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Connected Families: Programs for Families of Infants/Toddlers At Risk for Autism

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LOMA LINDA UNIVERSITY
School of Behavioral Health
in conjunction with the
Department of Counseling and Family Sciences

Connected Families: Programs for Families of Infants/Toddlers At Risk for Autism

by

Toni Carol Durnal Dunning

A Project submitted in partial satisfaction of
the requirements for the degree
Doctor of Marital and Family Therapy

June 2019

Each person whose signature appears below certifies that this dissertation in his/her opinion is adequate, in scope and quality, as a dissertation for the degree Doctor of Marital and Family Therapy.

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CONTENTS

Chapter

Appendices

TABLES

Tables Page

ABBREVIATIONS

ABA	Applied Behavior Analysis
ADL	Activities of Daily Living
ASD	Autism Spectrum Disorder
ASEBA	Achenbach System of Empirically Based Assessment
BAI	Beck Anxiety Inventory
BDI	Beck Depression Inventory
CBCL	Child Behavior Checklist 1 ½- 5 Years
CDC	Centers for Disease Control and Prevention
CDDS	California Department of Developmental Services
CFCG	Connected Families Caregiver Group
COS	Circle of Security
CPRT	Child Parent Relationship Therapy
DECA	Devereux Early Childhood Assessment
DECA I/T	Devereux Early Childhood Assessment Infant (1-18 months) and Toddler (18-36 months)
DIR	Developmental, Individual-difference, Relationship-based approach
DSM	Diagnostic and Statistical Manual of Mental Disorders
EISA	California Early Intervention Services Act
ESDM	Early Start Denver Model
FT	Family Therapy
IDEA	Individuals with Disabilities in Education Act

LDS	Language Development Survey 18-35 months
Lanterman	Lanterman Developmental Disabilities Act
PBS	Positive Behavior Support/Reinforcement
PBS/CT	Positive Behavior Support/Caregiver Training
PCIT	Parent Child Interaction Therapy
POS	Purchase of Service
PSI-4-SF	Parenting Stress Index™, Fourth Edition, Short Form
RCOC	Regional Center of Orange County
SSI	Social Support Index
TAS-45	Toddler Attachment Sort -45
VIPP-AUTI	Video-feedback Intervention to promote Positive Parenting for Children with Autism

EXECUTIVE SUMMARY OF THE DOCTORAL PROJECT

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by

Toni Carol Durnal Dunning

Doctor of Marital and Family Therapy, Graduate Program in
Counseling and Family Sciences
Loma Linda University, June 2019
Dr. Nichola Ribadu, Chairperson

Although children with secure attachment are known to have better outcomes, fostering secure attachment in an infant/toddler at risk for autism spectrum disorder is challenging. Some of the challenges stem from bi-directional, negative and ambiguous interaction sequences between the child and caregiver that cause emotional dysregulation and undermine caregiver confidence setting the stage for perpetual miscuing and mis-attunement—a pattern that can impact the entire family system leaving the child, caregiver, and family vulnerable to stress, anxiety, depression, and isolation.

Although the etiology of autism is a matter of intensive and ongoing research spanning many disciplines, there is converging agreement that there are familial (genetic), environmental (toxins), and nurturing factors. Caregivers who believe they played some part in their child's diagnosis often carry guilt and shame—and regardless are subject to public opinion which can be harsh and judgmental when the child does not conform to social and behavioral norms.

As a program development with a logic model and evaluation plan, Connected Families is designed to support the caregivers and families of infants/toddlers at risk for autism spectrum disorder (ASD) with the goals of fostering congruent communication

