) pathways that influence child outcomes apply to children with delays. Consequently, adoption of a broad developmental framework, even in the context of a more fine-tuned understanding of developmental processes for these children (Burack, Russo, Flores, Iarocci, & Zigler, 2012), seems warranted when considering approaches to early intervention (Guralnick, 2017). To some extent, the absence of comprehensive larger scale and longer-term intervention studies reflects an acceptance of the fact that children with delays and their families do benefit from current developmental early intervention programs. Comprehensive studies of early intervention are difficult and expensive to carry out and, in the absence of well-specified newly developed or competing models, little incentive exists to pursue this line of research. Studies that span both the infant/toddler and preschool periods are especially rare, despite the importance of service continuity across the early childhood period (Guralnick, 2017). Also, what is important to note is that while there is extensive research on developmental intervention for children with physical and intellectual disabilities and developmental delay, research on emotional early intervention to improve the quality of life of the child and his or her family is almost non-existent. This is despite the understanding of professionals in the field have about such an intervention that is important for children and their families.

However, to provide appropriate, research-proven care that does indeed help children with intellectual and physical disabilities and their families, long-term studies are needed to examine the effects of the treatments and early intervention on the mental development of young children.

Bibliography

Agaliotis, I., & Kalyva, E. (2008). Nonverbal social interaction skills of children with learning disabilities. *Research in developmental disabilities, 29*(1), 1-10.

Ainsworth, M. D., Blehar, M., Waters, E., & Wall, S. (1978). Patterns of attachment.

Al-Aoufi, H., Al-Zyoud, N., & Shahminan, N. (2012). Islam and the cultural conceptualisation of disability. *International Journal of Adolescence and Youth, 17*(4), 205-219.

Almasri, N. A., Palisano, R. J., Dunst, C. J., Chiarello, L. A., O'Neil, M. E., & Polansky, M. (2011). Determinants of needs of families of children and youth with cerebral palsy. *Children's Health Care, 40*(2), 130-154.

Alsem, M. W., Siebes, R. C., Gorter, J. W., Jongmans, M. J., Nijhuis, B. G. J., & Ketelaar, M. (2014). Assessment of family needs in children with physical disabilities: development of a family needs inventory. *Child: care, health and development, 40*(4), 498-506.

Andermann, A., Blancquaert, I., & Déry, V. (2010). Genetic screening: a conceptual framework for programmes and policy-making. *Journal of health services research & policy, 15*(2), 90-97.

Azeem, M. W., Dogar, I. A., Shah, S., Cheema, M. A., Asmat, A., Akbar, M., ... & Haider, I. I. (2013). Anxiety and depression among parents of children with intellectual disability in Pakistan. *Journal of the Canadian Academy of Child and Adolescent Psychiatry, 22*(4), 290.

Bailey Jr, D. B., Golden, R. N., Roberts, J., & Ford, A. (2007). Maternal depression and developmental disability: Research critique. *Mental retardation and developmental disabilities research reviews, 13*(4), 321-329.

- Bailey Jr, D. B., Skinner, D., & Warren, S. F. (2005). Newborn screening for developmental disabilities: reframing presumptive benefit. *American Journal of Public Health, 95*(11), 1889-1893.
- Baker, B. L., Blacher, J., Crnic, K. A., & Edelbrock, C. (2002). Behavior problems and parenting stress in families of three-year-old children with and without developmental delays. *American Journal on Mental Retardation, 107*(6), 433-444.
- Baker, B. L., Brightman, A. J., Blacher, J. B., Heifetz, L. J., Hinshaw, S. R., & Murphy, D. M. (2004). *Steps to independence: Teaching everyday skills to children with special needs*. Brookes Publishing Company. PO Box 10624, Baltimore, MD 21285.
- Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research, 47*(4-5), 217-230.
- Baker, J. K., Fenning, R. M., Crnic, K. A., Baker, B. L., & Blacher, J. (2007). Prediction of social skills in 6-year-old children with and without developmental delays: Contributions of early regulation and maternal scaffolding. *American Journal on Mental Retardation, 112*(5), 375-391.
- Baker, J. K., Fenning, R. M., Crnic, K. A., Baker, B. L., & Blacher, J. (2007). Prediction of social skills in 6-year-old children with and without developmental delays: Contributions of early regulation and maternal scaffolding. *American Journal on Mental Retardation, 112*(5), 375-391.
- Bates, E. (1975). Peer relations and the acquisition of language. *Friendship and peer relations, 259-292*.
- Bertule, D., & Vetra, A. (2014). The family needs of parents of preschool children with cerebral palsy: The impact of child's gross motor and communications functions. *Medicina, 50*(6), 323-328.
- Bertule, D., & Vetra, A. (2014). The family needs of parents of preschool children with cerebral palsy: The impact of child's gross motor and communications functions. *Medicina, 50*(6), 323-328.
- Bertule, D., & Vetra, A. (2014). The family needs of parents of preschool children with cerebral palsy: The impact of child's gross motor and communications functions. *Medicina, 50*(6), 323-328.
- Biringen, Z., & Robinson, J. (1991). Emotional availability in mother-child interactions: A reconceptualization for research. *American journal of Orthopsychiatry, 61*(2), 258-271.
- Bombard, Y., Miller, F. A., Hayeems, R. Z., Avar, D., & Knoppers, B. M. (2010). Reconsidering reproductive benefit through newborn screening: a systematic review of guidelines on preconception, prenatal and newborn screening. *European journal of human genetics, 18*(7), 751-760.

