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**Protective Factors and Barriers to Well-Being in Parents of Young Children with
Disabilities**

by

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A Starred Paper

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Chapter 1: Introduction

The link between poor mental health and having a child with special needs has been well documented (Baker-Ericzén et al., 2005; Hoyle et al., 2021; Kilburn & Shapiro, 2018; Norlin & Broberg, 2013; Peer & Hillman, 2014). It was accepted that a direct causal relationship existed until the late 1990s (Risdal & Singer, 2004). However, not all parents experience decreased well-being indicating that adjustment to having a child with disabilities varies and is more complex than was previously thought (Erickson Warfield et al., 1999; Kersh et al., 2006; Norlin & Broberg, 2013; Risdal & Singer, 2004). That being said, some studies have found that parents of children with developmental disabilities develop anxiety or depression five times more than parents of typically developing children (Hoyle et al., 2021). Studies focusing specifically on parents of infants and toddlers with a disability are more limited. Over the last five years, an average of 400,000 infants and toddlers, and their families, received early intervention programming as defined in Part C of the Individuals with Disabilities Education Act (IDEA) (Early Childhood Technical Assistance [ECTA] Center, 2022). Families in this stage of life are coming to terms with the fact that their child is developing atypically, making it a critical time frame in which to study parent development.

As outlined in the Individuals with Disabilities Education Act (2004), early intervention (EI) services are designed to support the family unit as a whole. Services are to reflect family priorities with the knowledge that better family functioning translates to better outcomes for the child (Crossman, Erikson Warfield, et al., 2018; Division for Early Childhood [DEC], 2014). Early Intervention best practice consists of services provided in the child's natural environment and routines-based interventions provided through a parent coaching model (DEC, 2014). This intervention methodology is supported by research which shows better outcomes for children

when interventions are embedded into daily routines (Rush & Sheldon, 2019). Parents receive coaching from EI practitioners to enrich their child's life in this way. Due to this method, heavy interaction and collaboration is needed with caregivers. It is critical to understand any stressors that could impeded a parent's ability to fully engage in services (Crossman, Erickson Warfield, et al., 2018).

Rationale for this Starred Paper

Early intervention is federally mandated to be a family-centered service. Current research on outcomes for parents of young children with disabilities who participate in early intervention programming is limited. Furthermore, the research that is available on parental outcomes focuses primarily on mothers, not fathers or other family members (Crossman, Parish, et al., 2018).

There is a need to collate the information available on caregiver outcomes to inform EI practitioners on ways to support families by better understanding the factors related to parental well-being. There is significant variation in family response to having a child with a disability exists and the pathways between variables are not consistently agreed upon (Erickson Warfield et al., 1999; Kersh et al., 2006; Norlin & Broberg, 2013; Risdal & Singer, 2004).

The importance of supporting parental well-being during early intervention is twofold. Early intervention services are designed to be family-centered so addressing parental challenges is within the scope of practice. Secondly, the literature supports a cyclical effect related to parental well-being and child outcomes (Cramm & Nieboer, 2011; Nelson et al., 2014; Peer & Hillman, 2014). A parent with positive well-being is more likely to make efficacious parenting choices which is linked to parental competence and confidence, benefiting the child (Peer & Hillman, 2014). In short, parents deserve to experience positive well-being not only because it is beneficial for them, but also because it is associated with better outcomes for their child.

The purpose of this paper is to gain an understanding of the stressors that parents of young children with disabilities face and the impact it has on caregiver well-being. The terms *caregiver* and *parent* will be used interchangeably to refer to the legal guardians of a child. Knowledge of the mechanisms and mitigating factors can then be applied to early intervention practice for the purpose of supporting parents, as individuals, and for the secondary effect of supporting their child's development.

Research Questions

This investigation will examine and address the following research questions by reviewing academic literature:

1. What are the stressors that caregivers of children with disabilities face?
2. What intervention strategies are available to support caregiver well-being?
3. What barriers exist to increasing supportive factors?
4. How does caregiver well-being factor into current best practice in early intervention?

Literature Review Organization

The literature review in Chapter Two is designed to merge findings from numerous studies to identify key variables that impact the well-being of parents of children with disabilities for the purpose of better supporting families who are participating in early intervention services. Google Scholar and PsychINFO were utilized to identify articles. Search terms, such as *early intervention*, *home visiting*, *toddlers with disabilities*, *infants with disabilities*, *developmental delay*, *parental well-being*, *parent stress*, and *caregiver well-being*, focused the search for potential sources. These articles were then narrowed down by date (1995-2022) and peer reviewed status. A variety of journals with relevant research were identified from related disciplines (i.e. child development, special education, psychology). Information was also pulled

from major organizations in the field, such as the Division of Early Childhood (DEC) and the Early Childhood Technical Assistance (ECTA) Center.

An initial review of the literature on this topic revealed several prominent researchers. They include Penny Hauser-Cram, Marji Erickson Warfield, Carl Dunst, and Morgan Crossman. One noted group of researchers (Hauser-Cram et al., 2001) completed a longitudinal investigation where data was gathered on young children with developmental disabilities and their parents from infancy to middle childhood. This seminal body of research is known as the Early Intervention Collaborative Study (EICS) and is the largest study conducted on this topic to date (Hauser-Cram et al., 2001). The raw data from the EICS was used as recently as 2018 as the foundation for new research (Crossman, Erickson Warfield et al., 2018; Crossman, Parish, et al., 2018). The current literature review will shed light onto parental well-being factors, discuss barriers to well-being, and apply this knowledge to early intervention, current best practice, and future recommendations. Table 1.1 summarizes a few of the key studies which will be used in developing chapter two.

Table 1.1

Key Studies in the Literature Review

Authors, Date, Title	Study Design	Variables	Findings
Erikson Warfield et al. 2000 <i>The effect of early intervention services on maternal well-being</i>	In-depth interview upon entrance to Part C EI services and when exiting	Stress Social Support Family Functioning	Parenting stress was positively correlated with children having motor impairment. Motor impairment was also negatively correlated with family cohesion and social support. Families with children who had cognitive delays appeared to experience greater benefits from service.