and increased secure attachment interactions between caregiver and child; improving caregiver support; and families' abilities to adapt to the changing needs of the neurodiverse child throughout development. First, using the caregiver-infant/toddler dyad as the agent of change, Connected Families first offers positive behavior support to the child and instruction to the caregiver. Second, caregivers attend the Connected Families Caregiver Group where they can connect with their own needs and goals; discover the challenges associated with ASD surrounding attachment; discuss and parenting models and positive behavior support while also having the opportunity to process experiences allowing each participant the opportunity to "feel felt." In addition, caregivers can learn filial play skills allowing for child-centered interaction with the caregiver. Video recordings are shared within the group and members deconstruct interactions and together identify unique communication characteristics of the infant/toddler and opportunities for caregiver engagement to promote secure attachment interactions with the caregiver functioning as both the secure base for the child's exploration and the safe haven to which the child returns when distressed. Finally, caregivers, siblings and other family members are offered the opportunity to participate in family therapy. The family therapy component is inherently systemic and structurally informed—therefore focused on rebalancing the family subsystems and addressing roles and responsibilities within the family system in a culturally sensitive manner. The purpose of family therapy is to challenge existing homeostasis that increases potential for isolation of family members and the collective decreased likelihood of family members attaining full potential, and to foster the family's ability to adapt to better support infant/toddler progression through developmental milestones.

Connected Families is distinctive from programs that focus on behavior and instead highlights the importance of relationship and the central role of marriage and family therapists in delivery of services to the infant/toddler , caregiver, and family system to benefit of healthy communities.

CHAPTER ONE

PROBLEM STATEMENT

Studies show that children with secure attachment have better outcomes across the lifespan (McKenzie & Dallos, 2017; Sroufe, 2005) and recent research demonstrates that children at risk for autism spectrum disorder (ASD) have the need and capacity for secure attachment (Beurkens, Hobson, & Hobson, 2013; McKenzie & Dallos, 2017; Teague, Gray, Tonge, & Newman, 2017). Yet, fostering secure attachment in an infant/toddler at risk for ASD can be particularly challenging due to the ambiguous, negative interactional patterns (Cortina & Liotti, 2010; Fonagy, Steele, Steele, Moran, & Higgit, 1991; Teague et al., 2017) that result when emotional dysregulation patterns of the infant/toddler undermine caregiver confidence and the caregiver's ability to respond to the child's needs. These patterns set the stage for ongoing miscuing in the caregiver-infant/toddler dyad further reducing the likelihood of attunement and the development of trust, with missed opportunities for soothing, support, and overall development.

These challenges directly impact the caregiver and the infant/toddler as well as other members of the family and persons with whom the family interact in multiple contexts. In this writing the term "infant/toddler," and derivatives of the term, refers to very young children from birth to age three while the term "caregiver" refers to the child's attachment figure(s) who are primarily involved with the child's care and development which may include parents (natural, step, adoptive, and/or foster), grandparents or others.

Current services provided to infants/toddlers through California's Regional Centers target developmental and behavioral outcomes and often include caregiver education and require the involvement of caregivers—yet, do not specifically address the critical importance of attachment security in the relationship between the infant/toddler and caregiver (RCOC, 2018). While it is important to acknowledge the contributions of existing programs to infants/toddlers and their caregivers and families—when services that are provided to infants/toddlers and caregiver education and support programs fail to address attachment needs, the infant/toddler and caregiver both remain vulnerable with the infant/toddler less likely to meet developmental milestones and go on to attain full potential. Caregivers, in turn can experience increased parental stress possibly coupled with mental health issues such as anxiety and depression (Derguy, Michel, Katia, Roux, & Bouvard, 2015; Karst & van Hecke, 2012; Keenan, Newman, Gray, & Rinehart, 2016). In addition, without necessary caregiver support the infant/toddler's challenges with regulation persist, potentially escalating caregiver challenges, which then lead to increased social isolation, inability to sustain employment due to caregiving issues, financial insecurity, and partner relationship instability or divorce—all of which increase the societal burden of care for families contextualized by ASD—an atypical neurodevelopmental condition that often extends across the lifespan (Derguy, Michel, Katia, et al., 2015; Karst & van Hecke, 2012; Keenan et al., 2016).

Moreover, a retrospective evaluation of a nationally representative sample identified differences in neurotypical children and children subsequently diagnosed at risk for ASD at age two, highlighting the importance of early intervention (Jeans, Santos, Laxman, McBride, & Dyer, 2013). Analysis of autism prevalence data that considered differences in diagnostic criterion over time using three different datasets reported on data from the California Department of Developmental Services, stating, "prevalence has increased by a factor of 25 from birth year 1970-2012, and by as much as a factor of 1000 from birth year 1931-2012" (Nevison, Blaxill, & Zahorodny, 2018). The Centers for Disease Control and Prevention concluded that one in 59 eight-year-olds in 11 participating states met diagnostic criterion for ASD (Baio et al., 2018).

