Critical Insights: Incidents that Help and Hinder Parents' Transition Related to Their Child's Developmental Diagnosis

By
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version of the following dissertation:

**Critical Insights: Incidents that Help and Hinder Parents' Transition Related to Their
Child's Developmental Diagnosis**

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Abstract

Individuals structure their lives around their expectations associated with phases of life (Becker, 1997). Starting a new job, starting a family and even dropping a child off for their first day of kindergarten are events that represent a change in an individual's social role. Individuals expectations about these changes and the meanings that are assigned to these events help people make sense of their world. An unanticipated transition can occur when an individual's life unfolds in surprising ways, such as when a child's development is different from what the parent expects (Broski & Dunn, 2018; Messias, Gilliss, Sparacino, Tong, & Foote, 1995).

Transition theories guide professional practice with families and children; and they inform how professionals describe events and stages in family life. Transition theories underpin how family research is conducted and in turn, may influence how families see themselves. For example, Kubler Ross's "stages of grief" is often used to describe how parents experience becoming the parent of a child with developmental differences (Burrell, Ives, & Unwin, 2017; Frye, 2015).

My dissertation study builds on the work of my three written comprehensive examinations. In my first comprehensive examination "Fostering Insights: A Strengths-Based Theory of Parental Transformation," I proposed an alternative to transition theories that are deficit based. I used theory derivation, a method of theory development that uses a source theory from a different field, to "open" an area of research for new insights. I used Dr. Martha Baird's "Theory of Cultural Transition in Refugee Women" as the source theory for the strengths-based theory of parental transformation. Theory derivation also includes reviewing relevant literature. Additionally, I conducted a content analysis of 5 autobiographies written by parents of a child with an autism spectrum disorder to provide examples of the theory's concepts.

The theory proposes that there are 3 stages associated with parental transition, an initial stage of parents' awareness of their child's differences, a liminal stage where parents are in between social roles, and a stage of transformation where parents adapt to their new social role. The theory also proposes there are three primary domains associated with parents' transition. The child domain relates to the parents'

focus on the child's differences and strengths. The connections with others domain relates to changes that occur in parents' relationships with their family, friends, and others in the community. The parental competence domain relates to parents' ability to discern what is best for themselves and for their family. This manuscript was the original submission and the basis for the article published in the Journal of Child and Family Studies (Broski & Dunn, 2018).

My second comprehensive exam, "Evaluating the Strengths Based Theory of Parental Transformation" builds on the work of my first paper by exploring questions about the adequacy of the theory to describe parents' experiences. An assumption of the theory is that parents transition involves "stages" of transition. While this concept is commonly accepted in transition theories, I wanted to evaluate this aspect of the theory, and challenge the notion that parents transition involves three stages. Thirty-two parents completed an online questionnaire consisting of 81 items derived from the strengths-based theory of parental transformation. The findings of this study indicate that parents associated the first stage of transition with becoming aware of their child's differences, the liminal stage was associated with uncertainty, the transformation stage was associated with recognizing their child's strengths and confidence in their parenting skills.

My third comprehensive exam, "Exploring the Development of Parents' Mental Models Related to Their Child's Developmental Diagnosis" builds on the work of my first and second papers by exploring how parents experience transition. In this study, I conducted a discourse analysis of responses to six open-ended survey questions. Twenty-two parents were eligible for inclusion in this study. The results revealed that parents associate awareness of their child's differences with searching for information and feelings of uncertainty and fearfulness. Parents associated the liminal stage of transition with frustration and confusion as the adapt to a new state. Parents associated the transformation stage with confidence, pride and adaptation.

My comprehensive examinations provided the foundational work leading to my dissertation study. My previous research indicated that parents experience changes in their thoughts, feelings, and behaviors throughout transition (Broski & Dunn, 2018a, 2018b). I also found discernible differences in

the social contexts parents referenced throughout transition, however it was not clear what facilitated transition and what process may stand in the way. My dissertation study focuses on characterizing incidents that parents describe as helping and hindering their transition related to their child's developmental diagnosis. The findings of this study indicate that incidents that helped parents in the early stages of transition are associated with using and allocating resources. Incidents that helped parents in the later stages of transition are associated with seeing possibilities for their child and for themselves. Incidents that that hindered parents' transition involved parents discovering a need to set boundaries, as well as the parent feeling uncertain or obligated.

Because parents influence outcomes for children, there is a need to provide an alternative to deficit-based frameworks to describe their transition. My dissertation research advances knowledge related to children and families by contributing to a growing body of research that provides an alternative to studies that suggest parents of children with developmental differences must grieve, be in denial or experience on-going sorrow. The strengths-based theory of parental transformation contributes to child and family research by providing a framework that aligns with contemporary paradigms of disability.

Acknowledgments and Dedication

In "A Tree Telling of Orpheus" Denise Levertov describes the story of a musician so gifted that a tree could hear and be moved by his music. The tree was changed by the music, and pulled its' roots "out of a thousand years layers of dead leaves." Through its transformation the tree stumbled and learned "what the lark seems to know." The doctoral journey is filled with experiences and people that are transforming. I am grateful to Dr. Winnie Dunn for a journey that challenged me to think differently. It has been an extraordinary experience learning from you.

Dr. Lisa Mische-Lawson, thank you for serving as the co-chair for my dissertation and for keeping me on track. Dr. Matt Lineberry, thank you for being the kind of mentor that I will strive to be for others. Dr. Evan Dean, thank you for your insight and guidance throughout this experience. Dr. Kristi Williams, thank you for your feedback on and helping me to understand how my research might apply to other fields of study.

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I dedicate this dissertation to my dad, Fred who taught me to pursue work I love. To my mom, Jane, who taught me the value of persistence, creativity, and humor when faced with seemingly unsolvable problems. To my brother, Brian, who continually inspires me with his "can-do" attitude and ability. To Iris, Melody, and Daphne who changed my world in all the best ways. And to Tom who truly "walks the walk" of love and support.

We see more…We feel…something that lifts our branches, that stretches our furthest leaf-tips further…. (Denise Levertov, 1968)

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Chapter 1: Fostering Insights: A Strengths-Based Theory of Parental Transformation

This chapter has previously been published in whole without any adaptations since publication and is reprinted here with permission. The published version can be found in Broski, J., Dunn, W. Fostering Insights: A Strengths-Based Theory of Parental Transformation. Journal of Child and Family Studies (2018) 27(4): 1275-86. https://doi.org/10.1007/s10826-017-0964-5.

Abstract

Parent's awareness that their child's development is not proceeding as they expected can create an unanticipated transition from being a parent to becoming the parent of a child with a developmental diagnosis. While many transition theories contribute to our understanding of how parents' experience change over time, many traditional transition models are not family-centered and do not provide a strengths-based perspective of parents' experiences during this transition. This paper describes the process of theory derivation to develop a strengths-based theory of parental transformation (STPT). We used the theory of well-being of refugee women experiencing cultural transition to gain insights into parents' experiences related to their child's diagnosis. We propose that the STPT addresses a gap in the literature by situating the diagnostic process within a strengths' based framework that aligns with contemporary perspectives regarding disability. The STPT emphasizes understanding parents' experiences and needs in ways that promote personal growth to support the parent and child.

Introduction

During the 20th century, theoretical models used to understand disability moved from a focus on pathology, impairments, and limitations to a perspective that aligns with developments in the field of positive psychology. Contemporary models of disability emphasize abilities, strengths, and support based on individuals' and families' needs (Little, Jordens, Paul, Montgomery, & Philipson, 1998). Family-centered practice and strengths-based approach have emerged as core principles of best-practice for working with children and families (Epley et al., 2010; Workgroup on Principles and Practices in Natural Environments, OSEP TA Community of Practice: Part C Settings, 2008). However, while providers typically claim "we've worked with families for 25 years, and we've always been family-centered" (Dunst, 2002, p. 147), family-centered care is more often a slogan than practice (Bailey et al., 2006). Family-centered practice is a philosophical perspective that organizations and providers use to deliver services to children and families (Workgroup on Principles and Practices in Natural Environments, 2008) and should be the primary perspective used by diagnostic evaluation teams (Braun, Dunn, & Tomchek, 2017; Prelock, Beatson, Bitner, Broder, & Ducker, 2003).

Understanding parents' experiences to provide support to families has emerged as an important priority for early intervention (Tomlinson et al., 2014) because parents' health and wellness affects their children (Bronfenbrenner, 1979; Morris & Bronfenbrenner, 2007). Improving support for parents of children with developmental disabilities is a global research priority (Tomlinson et al., 2014) and includes the need to better understand parent experiences and information needs while a family waits for diagnostic clarification (Crane, Chester, Goddard, Henry, & Hill, 2016). Early childhood and healthcare organizations recognize that improving support for parents and children is best accomplished through family-centered services (Kuo et al., 2012). The core principals of family-centered practice are balanced relationships between families and providers, family choice, individualized services and emphasizing the strengths of families' and individual's (Epley et al., 2010; Kuo et al., 2012; Millenson, DiGioia, Greenhouse, & Swieskowski, 2013). Family-centered practice stands in contrast to problem-focused practices that emphasize deficits (Trowbridge & Mische-Lawson, 2014) or staff-centered practices

(Ecenrod & Zwelling, 2000). A focus on problems or deficits is standard practice in many traditional models of care (Saleebey, 1996); as a result, many traditional transition theories do not align with the core principles of family-centered care because the theories do not recognize the diversity of families, or they reinforce deficit-based perspectives of disability. However, acknowledging the possibility of positive outcomes does not mean that the parents' or child's health conditions are ignored or willed away. Just as a failure in the medical model to identify relevant medical conditions increases health risks, in the strengths model, a failure to recognize a parent's condition increases the likelihood of ineffective supports (Buntinx, 2013). Increasingly, providers within medical settings recognize that children with complex chronic health conditions benefit from family-centered and strengths-based care (Ecenrod & Zwelling, 2000; Trowbridge & Mische-Lawson, 2014).

Research on parents' experiences surrounding their child's developmental diagnosis indicates parents often experience stress and uncertainty and higher levels of depression (Crane et al., 2016; Ho, Yi, Griffiths, Chan, & Murray, 2014; Mansell & Morris, 2004). Uncertainty is uncomfortable and may be associated with stress, anxiety, as well as negative or positive outcomes. Uncertainty influences parents' relationship with their child (Page et al., 2012), confidence (Stewart & Mishel, 2000) decision making (Guerriere, McKeever, Llewellyn-Thomas, & Berall, 2003), mental health (Stewart & Mishel, 2000), ability to live in the present moment (Rosenthal, Biesecker, & Biesecker, 2001), and acceptance of their child for who he or she is (Rosenthal et al., 2001).

While family-centered practice and strengths-based approach are not new, a gap remains between theory and practice. The purpose of this paper is to describe the process of theory derivation to develop Broski and Dunn's strengths-based theory of parental transformation (STPT). First, we describe theory derivation, the method we use to develop the STPT. Second, we provide a brief description of the source theory, the well-being of refugee women experiencing cultural transition ([RWCT]; Baird & Reed, 2015) including previous research on the RWCT. Third, we present the derived theory and discuss implications for future research.

Theory Derivation

Theory derivation is a method of theory development used to develop insights where existing theories have limited impact on practice. Theory derivation identifies ideas about the essence of practices and attempts to bridge the gap between research paradigms and practice. This process uses analogies from one field of study to develop insights in another field of study (Walker & Avant, 2005). The steps of theory derivation include: (a) evaluate current theory; (b) read widely for insight and analogies; (c) select a source theory for the derivation process; (d) identify source theory content for use in the derived theory; and (e) redefine the source theory (Walker & Avant, 2005).

Evaluate Current Theory

Transition is a universal experience that occurs over time, requires adaptation and shapes how people respond to change. Transition theories generally recognize three primary stages: (1) an initial phase that involves separation from a previous way of life; (2) an in between phase known as liminality, a state of being betwixt and between; and (3) a final phase that signifies the beginning of the individual's new social role (Kralik, Visentin, & van Loon, 2006; Meleis, 2010; Turner, 1969; van Gennep, 1960). Transition is a common theme in early childhood literature. From the child's birth to entering elementary school, there are many transitions; children may attend daycare or enter preschool, children may experience siblings being born into the family, and sometimes families move. For families that have children who seem vulnerable, the transition experience also includes a diagnostic process as parents seek knowledge and insights to better understand and support their children.

Individuals structure their expectations about each phase of life and assign meanings to life-events, and to their roles in those events (Becker, 1997). Individuals may feel at odds with themselves and with others when life unfolds in ways that do not match the individual's expectations (Becker, 1997). Work and leisure activities may change, and disruptions may occur in patterns of personal expression (Kleiber, Hutchinson, & Williams, 2002). Parents' awareness that their child's development is not proceeding as they expected often creates an unanticipated transition (Meleis, 2010; Messias, Gilliss, Sparacino, Tong, & Foote, 1995) from becoming a parent to becoming the parent of a child with a

developmental disability. While parents frequently perceive unexpected transitions as negative developments (Messias et al., 1995), all transitions require individuals to reflect on their lives in ways that can be transformative (Chick & Meleis, 1986; Kleiber et al., 2002).

Numerous transition theories contribute to our understanding of how families experience change over time. While many general concepts about transition contribute to our understanding of parents' transition, some traditional transition theories are not family-centered. To accurately portray the situation for families waiting for a developmental diagnosis, some family-change theories require updating. For example, Meleis (2015) indicates a change in health or illness, such as cancer, diabetes or autism can trigger a transition (p. 364). While we agree that concerns about the child's developmental progress may serve as a trigger for transition, many developmental diagnoses, including autism, do not represent a change in the child's health. Rather, the diagnosis represents how health care or education systems classify the child's functioning. While it may appear to be a minor incongruity, it is essential to frame developmental diagnoses accurately so that research paradigms and professional recommendations do not inadvertently imply a child with a developmental disability is sick or requires a cure.

Just as services provided throughout the diagnostic process occur along a spectrum of deficit-based or strengths-based practices, the theoretical frameworks researchers use to study parents' experiences reflect paradigms that range from deficit-based to strengths-based. Examples of research paradigms that inadvertently emphasize deficit-based perspectives include closely focusing on parents' interactions with the medical system, such as satisfaction with the diagnostic process, time required to receive a diagnosis and the number of professionals needed to obtain a diagnosis (Crane et al., 2016; Howlin & Moore, 1997; Siklos & Kerns, 2007). Other medical model perspectives include finding cures for deficits, and perceptions that professionals are best equipped to address developmental disabilities (Brueggemann, 2015). Implicit within some research paradigms is the idea that a clear diagnosis of the child is necessary before the parent can move on or reach closure (Mulligan, MacCulloch, Good, & Nicholas, 2012; Timmermans & Buchbinder, 2010).

At the other end of the research paradigm spectrum, studies that emphasize family-centered principles provide opportunities to enhance well-being rather than focus on deficits. For example, Steiner (2010) explored the use of strengths-based language to improve parent and child interactions and enhance parent well-being; and Braun et al., (2017) developed a framework to explore whether interdisciplinary clinicians write parent reports from a strengths perspective.

Additional evidence that there is a need for strengths-based research paradigms is apparent in some family development theories. Family development theory explains events that signify new stages in family life. However, family development theories perpetuate assumptions that there are typical families and typical family stages (Laszloffy, 2002). Family stress theory explains the importance of family adaptation and functioning (McCubbin & Patterson, 2008) however, family stress theory defines events (such as a diagnosis) as a crisis. Proponents of the neurodiversity movement, would eschew considering a developmental diagnosis a crisis and might be more likely to celebrate the unique strengths of the individual. Health-illness transition theory describes how a diagnosis of one member of the family creates unexpected transitions for other family members (Meleis, 2010). However, characterizing a developmental diagnosis as an illness reinforces a deficit-based perspective and suggests families and professionals should seek to cure children with developmental diagnoses.

The Parent Transformational Process Model ([PTPM] Scorgie, Wilgosh, & Sobsey, 2004) stands in contrast to other parent transition theories because the research paradigm is family-centered. In addition to describing parents' process of image-making, meaning-making, and transformation, the PTPM recognizes parents' strengths (Scorgie et al., 2004). The PTPM indicates that the absence of stress is not necessary for parent transformation and that some parents describe becoming stronger, more compassionate and self-defined due to having a child with a developmental disability despite describing the period surrounding diagnosis as traumatic (Scorgie & Sobsey, 2000). While the PTPM is family-centered, there is a need to explore developing a transition theory that places families at the center of the transition, rather than the child's diagnosis.

Read for Insights and Analogies

While theory derivation does not require a systematic literature review, we used a modified Critical Interpretive Synthesis (CIS) approach to guide our engagement with the literature. Rather than using a tightly focused research question we used the guiding question: What are parents' needs before and during the diagnostic process? Additionally, we were interested in understanding parents' experiences from a strengths-based perspective. Although CIS is an iterative approach, we will discuss our process in terms of phases. The initial phase of our literature review included a broad-based search of the literature to gain an overall understanding of parents needs surrounding the diagnostic process and transition in general. The second phase of our review focused on the concept of liminality; we reviewed memoirs written by parents of children with a developmental diagnosis in the third phase of our research.

Liminality. The concept of liminality, the state of being "betwixt and between" (Turner, 1969; van Gennep, 1960) emerged inductively and served as a focus for the second phase of our literature review. We searched EBSCOhost for the terms "liminal" and "diagnosis" in the title or abstract. This search resulted in the identification of 1,771 articles published between 1990 and 2015. Disciplines represented in this search include anthropology, political science, art, literature, health, and education. Results from variations of searches combining the terms "liminal," "parent," and "diagnosis" resulted in 62 articles. Topics identified in the search included patient and family experience, parent experience, immigrant/migrant experience, history, children, racial/ethnic/gender status and condition or illness. We extracted data from 22 articles describing empirical research that included examples of individuals' experiences before diagnosis. We identified three primary themes from our review of the literature (a) the individual; (b) tasks; and (c) the environment. Table 1 provides an overview of topics addressed by the articles.

Liminality is a concept originating from anthropological research on ceremonial rituals known as rites of passage. Rites of passage occur throughout an individual's life as they move from one occupation to another and assist individuals as they transition into their next role in life (Turner, 1969; van Gennep, 1960). Regardless of what the new role is, rites of passage mark social transitions that involve letting go

of a previous role, entering a transitional stage and reintegration (van Gennep, 1960). The state of being in between roles, or being neither here nor there is known as liminality.

Researchers have used the concept of liminality in studies of patients and caregivers in various health conditions and settings. Watson (2011), found parents experienced ambiguity and uncertainty after the birth of their very preterm infant. Liminality has also been used to describe patients and caregivers' cancer experience (Balmer, Griffiths, & Dunn, 2014; Brown, de Graaf, & Hillen, 2014; Ho et al., 2014) and other experiences associated with illness and death (Blandin & Pepin, 2015). Gibbons, Ross and Bevan's (2014) literature review on liminality as a conceptual framework for family caregiver rites of passage identified three phases universally experienced by caregivers. An event that results in a need to commit care for a family member or other loved one characterizes the pre-liminal stage. The liminal stage is a period of transition when social roles and relationships change. Uncertainty and suffering characterize this stage. Caregivers assume a new identity and find a new normal in the post-liminal stage (Gibbons, Ross, & Bevans, 2014).

Parents' narratives. The third phase of our literature review included studying memoirs written by parents of children with an autism diagnosis: (a*) Journey with Julian* (Ballen, 2012); (b) *Seeing Ezra* (Cohen, 2011); (c) *Following Ezra* (Fields-Meyer, 2011); (d) *Unstrange Minds* (Grinker, 2007); and (e) *The Horse Boy* (Isaacson, 2009). We selected memoirs based on the book's classification as a memoir or autobiography, popularity, and publication date. We used a reading guide to identify content related to parents' descriptions of their identity before, during and after the process of seeking and receiving an autism diagnosis, how parents describe noticing differences in their child development and how parents describe everyday activities.

Source Theory: Well-being in Refugee Women Experiencing Cultural Transition. We derive our theory from the RWCT (Baird, 2012). The utility of the source theory to provide insight in a new field drives the process of selecting a source theory. We selected the RWCT because it specifically addresses the concept of liminality, an experience explicitly described in transition literature (Kralik et al., 2006), in research, and implied in parents' narratives describing their experiences surrounding their child's

developmental diagnosis. Additionally, the RWCT addresses transition using language that is like parents' descriptions of the diagnostic process, which we describe in the theory derivation section.

The RWCT is a situation-specific theory resulting from studies of refugee women who resettled in the United States (Baird, 2012). Three themes serve as the foundation for the theory: (a) liminality: living between two cultures; (b) self-support: standing on our own; and (c) hope for the future (Baird, 2012; Baird & Reed, 2015). The concept of liminality underscores the importance of understanding strengths at every phase of transition, particularly when families feel they are in between two worlds (Baird & Reed, 2015).

Derived theory: Strengths-Based Theory of Parental Transformation

The purpose of Broski and Dunn's STPT is to provide a framework to conceptualize parents' experiences while they wait for a developmental diagnosis for their child. In the source theory, individuals' experience a change in culture resulting from a change in geographic landscape (Baird & Reed, 2015). In the derived theory, parents' experience a change that occurs in response to a shift in the parents' mental landscape. Mental landscape is a metaphor that refers to individual's cognitive representation of their environment (e.g., Chaney, 2010; Golledge, 1991; Ramsey, 2016).

The STPT (Figure 1) references three transition phases: (a) initial awareness of the new landscape, (b) rites of passage in the new landscape, and (c) transformation of self. Within each of the stages, we use three domains to describe parents' experiences while they wait for their child's diagnosis. We refer to these domains as the three C's of parent's mental landscape. The first C in the mental landscape represents the child. Parents' awareness of their child's behavior or functioning characterizes the child domain. The second C in the mental landscape is connections. Parents' experiences with friends, families, and professionals characterize the connections domain. The third C in the mental landscape is competence. Parents' concerns about fulfilling social roles characterize the competence domain.

Initial awareness of differences in the mental landscape. In the source theory, the first phase of individuals' transition is separation from their culture of origin and identity, which leads to confusion and then awareness of the new landscape. In the derived theory, the first phase is parents' initial awareness of

differences in their mental landscape. The mental landscape is the mental model individuals use to understand and navigate their lives; it reflects an individual's identity by referencing cultural values, personal preferences and geographic locations (Golledge, 1991). The memoirs included descriptions of parents feeling they had traveled to a new world. For example, Isaacson (2009) questioned if his son's diagnosis might not signal shutting down his life, but instead "be the gateway to the greatest adventure of all" (p. 48). Cohen (2011) argued that parents should not be judged "for the ways they've found to cope with this alien world of being a special needs family" (p. 137). Ballen (2012) described his experience as a "journey through the world of autism" (p. 1). Fields-Meyer (2011) described how shopping with son "is like landing in a foreign country, or the moon" (Chapter 14, section 2, para 13).

Child domain: Awareness of differences. In the initial awareness phase, parents notice differences in the child's behavior or development (Ballen, 2012; Isaacson, 2009). Ballen (2012) described his wife's awareness of differences, "I will never forget the determination in Martina's voice. She was the one who first began to think about this" (p. 2). Some parents described making lists of differences in their child's behavior. Fields-Meyer (2011) suggested his wife might be trying to make sense of chaos by compiling an inventory of their son's traits (Chapter 1, section 2, para. 4). Family, friends or acquaintances may trigger parents' awareness of differences (Cohen, 2011). False positives from newborn screening tests can also initiate parents' concerns about their child's development (Timmermans & Buchbinder, 2010).

Connections domain: Increasing distance. In the autobiographies we reviewed, all parents described a sense of distance or isolation from the world. In some cases, parents referenced their child's solitary behaviors. When a child's behavior does not appear typical, parents may not know what to tell people about their child's behavior (Midence & O'Neill, 1999) which can result in disruptions in their connections with others (Maciver et al., 2011). Parents also describe challenges in their relationship with their child when efforts to be close to the child do not seem to be successful (Desai, Divan, Wertz, & Patel, 2012; Farrugia, 2009). Confusion surrounding how to respond to their child's behavior in social settings creates barriers to social connections in the new mental landscape. Some parents report their

child's sensory patterns challenge the parent's ability to socialize. Cohen's memoir (2011) illustrated why she stopped going to social events and reaching out to her friends. Cohen described going to a birthday party with her child, but when all the children started singing happy birthday, she needed to take her child out of the house to accommodate her child's sensory needs. Cohen describes feeling childish, frustrated and alone as she looks in at the party from the outside, watching the other parents socialize while she stands outside with her child.

Parents may report strained connections when friends or family members seem not to understand what the parent is going through (Farrugia, 2009; Midence & O'Neill, 1999). Some of the memoirs we read echoed this sentiment. Cohen (2011) describes how her concerns about her child's development affected her relationship with her husband. "I cannot keep burdening Michael with these worries. . . Twice he's asked me 'Should I be worrying?' No! . . . Because I can't have Michael overly concerned. If he worries with me, who will pull me back? Who will keep us from falling more deeply into this endless fear" (p. 52).

Competence domain: Seeking confirmation. Individuals' ability to see and portray themselves as competent is an important aspect of self-identity. For parents, this includes parenting in ways they believe in and that others validate (Christiansen, 1999). In the initial awareness phase, parents report seeking confirmation with other parents or professionals to allay concerns about their child's behavior or development or to validate their observations (Tait, Fung, Hu, Sweller, & Wang, 2016). For example, Cohen (2011) describes her response to therapists when they asked why she had her child evaluated; "I'm supposed to…to be a good mom, I have to help him" (p. 26). Similarly, Isaacson (2009) describes responsible parenting as the reason he and his wife contacted the state's early childhood intervention program (p. 12).

Rites of passage in the new landscape. A central concept emerging from the theory of RWCT is liminality (Baird and Reed, 2015). The liminal stage occurs when individuals are on the threshold of a new way of life and in between social roles (Turner, 1969; van Gennep, 1960). Baird and Reed (2015) identified liminality as an important process in transition as well as a conundrum: "Someone experiencing

liminality can feel disconnected and uncomfortable yet have the capacity for growth and transformation…

There is a creative potential in liminality that can lead to opportunities to change and reformulate the self"

(p 31).

Child domain: Focus on concerns. In this phase, parents' awareness of differences in their child

becomes a primary focus. Even if the child does not have a diagnosis, parents may begin intense routines

to help their child. For example, a primary storyline in *Horse Boy*, Isaacson (2009) focused on his

family's decision to travel to Mongolia to meet with shamans to help their son, "I wanted something more

radical, something miraculous. Would taking him to the horses and shamanic healers of Mongolia provide

that. . . I could not get the idea out of my head" (p. 53). Cohen (2011) described concerns that she

recognized as contradictory, "I worry that it's not enough, and I also worry that it is too much, that the

therapies are stressing his tiny, not-even-two-year-old world" (p. 40).

Connections domain: Distance and isolation. During this phase, what begins as increasing

distance in relationships can lead to isolation. Because parents' new mental landscape does not seem to

match a normal way of life, parents can feel disconnected or isolated from their friends and family.

Parents who don't understand which direction to turn may feel disconnected from community care

systems (Farrugia, 2009). Parents may also feel disconnected if their child does not have a diagnosis,

"…one of the biggest things that I've found personally not having a diagnosis is that I do not belong

anywhere…. with my child being undiagnosed" (Pelentsov, Fielder, & Esterman, 2016). Cohen (2011)

described the rift she felt with other parents, "more and more I struggle to connect with parents who have

only typical children. Sometimes I feel dumbly angry at them; sometimes I envy them" (p. 137). Isaacson

(2009) described how he felt disconnected from others when people avoided his child; "he'd writhe on the

ground and babble…..climb the fences—then tantrum violently when prevented, often vomiting or

shitting his pants at the same time….other parents and visitors would cluck disapprovingly and move

away from the noise" (p. 22).

Competence domain: Searching for answers and experimentation. During the rites of passage

phase, parents may experiment with popular cures or other remedies from public sources (Armstrong,

1995; Timmermans & Buchbinder, 2010). Experimentation during liminality is associated with the process identity reconstruction (Beech, 2011). Experimentation may be a strategy parents use within the new mental landscape to learn its characteristics and limits. During this phase, parents' may expend a great deal of energy to fulfill their definition of what it means to be a good parent in their new role as a parent of a child with a developmental disability. For example, Cohen (2011) described searching for schools, diet supplements, and new strategies to encourage her son to eat. She described her need to "be running, moving, searching, finding" (p. 122). Cohen also described trying things she did not believe in; "driving through a town…. I stop in and see a psychic. Do I believe in psychics? Not really. But psychics have crystal balls, and I desperately needed one right now. . . I need to know if my son will be okay" (p. 112). Ballen (2012) described how trying to command his child to stop flapping or holding his child's shoulders did not help to reduce stimming behaviors. Ballen goes on to describe looking for opportunities to allow his son to move around in self calming ways when his son's movements would not be disruptive in public places. Eventually the family discovered having pen and paper available for his son to draw on could help keep his son calm (pp. 4-6). This trial and error approach

Transformation of self in the new landscape. The source theory indicates that despite individuals finding themselves in an unfamiliar place, replete with ambiguity and loss, the third phase of cultural transition provides creative potential (Baird & Reed, 2015). The source theory describes this as standing on our own two legs and having hope for the future. In the derived theory, parents' transformation occurs when they experience opportunities to grow and redefine themselves, their child and their family. All the memoirs we reviewed describe settling in and becoming at home in a new world. We use Baird's (2012) conceptualization of well-being to inform our conceptualization of self-transformation:

> A process measured over time in which one has adequate resources to meet basic physical, emotional, social, and spiritual needs. An individual with a sense of well-being experiences peace of mind, acceptance of life as it is presented, a sound physical condition, and a state of emotional and spiritual balance that leads to the belief that life is worth living (p.255).

In our reading of parents' memoirs, we found many instances of parents' describing a new sense of well-being. During this phase, parents' express understanding of their child's differences and unique strengths. Parents describe discovering new ways to see the world and often credit their child for teaching them important life lessons. It appears that parents embrace a wellness approach to parenting, an acceptance of life as it is. Cohen's (2011) recognition that being a good parent is not the same as needing to be perfect is an example of transformation and well-being:

The great feat in Ezra's and my story is that I do nothing. Finally, I do nothing. I let Ezra be who he is, and I let me be me, with all our limitations. I let Ezra show me that he doesn't need me to do anything but love him. I let him show me that I will be uncomfortable sometimes. I'll feel helpless. In our story, life doesn't suddenly become easy…that's just our lives together. There is no tragedy here (p. 278).

Child domain: Recognizing possibilities. In the early awareness phase, parents may itemize their child's weaknesses or compare their child to other children. Over time, these behaviors appear to diminish and parents begin to focus on their child's strengths rather than comparing their children to others (Grinker, 2008). Parents describe spending more time enjoying their children and less time thinking about problems (Lewis, Skirton, & Jones, 2010). Parents describe finding new possibilities regarding their child's differences, such as how well their child copes with medical procedures (Carmichael, Tsipis, Windmueller, Mandel, & Estrella, 2015). In his autobiography, Fields-Meyer (2011) reflects on an experience watching his three-year-old son walk ahead of him on a private road. He describes feeling fearful about his son's lack of awareness that he was getting too far ahead of his dad. Years later, Fields-Meyer summarizes his transformative experience:

This is the story of what happened in the ten years following that summer, a decade that has delineated a personal journey, beginning in darkness, winding through desperation, fascination, love and ultimately a sense of awe for our unique, exceptional son. . . I have watched from an increasing distance as he takes a path all his own. . . Long ago, I made my choice: to follow Ezra

and to watch, in awe and mystery, as my son makes his own unique way in the world (Prologue, para. 11-12).

Grinker (2008) described coming to see his child in a new light. "At the end of the day, when I tuck her in, she's not a case of autism, or even a child with social deficits and language delays. She's simply my daughter" (p. 35). Ballen (2012) described his son as having "something to contribute to this world. His creativity and imagination are immense and seem boundless" (p. 180).

Connections domain: New relationships. Research on family resilience indicates parents who have experienced challenges may participate in activities they perceive will help others. These activities may involve making connections with people they would not have met otherwise. It appears parents perceive that their altruistic actions honor their child or other family members who have shown them support (Lietz, 2011). For example, a parent participating in a fundraiser for a camp for children with autism, described her experience doing stand-up comedy with other parents:

> For months prior to the event we dissect our lives and bare our souls to a group of people who become our tribe. . . So for the past three years, and into the unforeseeable future, 'An Evening with the 'Rents' has become a part of who I am. I overcame my anxiety, stood up on that stage and shared my life, thoughts, and feelings with hundreds of strangers. And you know what? They laughed with me and they loved me for who I am and for what I am becoming. But even more importantly, I feel like I gave something back in return. I hope with all my heart that I have encouraged someone who was in the same place I was. I hope I have reminded them of who they are and inspired them to step out in faith. I hope that I planted a seed that will create new growth and joy in their life (Ray, 2017, Para. 2-5).

Throughout her memoir, Cohen (2011) described strained relationships with her family and other parents, in the end, she describes finding comfort in her relationships with others, "the other parents and I discuss these issues. . . it is such a relief to have other mothers to talk with, mothers who understand. After all this time, I feel seen by other people again" (p. 238). Isaacson (2009) described how his journey led to him starting a program for children with an autism diagnosis.

Upon our return from Mongolia, I managed to raise money to buy land to start an equestrian

program for PDD kids. Fifteen acres of gorgeous land. . . It is a place where children can play and

ride and be happy. . . Part of the proceeds from your purchase of this book will enable us to offer

scholarships to families who cannot afford equine therapy (p. 349).

Competence domain: Confidence in ability to discern. Parents of children with unidentified

differences report high motivation to obtain a diagnosis when their child is young, but the desire to

confirm a diagnosis can fade over time (Rosenthal et al., 2001). Parents also describe gaining the skills

they need to get things done for their child, such as getting appointments and services for their children

"I've had to learn to be that sort of person" (Lewis et al., 2010). In the third stage of STPT parents

recognize their wisdom (Ballen, 2012; Cohen, 2011; Fields-Meyer, 2011; Grinker, 2008; Isaacson, 2009)

and consider sharing their insights with others (Ray, 2017).

Grinker (2008) is philosophical about his transformation, "I am not a religious person, but there is

something profoundly meaningful, if not spiritual, about being the father of a child with autism that has

pushed me to consider lofty, abstract principles like truth, beauty, and goodness" (p. 23). Fields-Meyer

(2011) describes changing his thinking about his child's disability. Instead of viewing his son's

challenges as something to get past to get on with life, "I eventually learned that this is life. This is what

life is. It wasn't about finding the right expert for my child; it was about learning to be the right parent"

(Prologue, section 2, para. 1). Ballen (2012) characterizes his transformation regarding roles that have

meaning for him, being a dad and work. "Julian has inspired me to be a better man and given me clarity

on what it means to be a father. . . definitely the best job I've ever had" (p. 42). Isaacson (2009) describes

discovering new ways to think about work and leisure activities, "as for me, freed now from riding only

as part of Rowan's therapy, I found a whole new direction with horses. . . I put my insecurities aside,

started training. . . I began to discover my own inner horse boy" (p. 347).

Summary of the STPT. The memoirs we reviewed described awareness, liminal stages and

moving beyond a state of ambiguity. While these parents described finding new insights and meanings,

some researchers suggest there may be situations such as with a cancer diagnosis in which individuals'

experience sustained liminality (Little et al., 1998). Although parents frequently described gaining insights during a prolonged liminal state, there were also indications parents could experience a kind of instant insight, in other words, an ability to gain insight without a lengthy struggle with ambiguity. For example, Fields-Meyer (2011) described an experience toward the beginning of his memoir when a therapist suggested the family needed time to grieve for the child his son did not turn out to be.

> I realize something: I am not grieving. In fact, I feel no instinct to grieve…I'm not going to grieve. I am sure she thinks I am deluding myself. I know the truth. The one statement (that he needs time to grieve) has done more good for me than all the play therapy, than all the listening, all the advice. It has forced me to find and bring out something within myself. I feel full of love – for the boy who lines up the dinosaurs on the porch…My answer will never be to mourn. It will be to pour love on my son, to celebrate him, to understand, to support him, and to follow his lead. (Chapter 1, section 3, para. 27-30)

Discussion

The purpose of this paper is to describe a strengths-based theory of parents' transformation before their child's developmental diagnosis. Parents' unanticipated journey frequently involves developing awareness of changes in their mental landscape. We describe the STPT within the context of parents' developing awareness of those changes. The process of theory derivation initially involves developing a model without immediate knowledge of its accuracy.

Research on parents' experiences before their child receives a developmental diagnosis tends to focus on parents' experience with the diagnostic process and uncertainty surrounding their child's development. This focus inadvertently reinforces a medical model perspective. Parents with concerns about their child's development have experiences in addition to the diagnostic journey that contributes to the family and child's overall strengths and development. Ecological models of disability indicate that disability is a function of the interaction of the individual and the environment, rather than a deficit that resides in the individual (e.g., Pope & Brandt, 1997; Schalock et al., 2010). However, research and interventions that focus on parents' anxiety or stress associated with having a child with a developmental

diagnosis suggest limitations reside within the family. While the diagnostic process focuses almost exclusively on the child, parents have experiences throughout the diagnostic process that involve constructing new images of their children, themselves and their lives (Scorgie et al., 2004). Parents often associate a potential developmental diagnosis with images of disability that have formed through societal portrayal and beliefs about disability (Scorgie & Sobsey, 2000). The information parents receive at this time shapes images parents create of their child (Taanila, Syrjälä, Kokkonen, & Järvelin, 2002). Some parents live in a state of tension created by a need to construct hopeful child and life-trajectory images during pessimistic reports about their child (Steele, 2000). The need to balance joy and sorrow may cause parents to limit thinking about the future, and focus on the present (Kearney & Griffin, 2001). Not only do parents' experiences surrounding diagnosis influence image-making (Scorgie et al., 2004) reports and feedback from hospital personnel, agency workers, educators, extended family members and friends can shape parents' response to their child's diagnosis.