Borthwick-Duffy, S. A., & Eyman, R. K. (1990). Who are the dually diagnosed?. *American Journal on Mental Retardation*.

Bourke-Taylor, H., Cotter, C., & Stephan, R. (2014). Young children with cerebral palsy: families self-reported equipment needs and out-of-pocket expenditure. *Child: care, health and development*, 40(5), 654-662.

Bourke-Taylor, H., Howie, L., Law, M., & Pallant, J. F. (2012). Self-reported mental health of mothers with a school-aged child with a disability in Victoria: A mixed method study. *Journal of Paediatrics and Child Health*, 48(2), 153-159.

Bowlby, J. (1982). Attachment and loss: retrospect and prospect. *American journal of Orthopsychiatry*, 52(4), 664.

Brehaut, J. C., Kohen, D. E., Raina, P., Walter, S. D., Russell, D. J., Swinton, M., ... & Rosenbaum, P. (2004). The health of primary caregivers of children with cerebral palsy: how does it compare with that of other Canadian caregivers?. *Pediatrics*, 114(2), e182-e191.

Brestan, E. V., & Eyberg, S. M. (1998). Effective psychosocial treatments of conduct-disordered children and adolescents: 29 years, 82 studies, and 5,272 kids. *Journal of clinical child psychology*, 27(2), 180-189.

Bretherton, I. (1990). Communication patterns, internal working models, and the intergenerational transmission of attachment relationships. *Infant mental health Journal*, 11(3), 237-252.

Burack, J. A., Russo, N., Flores, H., Iarocci, G., & Zigler, E. (2012). The more you know the less you know, but that's OK: Developments in the developmental approach to intellectual disability. *The Oxford handbook of intellectual disability and development*, 3-12.

Burton, G., Sayrafi, I., & Srour, S. A. (2013). Inclusion or transformation? An early assessment of an empowerment project for disabled people in occupied Palestine. *Disability & Society*, 28(6), 812-825.

Cantwell, J., Muldoon, O., & Gallagher, S. (2015). The influence of self-esteem and social support on the relationship between stigma and depressive symptomology in parents caring for children with intellectual disabilities. *Journal of Intellectual Disability Research*, 59(10), 948-957.

Carnevale, F. A., Alexander, E., Davis, M., Rennick, J., & Troini, R. (2006). Daily living with distress and enrichment: the moral experience of families with ventilator-assisted children at home. *Pediatrics*, 117(1), e48-e60.

Castle, K., Imms, C., & Howie, L. (2007). Being in pain: a phenomenological study of young people with cerebral palsy. *Developmental medicine & child neurology*, 49(6), 445-449.