The very nature of an infant/toddler at risk for ASD, creates systemic challenges within an entire family system—often extending to others interacting with the family system (Beurkens et al., 2013; Connell, Halloran, & Doody, 2016; Derguy, Michel, M'Bailara, Roux, & Bouvard, 2015; Hobson, Tarver, Beurkens, & Hobson, 2016; Karst & van Hecke, 2012; Sim, Cordier, Vaz, Netto, & Falkmer, 2017). As a spectrum disorder, ASD varies in severity and intensity of symptoms, yet as neurodevelopmental disorder ASD affects communication and behavior in multiple contexts according to the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013). For example, infants/toddlers at risk for ASD frequently do not enjoy touch or being picked up, typically avoid eye contact and do not engage in social play or activities that involve joint attention with another person, frequently exhibit repetitive and restrictive behaviors and also experience extreme distress reactions (Sattler, 2014; ZERO TO THREE, 2016). An infant/toddler at risk for ASD may therefore become quite distressed and may engage in lengthy tantrums in a variety of settings while being difficult to soothe or redirect—a challenge that can create difficulty especially in caregiver-infant/toddler interaction with possible implications for increased caregiver stress and poor attachment outcomes early in child development (Goodman & Glenwick, 2012; Siller, Swanson, Gerber, Hutman, & Sigman, 2014; Skelly, 2007).

In addition to attending to the dysregulated infant/toddler, caregivers must attend to their own personal needs including activities of daily living (ADLs) and other responsibilities—possibly including a partner, other children, employment, spiritual practice, and/or social and community involvement. Thus, caregivers can easily find themselves in an untenable position with increased stress and the need for self-soothing/self-regulation—first for themselves—and second, to remain accessible and consistently and appropriately responsive to the needs of the infant/toddler. In addition, caregivers experience feelings of guilt (Baker-Ericzen et al., 2005; Rhodes, 2003) as well as grief and loss (Oppenheim, Koren-Karie, Dolev, & Yirmiya, 2012; van Ijzendoorn et al., 2007) and can benefit from assistance that promotes adaptive coping.

Further impacting the family system, parentification of the infant/toddler's siblings is common within families contextualized by ASD, although with both positive and negative sibling outcomes (Connell et al., 2016; Tomeny, Barry, Fair, & Riley, 2017). An Australian study of factors associated with negative co-parenting experiences in families of a child at risk for ASD, age 18 or under concluded, "Three factors were associated with negative co-parenting relationships: (1) family stress due to the child's diagnosis, (2) effects of the diagnosis on parents' relationship with their other children and (3) distance travelled to the nearest medical facility" (Sim, Cordier, Vaz, Parsons, & Falkmer, 2017, p. 83). Taken together, research suggests family members of an infant/toddler at risk for ASD are likely to struggle with dysregulated and problematic circular interactions with impact to family subsystems leading to chaotic, disorganized, and unpredictable engagement or disengagement that is problematic and potentially destabilizing for all family members.

Specifically, though the infant/toddler with features of ASD differs neurodevelopmentally from a typically developing peer, without diagnosis and early intervention caregivers are likely to expect their infant/toddler to develop and respond like a neurotypical child of the same chronological age. Imagine having such expectations and loving an infant/toddler who doesn't smile, respond to their name, make eye contact and who becomes easily distressed with transition or change—while unable to receive normal soothing and comfort for emotional regulation—and as a caregiver, an appropriate response is needed (Teague et al., 2017; Teague, Newman, Tonge, Gray, & Team, 2018). As this is a perpetual pattern that takes place every day, the caregiver experiences increasing fatigue, anxiety, and frustration and may question their own competency—all of which decrease the likelihood of responding to the infant/toddler in a manner that is ultimately helpful. The infant/toddler continues to struggle and does not meet developmental milestones, falling further behind and is easily identified by the family as "the problem." These patterns and the overlap of symptoms of autism with attachment insecurity are described by McKenzie and Dallos (2017) with Kissel and Nelson correlating severity of symptoms of autism with increased parenting stress (2016).