Future studies should explore how parents perceive and define the different stages of transition and should explore ways in which parent develop awareness in their mental landscape. Studies should explore using the STPT as a cognitive tool to assist parents in identifying unexpected opportunities to recognize insights about their child, develop a stronger sense of themselves as parents and consider new possibilities for their family. Because implementing strengths-based practice requires clarity about the approach, including operationalizing the constructs of the theory (Staudt, Howard, & Drake, 2001); there is a need to delineate how parents and providers determine the end of one stage and the start of the next phase. There is a need to determine what aspects of parents' experiences are not part of parents' transition experience. Future testing should empirically examine domain attributes and definitions. Evaluation of the theory should include examining the relevance of STPT to the delivery of family-centered care while families wait for a diagnosis.

Longitudinal research on parents' experiences surrounding their child's developmental diagnosis is complex, multifaceted and frequently misunderstood (Pedersen, Crnic, Baker, & Blacher, 2015). Future research should explore if families benefit from reflecting on their experiences through a strengths-based

framework. Additionally, future studies should investigate whether the STPT may contribute to implementing family-centered practice in clinical settings. Finally, studies should focus on determining if the concept of liminality, which provides a possible explanation for how and why parents experience ambiguity in the midst of transition, may provide a useful framework for parent education.

Limitations

We recognize several limitations of our methods and theory. CIS is useful when the purpose of the literature review is to generate theory. However, the iterative nature of this process is guided by emerging theory. Therefore, many aspects of the literature search would be difficult to reproduce. While we used multiple methods to triangulate evidence supporting the STPT, the first author is a parent of a child with a developmental diagnosis and while we were intentional about bracketing, we recognize the author's experience has the potential to bias our findings. Another potential for bias is the use of published parent memoirs. It is possible that parents who continue to struggle with transition would not be inclined to publish their stories or may not have the resources to share their stories in such a public way, so it is possible that these parents' voices could potentially be under-represented in popular press publications.

Improving support for children is best accomplished through family-centered services that recognize families' strengths. Some families may not receive a diagnosis for several years, while other families may never receive a diagnosis. We propose further testing of the STPT to determine its utility to provide an alternate explanation for providers and parents to consider. While we recognize waiting for a developmental diagnosis generates uncomfortable feelings of uncertainty, a theory of transformation provides an opportunity for parents and providers to discuss the future in a realistic yet hopeful manner.

References

Armstrong, D. (1995). The rise of surveillance medicine. *Sociology of Health and Illness*, *17*, 393–404.

Bailey, D., Jr., Bruder, M., Hebbeler, K., Carta, J., Defosset, M., Greenwood, C., … Barton, L. (2006). Recommended outcomes for families of young children with disabilities. *Journal of Early Intervention*, *28*, 227–251. https://doi.org/10.1177/105381510602800401

Baird, M. B. (2012). Well-being in refugee women experiencing cultural transition. *Advances in Nursing Science*, *35*, 249–263. https://doi.org/doi: 10.1097/ANS.0b013e31826260c0

Baird, M. B., & Reed, P. G. (2015). Liminality in cultural transition: Applying ID-EA to advance a concept into theory-based practice. *Research and Theory for Nursing Practice*, *29*, 25–37. https://doi.org/10.1891/1541-6577.29.1.25

Ballen, D. (2012). *Journey with Julian [Kindle Version]*. New York, NY: Strebor Books.

Balmer, C., Griffiths, F., & Dunn, J. (2014). A "new normal": Exploring the disruption of a poor prognostic cancer diagnosis using interviews and participant-produced photographs. *Health*. https://doi.org/10.1177/1363459314554319

Becker, G. (1997). *Disrupted lives: How people create meaning in a chaotic world*. Berkley, CA: University of California Press.

Beech, N. (2011). Liminality and the practices of identity reconstruction. *Human Relations*, *64*, 285–302. https://doi.org/10.1177/0018726710371235

Blandin, K., & Pepin, R. (2015). Dementia grief: A theoretical model of a unique grief experience. *Dementia*, *16*, 65–78. https://doi.org/10.1177/1471301215581081

Blows, E., Bird, L., Seymour, J., & Cox, K. (2012). Liminality as a framework for understanding the experience of cancer survivorship: A literature review. *Journal of Advanced Nursing*, *68*, 2155–64. https://doi.org/10.1111/j.1365-2648.2012.05995.x

Braun, M. J., Dunn, W., & Tomchek, S. D. (2017). A pilot study on professional documentation: Do we write from a strengths perspective? *American Journal of Speech-Language Pathology*, *26*, 972–981. https://doi.org/https://doi.org/10.1044/2017_AJSLP-16-0117

Bronfenbrenner, U. (1979). *The ecology of human development experiments by nature and design*.

 Cambridge, MA: Harvard University Press.

Broski, J., & Dunn, W. (2018). Fostering insights: A strengths-based theory of parental transformation.

 Journal of Child and Family Studies, 27, 1275–1286. https://doi.org/10.1007/s10826-017-0964-5

Brown, P., de Graaf, S., & Hillen, M. (2014). The inherent tensions and ambiguities of hope: Towards a

 post-formal analysis of experiences of advanced-cancer patients. *Health*, *19*, 207–225.

 https://doi.org/10.1177/1363459314555241

Brueggemann, B. (2015). Disability studies/disability culture. In M. Wehmeyer (Ed.), *The Oxford*

 handbook of positive psychology and disability (pp. 279–302). New York, NY: Oxford University

 Press.

Buntinx, W. (2013). Understanding disability: A strengths-based approach. In M. Wehmeyer (Ed.), *The*

 Oxford handbook of positive psychology and disability (pp. 7–18). New York, NY, USA: Oxford

 University Press.

Carmichael, N., Tsipis, J., Windmueller, G., Mandel, L., & Estrella, E. (2015). "Is it going to hurt?": The

 impact of the diagnostic odyssey on children and their families. *Journal of Genetic Counseling*,

 24, 325–335.

Cayless, S., Forbat, L., Illingworth, N., Hubbard, G., & Kearney, N. (2010). Men with prostate cancer

 over the first year of illness: Their experiences as biographical disruption. *Supportive Care in*

 Cancer, *18*, 11–9. https://doi.org/10.1007/s00520-009-0624-4

Chaney, D. (2010). Analyzing mental representations: The contribution of cognitive maps. *Recherche et*

 Applications En Marketing (English Edition), *25*, 93–115.

Chick, N., & Meleis, A. (1986). *Transitions: A nursing concern*. Boulder, CO: Aspen Publications.

Christiansen, C. H. (1999). Defining lives: Occupation as identity: An essay on competence, coherence,

 and the creation of meaning. *American Journal of Occupational Therapy*, *53*, 547–558.

 https://doi.org/10.5014/ajot.53.6.547

Cohen, K. (2011). *Seeing Ezra: A mother's story of autism, unconditional love, and the meaning of normal [Kindle Version].* Berkley, CA: Seal Press.

Crais, E. R., McComish, C. S., Humphreys, B. P., Watson, L. R., Baranek, G. T., Reznick, J. S., … Earls, M. (2014). Pediatric healthcare professionals' views on autism spectrum disorder screening at 12-18 months. *Journal of Autism and Developmental Disorders*, *44*, 2311–2328. https://doi.org/10.1007/s10803-014-2101-2

Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism*, *20*, 153–162. https://doi.org/10.1177/1362361315573636 PMID:25810370

Desai, M. U., Divan, G., Wertz, F. J., & Patel, V. (2012). The discovery of autism: Indian parents' experiences of caring for their child with an autism spectrum disorder. *Transcultural Psychiatry*, *49*, 613–637.

Dunst, C. J. (2002). Family-centered practices. *The Journal of Special Education*, *36*, 141–149. https://doi.org/10.1177/00224669020360030401

Ecenrod, D., & Zwelling, E. (2000). A journey to family-centered maternity care. *MCN, The American Journal of Maternal Child Nursing*, *25*(4), 178–185. https://doi.org/10.1097/00005721-200007000-00004

Eli, K. (2014). Between difference and belonging: Configuring self and others in inpatient treatment for eating disorders. *PloS One*, *9*, e105452–e105452. https://doi.org/10.1371/journal.pone.0105452

Epley, P., Gotto, G. S., Summers, J. A., Brotherson, M. J., Turnbull, A. P., & Friend, A. (2010). Supporting families of young children with disabilities: Examining the role of administrative structures. *Topics in Early Childhood Special Education*, *30*, 20–31. https://doi.org/10.1177/0271121410363400

Farrugia, D. (2009). Exploring stigma: Medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. *Sociology of Health & Illness*, *31*, 1011–1027.

Fields-Meyer, T. (2011). *Following Ezra: What one father learned about Gumby, otters, autism, and love from his extraordinary son [Kindle version]*. New York, NY: Penguin Group US.

Forss, A., Tishelman, C., Widmark, C., & Sachs, L. (2004). Women's experiences of cervical cellular changes: An unintentional transition from health to liminality? *Sociology of Health & Illness*, *26*, 306–325. https://doi.org/10.1111/j.1467-9566.2004.00392.x

Gibbons, S. W., Ross, A., & Bevans, M. (2014). Liminality as a conceptual frame for understanding the family caregiving rite of passage: An integrative review. *Research in Nursing & Health*, *37*, 423–436. https://doi.org/10.1002/nur.21622

Golledge, R. (1991). Cognition of physical and built environments. In T. Garling & G. Evans (Eds.), *Environment, cognition, and action: An integrated approach* (pp. 35–62). New York, NY: Oxford University Press, USA.

Grinker, R. (2007). *Unstrange minds: Remapping the world of autism*. New York, NY: Perseus Books Group.

Guerriere, D. N., McKeever, P., Llewellyn-Thomas, H., & Berall, G. (2003). Mothers' decisions about gastrostomy tube insertion in children: Factors contributing to uncertainty. *Developmental Medicine and Child Neurology*, *45*, 470–476. https://doi.org/https://doi.org/10.1111/j.1469-8749.2003.tb00942.x PMID:12828401

Halliday, L. E., Boughton, M. A., & Kerridge, I. (2015). Liminal reproductive experiences after therapies for hematological malignancy. *Qualitative Health Research*, *25*, 408–416. https://doi.org/10.1177/1049732314550006

Ho, H. S., Yi, H., Griffiths, S., Chan, D. F., & Murray, S. (2014). "Do It yourself" in the parent-professional partnership for the assessment and diagnosis of children with autism spectrum conditions in Hong Kong: A qualitative study. *Autism*, *18*, 832–844. https://doi.org/10.1177/1362361397012003

Howlin, P., & Moore, A. (1997). Diagnosis in autism: A survey of over 1200 patients in the UK. *Autism*, *1*, 135–162. https://doi.org/10.1177/1362361397012003

Isaacson, R. (2009). *The horse boy: A father's quest to heal his son* (1st ed.). New York, NY: Little,

    Brown and Co.

Jordan, J., Price, J., & Prior, L. (2015). Disorder and disconnection: Parent experiences of liminality when

    caring for their dying child. *Sociology of Health & Illness*, *37*, 839–855.

    https://doi.org/10.1111/1467-9566.12235

Kearney, P. M., & Griffin, T. (2001). Between joy and sorrow: Being a parent of a child with

    developmental disability. *Journal of Advanced Nursing*, *34*, 582–592.

    https://doi.org/10.1046/j.1365-2648.2001.01787.x

Kleiber, D. A., Hutchinson, S. L., & Williams, R. (2002). Leisure as a resource in transcending negative

    life events: Self-protection, self-restoration, and personal transformation. *Leisure Sciences*, *24*,

    219–235. https://doi.org/10.1080/01490400252900167

Kralik, D., Visentin, K., & van Loon, A. (2006). Transition: A literature review. *Journal of Advanced*

    Nursing, *55*, 320–329. https://doi.org/10.1111/j.1365-2648.2006.03899.x

Kuo, D. Z., Houtrow, A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M., & Neff, J. M. (2012). Family-

    centered care: Current applications and future directions in pediatric health care. *Maternal and*

    Child Health Journal, *16*, 297–305. https://doi.org/10.1007/s10995-011-0751-7

Laszloffy, T. A. (2002). Rethinking family development theory: Teaching with the systemic family

    development (SFD) model. *Family Relations*, *51*, 206–214. https://doi.org/10.1111/j.1741-

    3729.2002.206098.x

Lewis, C., Skirton, H., & Jones, R. (2010). Living without a diagnosis: The parental experience. *Genetic*

    Testing and Molecular Biomarkers, *14*, 807–815. https://doi.org/10.1089/gtmb.2010.0061

Lietz, C. A. (2011). Empathic action and family resilience: A narrative examination of the benefits of

    helping others. *Journal of Social Service Research*, *37*, 254–265.

    https://doi.org/10.1080/01488376.2011.564035

Little, M., Jordens, C. F., Paul, K., Montgomery, K., & Philipson, B. (1998). Liminality: A major

    category of the experience of cancer illness. *Social Science & Medicine*, *47*, 1485–1494.

    https://doi.org/10.1016/S0277-9536(98)00248-2

Maciver, D., Owen, C., Flannery, K., Forsyth, K., Howden, S., Shepherd, C., & Rush, R. (2011). Services

    for children with developmental co-ordination disorder: The experiences of parents. *Child: Care,*

    Health and Development, *37*, 422–429. https://doi.org/10.1111/j.1365-2214.2010.01197.x

Mansell, W., & Morris, K. (2004). A survey of parents' reactions to the diagnosis of an autistic spectrum

    disorder by a local service: Access to information and use of services. *Autism*, *8*, 387–407.

    https://doi.org/10.1177/1362361304045213

McCubbin, H. I., & Patterson, J. M. (2008). The family stress process: The double ABCX model of

    adjustment and adaptation. *Marriage & Family Review*, *6*, 7–37.

Meleis, A. (2010). *Transitions theory: Middle range and situation specific theories in nursing research*

    and practice. New York, NY: Springer Publishing Company.

Meleis, A. (2015). Transitions theory. In M. Smith & M. Parker (Eds.), *Nursing theories and nursing*

    practice (4th ed., pp. 361–380). Philadelphia, PA: F.A. Davis Company.

Mendelson, C. (2009). Diagnosis: A liminal state for women living with lupus. *Health Care for Women*

    International, *30*, 390–407. https://doi.org/10.1080/07399330902785158

Menkes, D. B., Davison, M. P., Costello, S. A., & Jaye, C. (2005). Stereotactic radiosurgery: The

    patient's experience. *Social Science & Medicine*, *60*, 2561–2573.

    https://doi.org/10.1016/j.socscimed.2004.11.021

Messias, D., Gilliss, C., Sparacino, P., Tong, E., & Foote, D. (1995). Stories of transition: Parents recall

    the diagnosis of congenital heart defect. *Families, Systems & Health*, *13*, 367–377.

    https://doi.org/https://doi.org/10.1037/h0089280

Midence, K., & O'Neill, M. (1999). The experience of parents in the diagnosis of autism: A pilot study.

    Autism, 273–285. https://doi.org/10.1177/1362361399003003005

Millenson, M. L., DiGioia, A. M., III, Greenhouse, P. K., & Swieskowski, D. (2013). Turning patient-centeredness from ideal to real: Lessons from 2 success stories. *The Journal of Ambulatory Care Management*, *36*, 319–334. https://doi.org/10.1097/JAC.0b013e3182a3e76dPMID:24402074

Moniz-Cook, E. (2006). Facing the future: A qualitative study of older people referred to a memory clinic prior to assessment and diagnosis. *Dementia*, *5*, 375–395. https://doi.org/10.1177/1471301206067113

Morris, P., & Bronfenbrenner, U. (2007). The bioecological model of human development. In W. Damon & R. Lerner (Eds.), *Theoretical models of human development* (5th ed., pp. 793–828). Hoboken, NJ: John Wiley & Sons, Inc.

Mulligan, J., MacCulloch, R., Good, B., & Nicholas, D. B. (2012). Transparency, hope, and empowerment: A model for partnering with parents of a child with autism spectrum disorder at diagnosis and beyond. *Social Work in Mental Health*, *10*, 311–330. https://doi.org/10.1080/15332985.2012.664487

Nettleton, S., Kitzinger, J., & Kitzinger, C. (2014). A diagnostic illusory? The case of distinguishing between "vegetative" and "minimally conscious" states. *Social Science & Medicine*, *116*, 134–141. https://doi.org/10.1016/j.socscimed.2014.06.036

Page, M. C., Fedele, D. A., Pai, A. L. H., Anderson, J., Wolfe-Christensen, C., Ryan, J. L., & Mullins, L. L. (2012). The relationship of maternal and child illness uncertainty to child depressive symptomotology: A mediational model. *Journal of Pediatric Psychology*, *37*, 97–105. https://doi.org/10.1093/jpepsy/jsr055

Pedersen, A. L., Crnic, K. A., Baker, B. L., & Blacher, J. (2015). Reconceptualizing family adaptation to developmental delay. *American Journal on Intellectual and Developmental Disabilities*, *120*, 346–370. https://doi.org/10.1352/1944-7558-120.4.346

Pelentsov, L. J., Fielder, A. L., & Esterman, A. J. (2016). The supportive care needs of parents with a child with a rare disease: A qualitative descriptive study. *Journal of Pediatric Nursing*, *31*, 207–218. https://doi.org/10.1016/j.pedn.2015.10.022

Pope, A., & Brandt, E. (1997). *Enabling America: Assessing the role of rehabilitation science and engineering* (1st ed.). Washington, D.C.: National Academies Press.

Prelock, P. A., Beatson, J., Bitner, B., Broder, C., & Ducker, A. (2003). Interdisciplinary assessment of young children with autism spectrum disorder. *Language, Speech, and Hearing Services in Schools*, *34*, 194–202. https://doi.org/10.1044/0161-1461(2003/016)

Ramsey, W. (2016). Untangling two questions about mental representation. *New Ideas in Psychology*, *40*, 3–12.

Ray, K. (2017). Finding myself through an evening with the 'Rents [Facebook]. Retrieved from https://www.facebook.com/notes/kris-ray/finding-myself-through-an-evening-with-the-rents/10211155839145495/

Rosenthal, E. T., Biesecker, L. G., & Biesecker, B. B. (2001). Parental attitudes toward a diagnosis in children with unidentified multiple congenital anomaly syndromes. *American Journal of Medical Genetics*, *103*, 106–114. https://doi.org/10.1002/ajmg.1527

Saleebey, D. (1996). The strengths perspective in social work practice: Extensions and cautions. *Social Work*, *41*, 296–305. https://doi.org/10.1093/sw/41.3.296

Schalock, R. L., Borthwick-Duffy, S. A., Bradley, V. J., Buntinx, W. H. E., Coulter, D. L., Craig, E. M., … Yeager, M. H. (2010). *Intellectual disability: Definition, classification, and systems of supports* (11th ed.). Washington, D.C.: American Association on Intellectual and Developmental Disabilities.

Scorgie, K., & Sobsey, D. (2000). Transformational outcomes associated with parenting children who have disabilities. *Mental Retardation*, *38*, 195–206. https://doi.org/10.1352/0047-6765(2000)0382.0.CO;2

Scorgie, K., Wilgosh, L., & Sobsey, D. (2004). The experience of transformation in parents of children with disabilities: Theoretical considerations. *Developmental Disabilities Bulletin*, *32*, 84–110.

Siklos, S., & Kerns, K. A. (2007). Assessing the diagnostic experiences of a small sample of parents of

children with autism spectrum disorders. *Research in Developmental Disabilities*, *28*(1), 9–22.

https://doi.org/10.1016/j.ridd.2005.09.003 PMID:16442261

Staudt, M., Howard, M. O., & Drake, B. (2001). The operationalization, implementation, and

effectiveness of the strengths perspective: A review of empirical studies. *Journal of Social

Service Research*, *27*(3), 1–21. https://doi.org/10.1177/004057360005700202

Steele, R. B. (2000). Unremitting compassion: The moral psychology of parenting children with genetic

disorders. *Theology Today*, *57*, 161–174. https://doi.org/10.1177/004057360005700202

Steiner, A. M. (2010). A strength-based approach to parent education for children with autism. *Journal of

Positive Behavior Interventions*, *13*, 178–189.

https://doi.org/doi/abs/10.1177/1098300710384134

Stewart, J. L., & Mishel, M. H. (2000). Uncertainty in childhood illness: A synthesis of the parent and

child literature. *Scholarly Inquiry for Nursing Practice*, *14*, 299–319;

Taanila, A., Syrjälä, L., Kokkonen, J., & Järvelin, M. R. (2002). Coping of parents with physically and/or

intellectually disabled children. *Child: Care, Health and Development*, *28*, 73–86.

https://doi.org/10.1046/j.1365-2214.2002.00244.x

Tait, K., Fung, F., Hu, A., Sweller, N., & Wang, W. (2016). Understanding Hong Kong Chinese families'

experiences of an autism/ASD diagnosis. *Journal of Autism and Developmental Disorders*, *46*,

1164–83.

Timmermans, S., & Buchbinder, M. (2010). Patients-in-waiting: Living between sickness and health in

the genomics era. *Journal of Health and Social Behavior*, *51*, 408–423.

https://doi.org/10.1177/0022146510386794

Tomlinson, M., Yasamy, M. T., Emerson, E., Officer, A., Richler, D., & Saxena, S. (2014). Setting global

research priorities for developmental disabilities, including intellectual disabilities and autism.

Journal of Intellectual Disability Research, *58*, 1121–1130. https://doi.org/10.1111/jir.12106

Trowbridge, K., & Mische-Lawson, L. (2014). Families with children with medical complexity and self-

      management of care: A systematic review of the literature. *Social Work in Health Care*, *53*(7),

      640–658. https://doi.org/10.1080/00981389.2014.916776

Turner, V. (1969). *The ritual process*. New York NY: Transaction Publishers/Routledge.

van Gennep, A. (1960). *The rites of Passage*. New York, NY: Routledge.

Walker, L., & Avant, K. (2005). *Strategies for theory construction in nursing*. Upper Saddle River, NJ:

      Pearson.

Watson, G. (2011). Parental liminality: A way of understanding the early experiences of parents who have

      a very preterm infant. *Journal of Clinical Nursing*, *20*, 1462–1471.

      https://doi.org/10.1111/j.1365-2702.2010.03311.x

Workgroup on Principles and Practices in Natural Environments, OSEP TA Community of Practice: Part

      C Settings. (2008). Agreed upon practices for providing services in natural environments.

      Retrieved from

      http://ectacenter.org/~pdfs/topics/families/AgreedUponPractices_FinalDraft2_01_08.pdf

Table 1.

Categories and representative examples before and at the time of diagnosis

Category	Example	Author
Separation	The experiences of liminality separates individuals from others	(Little et al., 1998)
Awareness	One enters liminality the moment there is a suspicion of a diagnosis	(Forss, Tishelman, Widmark, & Sachs, 2004; Jordan, Price, & Prior, 2015; Little et al., 1998; Mendelson, 2009; Nettleton, Kitzinger, & Kitzinger, 2014; Timmermans & Buchbinder, 2010)
Role Performance	Diagnosis seeking may be associated with being a "good parent"; prolonged diagnosis seeking may be an assault to identity and integrity	(Cayless, Forbat, Illingworth, Hubbard, & Kearney, 2010; Crais et al., 2014; Eli, 2014; Halliday, Boughton, & Kerridge, 2015; Jordan et al., 2015; Mendelson, 2009; Moniz-Cook, 2006; Timmermans & Buchbinder, 2010; Watson, 2011)
Uncertainty	Contradictory messages and communication from health care providers, making sense of risk,	(Blows, Bird, Seymour, & Cox, 2012; Forss et al., 2004; Jordan et al., 2015; Mendelson, 2009; Menkes, Davison, Costello, & Jaye, 2005; Moniz-Cook, 2006; Timmermans & Buchbinder, 2010)

Figure 1.
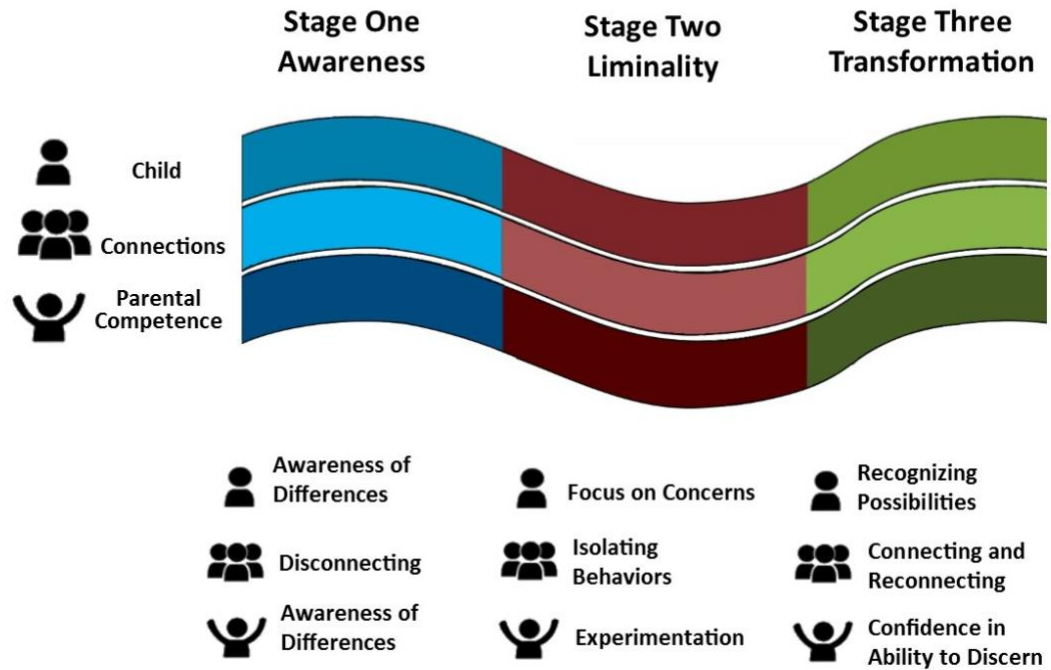Broski and Dunn's Strengths-Based Theory of Parental Transformation
Reprinted with permission. The published version can be found in Broski, J. & Dunn, W. Fostering insights: The strengths-based theory of parental transformation, Journal of Child and Family Studies (2018) 27: 1275. https://doi.org/10.1007/s10826-017-0964-5.

Chapter 2: Evaluation of the Strengths-Based Theory of Parental Transformation

Abstract

Previous studies have described stress and frustration related to parents' experiences before, during and after their child's developmental diagnosis. Parental awareness that their child' development is occurring differently from what they or others expected can create an unanticipated transition from being a parent to becoming the parent of a child with a diagnosis of a developmental disability (Broski & Dunn, 2017). Broski and Dunn's strengths-based theory of parental transformation (STPT) addresses a gap in the literature by situating parents' experience of the diagnostic process within a strengths-based framework. The STPT aligns with contemporary perspectives regarding disability by emphasizing a family-centered approach. The purpose of this study was to gain insights from parents about their transition experiences related to their child's developmental diagnosis. We developed an online questionnaire consisting of 81 items derived from the STPT. The items included statements that parents may say or think about their sense of competence, their social connections, and statements the parents may say or think about their child. Thirty-Two parents from the United States completed the survey. Participants identified behaviors that indicate specific strengths throughout each stage of parents' transition including awareness of their child's development, trying new strategies and gaining insight about themselves. Our research indicates that parents recognize multiple transformative experiences associated with their child's developmental diagnosis. Future research should focus on understanding the differences between the awareness and liminal stage of parents' transition.

Evaluation of the Strengths-Based Theory of Parental Transformation

Contemporary models of disability emphasize providing supports based on individuals' and families' needs (Little, Jordens, Paul, Montgomery, & Philipson, 1998); however, in practice, parents' needs receive little attention (Bailey Jr. et al., 2006; Pelentsov, Fielder, & Esterman, 2016). Because parent's health and wellness affect their children (e.g., Bronfenbrenner, 1986; Dunst, Trivette, & Hamby, 2014) it is essential to understand and support parents throughout the diagnostic process (Crane et al., 2016; Tomlinson et al., 2014b). The STPT (Broski, & Dunn, 2018) aligns with contemporary models of disability by recognizing parents' changing needs before and during the diagnostic process.

Literature Review

Transition theories contribute to our understanding of families' experiences around the diagnostic process. However, some traditional transition theories are not family-centered because the theories are not strengths-based. Because family-centered care is a cornerstone of service delivery, transition theories that are not strengths-based require updating to align with contemporary models of disability. For example, Kubler-Ross's Grief model (1969) is still used to describe parents' need to mourn the loss of the "normal" child (Allred & Hancock, 2012). Seeing parents as victims of a tragedy undermines the ability for parents and professionals to develop collaborative relationships necessary for family-centered care (Allred, 2015). Other descriptions of parents' transition frame parent's experiences in terms of being pre-diagnosis or post-diagnosis (Ho, Yi, Griffiths, Chan, & Murray, 2014b). A transition model that places the diagnosis at the center of the framework makes the child's diagnosis a kind of fulcrum upon which the parent's transition depends. Any model depending on the child's diagnosis for parents to experience aspects of transition or transformation inadvertently emphasizes a medical model and suggests that if a child has a condition that remains undiagnosed, parents may never experience transition. These frameworks stand in contrast to contemporary models of disability that recognize disability as a continuum of functioning and experience. Transition frameworks that a developmental diagnosis is a tragedy and that parents' grief is inevitable are still widely accepted (Allred & Hancock, 2012). Further, deficit and illness based

paradigms undermine establishing collaborative relationships between parents and providers (Allred, 2015).

There is considerable research on parents' experiences surrounding their child's diagnosis that describes higher levels of stress, anxiety, frustration and depression (Estes et al., 2009; Olsson & Hwang, 2001). While some parents experience higher levels of stress and depression, research that provides a "snapshot" of parents' experiences does not necessarily represent parents' experiences over time (Sobel & Cowan, 2003). Furthermore, parental experiences that include the full range of human experience does not preclude the use of a strengths-based paradigm (Rapp & Goscha, 2011).

Broski and Dunn's Strengths-Based Theory of Parental Transformation

The STPT describes three stages of parents' transition: awareness, liminality, and transformation. The STPT defines the first stage of transition as awareness. During this stage, parents begin to experience changes in their mental landscape regarding their expectations about their child's development. The STPT defines the second stage of transition as "liminality." Liminality is a concept derived from anthropology and indicates a time when individuals are transitioning to a new social role but have not yet formed a strong identity with the new role (e.g., Kralik, Visentin, & Van, 2006; Turner, 1995; van Gennep, 1960). Liminality is uncomfortable, yet important process in transition, perhaps because this phase presents conundrums that can leave individuals feeling in limbo or disconnected, yet gaining capacity for growth (Baird & Reed, 2015b). During this stage, parents may feel like they no longer recognize parts of their mental landscape as they are living on the threshold of a new way of life. The third stage of the STPT is transformation. In this stage, parents have learned to navigate their new mental landscape, and they have adequate resources to meet their needs (Baird, 2012b). Broski and Dunn propose parents recognize opportunities for growth as they redefine themselves in a new world during this stage (2017).

In addition to the three stages of transition, the STPT proposes there are three primary domains associated with parents' transition: parental competence, child, and connections with others. We propose that changes in the parental competence, child and connections domain relate to three stages of parental

transition. Figure 1 provides a graphic representation of the stages and domains of the STPT (Broski and

Dunn, 2018).

Parental competence and the STPT stages. The parental competence domain of the STPT

relates to parents' ability to see and portray themselves in ways they value, and others validate. The arc of

transformation in parental competence begins with parents seeking confirmation and may eventually

evolve to parents' recognizing their ability to navigate change and find answers. During the awareness

stage, the parental competence domain may involve parents seeking confirmation from experts about

parents' perceptions. During the liminal parents may experiment with new strategies to care for

themselves or their child. In the third stage of transition, parents may have more confidence in their

parenting skills and balancing their own needs with the needs of their family.

Child domain and the STPT stages. The child domain relates to statements or activities parents

say or think that include references to the child. The arc of transformation in the child domain begins with

parents' awareness of differences in their child's development to embracing the child's unique strengths.

During the awareness stage, parent behaviors that may include comparing their child's development to

other children or parents' noticing differences between their expectations and their observations about

their child's development. During the liminal stage, the child domain may include parents' intense focus

on their child's behavior and development and trying new things to see how they may help their child. In

the transformation stage, parents may embrace their child's unique strengths or recognize new

possibilities related to their child's functioning.

Connections domain and the STPT stages. The connections domain relates to parents'

interactions with friends, family, professionals or others in the community. The arc of transformation in

the connections domain may include parents' questioning how to fit in with their existing social circles to

expanding their social circle or letting go of social connections that no longer function for them. During

the awareness stage, the connections domain may include parents' confusion about what to tell their

family or friends about their child's development. During the liminal stage, parents may feel isolated from

family members or the community. During the transformation stage, parents may develop new

connections with people they have met because of their child. Parents may also decide to discontinue relationships that no longer fulfill them or work for them. Because current transition models do not provide a strengths-based approach to understanding parents' transition when there is a concern about the child's development there is a need to understand how parents' experience this transition.

To summarize, the STPT describes parental transition across three domains: parental competence, child, and connections. The purpose of this study was to gain insights about parents' transition experiences using a questionnaire based on the STPT and parents' mental model of transformation associated with their child's developmental diagnosis. This paper will address findings related to parents' transition experiences.

Methods

We conducted an exploratory study to gain insight into parents' transition experience. The target population was parents of a child with a neurodevelopmental diagnosis. Parents were eligible to participate if their child had a neurodevelopmental diagnosis. After providing consent, parents answer demographic questions about their background, child's diagnosis, and other medical conditions and then they completed the survey.

We developed an 81-item classification survey consisting of statements parents may say or think. We used the STPT as the basis for survey items including parent statements from peer-reviewed articles on parent and patient transition experiences and memoirs written by parents of children with an autism diagnosis.

We constructed the survey using Qualtrics, a web-based survey platform. The survey included a screening questionnaire, informed consent, demographic questionnaire, and transition survey items. Survey instructions indicated parents could classify statements in 1 of 4 categories: stage one, two or three of transformation or a category called "not part of parents' transition experience." Table 1 describes how we presented the stages of transition in the survey. The descriptions were intentionally vague to allow parents to apply their meanings to each stage of transition. Participants could also choose not to assign items to a category. Participants assigned each statement to a transition category. After assigning

statements to one of the four categories, participants were asked to review a list of all the items they had assigned to each of the categories. Participants could then decide to keep the statement in the category they originally assigned or they could decide to reclassify the item. After parents assigned statements to 1 of 4 categories, we asked two open-ended questions about each stage of transition. We will report the result of the open-ended responses in a separate paper.

Participants were volunteers that responded to information about the study. A convenience sample was appropriate because the purpose of this study included piloting survey questions related to the concepts of the STPT (Bock & Sergeant, 2002). We distributed recruiting information, including a link to the survey on Facebook and to organizations who work with children and families. We sent recruiting materials to the Association of University Centers on Disability, Leadership Education in Neurodevelopmental Disabilities programs, Kansas Families Together, Johnson County Developmental Supports in Kansas, Infant Toddler Services of Johnson County Kansas, Kansas Big Tent Coalition, Kansas Medicaid Functional Eligibility team and the National Council on Independent Living and the Association of Rural Independent Living Programs. The survey was available from February 2017 to June 2017. The University of Kansas IRB approved this study. Participants consented online before completing the survey. Because our purpose was to gain insights into an untested theory, a small sample size was appropriate for this study (e.g., Bryman, 2016; Stebbins, 2001).

After concluding data collection, we downloaded the dataset from Qualtrics to Microsoft Excel for analysis. We used descriptive statistics to examine demographic data and calculated frequency distributions for classification data. We developed a coding scheme to determine the STPT domain associated with the primary items in each of the transition stages. In this study, we defined items with 60% or of parents categorizing the item within the same transition stage as a "majority agreed upon item" (MAUI). Table 2 provides the coding scheme used to identify STPT domains.

We conducted an analysis of verbs for primary items to identify possible patterns in parent behaviors across the three transition stages. We used the Stanford online sentence parser analyze the structure of the MAUIs and tag the parts-of-speech including verbs. We used the following strategies to

enhance the trustworthiness of the results: peer debriefing, purposive sampling to focus on individuals who are particularly knowledgeable about the parental transition, maintaining an audit trail and maintaining an audit trail.

Results

Thirty-Two parents completed the survey; most participants were white, college-educated women. Our results indicated that the participants started the survey was 42 times, but we were unable to determine if those individuals dropped out or if they stopped taking the survey and later returned and completed the survey. Our findings indicated 88% (n=28) of the parents were the child's biological parent, 6% (n=2) were adoptive parents, and 6% (n=2) had some other relationship to the child. The sample included a wide range in parent ages; 34% (n= 9) of participants were in their 50s or 60s, 63% (n= 20) were in their 30s or 40s, 3% (n=1) were in their 20s and 6% (n= 2) did not indicate their age. Participants came from seven states from various parts of the United States including the northeast, southeast, mid-west, north, and southwest. Seventy-two percent (n=23) of parents indicated their child had an autism diagnosis, 13% (n=4) indicated their child had an intellectual disability and 16% (n=5) indicated their child had a neurodevelopmental diagnosis other than autism or intellectual disability. Sixty-three percent (n=20) of the children were male. The children's ages ranged from two to over 30 years old.

Figure 2 provides summary frequencies for MAUIs for each stage of the STPT. Table 3 indicates the domains for MAUIs for each stage of transition. Table 3 provides the results of the content analysis of primary parent behaviors related to each stage of parents' transition. Table 4 provides a summary of the verbs for MAUIs for the transition stages.

Discussion

Models of parent transition that emphasize grief and vulnerability contribute to research paradigms that are not family-centered.

Additionally, research that focuses on the increased burden on parents of children with a developmental diagnosis fails to describe parents' strengths, including the range of parents' growth and

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learning over time (King et al., 2006). The perception that family supports promote family capacity, how an intervention is conceived and delivered makes a difference in whether services will have a positive impact for the family (Sukkar, Dunst, & Kirkby, 2016). Identifying parents' strengths throughout the transition experience, provides opportunities to begin the practice of family-centered care, which recognizes parents' strengths and preferences. Additionally, identifying parents' strengths throughout the diagnostic process 'provides opportunities for professionals to gain insights about parents' values and priorities (King et al., 2006; Rapp & Goscha, 2011).