			<p>The intensity of EI services predicted positive change in social support helpfulness between entry and exit scores.</p> <p>Finally, no effects were found that EI services reduced maternal parenting stress.</p>
<p>Hauser-Cram et al. 2001</p> <p><i>Children with disabilities: A longitudinal study of child development and parent well-being</i></p>	<p>24 year longitudinal study of 183 children participating in Part C EI programs when study began</p> <p>Data taken (via interview, child assessment, questionnaires) 5 times between entry and child's 10th birthday</p>	<p>Type of Disability</p> <p>Child Factors</p> <p>Parent-related Stress</p> <p>Child-related Stress</p> <p>Child Outcomes</p> <p>Parent Assets</p> <p>Family Climate</p>	<p>Type of disability and child factors (personality, behaviors) associated with maternal stress (not paternal).</p> <p>Mother-child interaction was a predictor of child outcomes and parent well-being.</p> <p>For mothers, social support predicted change in stress. For fathers, problem-focused coping skills predicted change in stress.</p>
<p>Peer & Hillman 2014</p> <p><i>Stress and resilience for parents of children with intellectual and developmental disabilities: A review of key factors and recommendations for practitioners</i></p>	<p>Review of peer-reviewed quantitative and qualitative articles from CINAHL, PubMed, and PsychINFO databases from the years of 1986 and 2012.</p>	<p>Resilience</p> <p>Psychological Well-being (stress, anxiety, depression)</p>	<p>The following resilience factors for parents were identified: social support, optimism, coping style.</p>
<p>Crossman, Erickson Warfield, et al. 2018</p> <p><i>Associations between early intervention home visits, family relationships and competence for mothers of children with developmental disabilities</i></p>	<p>Data pulled from Early Intervention Collaborative Study (EICS)</p> <p>EICS was a longitudinal study of 190 families with children who had developmental disabilities who participated in Part C EI</p>	<p>Maternal Competence</p> <p>Intensity of EI</p> <p>Family Factors</p> <p>Helpfulness of EI</p>	<p>The researchers found the strongest relationship to be between the helpfulness of home visits and higher maternal competence. Positive family relationships were also highly associated with higher maternal competence.</p>

<p>Dunst et al. 2018</p> <p><i>Effects of contrasting approaches to the response-contingent learning of young children with significant developmental delays on parents' social-affective behavior</i></p>	<p>71 young children (average 17m old) and their caregivers (primarily mothers) split into two groups.</p> <p>Part C EI providers coded response-contingent behaviors and parent affect</p> <p>Correlational and closeness of fit statistical analyses</p>	<p>Asset-based Intervention</p> <p>Skills-based Intervention</p> <p>Self-efficacy</p> <p>Parental Affect</p>	<p>The asset-based intervention group found parents provided more child learning opportunities with desired outcomes.</p> <p>Asset-based intervention strategies had the added benefit of increasing parents' sense of self-efficacy to help their child and therefore supporting their psychological well-being.</p>
<p>Mas et al. 2019</p> <p><i>Family-centered practices and the parental well-being of young children with disabilities and developmental delay</i></p>	<p>Replication study in Spain to confirm or disconfirm relationships between variables listed in next column</p> <p>Data obtained through surveys of 415 family members recruited from early intervention programs in Spain</p>	<p>Family Centered practices</p> <p>Self-efficacy</p> <p>Parenting Confidence</p> <p>Parenting Competence</p> <p>Psychological Well-being</p>	<p>Family-centered methods were directly related to parental self-efficacy and parenting beliefs which were indirectly related to parent's psychological well-being.</p> <p>These findings were consistent with studies from North America analyzing the same variables.</p>
<p>Kilburn & Shapiro 2018</p> <p><i>The structure and function of social networks of mothers of young children with disabilities</i></p>	<p>Descriptive quantitative study</p> <p>88 mothers of children under 24m who were receiving Part C EI services</p> <p>Participants had two home visits where informed consent and completion of assessments occurred to gather data.</p>	<p>Social Support</p> <p>Stress</p> <p>Depression</p> <p>Anxiety</p>	<p>Connection between mother's mental health and certain types of support that can mitigate stress of having a child with disabilities.</p> <p>Emotional support had the biggest impact on stress.</p>
<p>Hoyle et al. 2021</p> <p><i>Mental health risks of parents of children with developmental disabilities: A</i></p>	<p>Longitudinal correlational study using data from Panel Study of Income Dynamics (1997-2017)</p>	<p>Stress</p> <p>Depression</p> <p>Anxiety</p> <p>Life Satisfaction</p>	<p>Parents of children with developmental disabilities were significantly correlated with an increase in mental health issues.</p> <p>Mothers were found to be 3x more likely to have anxiety or</p>

<i>nationally representative study in the United States</i>		Child Factors	depression and fathers were 2x more likely than parents who didn't have a child with a developmental disability.
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Definitions

Well-being: Psychological status impacted by positive emotions (happiness, confidence, competence, self-esteem) and negative emotions (stress, anxiety, hopelessness) (Nelson et al., 2014).

Stress: The result of perceived inability or difficulty handling “environmental transactions” (Peer & Hillman, 2014, p.94).

Resilience: The ability to withstand and recover from adverse experiences without negative impacts on one's well-being (Peer & Hillman, 2014).

Individuals with Disabilities Education Act (IDEA): The most recent federal law that outlines and regulates special education services (IDEA, 2004).

Early Intervention (EI): Federally mandated family-centered service provided to young children (age 0-3) who have been found to have a condition known to hinder development or show a delay in one or more areas of development as defined by Part C of IDEA (2004).

Individual Family Service Plan (IFSP): A document created after a young child is found to be eligible for EI services. It must include the child's present level of development in all five domains (cognitive, social-emotional, communication, physical, and adaptive), the family's resources, priorities, concerns for the child, measurable outcomes (goals), services to be provided (including frequency, intensity, and method), list of team members, and steps for transition when the child turns three (IDEA, 2004).

Young child with a disability: A child under the age of three that has been found to be eligible for Part C EI services (IDEA, 2004).

Chapter 2: Literature Review

The purpose of this paper is to gain an understanding of the factors that impact caregiver well-being in order to best support families in the context of EI. The following section describes a brief overview of EI and the due process requirements that guide programming.

History of Early Intervention (EI)

Early intervention, in its broadest sense, can refer to any program/action developed to support individuals who are at risk for poor outcomes. For the purpose of this paper, early intervention, or EI, will refer specifically to services outlined by Part C of the Individuals with Disabilities Education Act (IDEA). Early intervention is designated as a home visiting program to support infants and toddlers (birth to age 3) that have a delay in one or more areas of development or have a condition known to hinder typical development (IDEA, 2004). The five areas of development include cognitive, physical, communication, social emotional, and adaptive development (IDEA, 2004). In Minnesota, Part C services are provided free of charge through the public education system.