Caregiver exhaustion and frustration continue to mount, and roles may shift in the family with older neurotypical siblings declining peer contact—especially at home where there is chaos and potential for embarrassment—possibly taking on additional responsibilities (Tomeny et al., 2017). In a meta-synthesis that considered parents' management of symptoms of ASD, O'Nions, Happe, Evers, Boonen, and Noens describe the demands on parents to maintain constant vigilance, provide structure within chaos, and to prepare for every social encounter (2018). Neurotypical siblings face stressors due the unpredictability of embarrassing behaviors (Connell et al., 2016; Karst & van Hecke,

2012) and parentification owing to both parent and sibling needs for support (Tomeny et al., 2017). In an effort to attend to the needs of the children, caregivers may relinquish employment (Karst & van Hecke, 2012)—and with it the social and community support structures with their predictable outcomes and the income that was beneficial to the family and evidence of their competencies and contributions all of which potentially impact the family quality of life (Karst & van Hecke, 2012). The caregiver—in an effort to attend to the infant/toddler and possibly other children—can become more isolated and without structure and support (Karst & van Hecke, 2012), experience poorer mental health (Teague et al., 2018) and increased rates of anxiety and depression (Karst & van Hecke, 2012; Teague et al., 2018). Partner relationship challenges may easily arise from family stress and the impacts of the diagnosis on the couple relationship itself as well as with their other children (Sim, Cordier, Vaz, Netto, et al., 2017) though positive coping strategies within the couple dyad have been noted (Sim, Cordier, Vaz, Parsons, et al., 2017). In addition, caregivers and families may also have additional stressors such as poverty, single-parenting, co-occurring disorders including medical issues, or face challenges related to cultural or diversity issues. (Karst & van Hecke, 2012; Teague et al., 2018). These challenges are common to most special needs families (K. G. Shanahan, personal communication, April 25, 2019).

While this is an example of some of the interconnected circular interactions that occur within families where there is an infant/toddler at risk for ASD, it is not necessarily representative of any one family—nor does it represent the known specific experiences of any family in particular. Instead, although there are many variables and contextual factors, the example is provided to demonstrate how unmitigated ambiguous interaction sequences between caregivers and the infant/toddler at risk for ASD can escalate and quickly become problematic for the entire family system decreasing the system of support upon which the infant/toddler is dependent to meet developmental milestones.

Therefore, the systemic challenges of neurodiversity specific to ASD that can negatively impact family dynamics demand solutions that are research and theory-based to support the developmental and relational needs of the infant/toddler and caregiver. New programs that honor the importance of Developmental and Behavioral Theories and also draw upon the strengths of Attachment and Systems Theories to systemically address the relational and attachment needs of the infant/toddler at risk for ASD and the needs of caregivers that are vitally important for infants/toddlers, their families, and communities.

Connected Families is designed to foster increased secure attachment interactions in the caregiver-infant/toddler relationship leveraging the dyadic relationship as the agent of change and delivering services through three program components. First, positive behavior support training is provided to caregivers and delivered to infants/toddlers. Second a caregiver support group offers caregivers the opportunity to extend and experience mutual support as together they develop new skills for interacting with their infant/toddler based on the child's unique communication and interaction styles. New interactional patterns position the caregiver as the secure base and safe haven for infant/toddler creating new context within which developmental milestones can be met. Finally, family therapy is offered to the infant/toddler, caregiver(s), and siblings to challenge existing homeostasis and allow families to adapt to better support of the continued development of the infant/toddler.

CHAPTER TWO

LITERATURE REVIEW

To meet caregivers' and families' needs in support of the infant/toddler at risk for ASD, it is important to identify and consider the risks and protective factors, the importance early diagnosis and intervention, the impacts of diagnosis, and the evidence reported in current research. Additionally, it is critical to explore meanings of diagnosis across the lifespan, specifically considering the immediate experiences of caregivers and sibling family members in encounters with peers, schools, social settings as members of broader communities. Finally, it is necessary to explore legislative matters that impact current programs and their funding to develop research and evidence-informed solutions.