- Churchill, S. S., Villareale, N. L., Monaghan, T. A., Sharp, V. L., & Kieckhefer, G. M. (2010). Parents of children with special health care needs who have better coping skills have fewer depressive symptoms. *Maternal and child health journal*, 14(1), 47.
- Crnic, K., Hoffman, C., Gaze, C., & Edelbrock, C. (2004). Understanding the emergence of behavior problems in young children with developmental delays. *Infants & Young Children*, 17(3), 223-235.
- Dempsey, I., & Keen, D. (2008). A review of processes and outcomes in family-centered services for children with a disability. *Topics in early childhood special education*, 28(1), 42-52.
- Dillon-Wallace, J. A., McDonagh, S. H., & Fordham, L. A. (2014). How stable is the well-being of Australian mothers who care for young children with special health care needs?. *Journal of Child and Family Studies*, 23(7), 1215-1226.
- Dunn, N., Shields, N., Taylor, N. F., & Dodd, K. J. (2009). Comparing the self concept of children with cerebral palsy to the perceptions of their parents. *Disability and rehabilitation*, 31(5), 387-393.
- Dunst, C. J., Trivette, C. M., & Hamby, D. W. (2007). Meta-analysis of family-centered helping practices research. *Mental retardation and developmental disabilities research reviews*, 13(4), 370-378.
- Dunst, C. J., Trivette, C. M., & Hamby, D. W. (2008). *Research Synthesis and Meta-Analysis of Studies of Family-Centered Practices*. Winterberry Press Monograph Series. Winterberry Press. 8 Elk Mountain Road, Asheville, NC 28804.
- Dunst, C. J., Trivette, C. M., Hamby, D. W., & Bruder, M. B. (2006). Influences of contrasting natural learning environment experiences on child, parent and family well-being. *Journal of Developmental and Physical Disabilities*, 18(3), 235-250.
- Dykens, E. M. (2000). Annotation: Psychopathology in children with intellectual disability. *The Journal of Child Psychology and Psychiatry and Allied Disciplines*, 41(4), 407-417.
- Eccleston, C., & Malleon, P. (2003). Managing chronic pain in children and adolescents.
- Egeland, B., & Carlson, E. A. (2004). Attachment and psychopathology. *Attachment issues in psychopathology and intervention*, 27-48.
- Emerson, E. (2003). Mothers of children and adolescents with intellectual disability: social and economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties. *Journal of Intellectual Disability Research*, 47(4-5), 385-399.

- Feniger-Schaal, R., & Joels, T. (2018). Attachment quality of children with ID and its link to maternal sensitivity and structuring. *Research in developmental disabilities, 76*, 56-64.
- Feniger-Schaal, R., & Oppenheim, D. (2013). Resolution of the diagnosis and maternal sensitivity among mothers of children with intellectual disability. *Research in developmental disabilities, 34*(1), 306-313.
- Fischer, N., Church, P., Lyons, J., & McPherson, A. C. (2015). A qualitative exploration of the experiences of children with spina bifida and their parents around incontinence and social participation. *Child: Care, Health and Development, 41*(6), 954-962.
- Fischer, N., Church, P., Lyons, J., & McPherson, A. C. (2015). A qualitative exploration of the experiences of children with spina bifida and their parents around incontinence and social participation. *Child: Care, Health and Development, 41*(6), 954-962.
- Foley, G. M. (2006). The loss-grief cycle: Coming to terms with the birth of a child with a disability. *Mental health in early intervention: Achieving unity in principles and practice, 227-243*.
- Fortier, L. M., & Wanlass, R. L. (1984). Family crisis following the diagnosis of a handicapped child. *Family Relations, 13-24*.
- Gallagher, S., & Hannigan, A. (2015). Child problem behaviours are associated with obesity in parents caring for children with developmental disabilities. *Research in developmental disabilities, 36*, 358-365.
- Gallagher, S., & Whiteley, J. (2013). The association between stress and physical health in parents caring for children with intellectual disabilities is moderated by children's challenging behaviours. *Journal of health psychology, 18*(9), 1220-1231.
- Garvey, C. (1986). Peer relations and the growth of communication. *Process and outcome in peer relationships, 329-345*.
- Gibson, B. E., Teachman, G., Wright, V., Fehlings, D., Young, N. L., & McKeever, P. (2012). Children's and parents' beliefs regarding the value of walking: rehabilitation implications for children with cerebral palsy. *Child: care, health and development, 38*(1), 61-69.
- Gilson, K. M., Davis, E., Johnson, S., Gains, J., Reddihough, D., & Williams, K. (2018). Mental health care needs and preferences for mothers of children with a disability. *Child: care, health and development, 44*(3), 384-391.
- Gini, G., & Pozzoli, T. (2009). Association between bullying and psychosomatic problems: A meta-analysis. *Pediatrics, 123*(3), 1059-1065.
- Goldman, S. E., Malow, B. A., Newman, K. D., Roof, E., & Dykens, E. M. (2009). Sleep patterns and daytime sleepiness in adolescents and young adults with Williams syndrome. *Journal of Intellectual Disability Research, 53*(2), 182-188.