In the larger world of special education, students can qualify for support by meeting criteria in a variety of different categories (i.e. autism spectrum disorders, specific learning disabilities) (Minnesota Department of Education [MDE], 2022). However, since the future needs of an infant or toddler are hard to predict, a category specific to early childhood special education (ECSE) is often used called developmental delay. This allows for young children (age 0-6) who are “at risk” to be serviced preventatively without needing a diagnosis (IDEA, 2004).

Once a child has been found to be eligible, an individual family service plan (IFSP) is developed with the IFSP team (Early Childhood Technical Assistance Center, 2022). Members of this team vary depending on the child’s needs but must include the primary caregivers and a

service coordinator. Additional team members may include, but are not limited to, special education teachers, speech language pathologists, occupational therapists, physical therapists, psychologists, social workers, deaf/hard of hearing teachers, childcare providers, and vision teachers (IDEA, 2004). The individuals that develop the IFSP and provide services are referred to using a variety of terms such as early interventionist, practitioner, provider, or home visitor (Edwards, 2020). Services are designed to take place in environments where young children without disabilities spend most of their time, often the child's home or daycare (Early Childhood Technical Assistance Center, 2022).

Best Practice in Early Intervention

Recommended practice in early intervention has been summarized into seven competency areas by the Division for Early Childhood (DEC). These areas include leadership, assessment, environment, family, instruction, interaction, teaming and collaboration, and transition (DEC, 2014). The outcome most related to this discussion is *family*, which features the following themes: family-centered practice, family capacity-building practices, and family and professional collaboration. The DEC encourages interventionists to support family-identified goals (DEC, 2014). This means that the goals written in the IFSP should be based on what parents would like to work on. Interventionists are to take cultural and familial factors into account when building relationships and understanding family priorities. The same interventionist, or primary service provider, is encouraged to stay with the family to support relationships building and rapport (Rush & Sheldon, 2019).

Another competency area, *instruction*, informs on what interaction between interventionists and caregivers should look like (DEC, 2014). Parent coaching and embedding learning opportunities through a strengths-based approach yields the best outcomes (DEC, 2014).

Dunst et al. (2018) describes strengths-based, or asset-based, intervention as using “existing child behaviors as contingency behaviors” (p.3) meaning that current behavior is reinforced and shaped to reach the desired outcomes. The DEC supports asset-based practices as a means to encourage parental competence and confidence (2014). Historically, intervention has utilized a needs-based approach. The problem with that approach is that it requires more effort from the child to be successful because the focus is on missing skills, rather than shaping current skills (Dunst et al., 2018). Research shows that families who are taught to use a strengths-based approach are more likely to embed learning opportunities during daily routines (Crossman, Erickson Warfield, et al., 2014; DEC, 2014; Dunst, 2000; Dunst et al., 2018; Rush & Sheldon, 2019). This is called embedded learning (Dunst, 2000) or routines based intervention (Rush & Sheldon, 2019) in the literature and has been shown to yield better outcomes for both children and their caregivers.

Parental Well-being Variables

Well-being has been defined numerous ways in the literature. For this study, well-being is conceptualized as a psychological construct that is positively or negatively impacted by emotional responses to experiences (Nelson et al., 2014). This broad representation allows for articles that only analyze one factor of well-being, such as confidence, to be included. The specific variables of well-being that each investigation measured will be noted when describing the studies for the purposes of this literature review. In consistency with the literature, *subjective well-being*, *psychological well-being*, and *well-being* will be used interchangeably (Nelson et al., 2014).

The self-determination theory provides a framework for understanding the mechanisms by which having a child with special needs impacts well-being. This theory posits that the

fulfillment of three basic needs (autonomy, competence, and connectedness) is necessary to experience optimal psychological well-being (Deci & Ryan, 2008). For parents of children with special needs, there are inherent barriers to autonomy, competence, and connectedness that other parents don't face in the same way which will be discussed further below.

Other researchers have developed a simpler model to understand caregiver well-being (Cramm & Nieboer, 2011; Graungaard et al., 2011). They view stress as the mediating factor for parents of children with intellectual disabilities. Cramm and Nieboer (2011) used several layers of statistical analysis to control for independent variables and concluded that stress was the underlying factor that connected all other variables to decreased well-being. To understand intervention strategies that may support caregiver well-being, the factors that impact well-being must first be established.

Parental Competence

While positing on the mechanisms that impact well-being, Nelson et al. (2014) theorized that the positive emotions resulting from "children's first words or steps" boost well-being (p. 23). Therefore, if a child is not reaching developmental milestones in a timely manner, parenting stress may increase. When parenting children with disabilities, commonly accepted parenting strategies are not always effective. If the parenting strategy used generates the desired outcome, parental confidence is boosted (Dunst et al., 2018). Parental competence has been found to correlate with enjoyment, gratification, satisfaction, and positive social-affective behavior. These factors are commonly accepted to relate directly to psychological well-being (Nelson et al., 2014; Ritchie & Bryant, 2012). Since competence is related to well-being, parents who perceive themselves as less competent may experience decreased well-being. Parents that feel competent (i.e. are confident) in their parenting roles are more likely to support their child to optimal

outcomes (Crossman, Parish, et al., 2018). Nelson et al. (2014) concluded that there are reciprocal effects between parenting and well-being demonstrating that effective parenting is positively associated with caregiver well-being.

Crossman, Erickson Warfield, et al. (2018) found that the perceived helpfulness of EI and positive social support are the only two factors associated with higher maternal competence when they exited the program (at age three) when controlling for other variables such as child and family characteristics. Maternal competence was assessed using a subscale of the Parenting Stress Index. Crossman, Erickson Warfield, et al. (2018) found that positive familial relationships were associated with higher perceived maternal competence. Fathers who started with high parental competence demonstrated consistence levels of competence and confidence in their parenting skills throughout early childhood. In contrast, fathers who started with lower parental competence experienced decreasing competence and confidence as their child aged (Crossman, Parish, et al., 2018). This supports the notion of competence as a protective factor for caregiver well-being.

Parental Social Support

Supportive relationships are a mitigating factor for parents with and without children with disabilities (Bost et al., 2002; Crossman, Parish, et al., 2018; Graungaard et al., 2011; Hoyle et al., 2020; Kilburn & Shapiro, 2018; Nelson et al., 2014; Peer & Hillman, 2014). Parents in emotionally connected families are more likely to exhibit positive well-being (Erikson Warfield et al., 1999). Bost et al. (2002) found that new parents with strong supportive relationships experienced less depressive symptoms and more positive feelings towards parenthood. This finding is supported by Erikson Warfield et al. (1999) who concluded that support from immediate family members was positively associated with individual adaption to parenthood.