Risks and Protective Factors

Consideration of systemic risk and protective factors for caregivers and families and the infant/toddler at risk for ASD must address the neurodiversity of ASD within the context of family dynamics and function as well as factors related to the development of secure attachment. Infant/toddler risk factors are discussed because unmitigated caregiver self-blame and perception of guilt and has negative implications for caregiver mental health with possible extension to the entire family system. Therefore, caregiver implications and risk and protective factors for secure attachment are discussed in systemic context. Finally, factors related to social context and their implications are addressed.

Infant/Toddler

Although carrying risk for ASD carries profound implications that can vary widely in terms of presentation and severity across the lifespan, the etiology of ASD is a matter of ongoing inquiry and research with hypotheses landing in the very broad camps of genetic, environmental, and nurturing factors –while without exclusivity—though echoing potential caregiver guilt and shame and as well as social stigma.

Retrospective evaluation of Autism Brain Imaging Data Exchange (ABIDE) data using known subjects compared with controls reflects neurologic differences in the brain between ASD and neurotypicals (Di Martino et al., 2014; Nielsen et al., 2013; Riddle, Cascio, & Woodward, 2017) specifically noting disruption in anterior and posterior brain connectivity and function, as observed in resting-state *f*MRI (Heinsfeld, Franco, Craddock, Buchweitz, & Meneguzzi, 2018). Although outside the court of public judgment and opinion, and stopping short of a biomarker, the neurobiologic differences associated with ASD likely have implications social-emotional regulation and behavior .

Additionally, increasing agreement from both monozygotic and dizygotic twin studies concerning the relevance of genetic factors (de Zeeuw, van Beijsterveldt, Hoekstra, Bartels, & Boomsma, 2017) and environmental factors (Hoffman, Kalkbrenner, Vieira, & Daniels, 2012; C. D. Nevison, 2014) with other studies identify both and also noting gut differences influencing the gut-brain connection with vagal implications (Bölte et al., 2014) with Lasalle (2013) articulating the difference between heritability and the in utero environment. Calling for future studies of the interchange between genetic and environmental factors and stopping far short of making statements related to causation, Modabbernia, Velhorst and Reichenberg (2017) considered environmental risk factors using an evidence-based approach in examining earlier systematic reviews and meta-analyses noting factors associated with ASD included advanced paternal age, birth complications, and the presence of heavy metals. Other studies have noted that maternal use of *prescribed* opioids from three months preconception through pregnancy (Rubenstein et al., 2018) and inter-pregnancy intervals of less than 18 months or more than 60 months have also been correlated (Schieve et al., 2018). It is also generally accepted that boys are diagnosed more frequently than girls (de Zeeuw et al., 2017; Lai, Lombardo, Auyeung, Chakrabarti, & Baron-Cohen, 2015; Rubenstein, Wiggins, & Lee, 2015) with approximate ratios of 4:1 or 5:1 indicated, while some argue that existing diagnostics contain bias that more readily identify ASD in boys (Lai et al., 2015; Lasalle, 2013; Modabbernia et al., 2017; Szatmari, 2018) .

Despite the abundance of risk factors under investigation for autism *causation*, without clear understandings of autism etiology few protective factors have been identified, especially for the infant/toddler at risk for ASD, except *perhaps* for being female (Robinson, Lichtenstein, Anckarsater, Happe, & Ronald, 2013; Szatmari, 2018). What is perhaps important to notice is that autism has a strong familial association and having one child with ASD increases the likelihood of a younger child with an overall recurrence rate of 10.1% (Risch et al., 2014). Caregiver perceptions about the etiology of ASD, and their possible contributions to risk factors necessarily impact the dyadic relationship and the family overall (Da Paz, Siegel, Coccia, & Epel, 2018; Falk, Norris, & Quinn, 2014; McKenna Gulyn & Diaz-Asper, 2018). Despite the risk factors and challenges associated with ASD, attachment security has been identified as a protective factor in the child's social-emotional development (Teague et al., 2017, 2018).