The verbs associated the stages of transition offer insight into the active processes associated with transition and transformation. The MAUI verbs for the awareness stage include: thinking, noticing and wondering. A strengths-based perspective of parents' experiences during the awareness stage involves recognizing that thinking, noticing and wondering about their child's development and behavior describes parents' learning in the context of parenting. "Learning in context is paying attention to the interaction and intersection among people, tools, and context within a learning situation" (Hansman, 2001, p. 44).

There was only one MAUI that best with the liminal stage: "I keep trying new things, but I'm not sure if I'm doing the right things to help my child." The verbs "trying" and "doing" suggests parents experiment with different approaches during the liminal stage. Broski and Dunn's (2017) analysis of parent memoirs reported parents may try different diets, different schools or interventions to learn what works for their child. Experimentation during liminality may provide insight into interventions that are effective for their child, and parents may also discover they prefer certain interventions over others. The verbs "try" and "do" align with concepts of adult learning theory that indicates adults learn in many different ways including practicing, rehearsing and trial and error (van Merrienboer & Paas, 2003, p. 4).

Previous studies associate diagnostic uncertainty with emotional burden and stress (Håkstad, Obstfelder, & Øberg, 2015; Lenhard, Breitenbach, Ebert, Schindelhauer-Deutscher, & Henn, 2005), the findings of our study indicate parents become more comfortable with uncertainty throughout the transition process. For example, the awareness stage verbs "wonder" and "notice" suggest there are aspects of their child's development that parents are unsure of. In the transformation stage, parents

acknowledge they are unsure about the future, but they are sure they will be able to handle whatever comes next. Future studies should explore what factors contribute to parents becoming more comfortable with uncertainty.

Because this study was exploratory, the authors did not know what items parents might consider being "liminal." It is possible that there were not as many stages two items for parents to choose from compared to the other two stages of parents' transition. Future studies to explore if participants understand the survey items in the same way. The findings of our pilot study suggest the experience of being in between social roles is difficult to classify. The need to understand parent's liminal experiences is reinforced by Turner (1969/1995) that individuals experiencing liminality often "elude or slip through the network of classifications that normally locate states and positions in cultural space (p. 95)."

The STPT suggests parents' sense of role competence is related to helping their child. In this study, items in the awarenss stage did not specifically mention help; however, helping appears in liminal and transformation stage items. For example, references to helping in the liminal stage indicate parents try different things to help their child. In the transformation stage, there is an apparent shift in helping activities. Instead of parents helping the child, transformation stage items indicate something about their child has helped parents gain insight about themselves, have a better sense of humor and make new friends.

Transformation stage verbs suggest parents' strengths are dynamic throughout the stages of transition. Parents' strengths evolve from noticing and wondering in the awareness stage, to trying and doing in the liminal stage, and then to possessing, knowing and understanding in the transformation stage. For example, stage three verbs indicate parents move beyond noticing and wondering to sharing their learning. Future studies should explore the dynamic nature of parents' strengths throughout the diagnosis process and how those strengths align with the stages of knowledge development and transformative learning for adults (Taylor, 2006).

It is interesting to note there that several participants did not categorize any of the survey items into the awareness or liminal stage. It is possible that the parents we surveyed may have previous

experience with neurodevelopmental conditions. It is possible that enough time had passed since the parents' first awareness differences in their child's development or behavior was an integrated part of the family's experience. It is also possible that participants may have erred in completing the survey or the survey item was flawed.

The STPT proposes there are three domains associated with parents' transition; competence, child, and connections. The child domain was the only domain represented in the liminal stage. Therefore there is a need to understand if the STPT domains adequately describe parents' transition experiences. There is also a need to refine the STPT definitions. For example, the STPT proposes during the transformation stage parents may let go of social connections that no longer meet their needs. Broski and Dunn (2017) review of parent memoirs found evidence of this experience. However, this study did not support this aspect of the STPT. Future studies should investigate whether the presence (or absence) of certain domains in the stages of transition reflect some quality of transition or transformation. For example, it may be informative to know if focusing on the positive impacts of parental competence during the awareness stage or liminal stage assists families through the transition process.

This study provides preliminary evidence a questionnaire based on the STPT can provide insight about parents' transition experiences by asking parents to identify items they associate with different stages of transition and suggests the STPT can provide a strengths-based framework to understand parents' transition and transformation related to their child's diagnosis. This study also provides information that researchers should use to modify the STPT; for example, we found that the STPT domain definitions need to be clearer. We suggest additional criteria to more clearly define the domains to enhance the usability of the STPT. We provide the modified domain criteria in table 1. Additionally, future studies should ensure the survey considers domain items that are likely for each of the stages.

Strengths and Limitations

A limitation of the study is the heterogeneity of the small sample. Despite the small, diverse sample, our study indicates there are aspects of the transition experience that appear to be similar across

diverse socio-economic and geographic groups. The items we gathered from the literature may not represent the full experience of families, suggesting we need more items to reflect liminality.

Conclusions

The purpose of this study was to understand parents' transition experiences using the STPT. The STPT describes three stages of parents' transition: awareness, liminality, and transformation. The STPT proposes each stage of transition include parent behaviors associated with three domains; parental competence, child, and connections. This study indicates parents identified strengths-based behaviors at every stage of transition.

Future studies should include a rigorous assessment of the validity of the STPT including an evaluation of the assumptions and inferences associated with the model. Future studies should consider how the STPT might be used by parents and providers to understand where parents are on the transition spectrum. A potentially innovative contribution of the STPT is the concept of changes in parents' mental models during the transition. Future studies should determine if the STPT accurately describes families' transition experiences.

Family-centered care is a practice that recognizes parents, including those with temporary or chronic health conditions, have strengths. Research on parents' strengths is needed to improve understanding of parents' aspirations, competencies, values, and priorities. For both parents and providers, a strengths-based perspective can serve as a guide to explore possibilities that are hopeful and realistic; and should serve as a cornerstone for developing family-centered interventions.

References

Allred, K., & Hancock, C. (2012). On death and disability: Reframing educators' perceptions of parental

    response to disability. *Disability Studies Quarterly, 32*. http://dx.doi.org/10.18061/dsq.v32i4.1737

Allred, K. W. (2015). Engaging parents of students with disabilities: Moving beyond the grief model.

    Improving Schools, 18, 46–55. https://doi.org/10.1177/1365480214553745

Bailey, D., Jr., Bruder, M., Hebbeler, K., Carta, J., Defosset, M., Greenwood, C., … Barton, L. (2006).

    Recommended outcomes for families of young children with disabilities. *Journal of Early*

    Intervention, 28, 227–251. https://doi.org/10.1177/105381510602800401

Baird, M. B. (2012). Well-being in refugee women experiencing cultural transition. *Advances in Nursing*

    Science, 35, 249–263. https://doi.org/doi: 10.1097/ANS.0b013e31826260c0

Baird, M. B., & Reed, P. G. (2015). Liminality in cultural transition: Applying ID-EA to advance a

    concept into theory-based practice. *Research and Theory for Nursing Practice, 29,* 25–37.

    https://doi.org/10.1891/1541-6577.29.1.25

Bock, T., & Sergeant, J. (2002). Small sample market research. *International Journal of Market*

    Research; Henley-on-Thames, 44(2), 235–244. https://doi.org/10.1177/147078530204400205

Bronfenbrenner, U. (1986). Ecology of the family as a context for human development: Research

    perspectives. *Developmental Psychology, 22*, 723–742. https://doi.org/10.1037/0012-

    1649.22.6.723

Broski, J., & Dunn, W. (2018). Fostering insights: A strengths-based theory of parental transformation.

    Journal of Child and Family Studies, 27, 1275–1286. https://doi.org/10.1007/s10826-017-0964-5

Bryman, A. (2016). *Social research methods* (5th ed.). New York, NY: Oxford University Press.

Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of autism diagnosis:

    A survey of over 1000 parents in the United Kingdom. Autism: *The International Journal of*

    Research and Practice, 20, 153–162.

    https://doi.org/10.1177/1362361315573636 PMID:25810370

Dunst, C. J., Trivette, C. M., & Hamby, D. W. (2014). Relationships between family risk and opportunity factors and parent and child functioning. *Journal of Educational and Developmental Psychology, 4*(2), 10. https://doi.org/10.5539/jedp.v4n2p10

Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X.-H., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism, 13*, 375–387. https://doi.org/10.1177/1362361309105658

Håkstad, R. B., Obstfelder, A., & Øberg, G. K. (2015). Parents' perceptions of primary health care physiotherapy with preterm infants. *Qualitative Health Research.* https://doi.org/10.1177/1049732315608137

Hansman, C. A. (2001). Context-based adult learning. *New Directions for Adult and Continuing Education* (89), 43–52. https://doi.org/10.1002/ace.7

Ho, H. S., Yi, H., Griffiths, S., Chan, D. F., & Murray, S. (2014). "Do It yourself" in the parent-professional partnership for the assessment and diagnosis of children with autism spectrum conditions in Hong Kong: A qualitative study. *Autism, 18*, 832–844. https://doi.org/10.1177/1362361397012003

King, G. A., Zwaigenbaum, L., King, S., Baxter, D., Rosenbaum, P., & Bates, A. (2006). A qualitative investigation of changes in the belief systems of families of children with autism or Down syndrome. *Child: Care, Health and Development, 32*, 353–369. https://doi.org/10.1111/j.1365-2214.2006.00571.x

Kralik, D., Visentin, K., & van Loon, A. (2006). Transition: A literature review. *Journal of Advanced Nursing, 55*, 320–329. https://doi.org/10.1111/j.1365-2648.2006.03899.x

Kübler-Ross, E. (1969). *On death and dying*. New York: Macmillan.

Lenhard, W., Breitenbach, E., Ebert, H., Schindelhauer-Deutscher, H. J., & Henn, W. (2005). Psychological benefit of diagnostic certainty for mothers of children with disabilities: Lessons from Down syndrome. *American Journal of Medical Genetics*. Part A, 133A, 170–175. https://doi.org/10.1002/ajmg.a.30571

Little, M., Jordens, C. F., Paul, K., Montgomery, K., & Philipson, B. (1998). Liminality: A major category of the experience of cancer illness. *Social Science & Medicine, 47*, 1485–1494. https://doi.org/10.1016/S0277-9536(98)00248-2

Olsson, M. B., & Hwang, C. P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research, 45*, 535–543. https://doi.org/10.1046/j.1365-2788.2001.00372.x

Pelentsov, L. J., Fielder, A. L., & Esterman, A. J. (2016). The supportive care needs of parents with a child with a rare disease: A qualitative descriptive study. *Journal of Pediatric Nursing, 31*, 207–218. https://doi.org/10.1016/j.pedn.2015.10.022

Rapp, C. A., & Goscha, R. J. (2011). *The strengths model: A recovery-oriented approach to mental health services*. USA: Oxford University Press.

Sobel, S., & Cowan, C. B. (2003). Ambiguous loss and disenfranchised grief: The impact of DNA predictive testing on the family as a system. *Family Process, 42*, 47–57. https://doi.org/10.1111/j.1545-5300.2003.00047.x

Stebbins, R. A. (2001). *Exploratory research in the social sciences*. SAGE.

Sukkar, H., Dunst, C. J., & Kirkby, J. (Eds.). (2016*). Early childhood intervention: Working with families of young children with special needs*. New York: Routledge.

Taylor, K. (2006). Brain function and adult learning: Implications for practice. *New Directions for Adult and Continuing Education, 2006*(110), 71–85. https://doi.org/10.1002/ace.221

Tomlinson, M., Yasamy, M. T., Emerson, E., Officer, A., Richler, D., & Saxena, S. (2014). Setting global research priorities for developmental disabilities, including intellectual disabilities and autism. *Journal of Intellectual Disability Research, 58*, 1121–1130. https://doi.org/10.1111/jir.12106

Turner, V. (1969). *The ritual process: Structure and anti-structure*. New York, NY: Transaction Publishers; Routledge.

Table 1

Definitions provided in the survey

STPT Stage	Definition
One	Caregiver awareness
Two	Caregiver passage, or being "betwixt and between" stages, neither here nor there
Three	Caregiver transformation or transition
Not part of caregiver awareness, passage or transition	Experiences that do not fit parents' or caregivers' experiences while they wait for their child's developmental diagnosis

Table 2

Coding scheme used to identify STPT domains

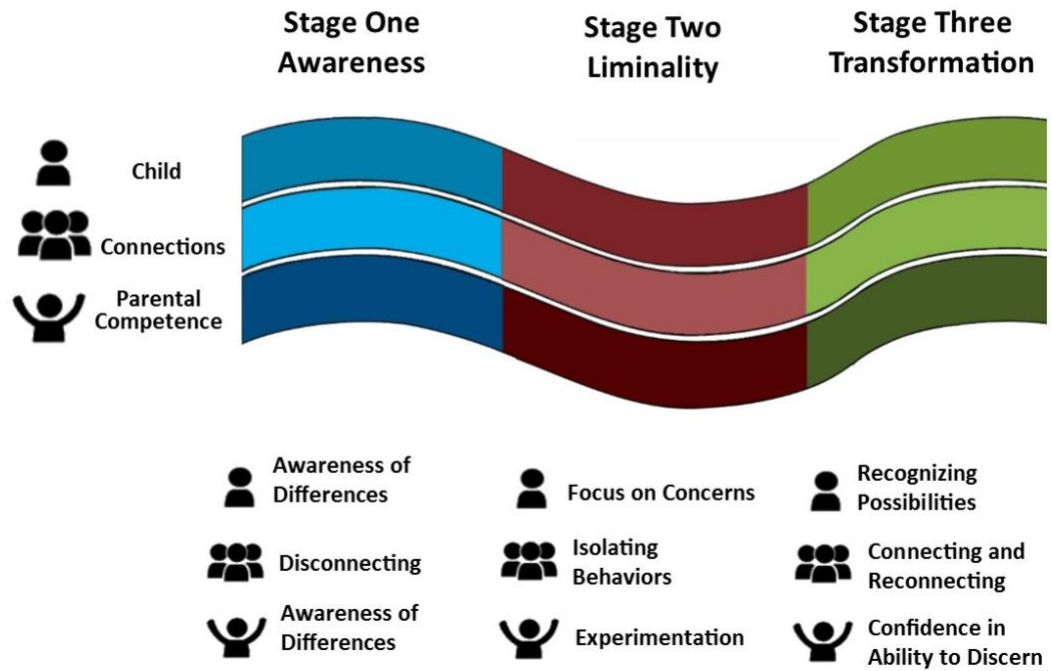| STPT Domain	Code	Rules	Examples
Competence	Parent Only	The sentence does not reference any other person or group.	I feel hopeful about the future.
Child	Parent + Child	The sentence refers to the child, but no other group.	I celebrate my child's uniqueness.
Connections	Parent + Others	The sentence includes references to other people, but does not specifically indicate the child	We may not be a typical family, but I would not have it any other way
	Parent + Child + Others	The sentence includes references to the child and other individuals or groups.	I like telling other people about my child.

Table 3

Results of the content analysis of STPT domains

	Parent	Parent + Child	Parent + Others	Parent + Others + Child
Awareness n=4	0 (0%)	2 (9%)	0 (0%)	2 (9%)
Liminality n=1	0 (0%)	1 (4%)	0 (0%)	0 (0%)
Transformation n=16	4 (17%)	7 (30%)	1 (4%)	4 (17%)
Not part of transition n=2	1 (4%)	0 (0%)	1 (4%)	0 (0%)

Table 4

Verbs associated with parents' experience during transition

Awareness Stage		Liminal Stage		Transformation Stage	
Verbs	Frequency	Verbs	Frequency	Verbs	Frequency
Notice	2	Do	1	Has	5
Talk	1	Help	1	Know	4
Think	1	Keep	1	Understand	3
Wonder	1	Try	1	Make	2
				Like	2
				Celebrate	1
				Change	1
				Collaborate	1
				Feel	1
				Find	1
				Go	1
				Handle	1
				Happen	1
				Help	1
				Learn	1
				Love	1
				Meet	1
				Regard	1
				Share	1
				Tell	1
				Use	1

Figure 1

Strengths-Based Theory of Parental Transformation (Broski & Dunn, 2018)

Reprinted with permission. The published version can be found in Broski, J. & Dunn, W. Fostering insights: The strengths-based theory of parental transformation, Journal of Child and Family Studies (2018) 27: 1275. https://doi.org/10.1007/s10826-017-0964-5.
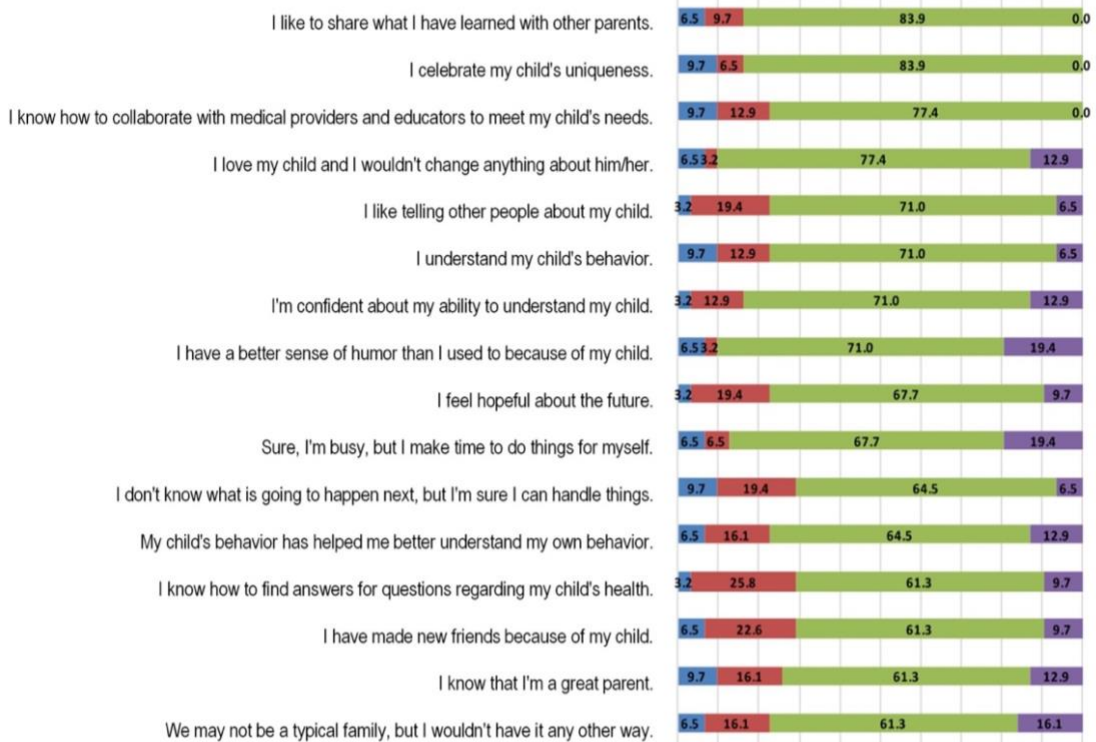
At Least 60% of Participants Indicate the Statements Fits Best with Stage One: Awareness

Statement	Awareness	Liminal	Transformation	Not part of parents experience
I think my child's behavior is different than other children his/her age.	71.0	9.7	9.7	9.7
I wonder if my child's behavior is typical.	64.5	6.5	9.7	19.4
I wonder if my child's development is okay.	64.5	12.9	19.4	3.2
I notice that my child doesn't talk as much as other children	61.3	6.5	12.9	19.4
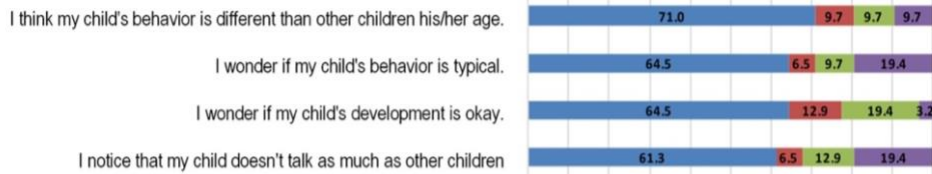
At Least 60% of Participants Indicate the Statement Fits Best with Stage Two: LIminality

Statement	Awareness	Liminal	Transformation	Not part of parents experience
I keep trying new things, but I'm not sure if I'm doing the right things to help my child.	12.9	64.5	12.9	9.7

At Least 60% of Participants Indicate the Statements Fits Best with Stage Three: Transformation

Statement	Awareness	Liminal	Transformation	Not part of parents experience
I like to share what I have learned with other parents.	6.5	9.7	83.9	0.0
I celebrate my child's uniqueness.	9.7	6.5	83.9	0.0
I know how to collaborate with medical providers and educators to meet my child's needs.	9.7	12.9	77.4	0.0
I love my child and I wouldn't change anything about him/her.	6.5 3.2		77.4	12.9
I like telling other people about my child.	3.2	19.4	71.0	6.5
I understand my child's behavior.	9.7	12.9	71.0	6.5
I'm confident about my ability to understand my child.	3.2	12.9	71.0	12.9
I have a better sense of humor than I used to because of my child.	6.5 3.2		71.0	19.4
I feel hopeful about the future.	3.2	19.4	67.7	9.7
Sure, I'm busy, but I make time to do things for myself.	6.5	6.5	67.7	19.4
I don't know what is going to happen next, but I'm sure I can handle things.	9.7	19.4	64.5	6.5
My child's behavior has helped me better understand my own behavior.	6.5	16.1	64.5	12.9
I know how to find answers for questions regarding my child's health.	3.2	25.8	61.3	9.7
I have made new friends because of my child.	6.5	22.6	61.3	9.7
I know that I'm a great parent.	9.7	16.1	61.3	12.9
We may not be a typical family, but I wouldn't have it any other way.	6.5	16.1	61.3	16.1

At Least 60% of Participants Indicate the Statements Fits Best with Stage Three: Transformation

Statement	Awareness	Liminal	Transformation	Not part of parents experience
I watch more TV than I used to.	0	16.1	6.5	77.4
Things would be easier if we had a pet.	6.5	12.9	12.9	67.7

Legend: Awareness (blue), Liminal (red), Transformation (green), Not part of parents experience (purple)

Figure 2
Statements 60% or more of the study participants indicated fit best with each stage of the STPT.

Chapter 3: Exploring the Development of Parents' Mental Models Related to Their Child's

Developmental Diagnosis

Abstract

Previous research reports that parents may experience higher levels of depression, stress, and uncertainty around the time when their child receives a diagnosis of a developmental disorder. However, there is mounting evidence that some parents experience positive transformation related to their child's diagnosis. The strengths-based theory of parental transformation proposes parents' mental models evolve. The purpose of the survey was to learn how parents of a child with a developmental diagnosis define and experience transition. We examined 22 parents' responses to 6 open-ended online survey questions responses. We used an exploratory mixed method design to analyze parents' responses. Our findings suggest parents associate awareness of their child's differences with feelings of uncertainty, fearful and search for information. Parents' descriptions as they experience becoming aware of their child's differences often focuses on the child and family. Parents' responses suggest they experience frustration and confusion as they adapt to a new state. Parents' descriptions of frustration, confusion and adapting often focus on providers and other people who are not family members. Parents' responses indicated that parents experience confidence, pride, and adaptation with learning to accept their child and themselves. Parents' descriptions of acceptance often focused on greater self-understanding and the need for self-care. The results indicate there are differences in the social contexts and processes that parents emphasize in their descriptions of transition associated with their child's developmental diagnosis. Future studies should explore the factors that help and hinder parents' ability to support their child.

Individuals assign meaning to life events based on their expectations about each phase of life (G Becker, 1997) but when parents are faced with an unexpected diagnosis, the diagnosis may create an unanticipated transition (Meleis, 2010; Messias et al., 1995) from being a parent to becoming the parent of a child with a developmental diagnosis (Boström & Broberg, 2014; Boström, Broberg, & Hwang, 2010; Broski & Dunn, 2018b). Transition requires adaptation and shapes how people respond to change. Transition theories generally recognize three primary stages: (1) an initial phase that involves separation from a previous way of life; (2) an in-between phase known as liminality, a state of being betwixt and between; and (3) a final phase that signifies the beginning of the individual's new social role (Kralik et al., 2006; Meleis, 2010; Turner, 1969; van Gennep, 1960a).

For most of the twentieth century, the models used to understand transition and disability focused on pathology and limitations. Broski and Dunn (2018b) proposed the strengths-based theory of parental transformation as an alternative to transition models that are not strengths-based or family-centered. There are three key features of the strengths-based theory of parental transformation that set it apart from other situation-specific transition theories. The strengths-based theory of parental transformation is: family-centered, recognizes transition may begin before the child's diagnosis is confirmed and describes parental transformation in terms of changes in parents' mental models (Broski & Dunn, 2018a, Broski & Dunn, 2018b).

Previous research indicates the diagnostic process is a critical stage for families (Crane et al., 2016; Mansell & Morris, 2004b). Early in the diagnostic process, parents frequently report the need to learn more about their child's condition, make appointments with multiple providers, and make decisions obtaining and paying for appropriate supports for their child (Crane et al., 2016; Mansell & Morris, 2004b). These tasks require sensemaking. Sensemaking is the process that people use to understand new information and make connections among people, places, and events in order to anticipate what to expect in the future (Klein, Moon, & Hoffman, 2006a, 2006b). Sensemaking is a particularly useful approach to explore parents' experiences with transition and transformation because sensemaking is a motivated effort to understand connections among people, places, and events and anticipate how to act effectively (G.

Klein et al., 2006a, p. 71) and focuses on understanding how people cope with and adapt to changing situations (Weick, Sutcliffe, & Obstfeld, 2005).

The sensemaking process begins with an initial point of view or framework which may involve multiple mental models (Klein, Moon, Hoffman, 2006). There are two basic processes that people use to make sense of information. The first process involves fitting new information into an existing frame, which may involve 1 or more mental models (Sieck, Peluso, Smith, Harris-Thompson, & Gade, 2007). The second process involves fitting a frame around the data.

Mental models are the cognitive representations people use to make sense of complex and uncertain situations. A mental model is comprised of an individual's identity, and the individual's unique frames of reference, cultural values, and personal preferences to make sense of information (Golledge, 1991). Mental models are the "maps" individuals use to organize and navigate the knowledge of their lives (e.g., Mumford, Watts, & Partlow, 2015; Rouse & Morris, 1986; Shen, Tan, & Siau, 2017). An additional feature of mental models is that while they may be deeply ingrained, mental models change as individuals gain experience and knowledge (e.g., Jones, Ross, Lynam, Perez, & Leitch, 2011; Klein, 2008). Research on mental models indicates that the development of a mental model is a learning process (Lowyck, 2008) and that learning in real-life situations involves the use of mental models (Greeno, 1989; Van Merriënboer & De Croock, 2007). While mental models are generally associated with learning and adaptation, mental models can also hinder change and opportunities for individuals (Schalock, Verdugo, Bonham, Fantova, & Van Loon, 2008).

Because mental models reflect an individual's sense of self and the world (e.g., Jonassen & Cho, 2008; Lowyck, 2008; Rouse & Morris, 1986), and reveal the connections an individual makes between things, processes and people (Van Merriënboer & De Croock, 2007), understanding an individual's mental model provides critical information that can be used to develop support for the family.

Figure 1 summarizes key features of the strengths-based theory of transformation. In a previous study, the first author used statements derived from autobiographies of parents of children with an Autism Spectrum Disorder to gain insight about parents' mental models related to their child's diagnosis and

parental transformation. Broski and Dunn (2018b) found parents' associated stage 1 (awareness of their child's differences) with thinking, noticing and wondering about their child's development and behavior. Stage 2 (liminality) was associated with trying new things to help their child. State 3 (transition) was associated with knowing, understanding and accepting their child and themselves. While this study used statements from the strengths-based theory of transformation to understand parents' mental models of transition, it is unclear how parents would describe stages of transition related to their child's diagnosis in their own words.

Research on sensemaking and mental models provides evidence that suggests the transition to becoming a parent of a child with a developmental disability does not exist as an abstract concept. Rather, parents' preferences exist as multiple internal representations or mental models that help them make sense of their experiences and guide their actions (Spector, p 12). Research suggests when parents make sense of a child's diagnosis they experience difficulties understanding the cause and prognosis (Dale, Jahoda, & Knott, 2006) and that understanding the ways in which parents make sense of their child's diagnosis is essential to develop effective family support (Dale et al., 2006). Denman, Smart, Dallos, & Levett (2016) identified sensemaking practices that include parents reframing conversations from a focus on problem behavior to talk about the child in a positive light. These studies suggest more information could help parents make sense of the child's diagnosis (Dale et al., 2006; Denman et al., 2016). However, sensemaking research also suggests more information is only helpful up to a certain point (G. Klein et al., 2006a, 2006b; Mastro, Flynn, & Preuster, 2014).

Previous studies designed to elicit individuals' mental models use graphics created by participants to depict concept maps that reflect their mental models (Cartmel, Smith, & Miller, 2016) or use text-based data (e.g., Haliko, Downs, Mohan, Arnold, & Barnato, 2018; Kim, 2013). Because mental models are characterized by identifying relationships among concepts, language can be used to "map" the connections between processes and people by exploring the relationships between nouns and phrases (Kim, 2013). The purpose of this study was to gain insight about parents' evolving mental models as they discover what it means to be parent to a child with a developmental disability. The goal of this study was

to address the research question: How do parents describe the changes in their mental model of transition related to their child's diagnosis?

Method

Reflexivity Statement

This study was conducted by two researchers with a range of personal and professional experiences working with families of a child with a developmental diagnosis. The first author is completing a Ph.D. in Therapeutic Science. She was a Leadership in Neurodevelopmental Disabilities (LEND) graduate student trainee at the Center for Child Health and Development (CCHD) at the University of Kansas Medical Center. The CCHD LEND program is nationally recognized for its expertise in the diagnosis and treatment of Autism Spectrum Disorders. The first author is the parent of a 17-year-old daughter with a "working" diagnosis of Coffin-Lowry syndrome, and she has served as a parent member on a state interagency coordinating council responsible for advising and assisting the governor and legislature on matters that impact Kansas families with children who have developmental delays. The second author is a Distinguished Professor of the Department of Occupational Therapy Education at the University of Missouri. Her research has brought a neuroscience perspective to the practice of occupational therapy through the development of the ecology of human performance, a model of sensory processing, and through her sensory processing assessments. The authors agree with position statements from the Division of Early Childhood and the National Association for the Education of Young Children's that indicate all families, with the appropriate supports, can support their child's learning and development early intervention.

Study Design

We utilized an exploratory, mixed-method research design to gain insight into parents' transition experiences related to their child's developmental diagnosis. Our constructivist approach recognizes the range of appropriate methodologies that can be combined to conduct multi-dimensional research. The qualitative components of this study were designed to gain parents' "information-rich" descriptions of stages of transition. The quantitative components of this study were designed to further explore and

corroborate the data (Spector, 2010).

Participants and Recruiting

We recruited parents through organizations that serve children and families including the Association of University Centers on Disability, Leadership Education in Neurodevelopmental Disabilities programs, Kansas Families Together, Johnson County Developmental Supports in Kansas, Infant Toddler Services of Johnson County Kansas, Kansas Big Tent Coalition, Kansas Medicaid Functional Eligibility team, the National Council on Independent Living and the Association of Rural Independent Living Programs. Individuals were eligible to participate if they were a parent of a child diagnosed with a developmental disability.

Sampling

We used purposive and snowball sampling strategies to recruit parents of children with a neurodevelopmental diagnosis and who also completed at least one of the open-ended responses to the survey (n=22). We used constant comparative analysis to identify emergent theme saturation. Studies using discourse analysis to reveal participant mental models report similar sample sizes to ours (Fujita & Brett, 2008; Maltseva, 2016; Manoharan & de Munck, 2017; Stevenson, Schoonen, & Glopper, 2003). Additionally, a smaller sample size is preferable for discourse analysis involving micro-analysis of participants' responses (Lazaraton, 2009).

Data Collection

Data collection involves eliciting participants mental models (Langan-Fox, Code, & Langfield-Smith, 2000). Our process for eliciting participants' mental models of transition is similar to the processes described by Gurel, Eryilmaz, & McDermott (2015) and Morgan, Fischhoff, Bostrom, & Atman (2001). The process includes activating participants' mental models by asking them to reflect on their experience, asking participants to identify relationships among statements, and responding to open-ended questions. Researchers may have difficulty distinguishing a mental model from perception. Grenier & Dudzinska-Przesmitzki (2015) suggest a perception is becoming aware of something and interpreting the awareness.

A mental model is a collection of past perceptions gathered from multiple experiences over time that are linked by a common theme or feature (Grenier & Dudzinska-Przesmitzki, 2015, p. 166).

We used Qualtrics, a web-based survey tool, for informed consent and for data collection. Participants were first asked to "reflect on your personal experience and select which part of caregiver transition fits best with each statement." Participants then sorted a list of 81 items into three categories (stage 1, stage 2 and stage 3 of transition). Participants were asked to review the list of items for each of the three stages of transition. Participants were then asked six additional open-ended questions (two questions for each stage of transition). The first question asked participants to write additional statements that parents might say or think that should be added to the list. Parents were then asked to define each stage of transition. A description of the items and sorting activity are described in a previous study (Broski & Dunn, 2018a).

Data Analysis

First, we used discourse analysis to analyze verb phrases for each stage of transition to explore processes and social contexts which parents associate with stages of transition. Second, we used descriptive statistics to explore similarities and differences in parents' descriptions across stages of transition. Third, we used constant comparison to examine the meanings parents associated with stages of transition.

Discourse Analysis. We used discourse analysis to explore the processes parents associated with each stage of transition, and the individuals that parents identified with the processes. Broadly speaking, discourse analysis leverages the rules of grammar to uncover relationships between concepts (Feiz & Strauss, 2014; Gee, 2014; Lazaraton, 2009). We used discourse analysis to explore the processes parents referenced in their descriptions of transition. By processes, we are referring to activities such as becoming aware of differences, meeting with doctors, and scheduling appointments. Processes are determined through analysis of verbs (Feiz & Strauss, 2014, pp. 27–29; Gee, 2014, p. 55).

We imported participant responses into RQDA (Ronggui & Huang, 2012) an open source Qualitative Analysis software package. We used the Stanford Online parser (Klein & Manning, 2003) to

identify verbs in participants' responses. The first author used the results from the parts of speech analysis to segment text into verb phrases for analysis. We used the verb from the verb phrase to code each of the text segments. After coding, we used FrameNet, a database similar to a dictionary, to identify meanings associated with the verbs. We used FrameNet because the database was designed around an assertion that "people understand the meaning of words largely by virtue of the frames which they evoke" (Ruppenhofer, Ellsworth, Petruck, Johnson, & Scheffczyk, 2010, p. 1). In addition to describing relationships among concepts, FrameNet references how people perceive, remember and reason about their experience (Reed & Pease, 2015, p. 139). The semantic frame typically includes a description of the process (the action or verb) and the agent (the person who is doing the action). Using FrameNet does not remove researcher interpretation; however, it provides an opportunity to bracket researcher impressions. We then used an iterative process to categorize the verb codes.

To identify the social domain of verb phrases that involved a person or group of people, we conducted an analysis of what group was initiating or doing the actions, the parent, child/family or other people not part of the family. We did not analyze verb phrases where an object is the cause of an action. For example, the verb phrase: "the cabinet is locked" would not be included in the analysis. However, the verb phrase: "my friend locked the cabinet" would be coded. The process code would be "locked," and the social domain code would be other people not part of the family. We were interested in learning about the relationships between the processes of transition and the social contexts parents associated with the processes of transition. We conducted a chi-square analysis to investigate if there were discernable differences in the frequencies of the process and social domains across the stages of transition. We used constant comparison to identify themes in parents' descriptions of transition.

To improve the rigor of the study we employed weekly peer debriefing to check for bias and review coding rules. Additionally, we received expert guidance throughout survey development, data collection, and analysis. To enhance the dependability of the results we used purposive sampling and recruited participants through organizations that serve families with a child with a developmental disability, and we maintained an audit trail in archives and analysis notes. Additionally, we conducted

internal audits regularly throughout data analysis. To ensure trustworthiness of our data collection

process, we used an online survey to collect open-ended responses from parents to standardize the process

of data collection (all participants received the same instructions and information during data collection).

To strengthen the rigor of this study we used multiple methods of data analysis (discourse analysis,

descriptive statistics and constant comparison) to triangulate data. We used ongoing peer debriefing and

consultation with a content expert to challenge possible biases of the author.

Results

Of the 32 parents participating in the first phase of research, 22 participants were eligible to

participate in this study because they included comments to the open-ended questions in the original

questionnaire (Broski & Dunn, 2018b). All participants were white (n=22) and reported having at least

some college education. Most of the participants were female (n=21) and from the Midwest (n=15). Fifty

percent (n=11) of the participants report earning $100,000 or more per year. The mean parent age was 44

(standard deviation 8.2).

Qualitative Results

Stage 1. We identified three main themes associated with stage 1 of transition: fear, uncertainty,

and searching. Parents' stage 1 descriptions focused more frequently on their child and family than on

people outside their family. Table 1 provides examples of coded participants' responses. When parents

described their child's performance, the parents' descriptions often revolved around searching for

information about their child's differences. "This stage is when you start to realize your child is different.

It is when you start looking at long, scary lists of what could be wrong, including lots of things that aren't

at all applicable to your child" (Riley). Some parents seemed to link their role performance as a parent

with their child's development. One parent indicated that although she was trying her best to help her

child, she felt other people had a negative impression of her parenting: "You feel something is wrong or

different with your child so you question yourself. People around you notice your kid is different and

assume you are a bad parent even though you feel like you are doing anything and everything for your

child" (Charlie).