Hauser-Cram et al. (2001) also found social support to predict parent-related stress for both mothers and fathers. Parents who have a lack of social support or have “non-empathic social relations” experience decreased emotional parenting capacity (Graungaard et al., 2011, p.129). In other words, non-supportive relationships can be toxic in situations where emotional resources are already limited due to the challenges of parenthood.

Spouse or Partner Relationship

Kilburn and Shapiro analyzed different types of support persons and support given on maternal psychological well-being for mothers of children with disabilities (2018). They found mothers who reported high concrete support (assistance with daily care tasks) provided by a spouse/partner were less likely to show depressive symptoms. Interestingly, for fathers, non-spousal social support was most indicative of parental competence (Kersh et al., 2006). Research has shown that the quality of the relationship between parents is associated with parental and child well-being, both for families with and without special needs children (Norlin & Broberg, 2013).

Norlin and Broberg (2013) found that marital quality was a better predictor of well-being than the child’s ability status or their frequency of undesirable behaviors. Similarly, analyses by Kersh et al. (2006) suggested that marital quality was a greater predictor of parenting stress and depression than child characteristics and socioeconomic status in both mothers and fathers. Nelson et al. (2014) note that couples who disagree on child rearing practices have decreased marital satisfaction which is related to well-being. This type of conflict can be a significant source of stress and occurs more frequently in families who have a child with disabilities (Kersh et al., 2006; Nelson et al., 2014). A slight increase in the likelihood of divorce (2.9% to 5.9%) for parents of a child with special needs has been established in the literature (Risdal & Singer,

2004). This suggests a direct effect between marital quality and parenting stress (i.e. better marriage, less child-rearing stress).

Support Provided by Professionals

Emotional support provided by professional helpers, i.e. early interventionists, predicts decreased stress levels in parents of children with disabilities (Kilburn & Shapiro, 2018). This finding supports the DEC recommended practice of building emotionally responsive relationships with families (DEC, 2014). The availability and helpfulness of formal support systems has been linked to mental health outcomes for parents in recent research by Hoyle et al. (2020) and is consistent with the literature (Cramm & Nieboer, 2011; Kilburn & Shapiro, 2018). One study found that intensity of EI services predicted increased feelings of support (Erikson Warfield et al., 2000). From these findings, it can be posited that frequent interaction with the early interventionists may allow for supportive relationships to be developed, therefore impacting caregivers feelings of social support.

Access to the Community

A family's ability to engage in their community may impact caregiver well-being in several ways. Parents who are active members of their community experience more daily variety, more opportunities to share in memory making as a family, and more social interaction (Nelson et al., 2014). However, research studying the impact of having a child on parental social network size is inconsistent (Cramm & Nieboer, 2011). It is logical that parents have less leisure time and therefore less resources to spend on building and maintaining social relationships (Nelson et al., 2014). It is also plausible that social network size increases with the birth of a child as family/friends may now be assisting with childrearing activities. Once the child is older, parents may find friendship other parents met through extracurricular activities. However, not all

activities are accessible or accepting of special needs children (Cramm & Nieboer, 2011).

Restriction in social activities is linked to parent stress indicating that the opportunity to socialize with others is a beneficial behavior for parents of children with special needs. Cramm and Nieboer's (2011) work expands upon the importance of social support, not only for concrete support, but also as an emotional or physical respite from child rearing activities.

Parental Attitude

Peer and Hillman (2014) identified coping style and optimism as significant factors in their meta-analysis on stress and resilience in parents with children with disabilities. While the authors noted that coping style and optimism may be areas for intervention, these factors are often also considered a personality trait. This paper will consider these variables to be both a personality trait and something that can be improved through environmental transactions.

Coping Skills

Coping styles are often broken down into two types: problem-focused and emotion-focused (Peer & Hillman, 2014). Research shows that problem-focused coping is more effective at mitigating stress in the long-term. This is true for parents of children with disabilities regardless of the level of functioning of the child (Erickson Warfield et al., 1999; Graungaard et al., 2011; Peer & Hillman, 2014). Problem-focused coping strategies identify a stressor and develop a plan to address the stressor which parallels best practice for goal writing in EI (Division for Early Childhood, 2004). Baker-Ericzén et al. (2005) found that providing education on positive coping strategy for parents of toddlers with autism spectrum disorder successfully improved their ability to cope with stress. They concluded that participants experienced decreased guilt, negative thoughts, feelings of inadequacy, and other depressive symptoms after

completing the program. Hauser-Cram et al. (2001) also found that problem-focused coping predicted a decrease in both paternal and maternal parent-related stress.

Positive Outlook

Optimism, or the expectation of positive outcomes, is also linked to parental well-being (Peer & Hillman, 2014). Parents who experience greater positive affect, meaning in life, and have their basic needs met report more contentment and satisfaction in their life (Nelson et al., 2014). Furthermore, positive affect significantly correlates with successful parenting behaviors (Peer & Hillman, 2014). Graungaard et al. (2011) found that *positive reappraisals*, i.e. finding positives in challenging situations, significantly influenced well-being and coping skills, even when other variables were held constant. In this way, optimism refills parents' emotional resources in order to continue caring for their special needs child despite adversity (Graungaard et al., 2011).

Child Factors

One might expect that the child's level of functioning would be a significant factor in parental well-being. Most research suggests that this isn't the case (Cramm & Nieboer, 2011; Dunst et al., 2007; Erikson Warfield et al., 1999; Olsson & Hwang, 2008; Woodman et al., 2015). For example, Erikson Warfield et al. found that factors not directly related to the child's ability level, such as family cohesiveness, income, and social support, were most predictive of parental stress (1999). In contrast, Hauser-Cram et al. (2001) noted changes in child and parent related stress levels for mothers depending on the child's type of disability. Similarly, Norlin and Broberg (2013) found that the child's cognitive status was the second strongest predictor of maternal well-being, after marital quality. The child related factor that is most consistently

associated with stress in the literature is behavioral problems (Cramm & Nieboer, 2011; Woodman et al., 2015).

The relationship between the parent and child can be impacted negatively when the child demonstrates higher than average negative emotions (Nelson et al., 2014). Mother-child interaction has shown to be a significant predictor of parental well-being and child outcomes (Hauser-Cram et al., 2001). It is accepted that children with disabilities demonstrate higher levels of externalizing behaviors than their typically developing peers which makes this a risk factor for caregiver well-being (Woodman et al., 2015). Nelson et al. (2014) found that parents of children with difficult temperaments consistently rated themselves lower in regards to their competence as parents.