- Groh, A. M., Fearon, R. P., van IJzendoorn, M. H., Bakermans-Kranenburg, M. J., & Roisman, G. I. (2017). Attachment in the early life course: Meta-analytic evidence for its role in socioemotional development. *Child Development Perspectives*, 11(1), 70-76.
- Guralnick, M. J. (1999). Family and child influences on the peer-related social competence of young children with developmental delays. *Mental retardation and developmental disabilities research reviews*, 5(1), 21-29
- Guralnick, M. J. (1999). Family and child influences on the peer-related social competence of young children with developmental delays. *Mental retardation and developmental disabilities research reviews*, 5(1), 21-29.
- Guralnick, M. J. (2005). Early intervention for children with intellectual disabilities: Current knowledge and future prospects. *Journal of Applied Research in Intellectual Disabilities*, 18(4), 313-324.
- Guralnick, M. J. (2006). Family influences on early development: Integrating the science of normative development, risk and disability, and intervention. *Handbook of early childhood development*, 44-61.
- Guralnick, M. J. (2011). Why early intervention works: A systems perspective. *Infants and young children*, 24(1), 6.
- Guralnick, M. J. (2017). Early intervention for children with intellectual disabilities: An update. *Journal of Applied Research in Intellectual Disabilities*, 30(2), 211-229.
- Guralnick, M. J., & Groom, J. M. (1987a). The peer relations of mildly delayed and nonhandicapped preschool children in mainstreamed playgroups. *Child Development*, 1556-1572.
- Guralnick, M. J., & Groom, J. M. (1987b). Dyadic peer interactions of mildly delayed and nonhandicapped preschool children. *American Journal of Mental Deficiency*.
- Guralnick, M. J., Paul-Brown, D., Groom, J. M., Booth, C. L., Hammond, M. A., Tupper, D. B., & Gelenter, A. (1998). Conflict resolution patterns of preschool children with and without developmental delays in heterogeneous playgroups. *Early Education and Development*, 9(1), 49-77.
- Hebbeler, K., Spiker, D., Bailey, D., Scarborough, A., Mallik, S., Simeonsson, R., & Nelson, L. (2007). Early intervention for infants and toddlers with disabilities and their families: Participants, services, and outcomes. *Menlo Park, CA: SRI International*.
- Herman, B. (2006). Responsive teaching: early intervention for children with Down syndrome and other disabilities. *Down Syndrome Research and Practice*, 11(1), 18-28.
- Hewetson, R., & Singh, S. (2009). The lived experience of mothers of children with chronic feeding and/or swallowing difficulties. *Dysphagia*, 24(3), 322-332.