Parents' stage 1 experiences often focused on a need for information. However, more information did not always result in a greater sense of understanding of their child or feeling better Some parents linked the process of information seeking with questions and uncertainty related to their role performance: "I'm not sure I'm going to be able to handle things if we get bad news" (Amelia). Several parents described feeling as though they were in an unfamiliar setting without a clear direction. "It's the stage where you are swimming in the unknown and waiting to find direction to the shore" (Peyton). However, parents also indicated the search for information about their child's behavior or development often resulted in more questions than answers "A frantic time. Here's the analogy - you see your kid failing and drowning, and you are trying to unlock the cabinet containing the life preservers. Someone throws you a giant key ring of 47 unmarked keys. Some cabinets are empty. Some have life preservers made of concrete. The clock is ticking, and your kid is going under" (Kennedy).

Parents' stage 1 experiences suggest some parents begin to question their assumptions early in the process of seeking diagnostic clarity. For example, Jamie recognized her child had specific likes and dislikes, but she also questioned whether she should be concerned about her child's preferences and development: "Maybe it's not just that boys talk later than girls, or boys are more aggressive, or just his personality"). Pamela described questioning her preconceived notions about her child's differences: "Am I the one with an "issue" and my child is perfect? Am I looking too hard for something? "(Pamela). Parents often reported feeling uncertain or fearful when they became aware of their child's differences. However, they also described trying to ignore evidence or information during stage 1: "[Stage 1] is best defined by a little voice deep inside that kept telling me something wasn't right. I tried to prove it wrong, but it kept getting louder" (Pamela). A common thread throughout parents' descriptions of stage 1 is the parents' recognition that there is some part of their mental model that is not in sync with their observations.

While most parents reported feeling fearful as noticed differences in their child's behavior, Kimberly indicated that becoming aware of her son's differences helped her gain insight about her own

role in her child's life: "An awakening! Being an advocate for your child the moment you realize he is different and wanting nothing more than for him to succeed" was Kimberly's response.

Stage 2. We identified three themes associated with stage 2: adaptation, confusion, and frustration. Parents described aspects of adaptation in their descriptions related to identifying possible solutions to help their child. The metaphors parents used to describe stage 2 emphasize loneliness and feeling suspended: "I think that stage two is characterized by feeling lost, which might feel like a lack of certainty about role and what to do next" (Abbie). Peyton described stage 2 as feeling as though "you are marching in place." Riley described stage 2 as "a long drift at sea."

While information seeking remains a central aspect of a parent's mental model of transition during stage 2, there is a shift in parent concerns related to information seeking. During stage 1 parents described seeking information to better understand their child; in stage 2, parents describe searching for information to solve a problem or make decisions. Taylor indicated, "[Stage 2] is a highly stressful navigation stage where the parent tries too hard to decipher what is good and what is bad information, and whom among the experts to trust, it is where a lot of trial and error, anxiety, self-pity, and self-doubt occurs in your ability to parent." In stage 1, parents seemed to weigh the consonance between their perceptions of their child's behavior or development and experts' observations of their child. However, in stage 2, parents described questioning experts' judgments about their child. For example, Taylor described discovering that professionals "don't always have answers" and sometimes make mistakes: "You find out, [providers]do not understand the big picture." Pamela reported that their service providers did not understand their families' schedule: "All my specialists/therapists keep saying 'just 15 minutes a day. . . ' do they not understand that five people [each] saying 15 minutes a day [in addition to] appointments, feeding, naps… is NOT going to happen"? Another parent described feeling mislead by some of the recommendations for treatment during stage 2: "I feel frustrated with the number of gimmicky 'treatments' targeting families like ours" (Ashley). These descriptions suggest some parents begin to reconsider how they relate to and think about their relationships with provider expertise during stage 2.

Stage 3. We identified four themes associated with stage 3: accepting, adapting, searching and pride. The metaphors parents used to describe stage 3 indicate parents adapt to many of the changes they encountered in stages 1 and 2. Peyton described gaining clarity in stage 3: "the future is becoming clearer…the fog is clearing." Kennedy described needing to "learn how to be like a general contractor, keeping on top of multiple simultaneous projects that work on different dimensions." These metaphors indicate parents' associate stage 3 with empowerment, clarity and "know-how."

In stage 3, parents also described feeling confident in their ability to understand their child. Parents reported understanding their child and making "peace with their child's diagnosis" (Harper). These comments are a contrast to the experiences parents reported in stage 1 and 2 when parents described seeking help from people outside the family for guidance about their child. Additionally, parents expressed a range of emotion related to their child and their family including feeling capable of "celebrating their child's uniqueness while advocating for his/her support."

Parents' descriptions of stage 3 indicate parents still experience fear and frustration, but they also describe feeling confident about their parenting. Taylor indicated she still experienced worry and panic. However, instead of perceiving her concerns as a shortcoming in her abilities, she suggests the challenges she experienced were related to the attitudes of other people and social systems. "You still panic and worry about the future for your child when tired or exhausted because those systems and attitudes out there are still so full of problems and even harmful actions can occur for your child, but you now have a fighting spirit, and you will speak up anytime." She goes on to say she recognizes there would be more challenges in the future, but she now had strategies to manage the difficult times that might be ahead: "This is the stage when you still will hit numerous challenges and roadblocks, but you have built up resilience and positive strategies for your child."

These comments suggest parents' mental models evolved during stage 1 and 2. In previous stages, parents described feeling like they might not "be able to handle bad news"(Amelia). In stage 3, parents were more confident despite continue to live with uncertainty: "This is the stage when caregivers understand that all the answers do not need to be present today" (Alex). In addition to gaining knowledge

and strategies to help their children, parents' descriptions of stage 3 indicated increased self-awareness: "Acceptance. Patience with myself, my child, and others …greater understanding of self" (Drew). Parents also indicated an awareness that they needed to develop new skills and that their old ways of addressing problems were no longer relevant: "Second-guessing has proven futile and is anything but helpful. In this stage, a caregiver is capable of celebrating their child's uniqueness while advocating for his/her child's necessary supports" (Alex).

Quantitative Results

Distinct words. The mean word count of parents' responses increased from stage 1 through stage 3. Word counts for each stage of transition are presented in Table 2. The results for a Wilcoxon Signed-Ranks Test indicated there is no statistically discernible difference in the median word count for each stage of transition. The number of distinct verbs used in descriptions of stages one, two, and three was 37 (28%), 39 (30%) and 54 (42%), respectively. We defined distinct verbs as verbs referenced one or more times in only one of the three stages of transition. Table 3 shows the distinct verbs most frequently used by parents in their descriptions of each stage of transition.

Parents' mental models of transition: Social contexts. To examine the social context of transition, we coded phrases according to who was referenced in the verb phrase (self, child and/or family, and other people not part of the family). We achieved reliability of 93% absolute agreement for social context coding. We used the first author's codes on any disagreements in coding. To examine whether parents referenced self, child/family, or other people not part of the family equally across categories, we performed a chi-square goodness of fit test. We found there were discernable differences in the frequency of parents' social context references across the stages of transition, X^2(2, N=480) =342.0, p<.001. Parents were most likely to reference self (73%), parents' references to child/family (14%) and other people not part of the family (13%) were nearly even. Overall the percentage of comments about child/family and others were similar across stages, but the distribution of comments was different. Parents' were most likely to refer to child/family (19%) when they described stage 1. Parents were most

likely to refer to others (professional or other people in the community) when they described stage 2 (21%). Parents were least likely to refer to others when they described stage 3.

The focus on parents was greatest in stage 1 (47%) and lowest in stage 2 (27%). The focus on child and family was greatest in stage 2 (42%) and was nearly the same for stage 1 and stage 3 (27% and 26%, respectively). The focus on others was greatest for stage 2 (68%) and lowest for stage 3 (5%).

Parents' mental models of transition: Processes. To examine the processes parents associated with transition we coded verb phrases that described "feeling," "thinking" or "role performance." We achieved 77% absolute reliability on process codes. Coding disagreements were addressed by using the first author's codes. We performed a One-Sample Chi-Square Test and found there was a discernable difference in the distribution of transition processes (feeling, thinking or role performance) in parents' responses relating to transition stages, X^2 (2, n=480) =52.21, p<.00. Parents were most likely to reference processes related to feeling in stage 2 (44%). Parents references to feeling processes were about even in their comments regarding stage 1 (27%) and stage 3 (28%). Parents were least likely to reference feeling processes in stage 1 (27%). Parents were most likely to reference processes related to role performance in stage 2 (41%) and stage 1 (35%). Parents were least likely to reference role performance in stage 3 (24%).

Discussion

The results of this mixed methods study suggest parents' mental models of transition include changes in parents' self-perception as well as changes in how parents experience relationships with their child, family, professionals and other people outside of their family. Additionally, parents' mental models of transition are associated with changes in processes of transition. These processes include cognitive processes (thinking and knowing), affective processes (feelings and values), and role performance (getting help, making appointments). A summary of the key features of parents' mental models of transition is provided in Figure 2.

The predominant characteristics of parents' mental models of stage 1 include an intense focus on self (parent) and child/family. The metaphors parents used to describe stage 1, such as "swimming in the

unknown" and "searching for answers," emphasized parents' feelings of uncertainty as they navigated uncertain territory. The key processes associated with stage 1 are primarily cognitive processes, such as knowing and understanding. Parents' sense-making experiences in stage 1 frequently revolved around their relationship with new information. For example, some parents describe feeling rushed to get information about their child's diagnosis and feeling afraid of what they may learn. Parents' relationship with information appears to be a conundrum associated with stage 1 of parents' transition. While the attainment of information was associated with parents' sense of cognitive empowerment (gaining understanding about their child), that same information was frequently associated with parents experiencing uncertainty.

Parents in our study were often aware that their observations about their child's development or behavior were different from their original expectations about their child. Parents' awareness of inconsistencies between their expectations about their child's development and their observations reveal some of the options individuals have when they encounter information that does not align with their existing mental model. Our findings align with research that suggests individuals learn by discovering what part of their mental models are no longer correct (Klein & Baxter, 2006). While some parents describe feeling resistant toward new information in stage 1, we also found evidence of parents challenging their mental models to accommodate the new information they were learning about their child: "Maybe my child is perfect, and I'm the one with the problem."

The predominant characteristics of stage 2 were: adaptation, confusion, and frustration. In stage 1, the social context of transition focused on the parent and child and/or family. In stage 2 the social context of transition focused on professionals and other people who are not family members. Parents' mental models of non-family members in stage 2 indicated parents may become more skeptical of providers' expertise. This skepticism may be an indication of changes related to parental empowerment. In particular, stage 2 seems to be associated with parents' desire for providers and other people outside of their family to see "the whole child." Parents' descriptions of their experiences with providers and other professionals reveal a shift in parents' mental models of people outside their family. In stage 1, it appears

to matter to parents when providers "agree" with the parents' observations about their child's behavior.

 In addition to the shift that occurs in parents' social context of transition, there is a shift in the processes parents emphasized in stage 2. While parents' experiences continue to reference thinking and understanding, there is a sharp increase in descriptions that emphasize feeling and values in stage 2. The feelings parents described in this study align with previous studies that indicate parents experience stressful emotions associated with their child's developmental diagnosis. It is noteworthy that parents in our study did not express frustration about their child's behaviors or development in stage 2, or any other stage of transition. This finding stands in contrast with literature that indicates the behaviors or development of children with a developmental disability result in an ongoing burden for parents.

The predominant characteristics of stage 3 are understanding one's self and acceptance of the child. The social context of stage 3 focuses primarily on parents. Parents' focus on themselves more in stage 3 than in stage 1 and 2. Conversely, parents' references to people outside the family are fewer in stage 3 than the other stages. The key processes associated with stage 3 were feelings, values and role performance. The metaphors parents used to describe stage 3 indicate parents were able to adapt to at least some of the changes they encountered in stages 1 and 2.

Existing literature frequently emphasizes parents' feelings related to their child's developmental diagnosis (e.g. Bonis, 2016; Nealy, O'Hare, Powers, & Swick, 2012; Osborne, McHugh, Saunders, & Reed, 2007) The parents in our study focused on cognitive processes (thinking and knowing) as well as processes related to affect (feelings and values) during this stage. This finding suggests that parents' feelings and values are dynamic and that feelings of uncertainty or sadness in stage 1 may lessen throughout transition (Milshtein, Yirmiya, Oppenheim, Koren-Karie, & Levi, 2010). This finding aligns with mental model research which indicates when people encounter new and unfamiliar situations, they may not be able to link the new information with their existing mental models (Klein & Baxter, 2006). This disconnect between parents' expectations and observations may prompt many parents to begin a

search for information.

The findings of this study should be interpreted in the context of its strengths and limitations. There are several limitations associated with this study. It is possible that some parents may not have included information in open-ended responses that had been addressed in the categorization portion of the study (Milshtein, Yirmiya, Oppenheim, Koren-Karie, & Levi, 2010). Our recruiting methods relied on the Internet and email distribution. Therefore, the results of this study cannot be generalized to parents of a child with a developmental disability without access to email or the Internet. Strengths of the study include the mixed methods design which allowed the investigators to explore a rich data set.

Additionally, the first author developed the process and social coding framework. While we were able to establish reliability for the social context coding framework, the process coding framework was exploratory. We used several strategies to strengthen the trustworthiness of this study including triangulation, processes to encourage honesty, expert guidance, and peer debriefing. We used strategies to ensure honesty in participants responses by allowing participants to not answer any questions they were not comfortable answering, thereby encouraging participants to answer questions honestly without fear of losing credibility (Shenton, 2004, p. 67). We used frequent debriefing sessions (Miles et al., 2014). Rigor in this study was strengthened by a careful and thorough approach to data collection and analysis, including using a coding scheme based on participants' responses (Trochim, 2006), and review of the survey by an interprofessional doctoral group to ensure transferability (Miles et al., 2014).

Implications

The findings of this study have several implications for providers. First, while research on parents' experiences related to their child's developmental diagnosis frequently emphasizes the emotional aspects of parents' experience, the findings of this study indicate parents' affective experiences do not remain the same throughout transition. This finding suggests caution should be used when interpreting studies which characterize parental affect, especially early in their child's developmental diagnostic process. Second, our findings indicate parents' mental models of transition encompass processes related to affect, cognition and performance. Future studies should seek to explore how processes related to

thinking and understanding influence parental performance and feelings. Our findings suggest that understanding parents' feelings within the context of cognitive and performance processes may be beneficial.

When parents' transitions are seen from a strengths-based perspective, dissatisfaction with a current situation or mental model may be desirable. Our study found that parents experience transition in terms of their own role performance. Additionally, parents who experience confusion, fear and uncertainty in the early stages of transition described gaining understanding and acceptance about their child's differences in stage 3. Receiving contradictory information was a common source of parental confusion early in the transition process, and future research is needed to understand how contradictory information may help or hinder parental empowerment during transition. Future studies should examine how parents' expectations influence parental transformation. While parents seem to experience changes in processes related to feeling, thinking and role performance during transition, it is not clear what activities are associated with parents' transformation. Research should explore the role of "gaps" in parents' mental models, dissatisfaction with the diagnostic process, and the relationship between dissatisfaction, empowerment, and transformation.

Conclusions

People use mental models to make sense of complex and uncertain situations. The results of this study indicate role performance is a core feature of parents' mental models of transition related to their child's developmental diagnosis. Parental role performance includes a variety of activities such as making appointments, paying bills and teaching their child. Our findings indicate that parents' mental models associated with their child's developmental diagnosis change throughout transition. These findings suggest that exploring parents' mental models may provide additional insight into how individuals navigate uncertainty and chaos. Future research should seek to identify processes or circumstances that enable parents to transform their experiences associated with uncertainty into experiences which they associate with greater self-awareness and empowerment.

References

Becker, G. (1997). *Disrupted lives: How people create meaning in a chaotic world*. Berkley, CA: University of California Press.

Bonis, S. (2016). Stress and parents of children with autism: A review of literature. *Issues in Mental Health Nursing*, *37*, 153–163. https://doi.org/10.3109/01612840.2015.1116030

Boström, P. K., & Broberg, M. (2014). Openness and avoidance: A longitudinal study of fathers of children with intellectual disability. *Journal of Intellectual Disability Research*, *58*, 810–821. https://doi.org/10.1111/jir.12093

Boström, P. K., Broberg, M., & Hwang, P. (2010). Parents' descriptions and experiences of young children recently diagnosed with intellectual disability. *Child: Care, Health and Development*, *36*, 93–100. https://doi.org/10.1111/j.1365-2214.2009.01036.x

Broski, J., & Dunn, W. (2018a). Evaluation of the strengths-based theory of parental transformation. Unpublished manuscript, Department of Occupational Therapy Education, Therapeutic Science Program, University of Kansas Medical Center, Kansas City, KS, United States.

Broski, J., & Dunn, W. (2018b). Fostering insights: A strengths-based theory of parental transformation. *Journal of Child and Family Studies*, *27*, 1275–1286. https://doi.org/10.1007/s10826-017-0964-5

Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism: The International Journal of Research and Practice*, *20*, 153–162. https://doi.org/10.1177/1362361315573636 PMID:25810370

Dale, E., Jahoda, A., & Knott, F. (2006). Mothers' attributions following their child's diagnosis of autistic spectrum disorder: Exploring links with maternal levels of stress, depression and expectations about their child's future. *Autism*, *10*, 463–479. https://doi.org/10.1177/1362361306066600

Denman, K., Smart, C., Dallos, R., & Levett, P. (2016). How families make sense of their child's

    behaviour when on an autism assessment and diagnosis waiting list. *Journal of Autism and*

    Developmental Disorders, *46*(11), 3408–3423. https://doi.org/10.1007/s10803-016-2873-7

Doyle, L., Brady, A.-M., & Byrne, G. (2016). An overview of mixed methods research – revisited.

    Journal of Research in Nursing, *21*, 623–635. https://doi.org/10.1177/1744987116674257

Feiz, P., & Strauss, S. (2014). *Discourse analysis*. New York: Routledge. Retrieved from

    https://www.book2look.com/book/2qjsRrYUA4

Fujita, N., & Brett, C. (2008). Rethinking analysis of progressive discourse in asynchronous online

    learning: An activity theory perspective. *Proceedings of the 8th International Conference of the*

    Learning Sciences, Toronto, Canada, I, (pp. 248–256).

    https://pdfs.semanticscholar.org/4e91/b46e2cc842fd4af4f59ecd0e47ab716177c7.pdf

Gee, J. P. (2014). *How to do discourse analysis: A toolkit*. New York: Routledge.

Greeno, J. (1989). Situations, mental models and generative knowledge. In K. Kotovsky & K. Klahr

    (Eds.), *Complex information processing: The Impact of Herbert A. Simon* (pp. 285–318).

    Hillsdale, NJ: Lawrence Erlbaum Associates, Publishers.

Grenier, R. S., & Dudzinska-Przesmitzki, D. (2015). A conceptual model for eliciting mental models

    using a composite methodology. *Human Resource Development Review*, *14*(2), 163–184.

    https://doi.org/10.1177/1534484315575966

Gurel, D. K., Eryilmaz, A., & McDermott, L. C. (2015). A review and comparison of diagnostic

    instruments to identify students' misconceptions in science. Eurasia Journal of Mathematics,

    Science & Technology Education, 11(5), 989–1008. DOI:

    https://doi.org/10.12973/eurasia.2015.1369a

Haliko, S., Downs, J., Mohan, D., Arnold, R., & Barnato, A. (2018). Hospital-based physicians'

    intubation decisions and associated mental models when managing a critically and terminally ill

    older patient. *Medical Decision Making*, *38*, 344–354.

    https://doi.org/10.1177/0272989X17738958

Kim, M. (2013). Concept map engineering: Methods and tools based on the semantic relation approach. *Educational Technology, Research and Development; New York*, *61*, 951–978. http://dx.doi.org/10.1007/s11423-013-9316-3

Klein, D., & Manning, C. (2003). Accurate unlexicalized parsing. In *Proceedings of the 41st Meeting of the Association for Computational Linguistics* (pp. 423–430). Retrieved from http://nlp.stanford.edu:8080/parser/

Klein, G., Moon, B., & Hoffman, R. R. (2006a). Making sense of sensemaking 1: Alternative perspectives. *IEEE Intelligent Systems*, *21*(4), 70–73. https://doi.org/10.1109/MIS.2006.75

Klein, G., Moon, B., & Hoffman, R. R. (2006b). Making sense of sensemaking 2: A macrocognitive model. *IEEE Intelligent Systems*, *21*(5), 88–92. https://doi.org/10.1109/MIS.2006.100

Kralik, D., Visentin, K., & van Loon, A. (2006). Transition: A literature review. *Journal of Advanced Nursing*, *55*, 320–329. https://doi.org/10.1111/j.1365-2648.2006.03899.x

Langan-Fox, J., Code, S., & Langfield-Smith, K. (2000). Team mental models: Techniques, methods, and analytic approaches. *Human Factors: The Journal of the Human Factors and Ergonomics Society*, *42*, 242–271. https://doi.org/10.1518/001872000779656534

Lazaraton, A. (2009). Discourse Analysis. In C. Heigham & R. Croker (Eds.), *Qualitative research in applied linguistics - A practical introduction* (pp. 242–259). United Kingdom: Palgrave Macmillan. Retrieved from //www.palgrave.com/us/book/9780230219526

Maltseva, K. (2016). Using correspondence analysis of scales as part of mixed methods design to access cultural models in ethnographic fieldwork: Prosocial cooperation in Sweden. *Journal of Mixed Methods Research*, *10*(1), 82–111. https://doi.org/10.1177/1558689814525262

Manoharan, C., & de Munck, V. (2017). The conceptual relationship between love, romantic love, and sex. *Journal of Mixed Methods Research*, *11*, 248–265. https://doi.org/10.1177/1558689815602151

Mansell, W., & Morris, K. (2004). A survey of parents' reactions to the diagnosis of an autistic spectrum

disorder by a local service: Access to information and use of services. *Autism*, *8*, 387–407.

https://doi.org/10.1177/1362361304045213

Mastro, K. A., Flynn, L., & Preuster, C. (2014). Patient and family-centered Care: A call to action for new

knowledge and innovation. *Journal of Nursing Administration*, *44*, 446–451.

https://doi.org/10.1097/NNA.0000000000000099

Meleis, A. (2010). *Transitions theory:Middle range and situation specific theories in nursing research*

and practice. New York, NY: Springer Publishing Company.

Messias, D., Gilliss, C., Sparacino, P., Tong, E., & Foote, D. (1995). Stories of transition: Parents recall

the diagnosis of congenital heart defect. *Families, Systems & Health*, *13*, 367–377.

https://doi.org/10.1037/h0089280

Miles, M., Huberman, A. M., & Saldana, J. (2014). *Qualitative data analysis: A methods sourcebook* (3rd

ed.). Los Angeles: SAGE Publications.

Milshtein, S., Yirmiya, N., Oppenheim, D., Koren-Karie, N., & Levi, S. (2010). Resolution of the

diagnosis among parents of children with autism spectrum disorder: Associations with child and

parent characteristics. *Journal of Autism and Developmental Disorders*, *40*(1), 89–99.

https://doi.org/10.1007/s10803-009-0837-x

Morgan, M. G., Fischhoff, B., Bostrom, A., & Atman, C. J. (2001). *Risk communication: A mental*

models approach (1st ed.). Cambridge ; New York: Cambridge University Press.

Nealy, C. E., O'Hare, L., Powers, J. D., & Swick, D. C. (2012). The impact of autism spectrum disorders

on the family: A qualitative study of mothers' perspectives. *Journal of Family Social Work*, *15*,

187–201. https://doi.org/10.1080/10522158.2012.675624

Novak, J. D., & Cañas, A. J. (2006). The origins of the concept mapping tool and the continuing

evolution of the tool. *Information Visualization*, *5*, 175–184.

https://doi.org/10.1057/palgrave.ivs.9500126

Osborne, L. A., McHugh, L., Saunders, J., & Reed, P. (2008). Parenting stress reduces the effectiveness of early teaching Interventions for autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *38*, 1092. https://doi.org/10.1007/s10803-007-0497-7

Reed, S. K., & Pease, A. (2015). A framework for constructing cognition ontologies using WordNet, FrameNet, and SUMO. *Cognitive Systems Research*, *33*, 122–144. https://doi.org/10.1016/j.cogsys.2014.06.001

Ronggui, H., & Huang, R. (2012). RQDA: R-based qualitative data analysis. Retrieved from http://rqda.r-forge.r-project.org/

Ruppenhofer, J., Ellsworth, M., Petruck, M., Johnson, C., & Scheffczyk, J. (2010). FrameNet II: Extended theory and practice. Retrieved from http://vrici.lojban.org/~gleki/mediawiki-1.19.2/files/fndata-1.5/frame-docs/book.pdf

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, *22*(2), 63–75. https://doi.org/10.3233/EFI-2004-22201

Sieck, W., Peluso, D., Smith, J., Harris-Thompson, D., & Gade, P. (2007). *FOCUS: A model of sensemaking*. Klein Associates. Retrieved from http://www.dtic.mil/docs/citations/ADA469770

Spector, J. M. (2010). Assessing progress of learning in complex domains. In *The 11th International Conference on Education Research* (pp. 1–13).

Stevenson, M., Schoonen, R., & Glopper, K. (2007). Inhibition or compensation? A multidimensional comparison of reading processes in Dutch and English. *Language Learning*, *57*(1), 115–154. https://doi.org/10.1111/j.1467-9922.2007.00414.x

Trochim, W. M. (2006). Deduction & Induction. Retrieved from https://socialresearchmethods.net/kb/dedind.php

Turner, V. (1969). *The ritual process: Structure and anti-structure*. New York, NY: Transaction Publishers; Routledge.

van Gennep, A. (1960). *The rites of passage*. New York: Routledge.

van Merriënboer, J., & De Croock, M. (2007). Performance-based ISD 10 steps to complex learning. *Performance Improvement, 41*(7), 35–40. https://doi.org/10.1002/pfi.4140410708

Weick, K. E., Sutcliffe, K. M., & Obstfeld, D. (2005). Organizing and the process of sensemaking. *Organization Science,* 2005, 409–421. https://doi.org/10.1287/orsc.1050.0133

Table 1
Examples of social domain and process codes across stages of transition

Domain	Process	Stage 1	Stage 2	Stage 3
<u>Parent</u>				
	Feeling	**Feel rushed** to get diagnosis from hearing "early detection and treatment is best" over and over.	I **feel frustrated** with the number of gimmicky "treatments" targeting families like ours.	**Patience** with myself, my child, and others.
	Thinking	**Noticing** something seems different, and there is a sense of questioning what is happening.	I never **know** what the best diet or therapy is.	This is when **you've figured out** how to move forward and really live in each moment.
	Performance	I'm not sure **I'm going to be able to handle** things if we get bad news.	**Finding** my way.	To **be determined** that your child knows that he is loved for who he is.
<u>Child and family</u>				
	Feeling	I wonder if my child's development **is okay.**	The stage where the "new" normal of life as an ASD family **becomes familiar.**	To be determined that your child knows that he **is loved** for who he is.
	Thinking	**We know** so many people who can help with this journey.	**Redefining** our family's "normal."	To be determined that your child **knows that he is loved** for who he is.
	Performance	A stage when the parent becomes aware that their child **is struggling** with behaviors.	This is the stage while the child **is growing up/learning/hopefully improving** to have the best life possible.	You have learned how to cope with the changes in your lifestyle to better **suit your child's needs.**
<u>Other people</u>				
	Feeling	People around you notice your kid is different and **assume you are a bad parent.**	So called "normal" people **are not accepting** of him and your family.	No statements.
	Thinking	Nobody **understands.**	Aware that people who are not having a similar experience **have NO idea** of what your family's journey is like.	No statements.
	Performance	I'm sick of everyone **being an expert** on my child.	I didn't know doctor's **made mistakes**, that they don't know everything.	It is scary, but you have support and people **who can help you** through the harder times.

Table 2

Word count (by stage) in parents' description of transition

	Stage 1	Stage 2	Stage 3
Total word count	825 (24%)	1211 (36%)	1364 (40%)
Mean number of words	38	55	62
Standard deviation	39	85	97
Minimum	0	0	1
Maximum	135	325	454
Number of distinct verbs	37	39	54

Table 3

Distinct verbs used two or more times in only one stage of transition

Stage 1 Verb	Frequency	Stage 2 verb	Frequency	Stage 3 verb	Frequency
Question	4	Afford	2	Build	2
Notice	3	Trust	2	Challenge	2
				Depend	2
				Experience	2
				Fluctuate	2
				Identify	2
				Love	2
				Improve	2
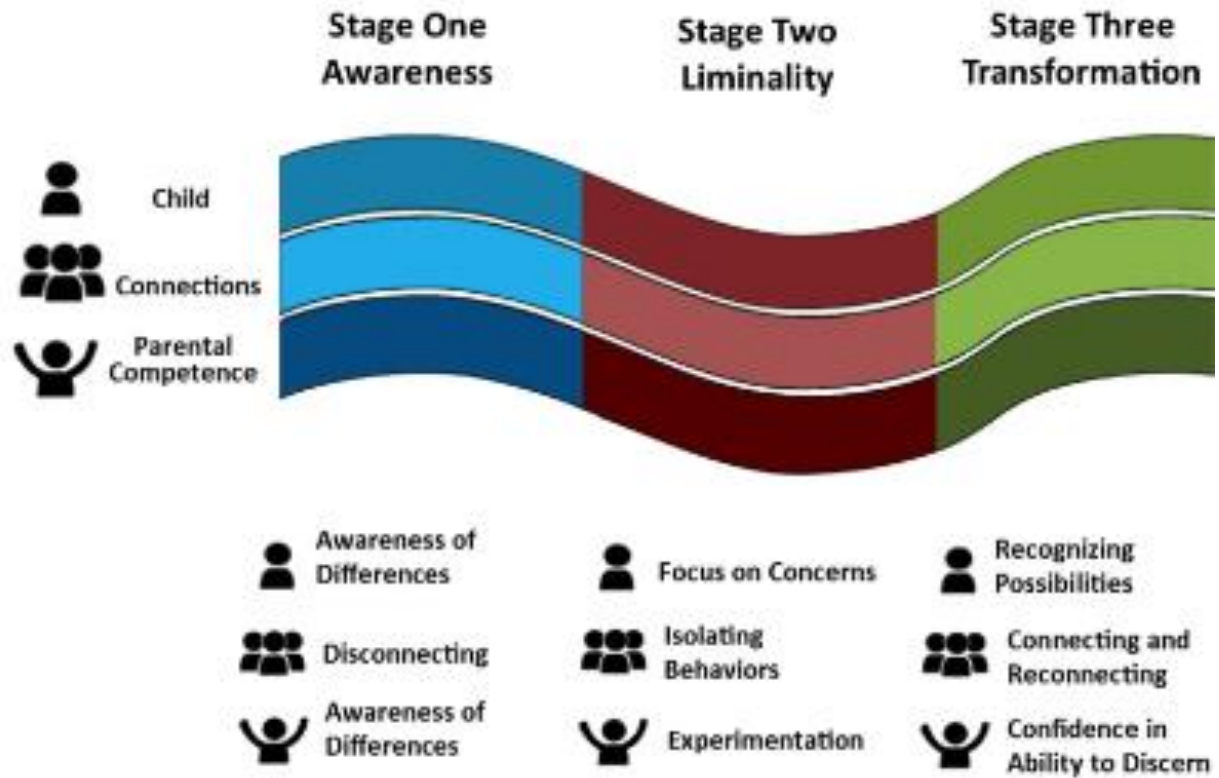
Figure 1

The Strengths-Based-Theory of Parental Transformation (Broski & Dunn, 2018b).

Reprinted with permission. The published version is available as Broski, J. & Dunn, W. Fostering insights: The strengths-based theory of parental transformation, Journal of Child and Family Studies (2018) 27: 1275. https://doi.org/10.1007/s10826-017-0964-5.

Parents' Mental Models of Transition Related to Their Child's Developmental Diagnosis

Key Concepts

Social Context

Processes

Stage 2

Key Concepts — Adaptation, confusion & frustration

Social Context — Self
Providers, people outside the family

Processes
Feelings & Values
-Uncomfortable Feelings
Role Performance
-Trying things out, experimenting

Stage 1

Key Concepts — Fear, uncertainty & searching

Social Context — Self, Child/Family

Processes
Thinking & Knowing
-Uncertainty
Role Performance
-Locating information
-Seeking help

Stage 3

Key Concepts — Accepting, adapting, searching & pride

Social Context — Self
Child and family

Processes
Feelings & Values
-Acceptance
-Honoring
Role Performance
-Helping others
Coordinating
Managing

Figure 2
Summary of parents' key concepts, social context and processes associated with parents' mental models of transition.

Chapter 4: Critical Insights: Incidents that Help and Hinder Parents' Transition Related to Their

Child's Developmental Diagnosis

Abstract

Research suggests that parents of a child with a developmental diagnosis such as an autism spectrum disorder, attention deficit disorder or obsessive-compulsive disorder experience transitions in how they see their child, themselves, and others in their life. However, it is not clear what events help or hinder parents' transition. The purpose of this study was to develop a composite picture of approaches that helped and hindered parents' acceptance of their child, connections with others, and parents' ability to discern strategies that are appropriate for their family.

We used the strengths-based theory of parental transformation as the framework to explore parents' experiences. We used a critical incident technique and qualitative content analysis to gather information about incidents that helped and hindered parents' transition. Twelve parents of children with a developmental diagnosis participated in interviews.

There were two themes associated with incidents that helped parents. The early stages of transition were associated with using and allocating resources. The later stages of transition were associated with seeing possibilities for the child and themselves. There were two themes associated with hindering parents transition involved the parents recognizing the need to set boundaries and parents feeling uncertain or obligated to engage in activities they would rather not participate in. Our findings suggest that incidents that parents described as hindering transition created opportunities to gain clarity about their values. Recognizing opportunities for the child and parent is associated with helping parents' transition related to their child's developmental diagnosis. Additionally, the findings of this study are used to refine the strengths-based theory of parental transformation.

Introduction

Individuals assign meaning to events based on their expectations about each phase of life (Becker, 1997). However, when a child's development does not correspond with parents' expectations, it may create an unanticipated transition (Meleis, 2010; Messias, Gilliss, Sparacino, Tong, & Foote, 1995) from being a parent to becoming the parent of a child with a developmental diagnosis (Boström & Broberg, 2014; Boström, Broberg, & Hwang, 2010; Broski & Dunn, 2018b). Transition theories contribute to professionals' and parents' understanding of how families experience change over time. Examples of transition theories include the health and illness transitions (Meleis, 2015), the stage model of grief (Kübler-Ross & Kessler, 2014), and the chronic sorrow theory (Eakes, Burke, & Hainsworth, 1998).

While these theories continue to be used to describe parents' transition associated with their child's developmental diagnosis (Allred, 2015; Masterson, 2010; Meleis, 2015) they do not seem appropriate to address transition for parents of a child with a neurodevelopmental diagnosis. The health and illness model suggest a change in health that requires prolonged diagnostic procedures or treatment protocols, such as autism, can trigger transition (Meleis, 2015). However, many neurodevelopmental diagnoses, including autism, do not represent a change in the individual's health; instead, the diagnosis indicates how health care or education systems classify the individual's functioning. The stage model of grief proposes that individuals move through denial, anger, bargaining, depression, and acceptance when responding to a tragedy in one's life. Educators have referenced this model when a parent advocates for goals for his/her child that an educator feels are unattainable, by labeling the parent as *being in denial* (Allred, 2015). This perspective assumes parents do not understand their child as well as disrupts the ability of parents and teachers to collaborate. The chronic sorrow theory proposes that having a child with a disability results in feelings of ongoing sadness and loss that may last throughout the parents' lifetime (even if the parent states they are not "in sorrow"). This perspective assumes a deficit-based perspective of the child's development.

Research and practices that suggest having a child with a developmental diagnosis is a tragedy or is analogous to the death of a loved one perpetuate perceptions that a disability is a deficit of the individual. These theories stand in contrast to a contemporary conceptualization that disability does not reside in the individual, but that disability is a function of the interaction of the individual and the environment (Buntinx, 2013; Pope & Brandt, 1997; Schalock et al., 2010). To develop a more accurate understanding of parents' experiences before, during and after their child's diagnosis, it is necessary to consider alternative approaches for describing parents' experiences.

Transition requires adaptation and shapes how people respond to change (Kralik, Visentin, & van Loon, 2006). Transition theories generally recognize three stages: (1) an initial phase that involves separation from a previous way of life; (2) an in-between phase known as liminality, where identity is in flux; and (3) a final phase that signifies the beginning of the individual integrating aspects of their new social role (Kralik et al., 2006; Meleis, 2010; Turner, 1969; van Gennep, 1960). While parents frequently perceive unexpected transition related to their child's diagnosis as a negative or stressful development (Bonis, 2016; Messias et al., 1995), all transitions require individuals to reflect on their lives in ways that can be transformative (Barclay-Goddard, King, Dubouloz, & Schwartz, 2012; Bonis, 2016; Broski & Dunn, 2018b; Chick & Meleis, 1986; Gassaway, Jones, Sweatman, & Young, 2017). The parent transformation model (Scorgie, Wilgosh, & Sobsey, 2004) and the strengths-based theory of parental transformation (Broski & Dunn, 2018b) provide strengths-based perspectives of parents' responses to their child's developmental diagnosis and are aligned with contemporary models of disability. The parent transformation model (Scorgie et al., 2004) emphasizes parents' internal processes associated with their development of ways of thinking about their children, themselves, and their lives. The strengths-based theory of parental transformation emphasizes that transition involves three primary stages: *awareness*, *liminality*, and *transformation* (Figure 1). Other key differences between the parent transformation model and the strengths-based theory of parental transformation are that the strengths-based theory of parental transformation proposes there are stages of transition and transition begins when parents become aware of their child's differences, rather than when the child is diagnosed. Some aspects of transition may not

sound as though they represent positive developments. For example, the liminal stage of transition is frequently associated with isolation from others. Isolation from others may be perceived as negative or positive developments, depending on a family's preferences. For example, parents may perceive isolation from others as a negative development if parents want to be involved with a certain group. Isolation may also be beneficial for parents who are reflecting on a new social identity.