Woodman et al. (2015) examined the relationship between maternal stress and child behavior problems at five age points between three and eighteen. Problem behaviors were further broken down into internalizing (i.e. anxiety, social withdrawal, and sadness) and externalizing behaviors (i.e. aggression, impulsiveness, non-compliance, hyperactivity). Maternal parenting stress and externalizing behaviors were found to have significant bidirectional effects at all ages (Woodman et al., 2015). Bidirectional effects have also been noted in the literature for internalizing behaviors and parenting stress (Cramm & Nieboer, 2015; Woodman et al., 2015). This indicates that child behaviors are associated with higher maternal stress. The reverse is also true: higher maternal stress is associated with increased child behaviors. These findings reinforce the need to address parental well-being as a means to support child development.

Family Factors

The primary family characteristic related to parental well-being in the literature is economic status (Dunst et al., 2007; Eisenhower & Blacher, 2006; Emerson et al., 2006; Erikson

Warfield et al., 1999; Kersh et al., 2006). Some researchers have found that around half (48%-67%) of the variation in adjustment to having a child with special needs can be explained by differences in socioeconomic status (SES) (Eisenhower & Blacher, 2006; Emerson et al., 2006). SES encompasses a variety of family economic variables such as income, social class, educational attainment, and financial security. The findings of Dunst et al. (2007) suggest that family income and socioeconomic status directly impact parent and family well-being. Families with higher income reported less parenting stress in the study by Erikson Warfield et al. (1999). While having children in general is a financial strain (Nelson et al., 2014), families who have a child with a disability are more likely to experience economic hardship (Emerson & Hatton, 2007). This may be due to a loss in income (inability to work as many hours outside the home due to therapy appointments, doctor's appointments, extra care needs) and additional costs (i.e. special equipment, therapy/medical bills) (Baker-Ericzén et al., 2005).

Not all researchers agree that low income alone is a risk factor for decreased well-being, however. Norlin and Broberg (2013) found that economic hardship is the mediating factor between income and well-being. Hardship is defined as “the number of items a family would like to have but could not afford” (Olsson & Hwang, 2008, p.1109). High economic hardship has been correlated with decreased well-being for fathers (Norlin & Broberg, 2013) and mothers (Olsson & Hwang, 2008).

Hoyle et al. (2021) found a higher rate of children with developmental disabilities in the lowest income group. This parallels previous research which found that low SES, poor parental mental health (i.e. well-being), and childhood disability demonstrate higher than expected comorbidity (Kersh et al., 2006). It is accepted that low SES individuals experience mental

health conditions such as depression at higher rates than the general public (Kersh et al., 2006). For families with a child with disabilities, this holds true.

Stress

Some researchers view stress as a risk factor to well-being (Norlin & Broberg, 2013) while others view it as a measurable outcome of well-being (Kersh et al., 2006). Stress is the result of perceived inability or difficulty handling “environmental transactions” (Peer & Hillman, 2014, p. 94). Elevated levels of stress can lead to clinical disorders such as anxiety or depression. The present study will consider stress to be an additional risk factor and mediating factor for well-being.

Children add additional stress to the family dynamic for all parents (Nelson et al., 2014). However, parents of children with disabilities have been found to have elevated levels of the stress hormone, cortisol (Graungaard et al., 2011). The care provided for children with disabilities often requires physical, emotional, social, and financial resources above and beyond what is needed for typically developing children and may not decrease as the child ages (Cramm & Nieboer, 2011).

In the literature, stress is broken down into two categories: child-related stress and parent-related stress. Child-related stress was defined by Erikson Warfield et al. (1999) as “stress associated with the child’s behavioral or temperamental characteristics such as demandingness, mood, and adaptability” (p.10). The aforementioned study defined parental stress as “stress associated with maternal adjustment to the parenting role” (p.10). This definition can be expanded to include any parent, not just mothers. The impact that parent-related and child-related stress have on parental well-being is not consistent in the literature. Some studies find that only parental stress is significantly correlated with caregiver well-being (Cramm & Nieboer,

2011) while others (Erickson Warfield et al., 1999) suggest that child-related stress is more closely related to parental well-being.

Stress has been determined to both directly and indirectly impact parenting styles (Fonseca et al., 2020). Parents who are experiencing significant levels of stress may not have the capacity to parent in a structured and emotionally responsive way. This reinforces the cyclical impact of parental well-being on child outcomes as started earlier. Research indicates positive outcomes for children who grow up in a structured and emotionally responsive home which aligns with the authoritative parenting style (Baumrind, 2013). Supporting parents to decrease their stress levels may be an effective intervention to improve the well-being of the parent and child.

Interventions to Improve Well-Being

Since stress appears to be a key factor in understanding parental well-being, interventions that reduce stress and/or boost coping skills are needed. Graungaard et al. (2011) discuss parenting capacity in terms of *emotional resources* (i.e. mental/emotional capacity to address challenging situations). Nine methods to protect and generate emotional resources for parents of young children with significant developmental or medical disorders were identified by Graungaard et al. (2011). These include emotional bonding, identifying supportive social relations, creating mental respite, meaning making, benefit finding (positive reappraisals), evaluating existential beliefs, taking action, normalization, and maintaining hope (Graungaard et al., 2011). Many of these themes are similar to the protective factors previously addressed such as social support (*identifying supportive social relations*) and coping skills (*benefit finding, taking action, maintaining hope, creating mental respite*).

Emotional resource creation was strongest when parents focused on the parent-child relationship (Graungaard et al., 2011). For families of child with significant negative behavior, this strategy could be particularly beneficial. Experimental research shows that happiness can be increased intentionally by increasing exposure to positive activities (Nelson et al., 2014). Another pathway, *positive reappraisal* (i.e. finding the positives in a given situation), was found to improve optimism, self-efficacy, and feelings of control. Interestingly, positive emotions seemed to act in a way that preserved emotional resources and mitigated the paralyzing feeling of stress, without actually decreasing the participant's stress levels (Graungaard et al., 2011). This knowledge can be applied to EI through the use of strengths-based intervention. Crossman, Parish, et al. (2018) also call for the use of strengths-based approaches that focus on developing parental resilience and competence, aspects of well-being.