- Hinds, P. S., Oakes, L. L., Hicks, J., Powell, B., Srivastava, D. K., Spunt, S. L., ... & Furman, W. L. (2009). "Trying to be a good parent" as defined by interviews with parents who made phase I, terminal care, and resuscitation decisions for their children. *Journal of Clinical Oncology*, 27(35), 5979.
- Howes, C., Rubin, K. H., Ross, H. S., & French, D. C. (1988). Peer interaction of young children. *Monographs of the society for research in child development*, i-92.
- Hsieh, H. C. (2008). Effects of ordinary and adaptive toys on pre-school children with developmental disabilities. *Research in Developmental Disabilities*, 29(5), 459-466.
- Kars, M. C., Duijnste, M. S., Pool, A., Van Delden, J. J., & Grypdonck, M. H. (2008). Being there: parenting the child with acute lymphoblastic leukaemia. *Journal of clinical nursing*, 17(12), 1553-1562.
- Kiernan, C., Reeves, D., & Alborz, A. (1995). The use of anti-psychotic drugs with adults with learning disabilities and challenging behaviour. *Journal of Intellectual Disability Research*, 39(4), 263-274.
- Kopp, C. B., Baker, B. L., & Brown, K. W. (1992). Social skills and their correlates: Preschoolers with developmental delays. *American Journal on Mental Retardation*.
- Kruijssen-Terpstra, A. J., Verschuren, O., Ketelaar, M., Riedijk, L., Gorter, J. W., Jongmans, M. J., ... & LEARN 2 MOVE 2-3 Study Group. (2016). Parents' experiences and needs regarding physical and occupational therapy for their young children with cerebral palsy. *Research in Developmental Disabilities*, 53, 314-322.
- Lang, R., Kett, M., Groce, N., & Trani, J. F. (2011). Implementing the United Nations Convention on the rights of persons with disabilities: principles, implications, practice and limitations. *Alter*, 5(3), 206-220.
- Levine, C. (2005). Acceptance, avoidance, and ambiguity: conflicting social values about childhood disability. *Kennedy Institute of Ethics Journal*, 15(4), 371-383.
- Levitan, G. W., & Reiss, S. (1983). Generality of diagnostic overshadowing across disciplines. *Applied Research in Mental Retardation*, 4(1), 59-64.
- Lifshitz, H., Merrick, J., & Morad, M. (2008). Health status and ADL functioning of older persons with intellectual disability: Community residence versus residential care centers. *Research in Developmental Disabilities*, 29(4), 301-315.
- Lindsay, S. (2016). Child and youth experiences and perspectives of cerebral palsy: a qualitative systematic review. *Child: care, health and development*, 42(2), 153-175.
- Lindsay, S., & McPherson, A. C. (2012). Experiences of social exclusion and bullying at school among children and youth with cerebral palsy. *Disability and rehabilitation*, 34(2), 101-109.

- Lindsay, S., Kingsnorth, S., Mcdougall, C., & Keating, H. (2014). A systematic review of self-management interventions for children and youth with physical disabilities. *Disability and Rehabilitation*, 36(4), 276-288.
- Liptak, G. S., O'Donnell, M., Conaway, M., Chumlea, W. C., Worley, G., Henderson, R. C., ... & Rosenbaum, P. (2001). Health status of children with moderate to severe cerebral palsy. *Developmental medicine and child neurology*, 43(6), 364-370.
- Mahoney, G., & MacDonald, J. (2007). Autism and developmental delays in young children: The responsive teaching curriculum for parents and professionals manual. *Austin, Texas: PRO-ED Inc.*
- Marvin, R. S., & Pianta, R. C. (1996). Mothers' reactions to their child's diagnosis: Relations with security of attachment. *Journal of Clinical Child Psychology*, 25(4), 436-445.
- Marvin, R. S., & Pianta, R. C. (1996). Mothers' reactions to their child's diagnosis: Relations with security of attachment. *Journal of Clinical Child Psychology*, 25(4), 436-445.
- Matson, J. L., Cooper, C., Malone, C. J., & Moskow, S. L. (2008). The relationship of self-injurious behavior and other maladaptive behaviors among individuals with severe and profound intellectual disability. *Research in Developmental Disabilities*, 29(2), 141-148.
- Matson, J. L., Fodstad, J. C., & Mahan, S. (2009). Cutoffs, norms, and patterns of comorbid difficulties in children with developmental disabilities on the Baby and Infant Screen for Children with aUtism Traits (BISCUIT-Part 2). *Research in Developmental Disabilities*, 30(6), 1221-1228.
- McCabe, H. (2007). Parent advocacy in the face of adversity: Autism and families in the People's Republic of China. *Focus on Autism and Other Developmental Disabilities*, 22(1), 39-50.
- McIntyre, L. L. (2008). Parent training for young children with developmental disabilities: Randomized controlled trial. *American Journal on Mental Retardation*, 113(5), 356-368.
- McIntyre, L. L. (2008). Parent training for young children with developmental disabilities: Randomized controlled trial. *American Journal on Mental Retardation*, 113(5), 356-368.
- Mcintyre, L. L., Blacher, J., & Baker, B. L. (2002). Behaviour/mental health problems in young adults with intellectual disability: The impact on families. *Journal of Intellectual Disability Research*, 46(3), 239-249.
- McIntyre, L. L., Blacher, J., & Baker, B. L. (2006). The transition to school: Adaptation in young children with and without intellectual disability. *Journal of Intellectual Disability Research*, 50(5), 349-361.