In our exploratory study of the strengths-based theory of parental transformation, parents categorized statements a parent may say or think about transition related to their child's developmental diagnosis into the stage of transition she or he believed best fit each statement (Broski & Dunn, 2018a). Parents could also indicate if the statement was not part of transition and they could add additional statements from their experience that they believed represented each of the stages of transition. Parents were also asked to write a definition for each stage of transition. This resulted in a coherent

Building on our exploratory study, the researchers conducted a second study using discourse analysis to understand how parents' descriptions of thinking, feeling, and actions varied across stages of transition and theoretical domains (Broski & Dunn, 2019). Results showed parents emphasized thinking and doing in the first (awareness) stage of transition. Parents emphasized thinking and doing in the second (liminal) stage of transition which included focusing on trying strategies to help their child. The social context was characterized by parents' emphasis on their interactions with other people who are not part of their family. Parents emphasized feeling and doing in the third (transformational) stage of transition which included parents reporting what they had learned during this stage. Parents' feelings focused on gaining confidence in their ability to parent, feeling proud of their child's accomplishments and accepting their child for who he or she is. While parents described that they still experienced uncertainty, they also described feeling they could handle what the future brings. The social context of greatest relevance to parents at this phase included interactions with the child and the immediate family.

These studies suggest that parents experience changes in their thoughts, feelings, and behaviours across the stages of transition (Broski & Dunn, 2018a, 2018b). Additionally, we found discernible differences in the social contexts' that parents emphasized in each stage of transition. While our research

indicates that parents experience changes across stages of transition, it is not yet clear what activities help or hinder parents' acceptance of their child's differences and what activities help or hinder parents' increasing confidence in their parenting ability – that is, the types of events that lead to movement or stasis in transition. The purpose of this study is to develop a composite picture of approaches that parents perceive as helping or hindering transition. This study focused on understanding parents' transition incidents related to their child's developmental diagnosis. The research questions researchers sought to answer were: 1) What critical incidents related to their child's developmental diagnosis do parents believe helped move parents from awareness toward liminality and from liminality into transformation? 2) What critical incidents related to their child's developmental diagnosis do parents believe hindered parents from moving from awareness toward liminality or hindered parents from moving from liminality toward transformation?

Methods

We used a qualitative research design to explore parents' transition related to their children's diagnosis. Specifically, the researchers used the critical incident technique (CIT). CIT provides a tight focus on an area of interest to provide rich data about the topic (Schendel et al., 2012; Ushioda, 2016). CIT is used to capture a holistic perspective of challenges associated with role performance (Bott & Tourish, 2016; Butterfield, Borgen, Amundson, & Maglio, 2005; Carpenter, 2018; Flanagan, 1954; Stitt-Gohdes, Lambrecht, & Redmann, 2000). CIT involves collecting stories about events that contribute to individuals' success or failure in certain situations (Carpenter, 2018; Flanagan, 1954; Stitt-Gohdes et al., 2000). We selected CIT because it is well-suited to investigate complex situations where there may be multiple strategies that could lead to success or failure (Stitt-Gohdes et al., 2000). CIT involves asking individuals to provide in-depth descriptions of events to gain insight into participants' thoughts, feelings, and behaviours (Stitt-Gohdes et al., 2000).

Following Institutional Review Board approval, we used snowball sampling during September and October of 2018 to recruit parents. The researchers distributed recruiting materials on Facebook and to organizations that serve families in Kansas and Missouri. Critical incident sample size is determined by

the number of critical incidents reported and whether the critical incidents "represent adequate coverage of the activity being studied" (Flanagan, 1954; Harenčárová, 2017). Guest (2006) reports 12 participants is often enough to reach thematic saturation, and that themes tend to stabilize after 6 participants. We slightly oversampled and purposively looked for contrasting cases to check for representativeness. We embedded the process of searching for contrasting cases within the overall data collection and data analysis process. Although our research focuses on strength-based approaches, we asked parents to reflect on aspects of events that helped and hindered their transition. This approach provided a means to search for contrasting and extreme cases.

Malterud, Siersma, & Guassora (2016) proposed the concept of *information power* to guide sample size determination. Information power is different from saturation and is related to internal validity. Information power suggests smaller samples are appropriate when the aim of the study is narrow, when there are highly specific characteristics required for the study when there is high-quality dialogue, and when case analysis is used (Malterud et al., 2016). The researchers used aspects of saturation and information power to guide the determination of sample size. Because the focus of our study was narrow and required specific inclusion criteria, a smaller sample size was appropriate. Inclusion criteria included being the parent of a child with a neuro-developmental diagnosis, such as autism spectrum disorder or attention deficit hyperactivity disorder; the child does not have a neuromuscular disorder, such as muscular dystrophy or cerebral palsy; the child was diagnosed at two years old (or older); the child was diagnosed no later than September 1, 2016; the child was at least six years old and younger than 26 years old; and the parent could speak and understand questions asked in English. We established the inclusion criteria for the child to be two years old or older because we suspected that transition is different for parents whose children are diagnosed before the child is born or around the time of the child's birth. Additionally, transition may be different for parents who must visit multiple providers or wait several months before their child's developmental diagnosis. We established the exclusion criteria because we suspect that transition experiences of parents of children with a developmental and neuromuscular

diagnosis may be different than the transition experiences of parents of children that do not have a neuromuscular diagnosis.

The recruiting information contained information about the study, eligibility criteria, and a link to the informed consent form for parents. Parents interested in participating contacted the student researcher by text message, email, or by completing an online parent information form. The researcher then emailed participants a copy of the informed consent and the interview questions so parents could review the questions before the interview.

Twelve parents (10 female, two male) participated in face-to-face semi-structured interviews which lasted approximately 60 minutes at a location of their choosing. All participants completed the semi-structured interview and a demographic survey. Participants self-reported race as White and ethnicity as not Hispanic, Latino or Spanish origin. They reported on six male and six female children (one child per one parent). Seven parents reported their income from $50,000 to $99,999 per year. All other parents reported income greater than $100,000 per year. Ten parents (83%) reported working full-time. Most parents were married (92%) and college educated (92%). Participants described their child's diagnoses as Asperger syndrome, apraxia of speech, autism spectrum disorder, attention deficit hyperactivity disorder, language disorder, obsessive-compulsive disorder, and/or sensory integration disorder. The children's ages ranged from 8 to 24 years old.

We used semi-structured interviews to collect thick, rich data for analysis. Figure 2 maps the interview questions with the domains and stages of the strengths-based theory of parental transformation. The first author used a form designed to assist the researcher in collecting contextual information and asking follow-up questions during the interview (Phillippi & Lauderdale, 2018). Participants could request a break at any time. After the interview, we provided participants with an online demographic survey. A researcher conducted a member check immediately following the interview to review any information from the interview that was unclear (Birt, Scott, Cavers, Campbell, & Walter, 2016). We then provided participants with a link to an online survey that was available until October 31, 2018, if they thought of additional information they wanted to provide to researchers. We informed participants that we

would provide them with a copy of our preliminary findings as well as an online form they could use to provide feedback on the findings. After completing the interviews, we uploaded the digital audio file to a transcription service using a secured system. We stored data on university servers according to institutional policies. All data were de-identified before analysis.

Data analysis

The first author began data analysis following the first interview, and analysis was ongoing until themes were stabilized. We defined data saturation as no new themes emerging from the data (Fusch & Ness, 2015; Guest, 2006). We used structural coding to identify critical incidents. Structural coding for this study is a deductive approach that segments the data according to specific questions asked during interviews (Saldana, 2012). We based preliminary codes (social, physical and temporal environment) on the ecology human performance (Dunn, Brown, & McGuigan, 1994). The ecology of human performance is a framework which provides guidelines for encompassing context in research and practice. All critical incidents received codes classifying the *temporal, physical, and social* environmental contexts of the incident. In the social environment category *family* refers to immediate and extended family. *Other people* refer to friends, neighbours, members of a support group, educators, doctors, therapists, and other providers. The physical environment category included *home environment*, which refers to incidents that occurred in the participant's home and *community environment* which refers to incidents that occur in locations other than the participant's home. The temporal environment category refers to the time frame of critical incidents. We determined the temporal environment by asking participants when the incident occurred.

We used the process described by Saldana as "theming the data" (Saldana, 2012, p. 175). We identified themes to unify the nature of incidents that helped or hindered parents' transition (DeSantis & Ugarriza, 2000). One researcher identified themes for the stages. To enhance the reliability of the themes, we randomly selected 20% of the items for coding by three other coders. We defined acceptable reliability as 80% agreement among the researchers. We used discussion and consensus until we reached

80% agreement. The researchers achieved 82% agreement among three coders for question 1 themes and 83% absolute agreement among three coders for question 2 themes.

We used multiple strategies to strengthen the quality of this study. To strengthen confirmability, we described our process of data collection and data analysis in detail. Our audit trail consisted of field notes collected during participant interviews, a journal maintained throughout data collection and analysis which documents our decision making throughout the study. We maintained this journal throughout the study to be self-aware about assumptions, values, biases, and how we made decisions throughout the study. We continued to explore competing theoretical perspectives throughout the analysis of data. To strengthen the dependability of our results, we developed clear research questions and used CIT, an analysis approach that is congruent with the research questions we sought to answer. We used multiple data quality checks to monitor for accuracy in our data management processes. For example, after coding, we conducted spot checks of the data for accuracy.

We used several commonly employed strategies as well as strategies that are specific to enhancing the credibility of CIT. The traditional strategies the researchers used to strengthen internal validity, credibility, and authenticity included recording interviews and using a professional transcription service to ensure we had accurately captured the participants' words. We used context-rich descriptions with the participants' own words (Geertz, 1973). We used peer, colleague, and expert review to evaluate if the "accounts ring true" (Miles et al., 2014, p. 313). We continued to consider alternate explanations throughout data analysis and remained attentive for negative cases. We sought to identify areas of uncertainty, and when we were uncertain about meaning, we conducted additional member checks whenever possible.

To strengthen transferability, we described the characteristics of our sample in such a way that other researchers could make comparisons with other samples. Additionally, we made recommendations and suggested settings that other researchers could evaluate our results. Finally, we reported a summary of findings to participants and invited their feedback. The researchers reported the results of the categories

of the social and physical environment that had the greatest number of responses for each interview question. Results are presented as a percentage of the items for each interview question.

<div align="center">**Results**</div>

Parents described 142 (64.3%) incidents they characterized as helping transition and 79 (35.7%) they characterized as hindering transition. Table 1 summarizes the frequencies of helping and hindering incidents across each of the questions asked during interviews. Figure 3 summarizes the characteristics of representative incidents that helped and hindered parents. Figure 4 summarizes the temporal context of the incidents. Figure 5 summarizes the themes, social environment and physical environment of incidents. We present the results of this study in the same order that questions were asked during the interview and by research question.

Research question one: What critical incidents related to their child's developmental diagnosis moved parents from awareness into liminality and from liminality into transformation?

The researchers identified two overarching themes associated with the incidents that moved parents from awareness toward liminality and from liminality toward transformation. *Using/allocating resources* involved the parent gathering, allocating or receiving information, supports, or other resources. *Seeing possibilities* involved the parent recognizing opportunities for their child, themselves or the community.

Helping to move toward focusing on the child's differences. All incidents that helped parents move toward focusing on the child's differences involved using/allocating resources. Most incidents involved people other than the family (58%). Incidents were evenly divided between the home, environment, and community. Incidents that helped parents frequently involved the parent gathering information about their child's behavior, by observing their child. For example, Jean, the mother of a 15-year-old son who was diagnosed with an autism spectrum disorder 12 years ago, described behaviours that seemed unusual for a two-year-old, which helped her focus on her child's differences: "As a toddler, he was overly obedient…. Like, if you said, 'Don't move,' he would not move. He would be a statue." Hannah, the mother of a 19-year-old who was diagnosed with obsessive-compulsive disorder 12 years

ago, described an incident that helped her move toward focusing on her child's differences. "She was five, and she had lost a hair bow. I said, 'Okay, we can look for it in the car…. we'll find it.' She got so upset that she threw up all over the floor…It made me want to seek out counselling because it…. was such a physical response."

Parents also indicated that receiving information from professionals helped them move toward focusing on their child's differences. Madison is the parent of a 20-year-old daughter with sensory differences. Madison indicated that she learned about her daughter's differences from daycare owners. Chandler, the mother of an eleven-year-old daughter who was diagnosed with an autism spectrum disorder five years ago, described not being aware that her daughter had differences until her daughter had an evaluation with Parents as Teachers which is a home visiting program which provides early detection of developmental delays to improve school readiness. "I could tell that something significantly different was happening.…they used a lot of words like 'red flags.'"

Helping to move toward recognizing the child's strengths. Most incidents that helped parents move toward recognizing their child's strengths involved seeing possibilities (78%), involved people outside of the family (57%), and occurred in the community environment (61%). Seeing possibilities frequently involved parents seeing their child in ways that offered parents a hopeful perspective. Shelley is a parent of a 24-year-old daughter who was diagnosed with Asperger syndrome when she was eight years old. Shelley indicated that home schooling helped her provide her daughter with an education that focused on her daughter's strengths, "I knew that [reading] was her thing. She loved to read. We based her curriculum on that…. I've raised very successful kids…. she will rule the world someday." Several parents described recognizing opportunities for their child when they found interventions that were a good match for their child. For example, Chandler described starting her daughter on medication as a turning point, "The medication freed up her mind to start processing language better and so when she started communicating, that definitely opened me up to…. how her little mind worked…. I never really knew before." Sophie is the mother of a 13-year-old son diagnosed with an autism spectrum disorder 11 years ago. Sophie discovered that her child had learned to replace broken tiles after watching her repair tiles in

their kitchen. Sophie described how his behaviours helped her consider future possibilities for her child when he gets older, "[He] could have a tile business…. There's so many things that he could do to find a fulfilling future."

Several parents described incidents in which using/allocating resources helped them move toward recognizing their child's strengths. Bev is the parent of a 12-year-old daughter who was diagnosed with an autism spectrum disorder ten years ago. Bev described how joining a support group helped her recognize possibilities for her child. "I think that was a huge turning point for me…. I felt more hope.'" Emily, the parent of a ten-year-old son who was diagnosed with attention deficit disorder five years ago described how her child's second-grade teacher helped her recognize her child's strengths, "I think what made a difference is she could relate to him. She saw his strengths, and she wanted him in the classroom more…. that was one of his best years."

Helping to move toward isolating. All incidents that helped parents move toward isolating themselves involved using/allocating resources (100%). Most incidents involved the family (53%) and occurred in a community setting (88%). Allocating resources often related to parents' decisions about whom to spend time with and how much time to spend with others. Several parents described incidents that involved experiences with family members. Emily described why she plans to not spend Independence Day with some of her extended family members. "Fourth of July ended up being quite horrible…. they think he should know how to behave …. we will not spend Fourth of July with them. … It's just not worth it." Sophie described why she has decided not to spend as much time with certain family members after they said Sophie's son's autism would go away if they would just would pray harder, "I don't have any need to see [them]…. [They] clearly have no idea what this is…. I just don't go."

Mia is the parent of an 11-year-old son who was diagnosed with an autism spectrum disorder nine years ago. Mia described being asked to leave a playgroup because of her son's differences. In this incident, allocating resources related to Mia leaving the playgroup and doing something different, "I tried to change. I started my own playgroup. People that I thought were my friends no longer wanted us to

come to playgroups. I recognized I needed to surround myself with people who understood what was going on in my life."

Helping to move toward connecting. Most incidents that helped parents move toward connecting with others involved seeing possibilities (67%), involved people other than the family (76%), and occurred in the community (81%) Many parents described how connecting with other families helped them recognize opportunities for their children and themselves. Bev described finding opportunities for personal growth by assuming a leadership position in a support group she attended. She also described discovering opportunities to make meaningful connections with other parents while sitting in the waiting room during her child's therapy appointments, "Somebody would eventually take the initiative to say, 'Hey, why don't we go get a cup of coffee or go out for a drink?'"

While most incidents involved situations like Bev's, there were seven incidents in this category in which parents described finding opportunities because of incidents that had been hurtful to them. For example, Mia went on to describe how she organized a playgroup for parents. The new group was more than just an opportunity to connect with others, the playgroup provided a means for her to advocate for social change: "Inclusion starts at the top, and when you educate parents, they are more able to respond to a situation differently than maybe they would out of ignorance." Jean described a similar situation in which members of her faith community told Jean that her family would have to remain in the foyer during worship services. This incident created an opportunity for Jean to work for change in her faith community,

> It was a horrible thing to happen, but…. It's kind of became almost a catalyst of feeling like I could advocate for kids…. It deepened it because…. the scripture of 'The Least of These' became very, very, very vivid and real…I think, for a while, there was a burning. . . a holy anger…. A righteous anger…. You start to feel like 'I'm going to make a difference!

While parents described connections with others as opportunities, they also characterized some connections as resources. For example, Shelley described how a couple set up a quiet space for her daughter during a Christmas party "They said, 'you can bring your snacks up here when you just need a

quiet place to read. This is your spot.' They knew that was important to [my daughter]." Shelley indicated this incident was an important turning point. It was an opportunity for her to recognize that her friends understood her and her daughter: "You need those people in your lives. That get you, and get your kid. There are good people, and if you isolate yourself you're not going to meet those good people."

Helping to move toward experimenting. All incidents in moving toward experimenting with strategies involved using/allocating resources. Most incidents involved people other than the family (62%) and occurred in the community (83%). For Hannah, allocating resources involved working with multiple providers: "The psychiatrist still wanted us to do the exposure therapy. The exposure therapy [provider] wanted us to talk to the psychiatrist…. it's kind of felt more like we were throwing things at it until something stuck." Tim described how allocating resources was essential for his child with learning differences: "Any time you have your bases covered, he does just fine. If you don't have your bases covered that's when things go to shit."

Allocating resources was related to experimenting even if a parent was unsure if the strategy would work. For example, Chandler described trying a visual schedule at home because it had been successful at school, "It was just a meltdown fiasco…. I was outside of the car, and she was in the car….and I'm like, 'All right, I'm gonna draw this out.' I drew her a picture….'this is where we're gonna go.'" Allocating resources was also related to the ongoing methods parents relied on to help their child. For example, Madison explained that she always kept a gym membership because swimming calmed her daughter. Bev described allocating time to spend time with other parents because it helped her learn what other families were doing to help their children.

Several parents described needing to allocate resources to understand their child better because they found support from professionals to be lacking. For example, Jean indicated that when doctors diagnosed her child with an autism spectrum disorder, she asked what she should do next, "[the doctor said] 'Oh, you should read this book,' that's this thick, literally, then 'we'll see them when they're in kindergarten.'" Allocating resources was also related to parents trying to help their friends and family understand their children's differences. For example, Chelsea described that she needed to help educate

her family because they "See a snapshot of my child's day. But I'm there every day…. I have a much bigger picture than they do." Allocating resources seems to be part of the parents' process to weigh decisions about strategies and interventions that are the best fit for their family. Several parents described allocating resources to send their child to a private school. Madison indicated she had her child attend a private school when her daughter started experiencing anxiety in large open spaces "She couldn't handle the large hallways… So, I had to switch her to parochial school, Catholic school so it'd be a smaller setting."

Helping to move toward discerning what is best for the family. Incidents associated with moving to ability to discern were evenly divided between using/allocating resources and seeing possibilities. Most incidents involved family members (58%). Incidents were evenly divided between community and home environment. Madison described how evaluating what was and what was not working helped her: "Sometimes you have to make changes. If what was working doesn't work anymore, then let's go to the next thing. That was how we worked her public school, private school, online education too. This way isn't working for her. Her needs are changing. So, what do we need to do to address that?" Jean described recognizing opportunities when she realized the activities her children were interested were not harmful, "Some families didn't like that their kids with autism would stim on something…. I guess what I felt mine were stimming on…. was educational stuff, so I was like, 'Have at it. Read!'"

Several parents described recognizing possibilities related to getting to know their child as a person. Michael stated quite simply what helps him have confidence in discerning: "I feel like the older he gets, the more I'm starting to know him." Madison described recognizing possibilities for her daughter and for herself when she insisted her daughter needed to live independently. "There's a point I had to mentally say to myself, 'I've done everything, and now it's time to give her independence." Madison indicated that because of her daughter's rigidness she would have lived at home forever. Madison felt she needed to tell her daughter, "You're an adult now, and you need your own space…. it wasn't going to be the right thing for her adulthood to live at home too much longer because she was a hermit."

Sophie described recognizing opportunities associated with letting go of contact with her support group, which she often referred to as a "cocoon." While Sophie indicated that the support group had been valuable, she also recognized opportunities to let go of some of the protections of the support group. "At a certain point, I didn't want anything to do with them anymore…I have been really happy. I'm working full-time…. He's going to high school next year. …There's still more things to look forward to."

Research question two: What critical incidents related to their child's developmental diagnosis hindered parents from moving awareness to liminality or kept parents from moving from liminality to transformation?

We identified two themes associated with the incidents that hindered parents' movement from awareness to liminality and from liminality into transformation, *feeling uncertain or obligated* and *finding the edges*. Feeling uncertain or obligated involved the parent describing discomfort or feeling that they lacked confidence. Feeling uncertain or obligated could also involve the parent stating that they must engage or participate in an event because it is expected of them. Finding the edges involved the parent determining they are at the edges of what the parent feels works for them or that the parent can tolerate. Finding the edges often involved a parent finally being able to take a stand on something that they had previously felt uncertain about, but the parent indicates that something has changed and they feel a clear direction about an action, or they are ready to take a stand on an issue.

Hindering moving toward focusing on differences. There were two themes associated with hindering moving to focusing on the child's differences: feeling uncertain/obligated (53%) and finding the edges (47%). Most events involved family members (60%) and occurred in the home environment (67%).

Parents' descriptions of incidents often involved details indicating that other people's comments led to them feeling uncertain about some aspect of their parenting or their child's development. Chandler indicated that other people's comments about her child appearing to be "so normal" made her feel less confident about her parenting. Hannah described that when her daughter was a child "She would not go into the bouncy. She would sit outside of the bouncy and hold her shoes and her siblings' shoes because

she didn't want them to get lost." Hannah could see that her child's worries about her siblings' shoes getting lost were not typical, but other parents' comments that her daughter was "so conscientious" left her feeling uncertain about her child's development. Bev indicated that it was not other people's comments that made her feel uncertain about her daughter's development, it was her preconceived ideas about autism "I didn't feel like she fit the mold."

Incidents related to finding the edges often involved parents recognizing they did not agree with the thinking of someone close to them. For example, Hannah indicated that her husband hindered her ability to focus on her child's differences when her husband joked that "OCD has always treated [him] well." Chandler indicated that there were times that the educational system hindered her from moving toward focusing on her child's differences because it felt slow "It's just their process. There was nothing that I was gonna do that was going to really change anything…. You get on a list and then four weeks later, you could do the next step and then the next." Chelsea described how professional help and intervention hindered her. Chelsea indicated that she had read that early intervention is better, but when she talked to her child's doctor about her daughter's behavior, the doctor stated, "This child's very alert, this child's very active, but we can't do anything, they're too young." Chelsea indicated this left her feeling uncertain about what to do next. She also indicated that the lack of alternatives to medication hindered her, "The only solution they are really giving me is medication and the medication caused depression, pretty bad. And she tried every kind for an entire year…. the lack of alternatives is frustrating to me."

Hindering moving toward recognizing strengths. Most themes associated with hindering moving to recognizing the child's strengths involved finding the edges (78%). Most incidents involved family members (61%) and occurred in the community environment (56%). Incidents that involved feeling uncertain often involved parents comparing their child to others. Chelsea described that comparing her child to others made her feel sad "Because I know I shouldn't do it. It makes me feel sad and resentful." Other incidents that involved feeling uncertain involved parents' worries about their child's development. Chandler described how focusing on her child's deficits hindered her from identifying the things her daughter was already able to do: "I think in the beginning I was just so wrapped up in the

things that I thought she was never going to be able to do." Mia described that she was "Dead set that we were gonna do all the right things and that when we got to the other side of that, he was gonna be ready to go to school, and that's not what happened." When Mia realized her son would still need supports after early intervention she described feeling "All this ambiguity…. basically, do everything you can, and where your child lands, you have no control over…. that was very hard."

Incidents associated with finding the edges often involved parents changing their behavior. For example, Bev described that seeing her daughter "Around neurotypical kids that don't have autism" hindered her from moving to recognizing her child strengths. Bev also indicated seeing her children around "neurotypical kids" led her to decide there were some things, like going to the zoo, that did not seem worth it for her. Finding the edges was also associated with parents feeling worn out, which also seemed to hinder them from recognizing their child's strengths. Jean described feeling "Like you have PTSD…. Those early years were hard. I think there was a few times where you just wanted to shut it all out." Jean went on to describe an event that caused her to stop going to the grocery store alone with her three children and hindered her from recognizing their strengths. Jean described walking across the grocery store parking lot, when her daughter slipped in a puddle of water, and her other two children took off: "Keith, he was my runner . . . he runs into the store and my other child, Steven, gets fascinated by the doors. I have a child in a puddle, one standing in the middle [of the parking lot] where cars are driving watching the doors, and the other one's in the store, I don't know where…. It was a disaster."

Hindering moving toward isolating. Most incidents associated with moving toward isolating involved feeling uncertain or obligated (67%). Most incidents involved other people not part of the family (56%) and occurred in a community environment (78%). Several parents described how feeling obligated hindered them from isolating themselves from others. For example, Chelsea described how the social expectations of spending holidays like Halloween with extended family felt like "Leading a sheep to slaughter" because her daughter would start the night happy because she wanted to see her cousins: "It's just something we have to do…. But [I] know…. this night isn't going to be fun. It's going to end up in tears, and knowing we have to do it anyway." Mia also described how social expectations hindered her

from isolating herself from her family: "There are some family members that you just can't make separation from…. The comment about my kid being contagious, that was a direct family member. I couldn't stop going to family functions."

Incidents associated with finding the edges involved parents recognizing they had reached a point where they were willing to let go of some "obligations." Sophie indicated she does not visit some family members: "I don't think the extra effort to spend time with family [is worth it] when they say something like…. For my own good and for his good, that he should be institutionalized. It'd be a lot better."

Hindering moving toward connecting. The theme finding the edges was associated with moving to connecting with others. Most incidents involved people other than the family (64%) and occurred in the community (64%). Finding the edges often involved aspects of connecting that parents felt was "artificial." Although Sophie indicated that autism support groups had been helpful, finding the edges represented moving back to her family's reality: "We always kind of move back into the normal kind of orbit, so at the end…. Your daily routine kind of prohibits reconnection because you're not in the same patterns and the same habits as you used to be…. Those were kind of artificial or temporary situations." Jean described another aspect of finding the edges that were related to her family becoming comfortable with who they are, "It makes people uncomfortable because we'll say, 'Our family's weird.' We embrace that with everything we are. . . My daughter, she loves to be weird. She'll say that. They've embraced their uniqueness."

Hindering moving toward experimenting. The theme finding the edges was associated with hindering parents from experimenting with strategies. Most incidents involved people other than the family (53%) and occurred in the community (59%). Finding the edges could sometimes look like parents focusing on limitations. For example, Bev indicated there were times she had concerns that an intervention might be detrimental: "If anything hindered me with those things it would be if I'm going to do something to hurt her and make it worse." Bev also described that recognizing her limits could also hinder experimenting with strategies: "I'm not one that has a lot of patience, so if I don't see results right away I'm like, 'I can't do this anymore. It takes too much effort.'" Jean described how other people

suggesting cures for autism limited her willingness to experiment with certain strategies. "You get into people who are like, 'Use these essential oils, and you'll cure your children…. [or] just pray harder.'"

Several parents described how other people in their life could hinder them. Mia indicated that professionals with "Confined ways of thinking about children with learning differences" could hinder experimenting with strategies. Mia described feeling like there are teachers who "Either they're not trained to use multi-sensory learning strategies, or they don't want to incorporate multi-sensory learning strategies" and "Administrators who have their box. 'This is what we do.'…. If your child doesn't fit in that box, then your child walks over there with those children that don't fit in that box."

Chelsea indicated that she felt professionals that focused on treating her daughter with medications hindered her ability to find better strategies for her daughter. Chelsea described how medications sedated her daughter and made her "Depressed and sad and angry." Chelsea said that although her child was less hyper and she was able to sit and watch a movie, it wasn't the right strategy. "I think it really hindered us with trying real strategies for things that would work and kind of just let her fall into more of the social norms by being in a daze…. I think that really kept me from working on other strategies."

Hindering moving toward discerning what is best for the family. The theme feeling uncertain or obligated was associated with hindering moving toward ability to discern. Most incidents involved family members (67%) and occurred in the home environment (56%). Several parents indicated that thinking they had identified a strategy that works only to find that the strategy did not work could hinder their ability to discern and would leave them feeling uncertain. For example, Tim described thinking his family had identified the ideal supports for his son after his son had a phenomenal second-grade year. Tim described feeling like after they had identified the "right recipe" all they would have to do is "make that happen." "Then we get to third grade, and it's like okay, well I thought we had the recipe. Is it the recipe we need to adjust or is it the application we need to adjust? Is it the recipe or the cook?"

Chelsea described how people's advice could hinder her from having the ability to discern. "I start having a lack of confidence. Maybe it is me…. I think it just that takes my confidence away, the

repetitive, in your ear, 'Well I do this with my kid and I don't let them get away with this.' I feel like that really can knock my own confidence down." Chelsea also indicated that research could make her feel uncertain because "You get so many different opinions." For example, she indicated reading the book ADD Does Not Exist and thinking, "'This really makes so much sense. I'm really understanding the position he's writing from'…. But that might be taking me in the wrong direction. And then you go to the doctor and they go 'Oh, this is what your child has.' So not being confident with myself based on the wrong research."

Discussion

We conducted a qualitative study using critical incident technique to develop a composite picture of experiences that parents described as helping or hindering transition related to their child's developmental diagnosis. Our findings align with previous studies that indicate transition requires adaptation and shapes how people respond to change (Kralik et al., 2006). Examples of how parents responded to change included learning about their child's diagnosis, accepting their child's differences, and recognizing their child's strengths. Parents adapted to change by modifying their use of resources. Parents described allocating their time to identify appropriate supports for their child. Parents also indicated there were times they reduced the amount of therapy for their child. Parents also responded to change by seeking opportunities to have their own needs met through attending support groups, making connections with others in their community, and sometimes deciding that there were instances, when they would prefer to take a break from others and be alone.

The results of this study extend the findings of Broski and Dunn (2018) that suggest parents' transition is associated with three primary transition orientations: child, other people, and parental competence (Figure 1). Parents ability to readily answer questions which asked about the child, other people and parent seem to indicate the three categories provide a useful framework to investigate parents' transition. However, we recommend several modifications to the strengths-based theory of parental transformation, which are reflected in figure 6. Firstly, we recommend that the term "domain" be revised to "orientation," as this term more accurately reflects parents transition experience. Secondly, we

recommend the description for the "others orientation" be changed from "distancing from others" to "awareness of tensions with others" which seems to more accurately describe parents transition from stage 1 to stage 2 of the "others orientation." Thirdly, we suggest that the third stage of transition is changed from "transformation" to "integration." While parents described transformational aspects to their transition experiences, parents' descriptions seem to suggest that parents are actively integrating what they learn throughout transition. Finally, the graphic which describes the strengths-based theory of parental transformation should be revised to indicate temporal differences in the child, others and parental competence orientations. While the authors do not feel the current study provides enough information to suggest how the temporal aspects of the model should be revised, this should be a focus for future studies. Our findings suggest that the early stages of parents' transition associated with the child orientation require parents to gather information and allocate resources to learn more about their child's differences.

While most parents we interviewed described aspects of sadness associated with their child's diagnosis, parents' descriptions of incidents that helped and hindered them were a stark contrast to results associated with the grief model and the chronic sorrow model. One area of departure is that while parents described aspects of sadness they did not describe a loss of quality of life. In particular, the parents we interviewed proudly described their children's accomplishments. While the chronic sorrow model suggests parents have less to look forward to as their children transition out of high school programs, the parents in our study were vocal about their appreciation of their child's strengths and looked forward to learning about their child's future contributions.

The findings of this study also support Broski and Dunn's premise that parents experience a liminal phase concerning their roles and interactions with others. In some cases, parents described feeling isolated from other people in their social circles from whom they did not want to be separated. In other instances, parents described actively separating from people they felt were not supportive of their child. On the surface, these findings seem to echo the findings of the chronic sorrow model. However, the parents in our study also described satisfaction in how they had navigated the changes they encountered in their social circles. Notably, Mia described becoming involved with advocating for inclusion as a result of

her experiences with a playgroup that excluded her because of her son's differences. Jean described becoming passionate about inclusion in her faith community as a result of her experiences with being excluded from worship services. Had we only asked parents what had hindered their transition, we might not have learned about how parents had become empowered through experiences that had initially been associated with sadness and loss for parents.

A challenging aspect of parents' transition is that as the parents' grow and learn, so does the child. Tim described this situation when he indicated he thought he had figured out the "right recipe" for his son's education, only to discover that there were contextual factors that made the recipe work one year and not the next. Additionally, as the child's classroom context changed, the child is growing and transitioning as well. This means that parent's ability to discern is never discovered "once and for all," but is a fluid and everchanging process for all members of the family. An additional component of transition that may further complicate parents' ability to integrate is that parents may develop an ability to be discerning in what aspect of parenting while they continue to seek confirmation or experiment with strategies in other aspects of parenting.

Most of the parents we interviewed described challenging experiences with their extended family. While our study focused on the transition of parents, one can imagine that grandparents, aunts, and uncles are navigating their own transitions. Future studies should explore factors that assist grandparents or spouses' transition, such as moving from "this is how I did things, and you turned out just fine" to "tell me how I can best support you." Additionally, future studies should investigate how the strengths-based theory of parental transformation may be modified and applied to provider's transitions as they gain more experience working with families.

When we conceptualized this study, we expected that we would learn about people, places, or things that helped or hindered parents' transition. We were surprised to hear parents' descriptions of the incidents that hindered them were often similar to those that helped them. For example, Chelsea described feeling hindered by her child's behavior that she felt made it difficult for her to spend time with her extended family. On the other hand, she admitted to being more introspective and reflective because of

the incidents that hindered her. This example seems to highlight differences in individuals' perceptions of similar situations. For example, Chelsea indicated her reflections regarding feeling angry with her family also helped her to bring her love for her daughter and her family into clearer focus.

While we found similarities between the incidents that helped and hindered parents, there seemed to be fundamental differences in incidents that hindered parents that were not present in the descriptions of incidents that helped parents. The incidents that hindered parents seemed to require parents to pause and reflect on their given circumstances. It is possible that pausing and reflecting provided parents with an opportunity to focus on what was needed to overcome the obstacle. It is also possible that the tensions and adversity associated with incidents that help and hinder parents are part of the "active ingredients" that help parents integrate their transition experiences. Future research should seek to better understand if incidents that hinder parents provide clarity which allows them to push through challenging situations. Our findings are consistent with previous research that parents construct new ways of thinking about their children, themselves and their lives (Scorgie et al., 2004).

The findings of this study stand in contrast to previous transition frameworks which suggest parents must experience and pass through stages of grief before they can move on (Kübler-Ross, 1970). Our findings fail to support the chronic sorrow model which suggests parents of a child with a developmental diagnosis experience on-going loss of quality of life, support, roles, and relationships (Springer, Turns, Masterson, Turns, & Masterson, 2017; Springer et al., 2017). Parents described some events that left them feeling raw, exhausted, and angry. However, parents also described experiencing profound insight, joy, and admiration of their child, deep and meaningful relationships with others, and the ability to make decisions about maintaining or discontinuing relationships or activities that no longer held meaning for them.

The results of this study should be evaluated in light of its strengths and challenges. Strengths of this study include a design to collect rich, contextual information about parents' experiences. However, our sample lacked racial and ethnic diversity. Future studies should seek to recruit racially and ethnically diverse parents. Our sample was balanced with respect to child gender, but parents were predominantly

female. The study includes insights from families who were white, educated, and who reported having access to resources, such as full-time or part-time work. Future studies should explore how varying access to such resources helps and hinders parents transition. There is the possibility of self-selection which might have influence results by recruiting parents who or had more positive feelings toward transition. There were also limitations concerning the temporal environment data. We were not able to collect temporal data for all of the incidents. Therefore it is possible that there is bias in the direction of the temporal aspects of the results.

A strength of this study was that we were able to include the parent reports from parents who were navigating experiences with a young child as well as reports from parents whose adult children had left home. Future studies should consider focusing on particular age ranges of the children. The design of this study requires participants to report past events; as a result, there is the possibility of recall bias. One strategy we used to control for recall bias was to provide participants with the questions we asked before the interview so they would have time to reflect on the questions.

Parents we interviewed vividly described their awareness of challenging events and how they learned to anticipate and plan strategies to navigate the challenging events in their future which suggests that parents transition involved a full range of experiences and emotions. They gathered information, experimented with strategies and then evaluated whether the strategies they identified worked, needed to be modified, or needed to be discontinued. They described refining their thinking, updating their understanding, and challenging their paradigms, and they sometimes challenged the people around them to reconsider their world views.

Implications for practice include identifying opportunities to widen the circle of practice. Early childhood providers should search for opportunities to include grandparents or other members of the extended family. Coaching parents in practical approaches for communicating with family members may be beneficial. Providers should recognize that parents have strengths that are evoked during transition. While providers may be eager to identify what helps families during a transition, our study revealed that incident that hindered parents often propelled parents to engage in activities that were meaningful to

them. We do not suggest that incidents that parents feel hinder them should be underestimated, diminished, or taken for granted. Instead, providers can support parents to explore ways of engaging their strengths during transition.