Parenting self-efficacy is associated with parental competence, confidence, and psychological well-being (Mas et al., 2019). The DEC recommended practices suggest that supporting the development of parental competence and confidence is a key outcome for effective early intervention (2014). Teaching families to embed learning opportunities is one aspect of recommended practice that has been found to increase child skill and decrease parental stress (Baker-Ericzén et al., 2005). Mas et al. (2019) confirmed the findings from previous researchers, Dunst and Trivette (2009) and Dunst et al. (2007), who found a positive effect on parenting self-efficacy for families that participated in a family-centered early intervention program. When families report feeling in control of their child's programming, better outcomes for the child are observed (Crossman, Erickson Warfield, et al., 2018; Dunst et al., 2007). Mas et al. (2019) noted significant positive correlations between the family-centered practices amongst these five variables: relationship building, parent participation, parenting competence, parenting

confidence, and positive parental well-being. While this data is correlational, it suggests that following early intervention best practice, specifically in regards to parent engagement and family centered practice, may encourage parental well-being.

Literature Summary

The literature revealed a complex relationship between having a young child with disabilities and parental well-being. There is significant variation in individual response to having a child with disabilities (Norlin & Broberg, 2013; Risdal & Singer, 2004; Erickson Warfield et al., 1999; Kersh et al., 2006). Successful adaptation “is dependent on the interplay between risk and protective factors” (Olsson & Hwang, 2008, p. 1103). Having a child with a disability, in and of itself, does not appear to directly impact parental well-being. Some research indicates that the parental response to having a child with special needs (i.e. coping skills, optimism) is most significantly related to their ability to function adaptively, therefore protecting their psychological well-being (Graungaard et al., 2011).

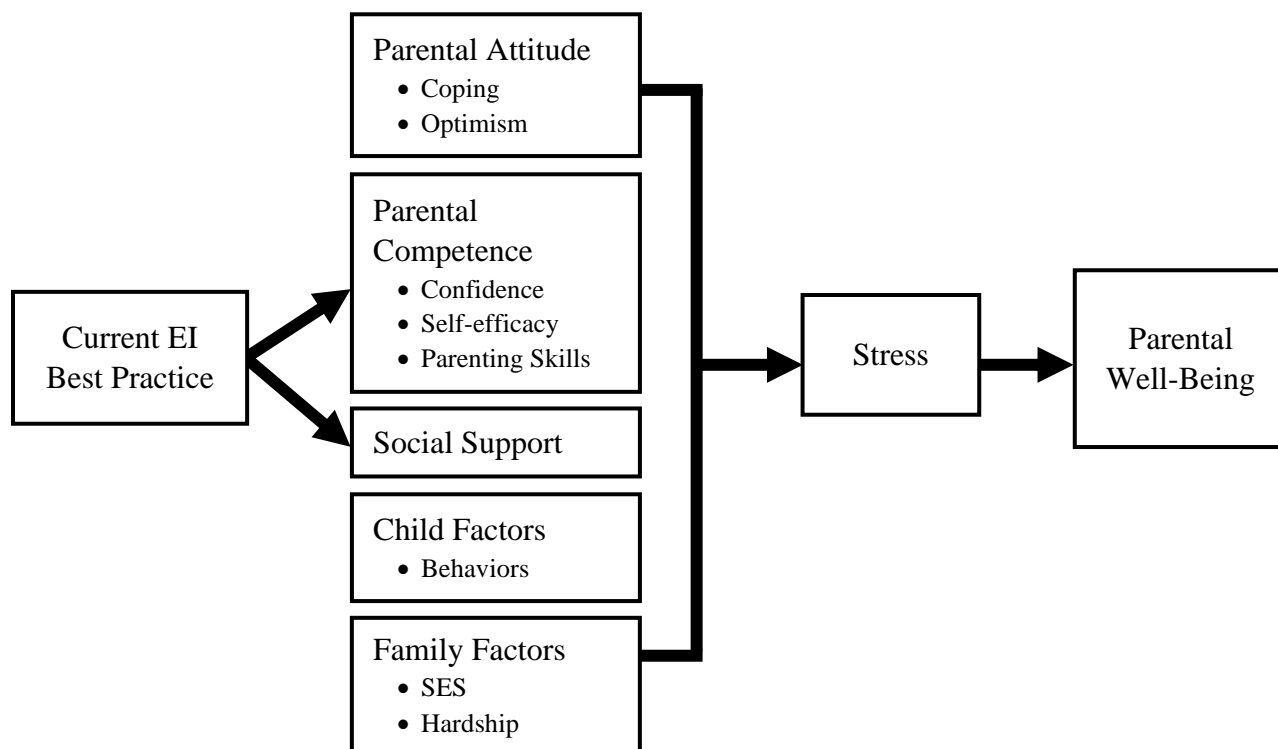
In the context of early intervention, this information can be merged with the current recommendations for best practice. Family-centered practices are designed to build parental competence through addressing outcomes (goals) that the family determines (DEC, 2014). These goals may be related directly to the child (i.e. reducing unwanted behaviors) or indirectly, through addressing larger family needs (i.e. support accessing mental health services). Decreased parental stress, improved parental competence, and improved child outcomes are associated with current recommendations for best practice, particularly the use of strengths-based interventions such as embedded learning opportunities (Dunst et al., 2018; Rush & Sheldon, 2019).

In the literature, variables were identified that impacted parental well-being. These variables were coded into five themes including: parental competence, parental social support,

parental attitude, child factors, and family factors. Cramm and Nieboer (2011) and Graungaard et al. (2011) posit that stress, more specifically, the response to stress, is the key mediating factor in whether or not parents of children with disability experience decreased well-being. Figure 2.1 illustrates a simplified model to aid in understanding the relationships between current best practice, the five well-being variables, stress, and parental well-being. These relationships have been identified and combined from multiple studies to generate Figure 2.1. The implications of Figure 2.1 will be addressed further in Chapter 3.

Figure 2.1

Model of Parental Well-Being Variables and EI Best Practice



Chapter 3: Results

It is widely accepted that parents of children with special needs experience decreased well-being when compared to parents of typically developing children (Baker-Ericzén et al., 2005; Hoyle et al., 2020; Kilburn & Shapiro, 2018; Norlin & Broberg, 2013; Peer & Hillman, 2014). However, there is significant individual variation in the outcomes of parents of children with disabilities (Erickson Warfield et al., 1999; Kersh et al., 2006). The early childhood stage of parenting a child with disabilities is unique since most child's disabilities are first identified during this stage. For individuals who work with this population, an understanding of the variables that impact parental well-being is needed in order to best serve families.