- Meltzer, L. J., & Mindell, J. A. (2006). Impact of a child's chronic illness on maternal sleep and daytime functioning. *Archives of Internal Medicine*, 166(16), 1749-1755.
- Mitchell, D. B., & Hauser-Cram, P. (2008). The well-being of mothers of adolescents with developmental disabilities in relation to medical care utilization and satisfaction with health care. *Research in Developmental Disabilities*, 29(2), 97-112.
- Myrbakk, E., & von Tetzchner, S. (2008). Psychiatric disorders and behavior problems in people with intellectual disability. *Research in Developmental Disabilities*, 29(4), 316-332.
- Nahal, M. S., Axelsson, Å. B., Imam, A., & Wigert, H. (2019). Palestinian children's narratives about living with spina bifida: Stigma, vulnerability, and social exclusion. *Child: care, health and development*, 45(1), 54-62.
- Nordin, M., Azlin, N., Hui Shan, E., & Zanudin, A. (2019). The Unmet Needs of Parents of Highly Dependent Children with Cerebral Palsy. *International Journal of Environmental Research and Public Health*, 16(24), 5145.
- Nordin, M., Azlin, N., Hui Shan, E., & Zanudin, A. (2019). The Unmet Needs of Parents of Highly Dependent Children with Cerebral Palsy. *International Journal of Environmental Research and Public Health*, 16(24), 5145.
- Olsson, M. B., & Hwang, C. P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of intellectual disability research*, 45(6), 535-543.
- Oppenheim, D. A. V. I. D., Dolev, S., Koren-Karie, N. I. N. A., Sher-Censor, E. F. R. A. T., Yirmiya, N. U. R. I. T., & Salomon, S. (2007). Parental resolution of the child's diagnosis and the parent-child relationship. *Attachment theory in clinical work with children: bridging the gap between research and practice*. New York: Guilford, 109-36.
- Palisano, R. J., Almarsi, N., Chiarello, L. A., Orlin, M. N., Bagley, A., & Maggs, J. (2010). Family needs of parents of children and youth with cerebral palsy. *Child: care, health and development*, 36(1), 85-92.
- Palisano, R. J., Almarsi, N., Chiarello, L. A., Orlin, M. N., Bagley, A., & Maggs, J. (2010). Family needs of parents of children and youth with cerebral palsy. *Child: care, health and development*, 36(1), 85-92.
- Plant, K. M., & Sanders, M. R. (2007). Reducing problem behavior during care-giving in families of preschool-aged children with developmental disabilities. *Research in developmental disabilities*, 28(4), 362-385.
- Powell, D., & Dunlap, G. (2010). Family-Focused Interventions for Promoting Social-Emotional Development in Infants and Toddlers with or at Risk for Disabilities. Roadmap to Effective Intervention Practices# 5. *Technical Assistance Center on Social Emotional Intervention for Young Children*.

- Ringdahl, J. E., Call, N. A., Mews, J. B., Boelter, E. W., & Christensen, T. J. (2008). Assessment and treatment of aggressive behavior without a clear social function. *Research in developmental disabilities, 29*(4), 351-362.
- Roux, G., Sofronoff, K., & Sanders, M. (2013). A randomized controlled trial of group Stepping Stones Triple P: A mixed-disability trial. *Family Process, 52*(3), 411-424.
- Rubin, K. H. (1993). The Waterloo Longitudinal Project: Correlates and consequences of social withdrawal from childhood to adolescence In Rubin KH & Asendorpf J (Eds.), *Social withdrawal, inhibition and shyness in childhood* (pp. 291–314).
- Saca-Hazboun, H., & Glennon, C. A. (2011). Cultural influences on health care in Palestine. *Clinical journal of oncology nursing, 15*(3).
- Saigal, S. (2000). Perception of health status and quality of life of extremely low–birth weight survivors: the consumer, the provider, and the child. *Clinics in perinatology, 27*(2), 403-419.
- Saigal, S., Rosenbaum, P. L., Feeny, D., Burrows, E., Furlong, W., Stoskopf, B. L., & Hoult, L. (2000). Parental perspectives of the health status and health-related quality of life of teen-aged children who were extremely low birth weight and term controls. *Pediatrics, 105*(3), 569-574.
- Sameroff, A. J., & Fiese, B. H. (2000). Transactional regulation: The developmental ecology of early intervention. *Handbook of early childhood intervention, 2*, 135-159.
- Schiariti, V., Sauve, K., Klassen, A. F., O'Donnell, M., Cieza, A., & Mâsse, L. C. (2014). 'He does not see himself as being different': the perspectives of children and caregivers on relevant areas of functioning in cerebral palsy. *Developmental Medicine & Child Neurology, 56*(9), 853-861.
- Schuengel, C., & Janssen, C. G. (2006). People with mental retardation and psychopathology: Stress, affect regulation and attachment: A review. *International review of research in mental retardation, 32*, 229-260.
- Schuengel, C., & Janssen, C. G. (2006). People with mental retardation and psychopathology: Stress, affect regulation and attachment: A review. *International review of research in mental retardation, 32*, 229-260.
- Schuengel, C., de Schipper, J. C., Sterkenburg, P. S., & Kef, S. (2013). Attachment, intellectual disabilities and mental health: Research, assessment and intervention. *Journal of Applied Research in Intellectual Disabilities, 26*(1), 34-46.
- Shields, N., Taylor, N. F., & Dodd, K. J. (2008). Self-concept in children with spina bifida compared with typically developing children. *Developmental Medicine & Child Neurology, 50*(10), 733-743.