Our research is part of a growing body of evidence that supports an awareness long present in successful relationships between families of children with developmental differences and the providers of services and supports who engage with these families. Namely, parents understand their children; and providers who respect and reflect parent voices have a keener understanding of the best ways to learn from, and constructively engage with, these families and their children. It is critical to recognize that the parents' journey to transformation begins when the uniqueness of the child is first observed, for that is the point at which transformation begins.

References

Allred, K. W. (2015). Engaging parents of students with disabilities: Moving beyond the grief model. *Improving Schools*, *18*, 46–55. https://doi.org/10.1177/1365480214553745

Barclay-Goddard, R., King, J., Dubouloz, C.-J., & Schwartz, C. E. (2012). Building on transformative learning and response shift theory to investigate health-related quality of life changes over time in individuals with chronic health conditions and disability. *Archives of Physical Medicine and Rehabilitation*, *93*, 214–220. https://doi.org/10.1016/j.apmr.2011.09.010

Becker, G. (1997). *Disrupted lives: How people create meaning in a chaotic world*. Berkley, CA: University of California Press.

Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. (2016). Member checking: A tool to enhance trustworthiness or merely a nod to validation? *Qualitative Health Research*, *26*, 1802–1811. https://doi.org/10.1177/1049732316654870

Bonis, S. (2016). Stress and parents of children with autism: A review of literature. *Issues in Mental Health Nursing*, *37*, 153–163. https://doi.org/10.3109/01612840.2015.1116030

Boström, P. K., & Broberg, M. (2014). Openness and avoidance: A longitudinal study of fathers of children with intellectual disability. *Journal of Intellectual Disability Research*, *58*, 810–821. https://doi.org/10.1111/jir.12093

Boström, P. K., Broberg, M., & Hwang, P. (2010). Parents' descriptions and experiences of young children recently diagnosed with intellectual disability. *Child: Care, Health and Development*, *36*, 93–100. https://doi.org/10.1111/j.1365-2214.2009.01036.x

Bott, G., & Tourish, D. (2016). The critical incident technique reappraised: Using critical incidents to illuminate organizational practices and build theory. *Qualitative Research in Organizations and Management: An International Journal*, *11*, 276–300. https://doi.org/10.1108/QROM-01-2016-1351

Broski, J., & Dunn, W. (2018a). Evaluation of the strengths-based theory of parental transformation.

Broski, J., & Dunn, W. (2018b). Fostering insights: A strengths-based theory of parental transformation. *Journal of Child and Family Studies*, *27*, 1275–1286. https://doi.org/10.1007/s10826-017-0964-5

Broski, J., & Dunn, W. (2019) Exploring parents' mental models related to their child's developmental diagnosis. Unpublished manuscript, Therapeutic Science Program, University of Kansas Medical Center, Kansas City, USA

Buntinx, W. (2013). Understanding disability: A strengths-based approach. In M. Wehmeyer (Ed.), *The Oxford handbook of positive psychology and disability* (pp. 7–18). New York, NY, USA: Oxford University Press.

Butterfield, L. D., Borgen, W. A., Amundson, N. E., & Maglio, A.-S. T. (2005). Fifty years of the critical incident technique: 1954-2004 and beyond. *Qualitative Research*, *5*, 475–497. https://doi.org/10.1177/1468794105056924

Butterfield, L. D., Borgen, W. A., Maglio, A.-S. T., & Amundson, N. E. (2009). Using the enhanced critical incident technique in counseling psychology research. *Canadian Journal of Counselling*, *32*, 265–282. https://eric.ed.gov/?id=EJ858080

Carpenter, C. (2018). Leveraging the critical incident technique (CIT) in identifying effective team learning thematic variables. In *2018 Conference Proceedings* (pp. 1–7). Manhattan, KS: New Prairie Press. http://newprairiepress.org/aerc/2018/papers/11

Chick, N., & Meleis, A. (1986). *Transitions: A nursing concern*. Boulder, CO: Aspen Publications.

DeSantis, L., & Ugarriza, D. N. (2000). The concept of theme as used in qualitative nursing research. *Western Journal of Nursing Research*, *22*, 351–372. https://doi.org/10.1177/019394590002200308

Dunn, W., Brown, C., & McGuigan, A. (1994). The ecology of human performance: A framework for considering the effect of context. *American Journal of Occupational Therapy*, *48*, 595–607. https://doi.org/10.5014/ajot.48.7.595

Eakes, G. G., Burke, M. L., & Hainsworth, M. A. (1998). Middle-range theory of chronic sorrow. *Image: The Journal of Nursing Scholarship*, *30*(2), 179–184. https://doi.org/10.1111/j.1547-5069.1998.tb01276.x

Flanagan, J. C. (1954). The critical incident technique. *Psychological Bulletin*, *51*, 327–358. https://doi.org/10.1037/h0061470

Fusch, P. I., & Ness, L. R. (2015). Are we there yet? Data saturation in qualitative research. *The Qualitative Report*, *20*(9), 1408–1416.

Gassaway, J., Jones, M. L., Sweatman, W. M., & Young, T. (2017). Peer-led, transformative learning approaches increase classroom engagement in care self-management classes during inpatient rehabilitation of individuals with spinal cord injury. *The Journal of Spinal Cord Medicine*, 1–9. https://doi.org/10.1080/10790268.2017.1385992

Guest, G. (2006). How many interviews are enough?: An experiment with data saturation and variability. *Field Methods*, *18*, 59–82. https://doi.org/10.1177/1525822X05279903

Harenčárová, H. (2017). Managing uncertainty in paramedics' decision making. *Journal of Cognitive Engineering and Decision Making*, *11*(1), 42–62. https://doi.org/10.1177/1555343416674814

Kralik, D., Visentin, K., & van Loon, A. (2006). Transition: A literature review. *Journal of Advanced Nursing*, *55*, 320–329. https://doi.org/10.1111/j.1365-2648.2006.03899.x

Kübler-Ross, E. (1970). *On death and dying*. New York, NY, US: Collier Books/Macmillan Publishing Co.

Kübler-Ross, E., & Kessler, D. (2014). *On grief and grieving: Finding the meaning of grief through the five stages of loss*. Simon and Schuster.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. SAGE.

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research*, *26*(13), 1753–1760. https://doi.org/10.1177/1049732315617444

Masterson, M. K. (2010). Chronic sorrow in mothers of adult children with cerebral palsy: An exploratory study. Retrieved from http://krex.k-state.edu/dspace/handle/2097/3906

Meleis, A. (2010). *Transitions theory: Middle range and situation-specific theories in nursing research and practice*. New York, NY: Springer Publishing Company.

Meleis, A. (2015). Transitions theory. In M. Smith & M. Parker (Eds.), *Nursing theories and nursing practice* (4th ed., pp. 361–380). Philadelphia, PA: F.A. Davis Company.

Messias, D., Gilliss, C., Sparacino, P., Tong, E., & Foote, D. (1995). Stories of transition: Parents recall the diagnosis of congenital heart defect. *Families, Systems & Health*, *13*, 367–377. https://doi.org/10.1037/h0089280

Miles, M., Huberman, A. M., & Saldana, J. (2014). *Qualitative data analysis: A methods sourcebook* (3rd ed.). Los Angeles: SAGE Publications.

Phillippi, J., & Lauderdale, J. (2018). A guide to field notes for qualitative research: Context and conversation. *Qualitative Health Research*, *28*(3), 381–388. https://doi.org/10.1177/1049732317697102

Pope, A., & Brandt, E. (1997). *Enabling America: Assessing the role of rehabilitation science and engineering* (1st ed.). Washington, D.C.: National Academies Press.

Saldana, J. (2012). *The coding manual for qualitative researchers*. SAGE Publications.

Schalock, R. L., Borthwick-Duffy, S. A., Bradley, V. J., Buntinx, W. H. E., Coulter, D. L., Craig, E. M., … Yeager, M. H. (2010). *Intellectual disability: Definition, classification, and systems of supports* (11th ed.). Washington, D.C.: American Association on Intellectual and Developmental Disabilities.

Schendel, D. E., Diguiseppi, C., Croen, L. A., Fallin, M. D., Reed, P. L., Schieve, L. A., … Yeargin-Allsopp, M. (2012). The study to explore early development (seed): A multisite epidemiologic study of autism by the centers for autism and developmental disabilities research and epidemiology (caddre) network. *Journal of Autism and Developmental Disorders*, *42*, 2121–2140. https://doi.org/10.1007/s10803-012-1461-8

Scorgie, K., Wilgosh, L., & Sobsey, D. (2004). The experience of transformation in parents of children

 with disabilities: Theoretical considerations. *Developmental Disabilities Bulletin*, *32*, 84–110.

Shogren, K. A. (2013). Positive psychology and disability: A historical analysis. *The Oxford Handbook of*

 Positive Psychology and Disability, 19–33.

Springer, N. P., Turns, B., Masterson, M., Turns, B., & Masterson, M. (2017, October 19). A systemic

 and contextual lens of disability: Family stress, ambiguous loss, and meaning making.

 https://doi.org/10.4324/9781315562490-2

Stitt-Gohdes, W. L., Lambrecht, J. J., & Redmann, D. H. (2000). The critical incident technique in job

 behavior research. *Journal of Vocational Education Research*, *25*(1), 59–84.

Turner, V. (1969). *The ritual process: Structure and anti-structure*. New York, NY: Transaction

 Publishers; Routledge.

Ushioda, E. (2016). Language learning motivation through a small lens: A research agenda. *Language*

 Teaching, *49*, 564–577. http://dx.doi.org/10.1017/S0261444816000173

van Gennep, A. (1960). *The Rites of Passage*. New York: Routledge.

Table 1
Frequencies of incidents that help and hinder parents

	Helped research question one (n=142)	Hindered research question two (n=79)
What incident/s stand out as helping or hindering you from moving from awareness of your child's differences to focusing on your child's differences?	26	15
What incident/s stand out as helping or hindering you from moving from focusing on your child's differences to recognizing your child's strengths?	23	18
What incident/s stand out as helping or hindering you from moving from distancing yourself from people who were not healthy for you to be around to isolating yourself?	17	9
What incident/s stand out as helping you move from isolating yourself to connecting or reconnecting with people?	21	11
What incident/s stand out as hindering you from moving from seeking confirmation from others to experimenting with strategies or interventions to help your child?	29	17
What incident/s stand out as hindering you from experimenting with strategies or interventions to having confidence in your ability to discern strategies or therapies that address your child or your family's preferences or values?	26	9

Figure 1

The strengths-based theory of parental transformation

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What incident/s stand out as helping or hindering you moving from:

Child Domain	1. Awareness of your child's differences to focusing on your child's differences? **Awareness of differences**	2. Focusing on your child's differences to recognizing your child's strengths? **Focusing on Differences**	**Recognizing Strengths**
Others Domain	3. Distancing yourself from people who were not healthy for you to be around to isolating yourself? **Distancing from Others**	4. Isolating yourself to connecting or reconnecting with people? **Isolating from others**	**Connecting with others**
Parent Domain	5. Seeking confirmation from others to experimenting with strategies or interventions to help your child? **Seeking confirmation**	6. Experimenting with to having confidence your ability to discern what works for your family? **Experimenting with strategies**	**Discerning what works for the family**

Figure 2

The figure depicts how the interview questions align with the domains associated with the strengths-based theory of parental transformation (child, others, and parent) and the stages of transformation

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Movement from the early stage of transition toward the middle stage	Movement from the middle stage of transition toward the late stage of transition
Child Domain	
Helps transition from awareness of the child's differences to focusing on the child's differences • Parent sensed the child's behavior was different from other children the same age • Spouse noticed the child's behavior was different • Parent recognized she was reluctant to label her child • Parent realized the child's language did not make sense • Daycare providers indicated they could not meet the child's needs • Professionals alerted parent to child's differences **Hinders transition from awareness of the child's differences to focusing on the child's differences** • Parent's preconceived ideas about autism • Spouse and friends saying "she's so normal" • Family members who did not understand the child's differences • School psychologist saying the child did not need supports • Spouse did not think the child needed supports • The parent did not want to accept the child's differences • Other people thinking the child's behavior was "cute"	**Helps transition from focusing on the child's differences to recognizing the child's strengths** • Teachers helped the parent recognize the child's strengths • Successful interventions, such as finding the right medication • Homeschooling the child helped the parent to focus on the child's strengths • Parent admiring the child's unique traits and skills • Not doing so much therapy all the time was helpful • Parent recognizing the child's growth **Helps transition from focusing on the child's differences to recognizing the child's strengths** • The parent being sleep deprived • The parent doing things that other families can easily do Teacher's negativity • Parent focusing on what the child could not do • Child perseverating on certain things • Child's struggles with homework • Parent's uncertainty about the child's diagnosis • Feeling "PTSD about everything"
Others Domain	
Helps transition from distancing to isolating from others • Friends not knowing how to relate • Grandparents not understanding the child's condition • The parent is asked to leave the playgroup • Faith community that was not inclusive • Parent deciding to stay home with the children • Extended family who do not understand the child's condition **Hinders transition from distancing from others to isolating** • Parent not having many friends in the area • Parent's desire to maintain connections with family and friends • Parent's and family's busy schedule	**Helps transition from isolating to connecting with others** • Parent participating with a support group • Parent connecting with other families • The parent taking time to get over feeling hurt • Parent feeling supported by the faith community • Parent educating family about her child • Other people including the child • Spouse connecting with others in the community **Hinders transition from isolating to connecting with others** • Parent not having energy • Parent feeling emotional when talking about her child • Parent feeling angry about her family yelling at her child • Family members who do not understand the child • Parent feeling annoyed by their child's behavior • Parent feeling like her life was compartmentalized
Parent Domain	
Helping transition from seeking confirmation from others to experimenting with strategies • Parent looking for guidance from professionals • Professionals who support the parent • Parent seeking to minimize the child's frustrations • Parent trying things that do and do not work • Parent's curiosity **Hindering transition from seeking confirmation from others to experimenting with strategies** • Lack of professional support • Professionals who are not up to speed • Other people's beliefs about the child • Parent trying things that do not work • Interventions that take too much time, effort, or are too far away	**Helping transition experimenting with strategies to discerning what is best for the family** • Child's response to the parent • Parent understanding the child's preferences • Parent recognizing the need to do something different • Parent seeing the child for who she/he is • Parent moving on from support groups • Parent recognizing that some interventions are not right for their child **Hindering transition experimenting with strategies to discerning what is best for the family** • Parent's limiting ideas about the child's skills • Parent's concern that an intervention might be harmful • Educators who act like the child is a problem • Parent's self-doubt • Family thinking they had figured out how to solve a problem, but discovering they had not

Figure 3
Representative characteristics of incidents that parents described as helping and hindering their transition.

Temporal Aspects of Incidents that helped parents' Transition
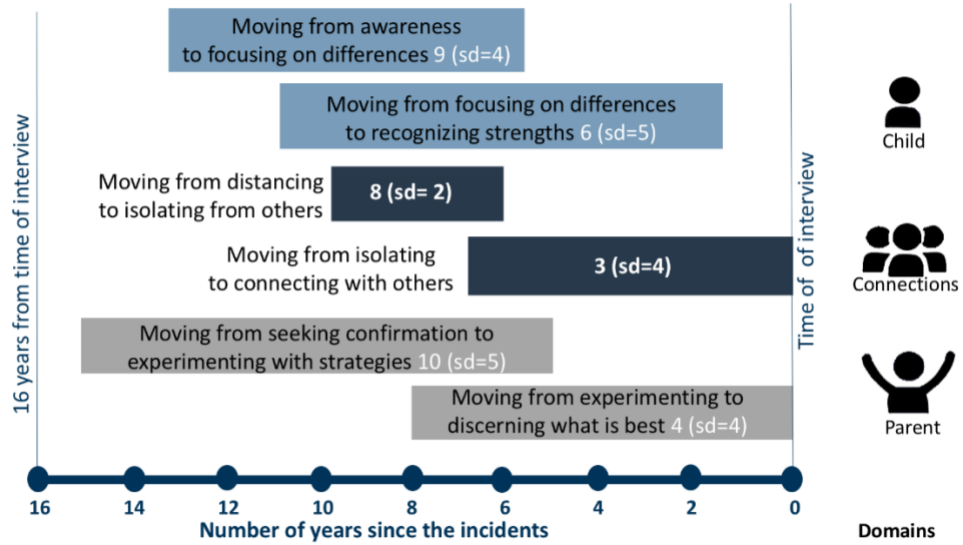
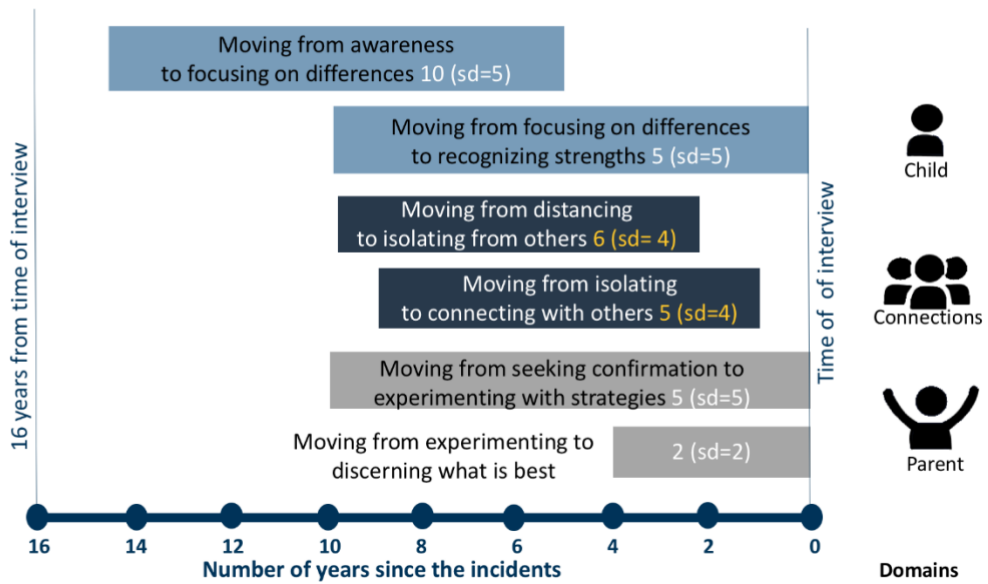**Temporal Aspects of Incidents that hindered Parents' Transition**

Figure 4

Summary of the temporal aspects of incidents that helped and hindered parents.

Parents provided their best estimation of when incidents occurred. Temporal data was available for 74% of all incidents. Temporal data is missing for 36 helping incidents and 22 hindering incidents.

Incidents that helped parents transition

Domain	Stage of transition	Themes		Social Environment		Physical Environment	
	Transition from:	Allocating Resources (n=97)	Seeing Possibilities (n=45)	Family (n=61)	Others (n=81)	Home (n=46)	Community (n=96)
Child	Awareness of the child's differences toward focusing on the child's differences.	100%	0%	42%	58%	50%	50%
Child	Focusing on the child's differences toward recognizing the child's strengths	22%	78%	44%	57%	39%	61%
Others	Awareness of tensions in relationships toward isolating from others.	100%	0%	53%	47%	12%	88%
Others	Isolating from others to making connections with others	33%	67%	24%	76%	19%	81%
Parent	Seeking confirmation from others to experimenting with strategies	100%	0%	38%	62%	17%	83%
Parent	Experimenting with strategies to discerning what works	50%	50%	58%	42%	50%	50%

Incidents that hindered parents transition

	Transition from:	Finding the Edges (n=53)	Feeling Uncertain (n=26)	Family (n=42)	Others (n=37)	Home (n=35)	Community (n=44)
Child	Awareness of the child's differences toward focusing on the child's differences.	53%	47%	60%	40%	67%	33%
Child	Focusing on the child's differences toward recognizing the child's strengths	78%	22%	61%	39%	44%	56%
Others	Awareness of tensions in relationships toward isolating from others.	44%	56%	44%	56%	22%	78%
Others	Isolating from others to making connections with others	100%	0%	36%	64%	36%	64%
Parent	Seeking confirmation from others to experimenting with strategies	100%	0%	47%	53%	41%	59%
Parent	Experimenting with strategies to discerning what works	0	100%	67%	33%	44%	56%

Figure 5

Themes, social environment, and physical environment of incidents that parents described as helping and hindering their transition.
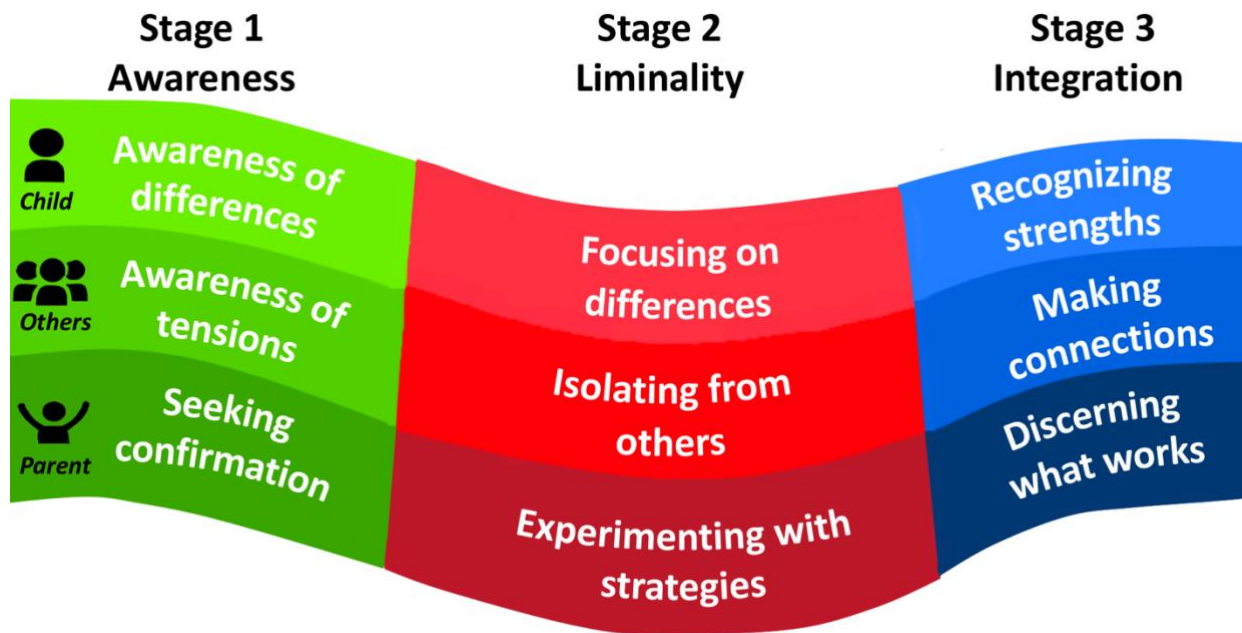
Figure 6

The author's revisions to the strengths-based theory of parental transformation based on the findings from this study. Stage 1 of the others orientation should be revised from "distancing from others" to "awareness of tensions." Stage 3 should be revised from "transformation" to "integration." Integration suggests parents' synthesizing and using what they have learned.

Chapter 5: Overall Conclusions

The purpose of my dissertation study was to develop a composite picture of approaches that parents describe as helping or hindering transition. Using critical incident technique, combined with thematic analysis, I identified two themes associated with incidents that helped parents and two themes associated with incidents that hindered parents. Incidents that helped parents in the early stages of transition involved allocating and using resources. Incidents that helped parents in the later stages of transition involved seeing possibilities for their child or themselves. Incidents that hindered parents involved finding the edges and feeling uncertain or obligated. Finding the edges often required parents to pause and reflect on their values.

The temporal data suggests parents' awareness of their child's differences occurs earlier in the transition and parents' ability to discern occurs much later. Because I was unable to collect temporal data for 26% of the incidents, caution should be used in interpreting these results. Future studies should explore the temporal aspects of parents' transition.

Theory development proceeds by proposing a theory and then testing the theory to determine the theory's usefulness in describing a phenomenon. The findings from the three studies I have conducted as part of my research in the Therapeutic Science program indicates that the strengths-based theory of parental transformation captures relevant features of parents' transition. The theory's proposition that parents transition can be described using the three domains, and three stages of transition is supported by the findings associated with this work. The results of my comprehensive examinations and my dissertation study contribute to research by providing an alternative to deficit-based theories to describe parents' transition.

Appendix A: Comprehensive Exam One

This appendix is the original manuscript for an article previously published with substantial revisions.

The published version can be found in Broski, J.A. & Dunn, W. Journal of Child and Family Studies

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Abstract

Parent's awareness that their child's development is not proceeding as they expected can create an unanticipated transition from being a parent to becoming the parent of a child with a developmental condition. We use theory derivation to develop the strengths-based theory of parental transformation [STPT] before their child's developmental diagnosis. In STPT, parents' experiences are associated with a change in mental landscape. Mental landscape is a metaphor that refers to the individual's mental representation of their environment (Chaney, 2010; Ramsey, 2016). Navigating new mental terrain requires parents to be aware of changes in the new mental landscape. We propose that parents' increased awareness and attention to their child and their own experiences can foster parental insight and facilitate transformation. The STPT extends the findings of Scorgie, Wilgosh, & Sobsey (2004) that parents'experiences after their child's diagnosis may be associated with personal transformation. We propose that parents' ability to evolve in the midst uncertainty provides a framework for parents and providers to think about parents' experiences during the diagnostic process in ways that promote personal growth.

Improving support for parents of children with developmental disabilities is a global research priority (Tomlinson et al., 2014a), including the need to better understand parent experiences and information needs while a family waits for diagnostic clarification and understanding of their child's developmental needs. (Crane, Chester, Goddard, Henry, & Hill, 2015). Furthermore, early childhood and health care organizations recognize that improving support for parents and children is best accomplished through family-centered services (Kuo et al., 2012b; The Joint Commission, 2010). Although there is no single definition of family-centered care, the core principals include balanced relationships between families and providers, recognition of families' strengths, provision of individualized services and facilitation of choice(Epley, Summers, & Turnbull, 2010).

The Parent Transformational Process Model (Scorgie, Wilgosh, & Sobsey, 2004b) contributes to the call to improve support for parents of children with developmental disabilities. The PTPM recognizes parents' strengths *after* their child's developmental diagnosis. The model describes parents' process of image-making, meaning-making, and transformation in order to identify patterns associated with parents' transformation (Scorgie et al., 2004b). Their research also indicates that the *absence* of stress is not necessary for transformation. Wilgosh and Scorgie(2006) found parents describe becoming stronger, more compassionate and self-defined as a result of having a child with a developmental disability despite describing the period surrounding diagnosis as "traumatic" (Scorgie & Sobsey, 2000b).

The PTPM (Scorgie et al., 2004b) provides a more hopeful perspective than some family change theories, but the need remains for a strengths-based theory to understand parents' experiences *before* their child's developmental diagnosis. Parents describe the process surrounding diagnosis as traumatic (Wilgosh, Nota, Scorgie, & Soresi, 2004); a process that may take more than three years (Crane et al., 2015). Additionally, some children at risk for a developmental diagnosis, will not receive a definitive diagnosis (Timmermans & Buchbinder, 2010).

Background

Parents often experience uncertainty while they wait for their child's developmental diagnosis (Crane et al., 2015; Ho, Yi, Griffiths, Chan, & Murray, 2014a; Mansell & Morris, 2004a). Although uncertainty is uncomfortable and may generate stress and anxiety, parental uncertainty can be associated with negative or positive outcomes. Uncertainty influences parents' relationship with their child (Page et al., 2012), confidence in their parenting ability (Stewart & Mishel, 2000), decision making (Guerriere, McKeever, PhD, & Berall, 2007), mental health (Stewart & Mishel, 2000), ability to live in the present moment (Rosenthal, Biesecker, & Biesecker, 2001), and acceptance of their child for who he or she is (Rosenthal et al., 2001). Understanding parents' experiences in order to provide support to families has emerged as an important priority for future research related to early intervention (Tomlinson et al., 2014a) because parents' health and wellness affect children's (Bronfenbenner, 1979; U. Bronfenbrenner, 1999; Urie Bronfenbrenner, 1985; Morris & Bronfenbrenner, 2007)(Bronfenbenner, 1979; Urie Bronfenbrenner, 1985)

Individuals structure their expectations about each phase of life and assign meanings to life-events, and their roles in those events (Gaylene Becker, 1997). When life unfolds in ways that run counter to an individual's expectations, they may feel at odds with others and themselves ((Gaylene Becker, 1997). Work and leisure activities may change, and disruptions may occur in patterns of personal expression (Kleiber, Hutchinson, & Williams, 2010). Parent's awareness that their child's development is not proceeding as they expected creates an unanticipated transition (Afaf Meleis, 2010; Messias, Deanne; Gilliss, Catherine; Sparacino, Patricia; Tong, Elizabeth; Foote, 1995) from becoming a parent to becoming the parent of a child with a developmental disability. While parents frequently perceive unexpected transitions as negative developments (Messias, Deanne; Gilliss, Catherine; Sparacino, Patricia; Tong, Elizabeth; Foote, 1995), all transitions require individuals to reflect on their lives in ways that can be transformative and that influences self-identity (Chick & Meleis, 1986b; Kleiber et al., 2010).

Transition is a common theme in early childhood literature. From the child's birth to entering elementary school, there are many transitions; children may attend daycare or enter preschool, children

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may experience siblings being born into the family, and sometimes families move. For families that have children who seem vulnerable, the transition experience also includes a diagnostic process as parents seek knowledge and insights to better understand and support their children.

Transition is a universal experience that occurs over time, requires adaptation and shapes how people respond to change (Debbie Kralik, Visentin, & van Loon, 2006). Theoretical frameworks (Debbie Kralik et al., 2006; Afaf Meleis, 2010; Turner, 1985; van Gennep, 1960b) recognize three primary stages associated with transition, including: 1) an initial phase that involves separation from a previous way of life 2) an in-between phase known as "liminality," being "betwixt and between and 3) a final phase that signifies the beginning of the individual's new social role.

Family-centered care is an innovative practice that emphasizes the strengths of families' and individual's (Kuo et al., 2012b; Millenson, DiGioia, Greenhouse, & Swieskowski) which stands in contrast to "problem-focused" practices that emphasize deficits. "Problem-focused" or deficit-based practices are standard practice in many traditional models of care (Dennis Saleebey, 2009). As a result, many traditional transition theories do not align with the core principles of family-centered care because the theories either do not recognize the diversity of families or they reinforce deficit-based perspectives of disability. For example, family development theory explains events that signify new stages in family life. However, family development theories perpetuate assumptions that there are "typical" families and "typical" family stages (Laszloffy, 2002b). Family stress theory explains the importance of family adaptation and functioning (McCubbin & Patterson, 2008a); however, family stress theory defines events (such as a diagnosis) as a "crisis." Proponents of the neurodiversity movement, would eschew considering a developmental diagnosis a "crisis" and might be more likely to celebrate the unique strengths that individual's functioning might provide. Health-illness transition theory describes how a diagnosis of one member of the family creates unexpected transitions for other family members (Afaf Meleis, 2010), however, characterizing a developmental diagnosis as an "illness" reinforces a deficit-based perspective and suggests a child with a developmental diagnosis needs to be "cured."

Research on parents' experiences during the diagnostic process reflects practices that fall along a spectrum of "traditional" (deficit-based) or "innovative" (family-centered) paradigms. For example, knowledge of parents' satisfaction with the diagnostic process, the time required to receive a diagnosis and the number of professionals needed to obtain a diagnosis (Crane et al., 2015; Howlin & Moore, 1997b; Siklos & Kerns, 2007b) helps us understand parents' interactions with the medical system. However, focusing on the diagnostic process inadvertently emphasizes medical-model perspectives. Other medical-model perspectives include finding a cure for "deficits," and perceptions that professionals are best equipped to address disability (Brueggemann, 2015b). Additionally, implicit in much of the research on parents experiences is that a clear diagnosis of the child is necessary before the parent can "move on" (Mulligan, MacCulloch, Good, & Nicholas, 2012; Timmermans & Buchbinder, 2010).

The purpose of this paper is to use theory derivation to develop a strengths-based theory of parental transformation. First, we describe theory derivation, the method we use to develop our theory. Second, to provide background on the source theory for our research, we briefly describe previous research on the origins and uses of the theory of well-being of refugee women experiencing cultural transition (Baird & Reed, 2015a). Third, we present our derived theory and use a case study to illustrate the theory in action and discuss implications for future research.

Theory Derivation

We based our theory development process on Walker and Avant's five steps for theory derivation (2010). Theory derivation is used when a theory from one discipline is adapted and changed for another discipline. Theory derivation is a useful method to examine data for new insights where existing theories have limited impact on practice (Walker and Avant, 2010). Although Walker and Avant describe these five basic steps of concept derivation, in practice the steps may be iterative or may occur simultaneously (2010):

1. Recognition of prior research on parental experiences before their children's diagnoses;
2. Read across varied disciplines to gain insight;
3. Select a source theory for the derivation process;

4. Identify source theory content for use in the derived theory;

5. Redefine the source theory using examples specific to parents' experiences before their child's diagnosis.

The process of theory derivation initially involves developing a model without immediate knowledge of its accuracy. Examination of the strengths and weaknesses of the conceptual framework occur in practice and research (Walker, Lorraine Olszewski. Avant, 2010, p. 17).

We reviewed the literature to gain an understanding of conceptualizations of separation, liminality, and integration of caregivers' experiences before receiving a diagnosis. Because few studies specifically address parents' resilience or competence *before* the diagnosis of a developmental disability, we took a broad view of the literature with application to developmental disabilities in order to apply the concepts to parents' experiences before their child's diagnosis. Our review of the literature also included reading autobiographical works of parents of children with a developmental diagnosis to gain insights about parents' experiences before their child's diagnosis.

Theory of Well-being of Refugee Women Experiencing Cultural Transition

We derive our theory from the theory of well-being of refugee women experiencing cultural transition [RWCT] by Baird (2012). The authors selected the theory of RWCT because it provides a strengths-based perspective of transition. Additionally, Baird and Reed's (2015) development of the concept of liminality underscores the importance of understanding strengths at every phase of transition, particularly when families feel they are "in between" two worlds. The theory of RWCT is a situation-specific theory resulting from studies with refugee women who resettled to the United States (Baird, 2012a). Three themes serve as the foundation for the theory of RWCT: 1) liminality: living between two cultures; 2) self-support: "standing on our own," and 3) hope for the future (Baird, 2012; (Baird & Reed, 2015a).

A central concept emerging from the theory of RWCT is liminality (Baird and Reed, 2015). The liminal stage often referred to as "betwixt and between" occurs when individuals are on the threshold of a

new way of life and in between social roles (Turner, 1985; van Gennep, 1960b). Baird and Reed (2015) identified liminality as an important process in transition as well as a conundrum:

Someone experiencing liminality can feel disconnected and uncomfortable yet have the capacity for growth and transformation. It has been suggested that there is a creative potential in liminality that can lead to opportunities to change and reformulate the self. (p 31)

According to Baird (2012), the two primary theoretical constructs in the theory of RWCT are well-being and transition. Baird (2012) defines the concept of wellness in the theory of RWCT as:

A process measured over time in which one has adequate resources to meet basic physical, emotional, social and spiritual needs. An individual with a sense of well-being experiences peace of mind, acceptance of life as it is presented, a sound physical condition, and a state of emotional and spiritual balance that leads to the belief that life is worth living (p. 254).

Derived Theory: A Strengths-Based Theory of Parental Transformation

The purpose of the strengths-based theory of parental transformation [STPT] is to provide a framework to conceptualize parents' experiences while they wait for a developmental diagnosis for their child. The STPT is consistent with family-centered practice and with ecological models of disability. In this paper, we define "parent" as a guardian, foster parent, adoptive parent, grandparent or other adult who engages in raising a child. In this paper "developmental condition" refers to conditions that are "innate to an individual" (Vargo, 2015, p. 5), "with onset in infancy or childhood" (World Health Organization, 2013). Examples of developmental conditions include communication and language diagnoses, autism spectrum disorders and Down syndrome.

In RWCT the source theory, individuals' experience a change in culture resulting from a change in geographic landscape (Baird and Reed, 2015). In the derived theory, parents' experience a change that occurs in response to a shift in the parents' mental landscape. Mental landscape is a metaphor that refers to an individual's cognitive representation of their environment (Chaney, 2010; Ramsey, 2016). Mental landscape is the mental map that individuals use to understand and navigate their lives; it reflects an

individual's identity by referencing cultural values, personal preferences and geographic locations (Golledge, 1992).

We use three domains to describe parents' experiences while they wait for their child's diagnosis. We refer to these domains as the *three C's* of parent's mental landscape. The first *C* in the mental landscape is *child*. Parents' awareness of their child's behavior or functioning characterizes the *child* domain. The second "C" in the mental landscape is *connections*. Parents' experiences with friends, families, and professionals, etc. characterize the *connections* domain. The third "C" in the mental landscape is *competence*. Parents' concerns about fulfilling social roles characterize the *competence* domain.

The derived theory also incorporates the three "C's" of the mental landscape within each of the three transition phases. We present the STPT in Figure 1. The STPT references three transition phases: 1) initial awareness of the new landscape, 2) rites of passage in the new landscape, and 3) transformation of self.

Initial Awareness of Differences in the Landscape

In the source theory, the first phase of individuals' transition is separation from their culture of origin and identity, which leads to confusion and then awareness of the new landscape. In the derived theory, the first phase is parents' initial awareness of differences in their mental landscape. A description from *Notes from Autism's Edges* (MothersVox, 2010) describes a mother's recognition that she was entering new terrain: "The contours of the landscape were obscured by well-meaning professionals who would tell us that it was simply too early to know if there was anything seriously amiss… "(p. 5).