Conclusions

The literature review was guided by four questions that are directly answered below:

1. What are the stressors that caregivers of children with disabilities face?

The stressors unique to families of children with disabilities include the anticipation of future care and intensity of care which have been linked to mental health outcomes for parents (Hoyle et al., 2020). All caregivers face a range of life stressors such as loss of income, moving, death of family member, and marital conflict. However, parents of children with disabilities appear to experience marital conflict and loss of income more often than parents of typically developing children (Olsson & Hwang, 2008). Parents of children with disabilities may incur extra costs to cover therapies, transportation, equipment, and childcare. Mothers of children with disabilities are less likely to be employed resulting in a loss of income or opportunity for income (Emerson & Hatton, 2007).

2. What intervention strategies are available to support caregiver well-being?

Utilizing recommended best practices during EI such as relationship building, focusing on family priorities, embedding learning opportunities, and parent coaching have been shown to improve parental confidence, competence, and self-efficacy (Dunst et al., 2007; Dunst & Trivette, 2009; Mas et al., 2019; Nelson et al., 2014). Parental confidence, competence, and self-efficacy are variables that predict parental well-being suggesting that following best practice is an intervention in and of itself. Graungaard et al. (2011) outlined nine coping strategies that were shown to preserve and generate emotional resources needed to successfully navigate having a child with disabilities. These include emotional bonding, identifying supportive social relations, creating mental respite, meaning making, benefit finding (positive reappraisals), evaluating existential beliefs, taking action, normalization, and maintaining hope.

3. What barriers exist to increasing supportive factors?

While individual barriers may vary, common themes include barriers to access to supports and parental fatigue. For parents of a child with a disability, it can be challenging to attend social activities to support their personal well-being due to lack of appropriate childcare (Cramm & Nieboer, 2011). Accessing supports located within the community can also be challenging. While there are numerous programs designed to support families with children with disabilities, navigating the system can be overwhelming. Parents may not have the cognitive means to locate or financial means to secure these types of services (Cramm & Nieboer, 2011). Hoyle et al. (2021) also noted cultural and language barriers exist to accessing and understanding services available.

In order for programs such as EI to be beneficial, parental engagement and involvement is needed (Crossman, Erikson Warfield, et al., 2018). For parents experiencing psychological

distress, active participation in an intervention program may be difficult. For parents of children with disabilities, sleep disturbances can extend past infancy as is common with certain disorders, such as autism spectrum disorders. Experiencing high stress for prolonged periods of time can also impact sleep along with emotional regulation systems. A lack of sleep impacts cognitive functioning, particularly our ability to regulate emotions and use efficacious coping strategies (Nelson et al., 2014). This researcher also suggests that a lack of training for interventionists on parental well-being is a current barrier in the field.

4. How does caregiver well-being factor into current best practice in early intervention?

Caregiver well-being factors into current best practice as an outcome of current best practice. Utilizing best practice (i.e. family-centered practice, embedded learning opportunities) has outcomes such as increasing parenting self-efficacy, competence, and confidence (Dunst et al., 2007; Dunst & Trivette, 2009; Mas et al., 2019; Nelson et al., 2014). All three of these variables are considered to be indicative of parental well-being (Mas et al., 2019). There is also evidence that parental well-being is positively impacted when interventionists provide social support through relationship development (Cramm & Nieboer, 2011; Erikson Warfield et al., 2000; Hoyle et al., 2020; Kilburn & Shapiro, 2018). Other factors of well-being such as parental attitude (i.e. coping skills, optimism), child factors, and family factors (i.e. SES, hardship) are not explicitly defined in the literature as outcomes of best practice. However, the use of family-centered practice allows for early interventionists to address any of the five areas if they are deemed important by the family (Pratt, 2012).

Discussion and Reflections

When I first began researching this topic, I wrongfully assumed that having a child with special needs would always impact parental well-being negatively. Based on the current review

of the literature, this is not the case. There is significant variation in psychological well-being outcomes for parents of young children with special needs (Erikson Warfield et al., 1999; Kersh et al., 2006). Understanding why some parents navigate having a child with special needs with relative ease can inform interventions to support parents who are struggling. However, the factors impacting well-being are complex and are not always consistent in the literature.

Parental well-being is best understood within the larger context of the individual's life which includes their social support, parenting skills, disposition, child's disposition, culture, and socioeconomic status (Olsson & Hwang, 2008). Consideration should be given to understanding the interplay between risk and protective factors. It is likely that the ability for protective factors to mitigate risk factors varies, based upon the individual's unique set of circumstances. It is also likely that the combination of certain risk factors exacerbates the challenging aspects of having a child with special needs (Nelson et al., 2014).

In this review of literature, the independent variables that were supported by multiple studies were grouped into five themes. These include parental competence, social support, parental attitude, child factors, and family factors. The overarching theme of *stress* emerged as a mediating factor in some research (Cramm & Nieboer, 2011; Graungaard et al., 2011; Norlin & Broberg, 2013) and a measure of well-being in others (Kersh et al., 2006; Olsson & Hwang, 2008; Peer & Hillman, 2018). Many factors of well-being appear to be interrelated and exhibit direct and indirect relationships which adds to the complexity of this topic. Figure 2.1 demonstrates a simplified model of these relationships with stress as a mediating factor.

The body of literature reviewed suggests that parental stress should be considered when recommending best practices and when evaluating the effectiveness of early intervention programs (Baker-Ericzén, 2005). Parents who exhibit lower levels of stress are more likely to

have children with better developmental outcomes (Olsson & Hwang, 2008). This supports the notion of reciprocal effects between parental well-being and child outcomes which calls for interventions that address both parental well-being and child behavior simultaneously. The results of early intervention impact trajectories for maternal stress and child behavior into adulthood, reinforcing the significance of effective EI programming (Woodman et al., 2015).

The primary purpose of this study was to determine if current best practice addresses caregiver well-being. When EI best practice is done with fidelity, parental competence (Dunst et al., 2007; Dunst & Trivette, 2009; Mas et al., 2019; Nelson et al., 2014) and social support (Cramm & Nieboer, 2011; Erikson Warfield et al., 2000; Hoyle et al., 2020; Kilburn & Shapiro, 2018) are improved. Although only two factors show clear connections to best practice at this time, all five factors of well-being can be addressed. Early interventionists can and should be addressing the family's concerns and priorities which can vary from visit to visit (Pratt, 2012). It is within the early interventionist's scope of practice to boost familial protective factors by utilizing best practice, helping parents develop adaptive coping skills, addressing child behavior, and sharing resources to ensure that their basic needs are being met. Early interventionists are in a unique position to identify and boost well-being protective factors for the families that they work with.