- Shikako-Thomas, K., Lach, L., Majnemer, A., Nimigon, J., Cameron, K., & Shevell, M. (2009). Quality of life from the perspective of adolescents with cerebral palsy: "I just think I'm a normal kid, I just happen to have a disability". *Quality of Life Research, 18*(7), 825.
- Sigman, M., Ruskin, E., Arbelle, S., Corona, R., Dissanayake, C., Espinosa, M., ... & Robinson, B. F. (1999). Continuity and change in the social competence of children with autism, Down syndrome, and developmental delays. *Monographs of the society for research in child development, i*-139.
- Singer, G. H. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American journal on mental retardation, 111*(3), 155-169.
- Taanila, A., Ebeling, H., Heikura, U., & Järvelin, M. R. (2003). Behavioural problems of 8-year-old children with and without intellectual disability. *Journal of pediatric neurology, 1*(01), 015-024.
- Tan, S. H. (2017). Assessing the needs of caregivers of children with disabilities in Penang, Malaysia. *Health & social care in the community, 25*(2), 447-457.
- Tong, A., Jones, J., Craig, J. C., & Singh-Grewal, D. (2012). Children's experiences of living with juvenile idiopathic arthritis: a thematic synthesis of qualitative studies. *Arthritis care & research, 64*(9), 1392-1404.
- Trivette, C. M. (2007). Influence of caregiver responsiveness on the development of young children with or at risk for developmental disabilities (Winterberry Research Syntheses Vol. 1, No. 12). *Asheville, NC: Winterberry Press. CAROL M. TRIVETTE AND CARL J. DUNST, 196.*
- Vogel, D. L., Wester, S. R., & Larson, L. M. (2007). Avoidance of counseling: Psychological factors that inhibit seeking help. *Journal of Counseling & Development, 85*(4), 410-422.
- Webster-Stratton, C. (2000). Oppositional–defiant and conduct-disordered children.
- Webster-Stratton, C. (2001). The incredible years: Parents, teachers, and children training series. *Residential treatment for children & youth, 18*(3), 31-45.
- Wilson, B. J. (1999). Entry behavior and emotion regulation abilities of developmentally delayed boys. *Developmental Psychology, 35*(1), 214.
- Wood, E., & Rosenbaum, P. (2000). The gross motor function classification system for cerebral palsy: a study of reliability and stability over time. *Developmental medicine and child neurology, 42*(5), 292-296.
- Woodgate, R. L., Edwards, M., & Ripat, J. (2012). How families of children with complex care needs participate in everyday life. *Social Science & Medicine, 75*(10), 1912-1920.

Woodgate, R. L., Edwards, M., Ripat, J. D., Borton, B., & Rempel, G. (2015). Intense parenting: a qualitative study detailing the experiences of parenting children with complex care needs. *BMC pediatrics*, *15*(1), 197.

Yamaguchi, R., Nicholson Perry, K., & Hines, M. (2014). Pain, pain anxiety and emotional and behavioural problems in children with cerebral palsy. *Disability and rehabilitation*, *36*(2), 125-130.