Child domain: Awareness of differences. In the initial awareness phase, parents notice differences in the child's behavior or development (Mulcahy & Savage, 2015; Ryan & Salisbury, 2012; Visootsak, Charen, Rohr, Allen, & Sherman, 2012). Isaacson (2009) describes how his wife's awareness of their child's differences began to worry them:

"When Rowan was eighteen months old, Kristin, as a psychologist trained in child development, began to be a little worried. Rowan wasn't pointing. Nor had he added any words to his limited

vocabulary…Nor did he show his toys to people as many infants do…Concerned that he might have some kind of speech delay, we contacted the state's early childhood intervention services and organized – responsible parents, you see – a weekly visit from a speech therapist" (p. 12)

Some parents make lists or articulate differences in their child's behavior (Fields-Meyer, 2011). Family or friends may trigger parents' concerns with comments or observations about the child's development (Cohen, 2011). False positives from newborn screening tests can also initiate parents' concerns about their child's development (Timmermans & Buchbinder, 2010).

Connections domain: Increasing distance. When a child does not have a diagnosis, parents may not know what to tell people about their child's behavior (Midence & O'Neill, 1999) which can result in disruptions in their connections with others (Maciver et al. 2011). Confusion surrounding how to respond to their child's behavior in social settings creates barriers to social connections in the new mental landscape. Some parents report their child's sensory patterns challenge the parent's ability to socialize. In her autobiography, *Seeing Ezra*, Cohen illustrates why she stopped going to social events and reaching out to her friends in a scene where she describes going to a birthday party with her child. When all the other children sing the birthday song, Cohen's child pulled her out of the house to get away from the sound. Cohen describes feeling childish, frustrated and alone as she looks in at the party from the outside, watching the other parents socialize while she stands outside with her child.

Couples may experience distance in their relationship when there is confusion about the child's behavior or when parents feel they do not share their concerns about their child (Midence & O'Neill, 1999). Parents report strained connections when friends or family members seem to not understand what the parent is going through (Farrugia, 2009; Midence & O'Neill, 1999). Parents also refer to challenges in their relationship with their child when efforts to be close to the child do not seem to be successful (Desai, Divan, Wertz, & Patel, 2012; Farrugia, 2009).

Competence domain: Seeking confirmation. Individuals' ability to see and portray themselves as competent is an important aspect of self-identity. For parents, this includes parenting in ways they believe in and that others validate (Christiansen, 1999). In the initial awareness phase, parents report

seeking confirmation with other parents or professionals to allay concerns about their child's behavior or development or to validate their observations (Tait, Fung, Hu, Sweller, & Wang, 2016). Issacson (2009) describes how his wife considered the decision to contact early childhood intervention as an act of "responsible parenting." Cohen (2011) described her response to therapists when they asked why she had her child evaluated; "I'm supposed to…to be a good mom, I have to help him" (p. 26).

Rites of Passage in the New Landscape

The "rites of passage in the new landscape" represents a liminal stage for parents. It is a period where parents' feel "betwixt and between" as they navigate the new landscape. In *Notes from Autism's Edge's* (MothersVox, 2010) a mother describes the sense of ambiguity she experienced before her child's developmental diagnosis:

> One of the first discoveries we made in this terrain is that things are not always what they appear to be, and, in fact, things are often quite the reverse of what one might expect. Most cultures have times or places of reversal or inversion – mirror worlds…. At such times, the king serves the peasant….the top is replaced by the bottom…Alice is in Wonderland…Everything is exactly as it usually isn't….How was I to know where I would come to reside…would be such a place" (MothersVox, 2010, pp. 8–9).

Child domain: Focus on concerns. In this phase, parents' awareness of differences in their child becomes a primary focus. When a parent suspects a potential diagnosis, they may describe a need to know more about the future, "I've caught myself asking….'will she be able to go to college? Will she be able to live on her own?'…. I want early intervention. I want to head off accidents…to be honest; I want more than a peek at the future. I want to control it. . . (Broski, 2003, p. 50).

Connections domain: Distance and isolation. During this phase, what begins as increasing distance in relationships may result in feeling isolated. Because parents' new mental landscape does not seem to match a "normal" way of life, parents can feel disconnected or isolated from their friends and family. Cohen (2011) describes her sense of isolation before her child's diagnosis: "I struggle to connect with parents who have only typical children. Sometimes I feel dumbly angry at them; sometimes I envy

them" (p. 137). Parents can also feel disconnected from community care systems since parents may not understand yet which direction to take (Farrugia, 2009). Other parents articulate a connection between their social identity and their child's diagnosis: "…one of the biggest things that I've found personally not having a diagnosis, is that I do not belong anywhere. That's something that I feel, with my child being undiagnosed" (Pelentsov, Fielder, & Esterman, 2015)

Competence domain: Searching for answers and experimentation. During the rites of passage phase, parents' often report experimenting with popular 'cures' or other remedies from public sources (Armstrong, 1995; Timmermans & Buchbinder, 2010). When parents experiment, perhaps it is their way of trying out strategies within the new mental landscape to learn its characteristics and limits. Parents' equate their search for answers about their child's condition with being a "good parent." Cohen (2011) describes searching for schools, dietary supplements, and new strategies to encourage her son to eat. She describes her need to always "be running, moving, searching, finding" (p. 122) as part of her quest to be a "good mother."

Transformation of self

The source concept reports that despite individuals finding themselves in an unfamiliar place, replete with ambiguity and loss, the third phase of cultural transition provides creative potential (Baird & Reed, 2015a). Individuals describe this experience as "standing on our own two legs" and having hope for the future. In the derived theory, parents' transformation of self occurs as they experience opportunities to grow and redefine themselves, their child and their family unit. A mother wrote about one such transformation experience. In the midst of a debilitating migraine, MothersVox reports her daughter demanded to watch a certain program on television. After marshaling all her energy to meet her child's demand MothersVox (2010) describes her "worst parenting moment" as evidence of progress:

> There. Your show is on. Watch it. And I do not want to hear another word from you, young
>
> lady…And then I realized I'd said something I'd never said in all the years I'd been parenting her
>
> – I told her to stop talking…Hallelujah---I can be just as bad a parent as the next parent and she'll
>
> survive. I never thought I'd be proud of my worst moment. But therein lies the secret…what's

bad is bad, what's good is bad, and now, farther into the journey, even what's bad can be good. (p. 9)

Child domain: Recognizing possibilities. In the early awareness phase, parents often itemize their child's weaknesses or compare their child to other children. Over time, these behaviors appear to diminish (Isaacson, 2009). Parents report benefits to not comparing their child with other children and recognize that every child is different. Parents also seem to be able to spend more time enjoying their children and less time thinking about problems (Lewis, Skirton, & Jones, 2010). Parents describe finding new possibilities regarding their child's differences (Carmichael, Tsipis, Windmueller, Mandel, & Estrella, 2015) Carmichael (2015) reported that parents spoke with pride about how well their child coped with medical procedures. In his autobiography, Fields-Meyer (2009) describes watching his three-year-old son walk ahead of him on a private road. He describes feeling fearful about his son's lack of awareness that the two were no longer side by side. But Fields-Meyer reports the experience was also a moment of recognition of his child's strengths. His son was confident, and he could follow his own path.

Connections domain: Improved relationships. Parents describe gradually building a network of friends that include parents of children with special needs, and some parents report developing positive relationships with providers. These parents said they felt regarded as active participants in the diagnostic process or perceived as an expert in their child's condition. Parents also report gaining support from health visitors or early intervention providers.

Competence domain: Being empowered. Parents of children with unidentified differences report high motivation to obtain a diagnosis when their child is young (seeking confirmation), but their desire to confirm a diagnosis often fades over time (Rosenthal et al., 2001). **"**The nights I wake up at 3:00 in the morning wondering what kind of condition this might have gotten fewer and farther between….I spend more time in the present (Broski, 2003, p. 51). Parents also describe gaining the skills they need to get things done for their child. Parents report learning how to get appointments and services for their children "I've had to learn to be that sort of person (Lewis et al., 2010).

Fields-Meyer (2011) describes his thoughts after a family therapist suggests he needs time to grieve for the child his son did not turn out to be.

"I realize something: I am not grieving. In fact, I feel no instinct to grieve...I'm not going to grieve. I am sure she thinks I am deluding myself. I know the truth. The one statement (that he needs time to grieve) has done more good for me than all the play therapy, than all the listening, all the advice. It has forced me to find and bring out something within myself. I feel full of love – for the boy who lines up the dinosaurs on the porch...My answer will never be to mourn. It will be to pour love on my son, to celebrate him, to understand, to support him, and to follow his lead.

Construction of a model case

Walker and Avant (2010) recommend the use of a model case to illustrate defining attributes of the derived theory. We present the following case based on the authors' clinical and personal experiences. Figure 2. Includes codes for this case study that correspond the STPT.

Shannon is the mother of two-year-old Willa. When Willa was a few weeks old, Shannon became aware that Willa's development did not match the developmental milestone charts on early childhood websites (A). When Willa is six months old, Shannon asks their pediatrician about Willa's development (C). Their pediatrician suggests a genetic condition might explain why Willa is slow meeting developmental milestones. The pediatrician recommends Shannon make an appointment for Willa to see a pediatric geneticist. During the next year and a half, numerous doctors would order tests and evaluate Willa's development. Shannon takes Willa to the neighborhood playground but feels disconnected from other parents because Willa needs more assistance than other children, which leaves less time for Shannon to socialize (B). Several nights a week Shannon is up late searching for information on the Internet that might explain Willa's development (D, E). Shannon works in an office during the day and spends evenings taking care of Willa. Shannon and Willa participate in a gymnastics program one night a week.

Willa's medical history documents her development, specialist recommendations, and test results. Shannon's journey may receive little or no attention from professionals, despite the impact this transition (of having a child that may have a developmental diagnosis) has on mother and child.

Shannon feels caught between relief and concern when genetic tests do not detect a degenerative condition, but the geneticist recommends returning to the clinic for more testing next year because advances in technology may be able to identify a condition at that time. Shannon decides to try other activities with Willa in the community(F). Some of the programs don't' feel like a good match for Shannon. Shannon feels disconnected from other parents at a community program when parents seem competitive about their children's skills, but she feels a sense of belonging when her daughter participates in group activities that focus on social skills rather than competition. Shannon discovers that Willa enjoys programs that have a music focus (G). Shannon decides to take Willa to a coffee shop where a couple of Shannon's musician friends play the guitar and sing (H). Shannon occasionally senses others judge her parenting skills, but Shannon also knows that the routines she develops with her daughter meet both their needs (I).

Discussion

As parents become aware that their child is not developing as they expected, and while they await a diagnosis that might lead them to a better understanding of their child, an unanticipated transition often begins -- from being a parent to becoming the parent of a child with a developmental condition. Parents' unanticipated journey frequently involves developing awareness of changes in their mental landscape. Learning to navigate new terrain can be uncomfortable for parents, but the rugged path may also provide unexpected opportunities for parents to develop a stronger sense of themselves as parents. As parents gain insights, perceptions of the possibilities for their families emerge.

Perspective of Parents' Experiences

Research on parents' experiences before their child receives a developmental diagnosis tends to focus on parents' experience with the diagnostic process, and uncertainty surrounding their child's development. This focus inadvertently reinforces a medical-model perspective. Parents with concerns

about their child's development have experiences other than the *diagnostic journey* that contribute to the family and child's overall strengths and development.

Ecological models of disability indicate that disability is a function of the interaction of the individual and the environment, rather than residing in the individual (Brandt & Pope, 1997; (Schalock et al., 2009). However, research and interventions that focus on parents' anxiety or stress associated with having a child with a developmental diagnosis suggest limitations reside within the family. To develop a complete understanding of parents' experiences while they wait for their child's diagnostic process, we must consider alternatives to describing parents' experiences from a deficit-based perspective. We must look beyond the obvious stress and anxiety to consider parents' strengths.

Parents who wait for a diagnosis develop resilience and insights about their child and themselves (Fields-Meyer, 2011). Parents who meet with multiple providers before their child's diagnosis may develop confidence in their own observations when they learn there is no single way "experts" view children (Cohen, 2011). Parents' experiences of awareness of their child's differences, or awareness about their desire to fulfill their parenting role, for example, may be steps toward mindfulness. Mindfulness is commonly defined as being attentive and aware of what is taking place in the present (Brown & Ryan, 2003). Over time, some parents may begin to become aware of the present moment "without judgment"; experiences that may explain why some parents' transformational experiences while they wait for their child's diagnosis.

As parents learn to adapt to the new "landscape," they may develop fresh ways to think about old problems like the creators of "SensoryTreat," (Steinberg, 2014) a technology platform that includes a mobile application designed to empower parents to plan for sensory breaks or treats for children with strong sensory preferences. In this case, a combination of parents' strengths and a recognition of their child's preferences provide an opportunity for the parents to gain insight and connect with other families discovering successful strategies.

Parents of children with an autism diagnosis in Kansas City, Missouri have been finding new ways to use their strengths and gain transformative insights about their identity. Parents from varied

walks of life recognize the humor and humanity in their families' journeys as they perform stand up comedy routines about their families' stories (Camp Encourage, 2016). These parents' demonstrate that when we expand our perspective to see a more realistic and holistic view of families, we will discover new opportunities to support families; employing methods that best meet their needs and match their authentic experiences.

Use Authentic Family-Centered Services

Although providers typically claim "we've worked with families for 25 years, and we've always been family-centered" (Dunst, 2002, p. 1), family-centered practice is more often a slogan than a practice (D. B. Bailey et al., 2006). Family-centered service is a strong foundational philosophical perspective that organizations and providers use to deliver services to children and families (Workgroup on Principles and Practices in Natural Environments, 2008a) and should be the primary perspective used by diagnostic evaluation teams. Examples of family-centered activities include: identifying preferred activities that families engage in to build on their strengths and interests; identifying families' strengths and competences; building on formal and informal supports that match parents and children's interests; and involving families in discussions about what they want and what they enjoy (Workgroup on Principles and Practices in Natural Environments, 2008b).

Support Families During Transitional Periods

The diagnostic process focuses almost exclusively on the child. However, parents' have experiences throughout the diagnostic process that involve constructing new images of their children, themselves and their lives (Scorgie et al., 2004b). Parents often associate a potential developmental diagnosis with images of disability that have formed through societal portrayal and beliefs about disability (Scorgie & Sobsey, 2000). The Information parents receive at this time shapes images parents create of their child (Taanila, Jarvelin, & Kokkonen, 1998). Some parents live in a state of tension created by a need to construct hopeful child and life-trajectory images in the midst of pessimistic reports about their child (Steele, 2000). The need to balance joy and sorrow may cause parents to limit thoughts of the future, instead of focusing on the present (Kearney & Griffin, 2001). Not only do parents' experiences

surrounding diagnosis influence image-making (Scorgie et al., 2004b) reports and feedback from hospital personnel, agency workers, educators, extended family members, and friends can shape parents' response to their child's diagnosis.

Numerous transition theories contribute to our understanding of how families experience change over time. While many of the "big picture" concepts about transition contribute to our understanding of parents' transition, some traditional transition theories are not family-centered. In order to accurately portray the situation for families waiting on a developmental diagnosis, some family change theories require updating. For example, Meleis (2015) indicates a change in health or an illness, such as autism can trigger transition. However, many developmental diagnoses, including autism, do not represent a change in the child's *health*. Rather, the diagnosis represents *how health care or education systems classify the child's functioning*. While it may appear to be a minor incongruity, it is important to frame developmental diagnosis accurately so that professionals do not inadvertently imply a child with a developmental disability is "sick" or needs to be cured.

The PTPM (Sobsey and Scorgie, 2004) describe how parent's transitional experiences may result in parental transformation. Transformational experiences are often associated with mindfulness (Rothwell, 2006; Schoeberlein, D. R., & Sheth, 2009; Shapiro, Carlson, Astin, & Freedman, 2006). Definitions generally describe mindfulness as paying attention to the present moment on purpose and without judgment (Brown & Ryan, 2003; Kabat-Zinn, 2006) Mindfulness appears to influence individual experiences with changes that lead to shifts in how people view themselves and the world. Some researchers suggest that parents of children with developmental conditions engage in mindfulness practice (Hwang, Kearney, Klieve, Lang, & Roberts, 2015).

We believe there are important similarities between the PTPM (Scorgie et al., 2004) and STPT. For example, both theories recognize the potential for parent transformation. The PTPM describes parent's transformation *after* their child's diagnosis; in contrast, STPT focuses on parents' transformation *before* their child's diagnosis. The PTPM (Scorgie et al., 2004b) operationalizes the internal principles of parents' transformation which are bonding, image-making, meaning-making, and choice-making, while

the STPT describes a process of parents transformation that focuses on three domains of parents lived experiences which we describe as the child, connections and competence domains. Additionally, STPT uses the metaphor of "mental landscape" to describe parents' awareness of a change in their cultural terrain.

Practice and Research implications

Longitudinal research on parents' experiences surrounding their child's developmental diagnosis is complex, multifaceted, and frequently misunderstood (Pedersen, Crnic, Baker, & Blacher, 2015). We propose the STPT: may be used to better understand parents' experiences while they wait for their child's diagnosis; contributes to the call for research to better understand parents' experiences (Crane et al., 2015) and provides an initial framework to assist providers in recognizing positive aspects of the pre-diagnosis journey. The STPT incorporates the concept of liminality, which provides a possible explanation for how and why parents experience ambiguity in the midst of transition.

Practice and research implications include use of the STPT to consider alternate explanations to reframe parents' experiences. Instead of framing discussions around, "what is wrong with your child?" we can begin to explore all the possibilities for the family with the characteristics a particular diagnosis might offer. Instead of emphasizing the rigid, ritualistic patterns of behavior, using STPT, we might explore ways the family organizes daily routines to include the child's tendencies, or we might discuss what areas the parents enjoy having routines.

Practitioners, researchers and parents may also use the theory to eliminate descriptions that emphasize deficit-based perspectives and which perpetuates the idea that the child or family needs to be "cured" or "fixed." The STPT provides the opportunity to acknowledge and gain insights about all aspects of a child's personality, which resonates with the parents' experiences with the child. Additionally, our theory may be used to guide the development of family-centered supports before a child receives a diagnosis, a time during which families frequently have unmet needs.

Limitations

We recognize several limitations of this theory. First, most research on parents' experiences before their child's developmental diagnosis focuses on parents' experiences of the diagnostic process and not on parents' lived experiences. Secondly, much of the existing research on parents' experiences before their child's diagnosis emphasizes a deficit-based perspective. As a result, we conducted our literature review across disciplines that could illuminate parents' experiences. Finally, there is a need to validate and test the STPT with parents. Use of focus groups and interviews with parents will make it possible to understand how to strengthen the theory. Future studies might include developing resources that focus on parents' competence while they wait for their child's developmental diagnosis.

Conclusion

Improving support for children is best accomplished through family-centered services that recognize families' strengths. The STPT extends the findings of Scorgie, Wilgosh, & Sobsey (2004) that parents'experiences after their child's diagnosis may be associated with personal transformation. Some families' may not receive a diagnosis for several years, while other families may never receive a diagnosis.

The STPT provides an alternate explanation for providers and parents to exploresupports the concepts of strengths-based approaches and family-centered practice. While we recognize that waiting for a developmental diagnosis generates uncomfortable feelings of uncertainty, a theory of transformation provides an opportunity for parents and providers to discuss the future in a realistic yet hopeful manner.

References

Armstrong, D. (1995). The rise of surveillance medicine. *Sociology of Health and Illness, 17,* 393–404. https://doi.org/BA

Bailey, D., Jr., Bruder, M., Hebbeler, K., Carta, J., Defosset, M., Greenwood, C., … Barton, L. (2006). Recommended outcomes for families of young children with disabilities. *Journal of Early Intervention, 28*, 227–251. https://doi.org/10.1177/105381510602800401

Baird, M. B. (2012). Well-being in refugee women experiencing cultural transition. *Advances in Nursing Science, 35*, 249–263. https://doi.org/doi: 10.1097/ANS.0b013e31826260c0

Baird, M. B., & Reed, P. G. (2015). Liminality in cultural transition: Applying ID-EA to advance a concept into theory-based practice. *Research and Theory for Nursing Practice, 29*, 25–37. https://doi.org/10.1891/1541-6577.29.1.25

Becker, G. (1997). *Disrupted lives: How people create meaning in a chaotic world*. Berkley, CA: University of California Press.

Boniwell, I. (2008). *Positive psychology in a nutshell: A balanced introduction to the science of optimal functioning*. Milton Keynes, United Kingdom: Open University Press.

Bronfenbrenner, U. (1979). *The ecology of human development experiments by nature and design*. Cambridge, MA: Harvard University Press.

Broski, J., & Dunn, W. (2018). Fostering insights: A strengths-based theory of parental transformation. *Journal of Child and Family Studies, 27*, 1275–1286. https://doi.org/10.1007/s10826-017-0964-5

Desai, M. U., Divan, G., Wertz, F. J., & Patel, V. (2012). The discovery of autism: Indian parents' experiences of caring for their child with an autism spectrum disorder. *Transcultural Psychiatry, 49*, 613–637. https://doi.org/10.1177/1363461512447139

Dunst, C. J., Bruder, M. B., & Espe-Sherwindt, M. (2013). Family Capacity-Building in Early Childhood Intervention: Do Context and Setting Matter? *School Community Journal, 24*, 37–48. http://www.adi.org/journal/2014ss/SCJSpringSummer2014.pdf#page=37

Farrugia, D. (2009). Exploring stigma: Medical knowledge and the stigmatization of parents of children diagnosed with autism spectrum disorder. *Sociology of Health & Illness, 31*, 1011–1027. https://doi.org/10.1111/j.1467-9566.2009.01174.x

Fields-Meyer, T. (2011). *Following Ezra: What one father learned about Gumby, otters, autism, and love from his extraordinary son* [Kindle version]. New York, NY: Penguin Group US.

Golledge, R. (1991). Cognition of physical and built environments. In T. Garling & G. Evans (Eds.), *Environment, cognition, and action :An integrated approach* (pp. 35–62). New York, NY: Oxford University Press, USA.

Guerriere, D. N., McKeever, P., Llewellyn-Thomas, H., & Berall, G. (2003). Mothers' decisions about gastrostomy tube insertion in children: Factors contributing to uncertainty. *Developmental Medicine and Child Neurology, 45*(7), 470–476. https://doi.org/10.1111/j.1469-8749.2003.tb00942.x

Ho, H. S., Yi, H., Griffiths, S., Chan, D. F., & Murray, S. (2014). "Do It yourself" in the parent-professional partnership for the assessment and diagnosis of children with autism spectrum conditions in Hong Kong: A qualitative study. *Autism, 18*, 832–844. https://doi.org/10.1177/1362361397012003

Howlin, P., & Moore, A. (1997). Diagnosis in autism: A survey of over 1200 patients in the UK. Autism: *The International Journal of Research and Practice, 1,* 135–162. https://doi.org/10.1177/1362361397012003

Hwang, Y.-S., Kearney, P., Klieve, H., Lang, W., & Roberts, J. (2015). Cultivating mind: mindfulness interventions for children with autism spectrum disorder and problem behaviors, and their mothers. *Journal of Child and Family Studies, 24*, 3093–3106. https://doi.org/10.1007/s10826-015-0114-x

Kabat-Zinn, J. (2006). Mindfulness-based interventions in context: Past, present, and future. Clinical Psychology: *Science and Practice, 10*, 144–156. https://doi.org/10.1093/clipsy.bpg016

Kearney, P. M., & Griffin, T. (2001). Between joy and sorrow: Being a parent of a child with developmental disability. *Journal of Advanced Nursing, 34*, 582–592. https://doi.org/10.1046/j.1365-2648.2001.01787.x

Kleiber, D. A., Hutchinson, S. L., & Williams, R. (2002). Leisure as a resource in transcending negative life events: Self-protection, self-restoration, and personal transformation. *Leisure Sciences, 24,* 219–235. https://doi.org/10.1080/01490400252900167

Kralik, D., Visentin, K., & van Loon, A. (2006). Transition: A literature review. *Journal of Advanced Nursing, 55,* 320–329. https://doi.org/10.1111/j.1365-2648.2006.03899.x

Kuo, D. Z., Houtrow, A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M., & Neff, J. M. (2012). Family-centered care: Current applications and future directions in pediatric health care. *Maternal and Child Health Journal, 16*, 297–305. https://doi.org/10.1007/s10995-011-0751-7

Laszloffy, T. A. (2002). Rethinking family development theory: Teaching with the systemic family development (SFD) model. *Family Relations, 51*, 206–214. https://doi.org/10.1111/j.1741-3729.2002.206098.x

Lewis, C., Skirton, H., & Jones, R. (2010). Living without a diagnosis: The parental experience. *Genetic Testing and Molecular Biomarkers, 14*, 807–815. https://doi.org/10.1089/gtmb.2010.0061

Maciver, D., Owen, C., Flannery, K., Forsyth, K., Howden, S., Shepherd, C., & Rush, R. (2011). Services for children with developmental co-ordination disorder: The experiences of parents. *Child: Care, Health and Development, 37,* 422–429. https://doi.org/10.1111/j.1365-2214.2010.01197.x

Mansell, W., & Morris, K. (2004). A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service: Access to information and use of services. *Autism, 8*, 387–407. https://doi.org/10.1177/1362361304045213

McCubbin, H. I., & Patterson, J. M. (1983). The family stress process: The double ABCX model of adjustment and adaptation. *Marriage & Family Review, 6,* 7–37. https://doi.org/10.1300/J002v06n01_02

Meleis, A. (2015). Transitions theory. In M. Smith & M. Parker (Eds.), *Nursing theories and nursing practice* (4th ed., pp. 361–380). Philadelphia, PA: F.A. Davis Company.

Midence, K., & O'Neill, M. (1999). The experience of parents in the diagnosis of autism: A pilot study. *Autism,* 273–285. https://doi.org/10.1177/1362361399003003005

Millenson, M. L., DiGioia, A. M., III, Greenhouse, P. K., & Swieskowski, D. (2013). Turning patient-centeredness from ideal to real: Lessons from 2 success stories. *The Journal of Ambulatory Care Management, 36*, 319–334. https://doi.org/10.1097/JAC.0b013e3182a3e76dPMID:24402074

MothersVox. (2010). Notes from autism's edges. *In Gravity pulls you in: Perspectives on parenting children on the autism spectrum.* K. A. Forman & Vicki (Eds.) (pp. 5–10). Bethesda, MD.

Mulligan, J., MacCulloch, R., Good, B., & Nicholas, D. B. (2012). Transparency, hope, and empowerment: A model for partnering with parents of a child with autism spectrum disorder at diagnosis and beyond. *Social Work in Mental Health, 10,* 311–330. https://doi.org/10.1080/15332985.2012.664487

Page, M. C., Fedele, D. A., Pai, A. L. H., Anderson, J., Wolfe-Christensen, C., Ryan, J. L., & Mullins, L. L. (2012). The relationship of maternal and child illness uncertainty to child depressive symptomatology: A mediational model. *Journal of Pediatric Psychology, 37*, 97–105. https://doi.org/10.1093/jpepsy/jsr055

Pedersen, A. L., Crnic, K. A., Baker, B. L., & Blacher, J. (2015). Reconceptualizing family adaptation to developmental delay. *American Journal on Intellectual and Developmental Disabilities, 120*, 346–370. https://doi.org/10.1352/1944-7558-120.4.346

Pelentsov, L. J., Fielder, A. L., & Esterman, A. J. (2016). The supportive care needs of parents with a child with a rare disease: A qualitative descriptive study. *Journal of Pediatric Nursing, 31*, 207–218. https://doi.org/10.1016/j.pedn.2015.10.022

Pope, A., & Brandt, E. (1997). *Enabling America: Assessing the role of rehabilitation science and engineering* (1st ed.). Washington, D.C.: National Academies Press.

Ramsey, W. (2016). Untangling two questions about mental representation. *New Ideas in Psychology, 40*, 3–12. https://doi.org/10.1016/j.newideapsych.2015.01.004

Rosenthal, E. T., Biesecker, L. G., & Biesecker, B. B. (2001). Parental attitudes toward a diagnosis in children with unidentified multiple congenital anomaly syndromes. *American Journal of Medical Genetics, 103,* 106–114. https://doi.org/10.1002/ajmg.1527

Rothwell, N. (2006). The different facets of mindfulness. Journal of Rational-Emotive & Cognitive-*Behavior Therapy, 24*, 79–86. https://link.springer.com/article/10.1007/s10942-006-0023-4

Ryan, S., & Salisbury, H. (2012). "You know what boys are like": Pre-diagnosis experiences of parents of children with autism spectrum conditions. *The British Journal of General Practice: The Journal of the Royal College of General Practitioners, 62*, 378–383. https://doi.org/10.3399/bjgp12X641500

Saleebey, D. (1996). The strengths perspective in social work practice: Extensions and cautions. *Social Work, 41*, 296–305. https://doi.org/10.1093/sw/41.3.296

Schalock, R. L., Borthwick-Duffy, S. A., Bradley, V. J., Buntinx, W. H. E., Coulter, D. L., Craig, E. M., … Yeager, M. H. (2010*). Intellectual disability: Definition, classification, and systems of supports* (11th ed.). Washington, D.C.: American Association on Intellectual and Developmental Disabilities.

Schoeberlein, D. R., & Sheth, S. (2009). *Mindful teaching and teaching mindfulness: A guide for anyone who teaches anything*. Sommerville, MA: Wisdom Publications.

Scorgie, K., & Sobsey, D. (2000). Transformational outcomes associated with parenting children who have disabilities. *Mental Retardation, 38*, 195–206. https://doi.org/10.1352/0047-6765(2000)0382.0.CO;2

Scorgie, K., Wilgosh, L., & Sobsey, D. (2004). The experience of transformation in parents of children with disabilities: Theoretical considerations. *Developmental Disabilities Bulletin, 32*, 84–110. https://eric.ed.gov/?id=EJ848193

Shapiro, S. L., Carlson, L. E., Astin, J. A., & Freedman, B. (2006). Mechanisms of mindfulness. *Journal of Clinical Psychology, 62*, 373–386. https://doi.org/10.1002/jclp.20237

Siklos, S., & Kerns, K. A. (2007). Assessing the diagnostic experiences of a small sample of parents of children with autism spectrum disorders. *Research in Developmental Disabilities, 28*(1), 9–22. https://doi.org/10.1016/j.ridd.2005.09.003 PMID:16442261

Steinberg, O. (2014). Sensory Treat: Making sensory home programs fun & easy. Retrieved from https://sensorytreat.com/#about

Stewart, J. L., & Mishel, M. H. (2000). Uncertainty in childhood illness: A synthesis of the parent and child literature. *Scholarly Inquiry for Nursing Practice, 14*, 299-319;

Taanila, A., Jarvelin, M.-R., & Kokkonen, J. (1998). Parental guidance and counselling by doctors and nursing staff: parents' views of initial information and advice for families with disabled children. *Journal of Clinical Nursing, 7*, 505–511.

Tait, A. R., Voepel-Lewis, T., Malviya, S., & Philipson, S. J. (2005). Improving the readability and processability of a pediatric informed consent document: Effects on parents' understanding. *Archives of Pediatrics & Adolescent Medicine, 159*(4), 347–352. https://doi.org/10.1001/archpedi.159.4.347

Tait, K., Fung, F., Hu, A., Sweller, N., & Wang, W. (2016). Understanding Hong Kong Chinese families' experiences of an autism/ASD diagnosis. *Journal of Autism and Developmental Disorders, 46*(4), 1164–1183. https://doi.org/10.1007/s10803-015-2650-z

The Joint Commission. (2010). Advancing effective communication, cultural competence, and patient- and family-centered care: A roadmap for hospitals. Oak Terrace, IL: The Joint Commission. Retrieved from https://www.jointcommission.org/roadmap_for_hospitals/

Timmermans, S., & Buchbinder, M. (2010). Patients-in-waiting: Living between sickness and health in the genomics era. *Journal of Health and Social Behavior, 51*, 408–423. https://doi.org/10.1177/0022146510386794

Tomlinson, M., Yasamy, M. T., Emerson, E., Officer, A., Richler, D., & Saxena, S. (2014). Setting global

    research priorities for developmental disabilities, including intellectual disabilities and autism.

    Journal of Intellectual Disability Research, 58, 1121–1130. https://doi.org/10.1111/jir.12106

Turner, V. (1986). Betwixt and between: The liminal period in rites de passage. In L. C. Mahdi, S. Foster,

    & M. little (Eds.), *The forest of symbols* (pp. 93–111). Ithaca, NY: Cornell University Press.

van Gennep, A. (1960). *The rites of passage*. New York: Routledge.

Vargo, F. E. (2015). *Neurodevelopmental disorders: A definitive guide for educators*. New York NY: W.

    W. Norton & Company.

Visootsak, J., Charen, K., Rohr, J., Allen, E., & Sherman, S. (2012). Diagnosis of fragile X syndrome: a

    qualitative study of African American families. *Journal of Genetic Counseling, 21*, 845–853.

Walker, L., & Avant, K. (2005*). Strategies for theory construction in nursing*. Upper Saddle River, NJ:

    Pearson.

West, C., Stewart, L., Foster, K., & Usher, K. (2012). The meaning of resilience to persons living with

    chronic pain: an interpretive qualitative inquiry. *Journal of Clinical Nursing, 21*, 1284–1292.

Wilgosh, L., Nota, L., Scorgie, K., & Soresi, S. (2004). Effective life management in parents of children

    with disabilities: A cross-national extension. *International Journal for the Advancement of*

    Counselling, 26, 301–312.

Workgroup on Principles and Practices in Natural Environments. (2008). Seven Key Principles: Looks

    Like/Doesn't Look Like. Retrieved from

    http://ectacenter.org/~pdfs/topics/families/AgreedUponPractices_FinalDraft2_01_08.pdf

Workgroup on Principles and Practices in Natural Environments, OSEP TA Community of Practice: Part

    C Settings. (2008). Agreed upon practices for providing services in natural environments.

    Retrieved from

    http://ectacenter.org/~pdfs/topics/families/AgreedUponPractices_FinalDraft2_01_08.pdf

World Health Organization. (2013). *Autism spectrum disorders & other developmental disorders*.

    Geneva, Switzerland.

Broski and Dunn's
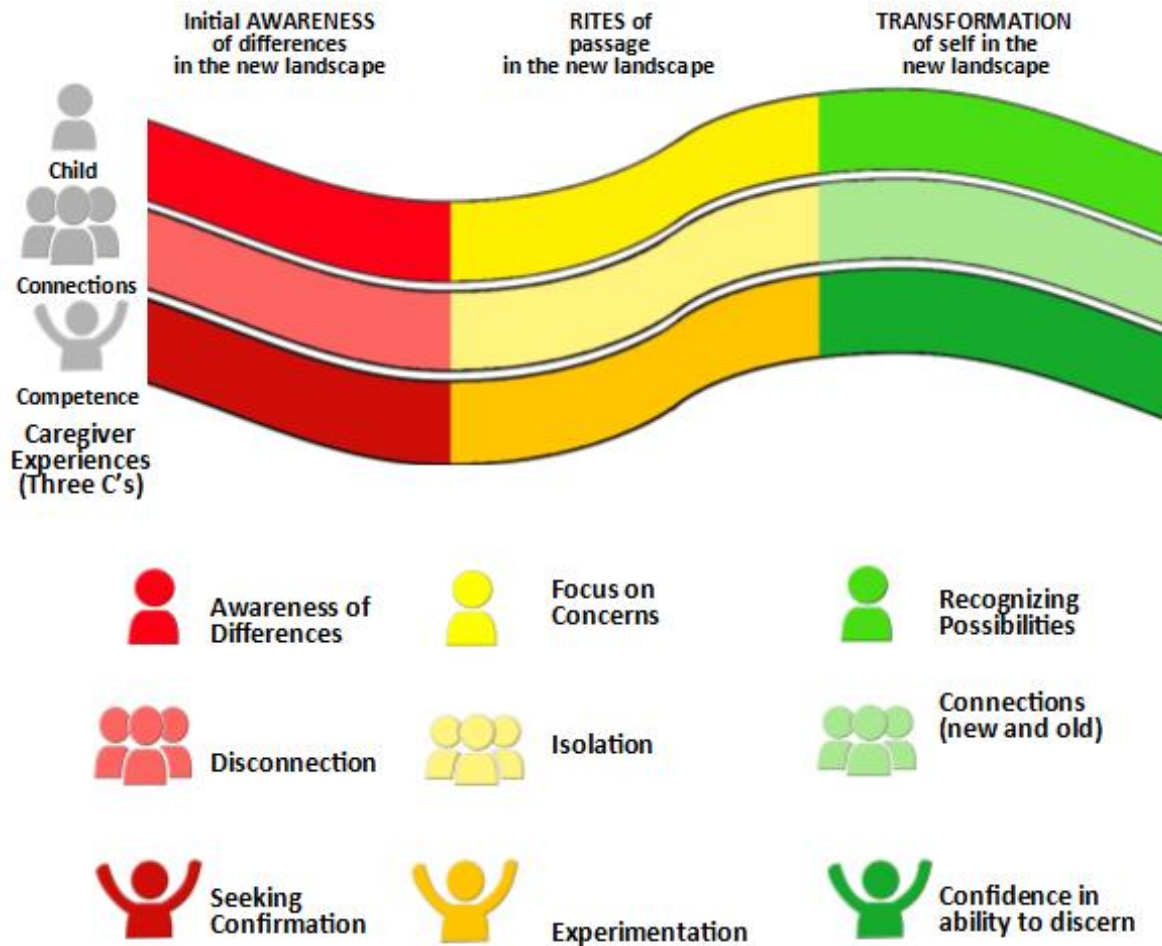# Strength's Based Theory of Parental Transformation

Figure 1. Broski and Dunn's Strengths-Based Theory of Parental Transformation
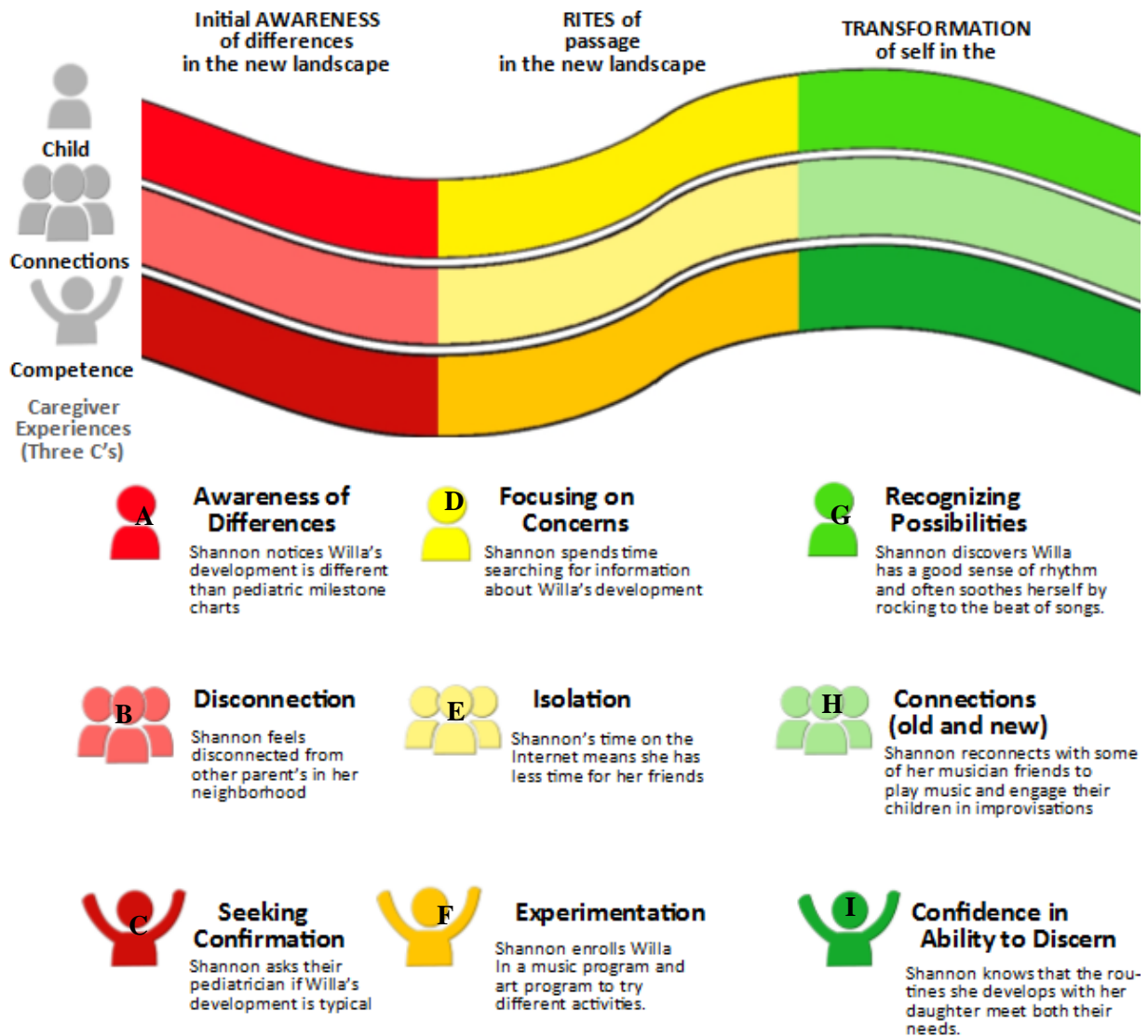
Figure 2. A Case Study using Broski and Dunn's STPT

Appendix B: Comprehensive Exam Two Study Documents - Evaluation of the Strengths-Based

Theory of Parental Transformation

Volunteers needed
for Study
STRENGTHS-BASED
THEORY OF CAREGIVER
TRANSFORMATION

Parents of individuals with an autism or other developmental diagnosis needed for study on care provider transformation. Our research seeks to understand caregivers' experiences surrounding their child's diagnosis. We are recruiting caregivers of children with a developmental condition such as autism or other neurodevelopmental condition or suspected of having autism or similar condition. Participation will include completing an online survey.