Recommendations for Future Research

There is a need for additional research to truly understand the factors and mechanisms at play. A list of recommendations for future studies is listed below based on identified gaps in the literature that are supported by other researchers.

1. Research Focusing on Part C EI Families

While early intervention, as outlined in Part C of IDEA, is a specific program to the United States, it should be prioritized as a subject of research to determine its effectiveness, particularly in relation to parental outcomes. The DEC's recommended practices consider parental competence to be a primary goal because of the known positive impact on developmental outcomes for the child (2014). However, relatively little research on parental outcomes for this demographic (children ages 0-3) has been conducted (Hoyle et al., 2021).

2. Longitudinal Research

Additional information is needed to determine which supports and services impact family well-being over time (Crossman, Parish, et al., 2018; Turnbull et al., 2007). It may be that early childhood is a unique time for parenting a child with a disability. This idea is supported by the increased rate of depression in mothers who experienced negative life events while their children were in the early childhood stage (Erikson Warfield et al., 1999). Woodman et al. (2014) noted differences in maternal stress and which factors related to stress at multiple age points between three and eighteen. Another study found that parental stress was consistent but child-related stress increased through early childhood (Erickson Warfield et al., 1999). Longitudinal work is needed to further the understanding of parental well-being over time (Cramm & Nieboer, 2011; Risdal & Singer, 2004).

3. Research including Fathers

Multiple studies noted the lack of literature focusing on fathers of children with disabilities (Baker-Ericzén et al., 2005; Crossman, Parish, et al., 2018; Kersh et al., 2006; Olsson & Hwang, 2008). Olsson and Hwang (2008), included fathers of children with intellectual disabilities and found that, unlike mothers, fathers had similar levels of depression when

compared to fathers of typically developing children. Another noted difference found by Kersh et al. (2006) is that child self-injury behavior was associated with decreased well-being for fathers but not mothers. Norlin and Broberg's hypothesis that parents of children with intellectual disability experience decreased well-being was only confirmed for mothers (2013). Given that the limited research shows differences between paternal and maternal outcomes, additional research is needed.

4. Research on Diverse Populations

Research focusing on diverse populations is needed to understand how factors such as culture, socioeconomic status, ethnicity, and child diagnosis impact parental well-being. Research across different cultures, focusing specifically on infants and toddlers with disabilities and their families, is limited (Turnbull et al., 2007). Furthermore, the diverse research that exists on this topic is not in agreement. Hoyle et al. (2021) found differences in anxiety/depression rates between Hispanic, white, and black mothers of children with developmental disabilities. In contrast, Mas et al. (2019) found similar relationships between variables when attempting to replicate an American study by Dunst et al. (2007) in Spain. Both of these studies created correlational models to understand the relationships between family-centered practices, parenting beliefs, and parental well-being. Early intervention families also differ significantly in their child's disability status and needs. Erikson Warfield et al. (2000) found differing outcomes for parents of children with cognitive vs. motor delays. In order to be able to generalize findings on this topic, additional research is needed that includes, and compares, outcomes for families with different demographics.

Recommendations for Practice

It is said that it takes an average of seventeen years for research to go into practice (Niven, 2017). The value of supporting the whole family during early intervention was established in the 1990s (Erickson Warfield et al., 1999). The research on this topic has largely remained consistent over the past twenty years. While there is more research to be done to understand specific processes, there is enough research to support the implementation of these recommendations.

1. Address parental well-being

Since the literature is clear on the impact of stress for both caregiver and child outcomes, it is prudent to take data and address family well-being by providing emotional support and education on efficacious coping strategies. Research indicates that data on family well-being is rarely gathered during services (Crossman, Parish, et al., 2018). Early intervention programs should consider implementing a measure of social support and/or family cohesion (Erickson Warfield et al., 1999).

Collect Data on Family/Caregiver Wellbeing

In order to address parental well-being, early interventionists will need to gather data on family well-being. This can be achieved a number of ways. Tools such as the Beach Center Family Quality of Life Survey (Beach Center on Disabilities, 2006) or Family Outcomes Survey-Revised: Part C (Early Childhood Outcomes Center, 2010) have already been created for this purpose. Early intervention teams may choose to develop a set of questions structured as a questionnaire or interview to be incorporated into the initial evaluation of the child. In the IFSP, there is a section, titled *Family Directed Assessment*, which allows for families to share their concerns, priorities, resources, supports, and services (Pratt, 2012). Early interventionists should

use this opportunity to explain what family-centered practices mean and to gather information on family functioning. Creating this precedent during the first few visits allows for early interventionists to revisit, monitor, and address changes in parental well-being.

Provide Emotional Support

One study found that early interventionists “rarely” provided emotional support at every visit with families (Kilburn & Shapiro, 2018). However, emotional support was the only statistically significant variable that they analyzed in relation to professional helpers’ (i.e. early interventionists’) ability to decrease stress for mothers (Kilburn & Shapiro, 2018). Since early intervention requires significant collaboration between practitioners and caregivers, supportive relationships should be development. Providing emotional support is a part of healthy relationship development. If additional support is needed, early interventionists may assist families in growing their formal or informal support networks (Crossman, Parish, et al., 2018). This may consist of connecting a family with local parenting support groups, early childhood family education classes, or other families in the program (if allowed based on privacy regulations).

Support Caregiver Development of Coping Skills

Early intervention teams should encourage families that are experiencing heightened or prolonged periods of stress to address the situation. This may consist of connecting a family with local support groups or counseling centers. It could also be as simple as leading the parent in positive reappraisal exercises during home visits as outlined by Graungaard et al. (2011). Early interventionists may need training on effective stress management techniques to teach families. Parental stress and child behavior should be addressed simultaneously to generate the best results for both the child and parent.

2. Utilize evidence-based practice in EI

While it may seem redundant to best practice as a recommendation, the research indicates that evidence-based practice is not utilized in EI consistently. Evidence-based practices were used to develop the DEC's recommended practices guide (2014). When these guidelines are followed, not only does the child benefit, but the whole family (Mas et al., 2019).

Professional Development Opportunities

Turnbull et al. (2007) summarized findings from an early intervention community of practice summit by stating: "the field of early intervention has focused primarily on implementing family-centered practices by focusing on how families and professionals should interact" (p.187). They call for more attention to be given to the types of supports and services that should be offered based on the literature. In order for EI programs to implement true family-centered practices and address caregiver well-being, professional development opportunities are needed to address gaps in knowledge amongst early intervention teams.

"Do the best you can until you know better. Then when you know better, do better."

-Maya Angelou

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