Parent Survey

http://tinyurl.com/KUMCParentSurvey

Online Informed Consent Form

Caregiver Recruitment Letter and Informed Consent

You are being asked to consider a research study titled "Caregiver Transformation" led by Dr. Winnie Dunn and Julie Broski because you are a caregiver of a child with a developmental diagnosis. We are recruiting research participants to help us understand parents' transition experience surrounding their child's developmental diagnosis. Participation involves completing a survey that will take about 20 minutes. There are no personal benefits or risks to participating in this study. Participation is voluntary, and you can stop taking the survey at any time. If you have any questions, please contact Julie Broski at jbroski@kumc.edu. If you have questions about the rights of research participants, you may contact the KUMC Institutional Review Board (IRB) at (913) 588-1240 or humansubjects@kumc.edu. If you are interested in participating in this study, continue to the next page to begin taking the survey. Thank you!

Data Collection Forms
Demographic Survey

Does your child have a diagnosis of an autism spectrum disorder?

Yes, my child received this diagnosis by a health care professional or educator. (1)

No, my child does not have this diagnosis. (2)

Does your child have a diagnosis of Asperger Syndrome?

Yes, my child received this diagnosis by a health care professional or educator. (1)

No, my child does not have this diagnosis. (2)

Does your child have an intellectual disability?

Yes, my child received this diagnosis by a health care professional or educator. (1)

No, my child does not have this diagnosis. (2)

Does your child have a diagnosis of pervasive developmental disorder not otherwise specified (PDD-

NOS)?

Yes, my child received this diagnosis by a health care professional or educator. (1)

No, my child does not have this diagnosis (2)

Does your child have a neuro-developmental diagnosis that was not quickly apparent to the family prior

to an appointment with a healthcare or education professional?

Yes, my child received a neuro-developmental diagnosis by a health care professional or

educator.

No, my child does not have this diagnosis. (2)

What was your child diagnosed 3 or more years ago?

Yes (1)

No (2)

Is your child 7 years of age or older?

Yes (1)

No (2)

What is your year of birth? _____

What is the highest level of school you have completed or the highest degree you have received?

Less than high school degree (1)

High school graduate (high school diploma or equivalent including GED) (2)

Some college but no degree (3)

Associate degree in college (2-year) (4)

Bachelor's degree in college (4-year) (5)

Master's degree (6)

Doctoral degree (7)

Professional degree (JD, MD) (8)

Are you Spanish, Hispanic, or Latino or none of these?

Yes (1)   None of these (2)

Are you Spanish, Hispanic, or Latino?

Spanish (1)   Hispanic (2)   Latino (3)

Choose one or more races that you consider yourself to be:

White (1) Black or African American (2) American Indian or Alaska Native (3) Asian (4)

Native Hawaiian or Pacific Islander (5)   Other (6) _____

What is your sex?

Male (1)   Female (2)

Information about income is very important to understand. Please indicate the answer that includes your

entire household income in (previous year) before taxes.

Less than $10,000 (1) $10,000 to $19,999 (2) $20,000 to $29,999 (3) $30,000 to $39,999 (4)

$40,000 to $49,999 (5) $50,000 to $59,999 (6) $60,000 to $69,999 (7) $70,000 to $79,999 (8)

$80,000 to $89,999 (9) $90,000 to $99,999 (10) $100,000 to $149,999 (11)

$150,000 or more (12)

What is your ZIP code? _____

Which of the following best describes your sexual orientation?

     Heterosexual (straight) (1)   Homosexual (gay) (2)   Bisexual (3)

     Other (4)   Prefer not to say (5)

Are you now married, widowed, divorced, separated or never married?

     Married (1)   Widowed (2)   Divorced (3)   Separated (4)   Never

     Married (5)

How many people are living or staying at this address?

     1 (1)   2 (2)   3 (3)   4 (4)   5 (5)   6 (6)   More than 6 (7)

Which statement best describes your current employment status?

     Salaried or hourly employee   Self-employed   Retired   Not employed

     Prefer not to answer

Please tell us about your child

What is your child's primary diagnosis?

     Intellectual disability   Autism Spectrum Disorder   Asperger Syndrome

     PDD-NSS   Other _____

Does your child have other conditions/diagnosis? If so please list below:_____

Who diagnosed your child's condition?

     A health care professional   An educator   Other

Does your child require on going medical care?

     My child receives medical care more than 1 time every 4 months

   My child receives medical care about 1 time every 6 months

     My child receives medical care about 1 time (or less) every year

Becoming the caregiver of a child with a developmental condition often involves an unanticipated transition as caregivers become aware that their child's development is different than what they expected. The purpose of this study is to learn about caregivers' perspectives about the transition process while they wait for their child's developmental diagnosis. Transition is a universal experience; a transition is not a single event, but is best described as an inner re-orientation to changes in one's life. This graphic describes how different aspects of caregivers' experiences while they wait for their child's developmental diagnosis. Stage 1 is in green, it represents caregiver awareness. Stage 2 is light purple, it represents caregiver passage, or being "betwixt and between" stages, neither here nor there. Stage 3 is blue, it represents caregiver transformation. The grey box represents experiences that you would not consider part of caregivers' transformation while they wait for their child's diagnosis.

Part One: Assign Caregiver Statement into Transition Categories

In the survey that follows, there are 81 statements caregivers may (or may not) think or say. Please reflect on your personal experience and select which part of caregiver transition fits best with each statement. You will select from the following categories: Stage 1 - Awareness, Stage 2 - Passage, Stage 3 – Transformation, and Not Part of Caregivers' Experience
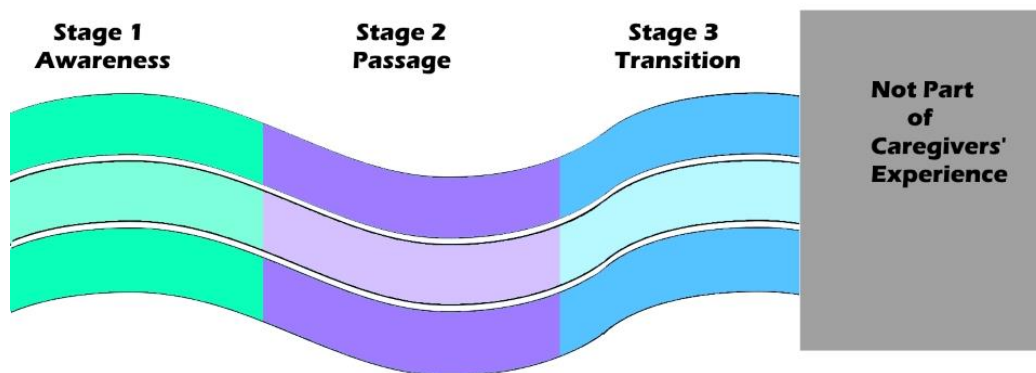
1. I keep trying new things, but I'm not sure if I'm doing the right things to help my child.

2. I don't really think about the future, I'm too busy trying to figure out what to do next.

3. I spend most of my time trying to help my child, even if it means I'm going to run myself ragged.

4. My child's behavior makes it difficult to maintain friendships.

5. I feel like I'm losing time if I'm not doing as much as I can to help my child.

6. I wonder if we can find a babysitter who can care for our child.

7. I feel like I'm trying to find my way.

8. Sometimes I feel angry with parents of typical children.

9. Sometimes I will do something different just to see if it will help our family.

10. I don't know what to tell people about my child's behavior.

11. Sometimes I feel isolated from my friends.

12. I'm not able to spend as much time with my friends because of my child.

13. I feel lost.

14. Sometimes I blame myself for my child's behavior.

15. I focus most of my energy on my child.

16. Professionals are not doing enough to help my child.

17. I don't spend enough time helping my child.

18. I'm thinking about changing my schedule at work because of my child.

19. We miss out on some activities because of my child's behavior.

20. It's impossible to find a babysitter who can care for our child so we rarely go out.

21. I'd rather skip going to a party than have to explain my child's behavior.

22. I wonder what other parents do when their child acts like this.

23. I would like someone to tell me what is going to happen with my child.

24. It's scary when you don't know what to do next.

25. I feel like I'm more concerned with my child's development or behavior than the doctor is.

26. My child seems pretty happy.

27. I don't like what's happening to our family, it feels scary.

28. I spend more time searching for answers about my child than I spend with my child.

29. I can't hire a babysitter who will know what to do for my child.

30. We go out less than we used to because of our child's behavior.

31. I wish someone could teach me how to be a good parent for my child.

32. My child does some things that surprise me.

33. I know my child prefers routines, but sometimes it's important for the rest of the family to do something different.

34. Isn't there anyone who can tell me what I can do to help my child?

35. I make lists about my child's behavior.

36. Well, actually, I think I'm probably a little on the spectrum, too.

37. I'm more serious about things than I used to be because of my child.

38. Life would be better if my child had a diagnosis.

39. I worry about my child's behavior.

40. I notice things about my child's behavior that professionals don't seem to notice.

41. My child's behavior is surprising sometimes, but it keeps life interesting.

42. My friends know what I'm going through.

43. I know how to find answers for questions regarding my child's health.

44. I search for answers about my child's behavior on the Internet.

45. I don't want to burden my partner with my concerns about my child.

46. Sure, it would be great if we had a diagnosis, but that wouldn't change our lives.

47. I have made new friends because of my child.

48. Where can I go to get my questions answered about my child?

49. Sometimes I wonder if my child can hear me when I'm talking.

50. I'm not sure I'm going to be able to handle things if we get bad news.

51. My child might have a meltdown when we go shopping, I just take a deep breath and know that all parents have moments like this.

52. I don't know what is going to happen next, but I'm sure I can handle things.

53. I feel hopeful about the future.

54. I like telling other people about my child.

55. I notice my child doesn't like changes in his or her schedule.

56. I think my child is sensitive to certain materials.

57. It's embarrassing when my child makes loud sounds in the store.

58. I know that I'm a great parent.

59. My child's behavior isn't really an issue for our family.

60. We may not be a typical family, but I wouldn't have it any other way.

61. My child's behavior has helped me better understand my own behavior.

62. I watch more TV than I used to.

63. I wonder if my child's development is okay.

64. Sometimes I aggressively try to change my child's behavior.

65. I'm more or less than same person I always was because of my child.

66. I understand my child's behavior.

67. I know how to collaborate with medical providers and educators to meet my child's needs.

68. Things would be easier if we had a pet.

69. I feel like I can balance my needs, my child's needs, and my relationship with my partner.

70. I'm confident about my ability to understand my child.

71. I think my child's behavior is different than other children his/her age.

72. I like to share what I have learned with other parents.

73. I wonder if my child's behavior is typical.

74. I notice that my child doesn't talk as much as other children.

75. I wonder if other children line their toys up like my child does.

76. I celebrate my child's uniqueness.

77. Sure, I'm busy, but I make time to do things for myself.

78. I get enough sleep.

79. I wonder if this typical behavior for a child, my other children did not behave this way when they were the same age.

80. I have a better sense of humor than I used to because of my child.

81. I love my child and I wouldn't change anything about him/her.

Part Two: Review your list

Stage one: Awareness. These are the statements you indicated fit BEST with Stage 1 Awareness. If you believe all these statements fit BEST with Stage 1 Awareness, click on the button to keep your stage 1 list the way it is you can advance to the next page. If there are any statements you would like to move from Stage 1 to another stage you can select statements to move to another category.

(A list of the statements the individual selected as belong to "Stage 1" appear here)

Stage two: Passage. These are the statements you indicated fit BEST with Stage 2 Passage. If you believe all these statements fit BEST with Stage 2 Passage click on the button to keep your stage 2 list the way it is you can advance to the next page. If there are any statements you would like to move from Stage 2 to another stage you can select statements to move to another category.

(A list of the statements the individual selected as belong to "Stage 2" appear here)

Stage 3: Transformation. These are the statements you indicated fit BEST with Stage 3 Transformation. If you believe all these statements fit BEST with Stage 3 Transformation click on the button to keep your stage 3 list the way it is you can advance to the next page.

If there are any statements you would like to move from Stage 3 to another stage you can select statements to move to another category.

(A list of the statements the individual selected as belong to "Stage 3" appear here)

Not Part of Caregivers' Experience. These are the statements you indicated fit BEST with Not Part of Caregivers' Experience. If you believe all these statements fit BEST with Not Part of Caregivers' Experience click on the button to keep your stage 3 list the way it is you can advance to the next page. If there are any statements you would like to move from Not Part of Caregivers' Experience to another stage you can select statements to move to another category.

(A list of the statements the individual selected as belong to "Not Part of Caregivers' Experience" appear here)

Appendix C: Comprehensive Exam Three Study Documents - Exploring the Development of

Parents' Mental Models Related to Their Child's Developmental Diagnosis

Volunteers needed for Study
STRENGTHS-BASED THEORY OF CAREGIVER TRANSFORMATION

Parents of individuals with an autism or other developmental diagnosis needed for study on care provider transformation. Our research seeks to understand caregivers' experiences surrounding their child's diagnosis. We are recruiting caregivers of children with a developmental condition such as autism or other neurodevelopmental condition or suspected of having autism or similar condition. Participation will include completing an online survey.

Parent Survey

http://tinyurl.com/KUMCParentSurvey

Online Informed Consent Form

You are being asked to consider a research study titled "Caregiver Transformation" led by Dr. Winnie Dunn and Julie Broski because you are a caregiver of a child with a developmental diagnosis. We are recruiting research participants to help us understand parents' transition experience surrounding their child's developmental diagnosis. Participation involves completing a survey that will take about 20 minutes. There are no personal benefits or risks to participating in this study. Participation is voluntary, and you can stop taking the survey at any time. If you have any questions, please contact Julie Broski at jbroski@kumc.edu. If you have questions about the rights of research participants, you may contact the KUMC Institutional Review Board (IRB) at (913) 588-1240 or humansubjects@kumc.edu. If you are interested in participating in this study, continue to the next page to begin taking the survey. Thank you!

Data Collection Forms
Demographic Survey

Does your child have a diagnosis of an autism spectrum disorder?

     Yes, my child received this diagnosis by a health care professional or educator. (1)

     No, my child does not have this diagnosis. (2)

Does your child have a diagnosis of Asperger Syndrome?

     Yes, my child received this diagnosis by a health care professional or educator. (1)

     No, my child does not have this diagnosis. (2)

Does your child have an intellectual disability?

     Yes, my child received this diagnosis by a health care professional or educator. (1)

     No, my child does not have this diagnosis. (2)

Does your child have a diagnosis of pervasive developmental disorder not otherwise specified (PDD-NOS)?

     Yes, my child received this diagnosis by a health care professional or educator. (1)

     No, my child does not have this diagnosis (2)

Does your child have a neuro-developmental diagnosis that was not quickly apparent to the family prior to an appointment with a healthcare or education professional?

     Yes, my child received a neuro-developmental diagnosis by a health care professional or educator.

     No, my child does not have this diagnosis. (2)

What was your child diagnosed 3 or more years ago?

     Yes (1)

     No (2)

Is your child 7 years of age or older?

     Yes (1)

     No (2)

What is your year of birth? _____

What is the highest level of school you have completed or the highest degree you have received?

       Less than high school degree (1)

       High school graduate (high school diploma or equivalent including GED) (2)

       Some college but no degree (3)

       Associate degree in college (2-year) (4)

       Bachelor's degree in college (4-year) (5)

       Master's degree (6)

       Doctoral degree (7)

       Professional degree (JD, MD) (8)

Are you Spanish, Hispanic, or Latino or none of these?

       Yes (1)   None of these (2)

Are you Spanish, Hispanic, or Latino?

       Spanish (1)   Hispanic (2)   Latino (3)

Choose one or more races that you consider yourself to be:

       White (1) Black or African American (2) American Indian or Alaska Native (3) Asian (4)

       Native Hawaiian or Pacific Islander (5)   Other (6) _____

What is your sex?

       Male (1)   Female (2)

Information about income is very important to understand. Please indicate the answer that includes your

entire household income in (previous year) before taxes.

       Less than $10,000 (1) $10,000 to $19,999 (2) $20,000 to $29,999 (3) $30,000 to $39,999 (4)

       $40,000 to $49,999 (5) $50,000 to $59,999 (6) $60,000 to $69,999 (7) $70,000 to $79,999 (8)

       $80,000 to $89,999 (9) $90,000 to $99,999 (10) $100,000 to $149,999 (11)

       $150,000 or more (12)

What is your ZIP code? _____

Which of the following best describes your sexual orientation?

      Heterosexual (straight) (1)   Homosexual (gay) (2)   Bisexual (3)

      Other (4)   Prefer not to say (5)

Are you now married, widowed, divorced, separated or never married?

      Married (1)   Widowed (2)   Divorced (3)   Separated (4)   Never

      Married (5)

How many people are living or staying at this address?

      1 (1)   2 (2)   3 (3)   4 (4)   5 (5)   6 (6)   More than 6 (7)

Which statement best describes your current employment status?

      Salaried or hourly employee   Self-employed   Retired   Not employed

      Prefer not to answer

Please tell us about your child

What is your child's primary diagnosis?

    Intellectual disability   Autism Spectrum Disorder   Asperger Syndrome

    PDD-NSS   Other _____

Does your child have other conditions/diagnosis? If so please list below:_____

Who diagnosed your child's condition?

    A health care professional   An educator   Other

Does your child require on going medical care?

    My child receives medical care more than 1 time every 4 months

    My child receives medical care about 1 time every 6 months

    My child receives medical care about 1 time (or less) every year

<center>**Parent Statements and Definitions**</center>

Caregiver statements were completed after sorting the transition statements provided in Appendix B.

Now that you have assigned all the caregiver statements into categories, think about what caregiver

statements you believe are missing from the list.

Is anything missing from the Stage 1 List?

Here is the list of statements you indicated fit best with Stage 1 Awareness.

(Stage 1 list appears here)

As you think about this list, are there any statements you feel are missing from this list? Please write

down additional statements you think should be included in Stage 1.

Is anything missing from the Stage 2 List?

Here is the list of statements you indicated fit best with Stage 2 Passage.

(Stage 2 list appears here)

As you think about this list, are there any statements you feel are missing from this list? Please write

down additional statements you think should be included in Stage 2.

Is anything missing from the Stage 3 List?

Here is the list of statements you indicated fit best with Stage 3 Transformation.

(Stage 3 list appears here)

As you think about this list, are there any statements you feel are missing from this list? Please write

down additional statements you think should be included in Stage 2.

Defining Transition Categories

We intentionally created very brief descriptions for each of the 4 categories. Now we would like you to

think about how you would define each of the 4 caregiver categories. We will use participants' definitions

to help us develop a tool to share with caregivers and professionals to better understand how caregivers

who have experienced transition understand their transition experience.

How would you define Stage 1 Awareness?

How would you define Stage 2 Passage?

How would you define Stage 3 Transformation?

What does it mean if a statement isn't part of caregivers' transition experience?

Thank you for your participation in this phase of our study.

Please click here if you would like to participate in a focus group or completing an online card sort.

Appendix D: Study Documents for Critical Insights: Incidents that Help and Hinder Parents'

Transition Related to Their Child's Developmental Diagnosis

Informed Consent Documents
Recruiting Flyer

A research study to learn about events that helped and hindered parents transition related to their child's developmental diagnosis

The purpose of this study is to learn about events that helped and hindered parents transition related to their child's developmental diagnosis.

You can participate in this study if:
You are the parent of a child with a neuro-developmental diagnosis such as:
 of autism spectrum disorder diagnosis, intellectual disability or attention deficit hyperactivity disorder and your child does not have a neuromuscular disorder such as muscular dystrophy or cerebral palsy.
Your child was diagnosed when he or she was at least two years old; and
Your child received the diagnosis no later than September 1, 2016; and
Your child is at least six years old and younger than 26 years old, and
You can speak and understand questions asked in English.

If you would like to be contacted about participating in this study follow this link to:
www.tinyurl.com/parentsinsights or contact Julie Broski at jbroski@kumc.edu.
A copy of the informed consent form is available at online at www.tinyurl.com/InsightsConsent. Thank you!

Online Parent Information Form

Thank you for your interest in the Parents' Insights Study. We are recruiting participants to help us learn about parents' experiences that helped or hindered parents' ability to support their child, and help us learn about parents' experiences related to their child's developmental diagnosis that helped or hindered parents' confidence in their parenting ability.

You can participate in this study if:

- You are the parent of a child with a neuro-developmental diagnosis such as:

- autism spectrum disorder diagnosis, intellectual disability or attention deficit hyperactivity disorder, and

- your child does not have a neuromuscular disorder such as muscular dystrophy or cerebral palsy, and

- your child was diagnosed when he or she was at least two years old, and

- your child received the diagnosis no later than September 1, 2016, and

- your child is at least 6 years old and younger than 26 years old, and

- you can speak and understand questions asked in English.

Yes, I am interested in participating _____   No, I am not interested in participating _____

Please enter your first and last name in the form below. You may also contact Julie Broski at jbroski@kumc.edu. First and Last Name _____

Please enter a cell phone number and/or email address we may use to send you a text message or email.

_____

Please review your contact information to make sure everything is correct so we can reach you! A researcher will contact you soon! In the meantime, a copy of the informed consent is available at www.tinyurl.com/InsightsConsent. You can complete the consent form now or when you meet with the researcher. If you have any questions, feel free to contact us at jbroski@kumc.edu.

Thank you. Your response has been recorded.

Informed Consent

We are contacting you because you are a parent of a child with a developmental diagnosis. We are recruiting participants to help us learn about events that helped or hindered parents' transition related to their child's developmental diagnosis. You can participate in this study if:

You are the parent of a child with a neuro-developmental diagnosis such as:

autism spectrum disorder diagnosis, intellectual disability or attention deficit hyperactivity disorder, and

your child does not have a neuromuscular disorder such as muscular dystrophy or cerebral palsy, and

your child was diagnosed when he or she was at least two years old, and

your child received the diagnosis no later than September 1, 2016. and

your child is at least six years old and younger than 26 years old, and

you can speak and understand questions asked in English.

Participation involves completing a survey and an interview. The online survey will take about two minutes. The interview will take about 60 minutes, and we will make an audio recording of the interview. You can take a break or stop the recording at any time. A professional transcriptionist will transcribe the interview. We will assign a code or "fake name" so you the person who transcribes the recording will not know who you are. We will remove your name from data that will be used for analysis. The research team will store recordings on the University of Kansas Medical Center (KUMC) servers which will be retained for seven years as required by KUMC Institutional Review Board (IRB) Policy. In addition to the interview questions, we will collect demographic information including age, gender, educational status, household income, and health status. We will contact you by phone or email to share information about the study with you. After the interview, if you think of something else that you would like to add, you will have a link to an online survey where you can add additional information. This survey will take about 5 minutes to complete and is optional. After the researchers conduct a preliminary data analysis, you will receive an email from a member of the research team with a link to the study results. You will be able to

review the initial findings of the study. We will not use your real name in any publication or presentation related to this study. We will not share our identifiable information with anyone unless (a) law or university policy requires it, or (b) you give written permission. It is possible, however, with internet communications, that through intent or accident someone other than the intended recipient may see your response. There are no personal benefits or risks to participating in this study. Participation is voluntary, and you can stop taking the survey and stop the interview at any time. If you have any questions, please contact Julie Broski at jbroski@kumc.edu. For questions about the rights of research participants, you may contact the KUMC IRB at (913) 588-1240 or humansubjects@kumc.edu

Consent to participate in the Parents' Expectations and Acceptance study.

_____I agree to participate in the study. _____I do not agree to participate in the study.

First and Last Name _____

Parent Interview Information
Parent Interview Date, Time, Location and Interview Questions

We are writing to confirm your interview for the Parents Insights study.

We will meet on *meeting date and time information*

The meeting will be at *meeting location information*

We are interested in learning about how parents transition from one stage or phase of transition related to their child's diagnosis to another stage. If one of the questions does not seem to apply to your situation that's okay, we will move to the next questions. Please take a few minutes before the interview to think about the following questions:

1. What incident/s stand out as helping or hindering you moving from awareness of your child's differences to focusing on your child's differences?

2. What incident/s stand out as helping or hindering you from moving from focusing on your child's differences to recognizing your child's strengths?

3. What incident/s stand out as helping or hindering you distancing yourself from people who were not healthy for you to be around to isolating yourself?

4. What incident/s stand out as helping or hindering you from isolating yourself to connecting or reconnecting with people?

5. What incident/s stand out as helping or hindering you moving from seeking confirmation from others to experimenting with strategies or interventions to help your child?

6. What incident/s stand out as helping or hindering you experimenting with strategies or interventions to having confidence your ability to discern strategies or therapies that address your child or your family's preferences or values?

The interview will take approximately 60 minutes. After the interview, you will be asked to complete a short (less than 5 minutes) demographic survey. If you have any questions, please contact Julie Broski. We will send you a text message about 24 hours before the interview. Thank you.

Interview Documents
Data Collection Matrix

	Social Context	Physical Environment	Temporal	Behaviors	Thinking	Beliefs and Feelings	Themes
1. What incident/s stand out as helping you move from awareness of your child's differences to focusing on your child's differences (research question one)?							
2. What incident/s stand out hindering you from moving from awareness of your child's differences to focusing on your child's differences (research question two)							
3. What incident/s stand out as helping you move from focusing on your child's differences to recognizing your child's strengths (research question one)?							
4. What incident/s stand out as hindering you from moving from focusing on your child's differences to recognizing your child's strengths (research question two)?							
5. What incident/s stand out as helping you move from distancing yourself from people who were not healthy for you to be around to isolating yourself (research question one)							
6. What incident/s stand out as hindering you from moving from distancing yourself from people who were not healthy for you to be around to isolating yourself (research question two)?							
7. What incident/s stand out as helping you move from isolating yourself to connecting or reconnecting with people (research question one)?							
8. What incident/s stand out as hindering you from move from isolating yourself to connecting or reconnecting with people (research question two)?							
9. What incident/s stand out as helping you move from seeking confirmation from others to experimenting with strategies or interventions to help your child (research question one)?							
10.What incident/s stand out as hindering you from moving from seeking confirmation from others to experimenting with strategies or interventions to help your child (research question two)?							
11. What incident/s stand out as helping you experiment with strategies to having confidence your ability to discern strategies that address your child or your family's preferences or values (research question one)?							
12. What incident/s stand out as hindering you from experimenting with strategies to having confidence your ability to discern strategies that address your child or your family's preferences or values (research question two)?							

Follow up questions

In what way/s did the incident change your thinking?|
In what way/s did the incident change your beliefs or values?
In what way/s did the incident change what you do?
What were your feelings about the incident?
Where did the incident occur?
Who was involved in the incident?
When did the incident occur (days, weeks, months or years ago)?
About how old was your child when the incident occurred?

2018 Parent Study Demographics

The answers you provide in this survey will help us describe the results of our study. We will not link any of your answers on this survey with your interview data or other information that will be connected to you. Before I analyze the demographic data, I will remove the date and time information so no information from this survey will be linked to you in any way during analysis.

Parent Code Name _____

How old is your child? _____

How many years ago was your child diagnosed with a developmental diagnosis? _____

What diagnosis did your child receive?

What is your child's sex_____?

Are you Hispanic or Latino?   Yes   No   Don't know/not sure

What is your race? Do you consider yourself. . . (select one or more)?

      Asian or Pacific Islander   Hispanic or Latino   White/Caucasian

      Black/African American   Other

What was your total household income last year? _____

What best describes your employment status?

      Employed full-time   Employed part-time   Work from home   Not working

What best describes your status?

      Single/Divorced/Separated   Married/Living with a partner

What is your age?_____

What is your sex? _____

What is the highest degree or level of school you have completed?

      Highschool   College   Graduate school

Additional Information Following the Interview – Participant Form

Thank you for your participation! The information you provided will help us better understand how parents gain insights about their expectations and acceptance related to their child's ASD or other neuro-developmental diagnoses. If you think of additional information when you get home that you think would be helpful you can add that information to the study using this link:

www.tinyurl.com/moreinsight

Your study code name is: _____

If you'd like, you can use your study code name (pseudonym) if you'd like the additional information to be added to anything you've shared today. However, if you'd like to add information anonymously, you can leave the name blank in the online survey. For your convenience, we will send an email to you with this information, as well.

If you have any questions about the study, please email Julie Broski at jbroski@kumc.edu.

Additional Information Following the Interview – Data Collection Form

Thank you for any additional thoughts you might have about the interview or other information you would like to add. **What is your study code name? (If you don't remember, or you'd prefer not to say, you can leave this field blank**) _____

We are interested in learning about how parents transition from one stage or phase of transition related to their child's diagnosis to another stage. If one of the questions does not seem to apply to your situation that's okay, we will move to the next questions.

Describe the incident

Indicate individuals who were involved

> Me   My child or other immediate family members   Other people not part of the family

Where did the event take place (select all that apply)?

> Home   Community setting   Institutional setting (non-inclusive, non-community setting)

How long ago did the event occur?

In what ways did your thinking change?

In what ways did your feelings or beliefs change?

In what ways did your actions or behaviors change?

This incident is about (select all that apply)

> An incident that helped or hindered me move from moving from awareness of my child's differences to focusing on my child's differences?
>
> An incident that helped or hindered distancing myself from people who were not healthy for me to be around to isolating myself.
>
> An incident that helped or hindered me from isolating myself to connecting or reconnection with people.
>
> An incident that helped or hindered me moving from seeking confirmation from others to experimenting with strategies or interventions to help my child?

An incident that helped or hindered me experimenting with strategies (or therapies) to having

confidence in my ability to discern strategies (or therapies) that address my child's or my family's

preferences and values?

I'm not sure.

Do you have another incident to add?

Yes   No, I'm done

Member Check Documents
Preliminary Findings Information

Thank you for participating in our study about parents' transition experiences!

Here's a link to the preliminary findings of our study. We'd like to invite you to review our

study findings. We wanted to share our findings with you and we'd sure love to learn your thoughts about

the study! Please feel free to let us know what you think by leaving your comments

at http://tinyurl.com/ParentStudyFindings or send your response to jbroski@kumc.edu. Thank you so

much for participating!

Preliminary Findings Form

Thank you for being a part of our study to help us learn how parents experience transition! Please find a

summary of the results of the study for your review. We would love to learn your thoughts about our

findings.

Incidents that helped parents

We identified two dominant themes associated with the incidents that helped parents'

transition:

1. Gathering, using and allocating resources

2. Seeing possibilities

Gathering, using and allocating resources includes:

- Receiving information from professionals (gathering information)

- Observing the child (gathering information)

- Deciding whether or not to spend time with someone or how much time to spend with someone (allocating resources)

- Deciding how much time to spend with a support group or on interventions (allocating resources)

- Making a decision not to spend time with people who were not helpful for the family (allocating resources)

- Trying a strategy or intervention (allocating resources, using resources)

Gathering, using and allocating resources is associated with the following:

- Focusing on the child's differences

- Distancing from others

- Experimenting with strategies

- Discerning what is best for the family

Seeing possibilities includes:

- The parent recognizing opportunities for their child, themselves or for the community

- Seeing their child in new ways that offered parents a more hopeful perspective.

- Recognizing opportunities for their child when they found interventions that were a good match for their child.

- Getting to know their child as a person

- Understanding how their child thinks

- Seeing their child's strengths

Seeing possibilities is associated with:

- Focusing on the child's strengths

- Connecting with others

- Discerning what is best for the family

Incidents that hindered parents

We identified 2 dominant themes associated with "hindering parents" transition

- Feeling uncertain or obligated

- Finding the edges

Feeling uncertain or obligated includes:

- Feeling discomfort

- Lacking confidence

- Doing something because it's expected of them, not because they want to

- Being given unsolicited advice

- Comparing the child to other children

- Feeling like they have to spend the holidays with extended family, even though they know it's going to turn out bad

- The parent thinks they had figured out an intervention or strategy, but discovering it doesn't work

    Feeling uncertain is primarily associated with hindering

- Distancing from others

- Discerning what is best for the family.

 Finding the edges includes:

- The parent determines they are at the edges of what the parent feels works for them or can be tolerated

- Recognizing they did not agree with the thinking of someone close to them

- Being asked to not participate with a group, or being asked to leave a group

- Deciding not to spend the extended holidays with family members, even though it is expected

- Focusing on limitations

- often involved a parent finally being able to take a stand on something that they had previously felt uncertain about, but the parent indicates that something has changed and they feel a clear direction about an action,

- The parent is ready to take a stand on an issue

Finding the edges was primarily associated with:

- Focusing on the child's differences

- Focusing on the child's strengths

- Connecting with others and

- Experimenting with strategies

We found similarities between the incidents that helped and hindered parents (some parents indicated that the things that help them are sometimes the same things that hinder them). While none of the incidents prevented parents from eventual transition, the incidents that hindered parents often prompted them to pause and reflect on their given circumstances. Taking the time to feel emotions,

including feeling hurt or angry seemed to lead to a kind of clarity which provided parents with a focus to help them overcome obstacles.

Our findings are consistent with previous research that indicate parents' experiences include constructing new ways of thinking about their children, themselves and their lives. Our findings stand in contrast, however, to the chronic sorrow model which suggests parents of children with a developmental disability continue to experience loss of quality of life, loss of support, loss of roles and loss of relationships and that parents lack the ability to speak out for their needs. While the parents we interviewed described experiences that were often challenging and sometimes left them feeling raw, exhausted and angry, parents also described experiencing profound insight, joy, admiration of their children, deep and meaningful relationships with others. Additionally, parents described the ability to make decisions about maintaining or discontinuing relationships or activities that were no longer constructive. Parents also reported that there were times they spoke out when they did not feel their children received appropriate consideration or services. These findings are not consistent with the chronic sorrow model.

Parents of children with neuro-developmental differences can provide insights about how individuals face unexpected transitions. Parents in our study described being sensitive to circumstance that disrupted routines for their family. Parents also described seeking to move forward in ways to meet their children's needs as well searching for ways to meet their own needs. All parents we interviewed described aspects of awareness of situations that were challenging for their family and described planning ahead to help their child and family navigate events in the future that parents anticipated would be challenging. Parents gathered information, experimented with strategies and evaluated whether the strategies they identified worked, needed to be modified or discontinued. Parents frequently described refining their thinking, updating their understanding and challenging their own paradigms. Parents sometimes challenged the people around them to reconsider their world views. All of these behaviors were part of the strategies and approaches that parents used in moving from awareness of their child's differences to transformation.

Comments to the researchers about the findings.

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Thank you, again for participating!