Caregiver

As caregivers and siblings provide the primary support system for the infant/toddler at risk for ASD, their risk and protective factors must also be considered and addressed. Therefore, turning attention to families Falk, Norris, and Quinn (2014) examined the experiences of parents with one or more children diagnosed with ASD in working some of constructs of parental stress, anxiety, and depression differentiating the responses of women and men. More specifically, when mothers perceived they did not have influence over their child's behavior and development –the perception of control— they were increasingly prone to depression and anxiety (Falk et al., 2014). Noting that within their structural equation modeling, there was an assumption that having a child with ASD would involve parental perception of having low social support, Falk, et.al. (2014) also noted that lack of social support was a predictor of paternal stress, anxiety, and depression—with social support being identified with having emotional help and support from family and friends and support for care of the child with autism along with some economic support. Caregivers need for social support has therefore been identified as important by Falk, Norris, and Quinn (2014) as well as McKenna Gulyn and Diaz-Asper (2018).

A qualitative study of resiliency of caregivers of persons with autism identified risk, protective, and overlapping factors using questionnaires distributed and completed through SurveyMonkey with recruitment through the Interactive Autism Network. Risk factors identified that were supported by rich data collection included: stressful and out-of-control, challenging, overwhelming and draining, unpredictability and worry about the future, negative responses from others/lack of public awareness, and lack of resources.

Protective factors identified included: rewarding and serving a purpose, love of the child, celebrating small accomplishments, learning experience, acceptance and care become easier, and family togetherness. Overlapping factors –which were identified as both risk and protective factors—included: challenging/frustrating and rewarding and mixed emotions (Bekhet & Matel-Anderson, 2017).

A qualitative study in France assessed needs related to parenting a child with ASD noting the importance of emotional and relational support, stating, "providing appropriate group support for the highest priority needs… multifamily groups are conducive to the creation of a social network allowing the state of isolation to be broken down and leading to de-stigmatisation (Asen, 2002)" (Derguy, Michel, M'Bailara, et al., 2015). Additionally the importance of parenting confidence and the attachment relationship between the caregiver and infant/toddler is identified as central to overall development (Fletcher, 2016; Goodman & Glenwick, 2012; C. Nevison et al., 2018; Perry & Flood, 2016; Sigman, Dijamco, Gratier, & Rozga, 2004).

Family System and Secure Attachment

Discussion thus far has considered risk and protective factors for the infant/toddler and for the caregiver—both of whom also function within a family system. Karst notes that caregivers and families feel stress long before diagnosis and experience some relief as having a diagnosis can help make sense of the challenges and allow focus to shift to treatment (Karst & van Hecke, 2012). A Canadian study that examined family coping at the point the child transitioned to school and two years post with child behavior as an outcome versus predictor variable (e.g., not addressing the bidirectionality of the child behavior and parent stress) identified, “four family profiles based on socioeconomic risk, coping strategy utilization, family functioning, available social supports, and perceptions of family-centered support” (Zaidman-Zait, Mirenda, Szatmari, Duku, Smith, Vaillancourt, Volden, Waddell, Bennett, Zwaigenbaum, Elsabaggh, & Georgiades, 2018) noting the most disadvantaged profile as “Elevated Disengaged Coping with Limited Social Resources” whereas “Engaged…” profiles showed increased coping (Zaidman-Zait, Mirenda, Szatmari, Duku, Smith, Vaillancourt, Volden, Waddell, Bennett, Zwaigenbaum, Elsabaggh, Georgiades, et al., 2018). These findings are congruent with Altiere and Von Kluge (2009) who positively correlated adaptive coping in ASD families with “enmeshed” styles of cohesion. This characteristic was also identified among Asian families, possibly owing to collectivist versus individualist cultural perspectives (Xue, Ooh, & Magiati, 2014).

Although not specifically addressed by Zaidman-Zait, et. al., as described earlier, the negative and ambiguous interaction sequences are frequently confusing and potentially dysregulating to the caregiver and infant/toddler while carrying implications for broader family interaction and stability. Karst suggests that although the neurodiverse, though differing in social awareness might “pick up on …negatively affected by parent conflict” (Karst & van Hecke, 2012, p. 253). Yet, the infant/toddler is wholly dependent on the family system for nurture, growth, and social-emotional development throughout childhood with attachment security identified as a protective factor (Teague et al., 2017, 2018).

McKenzie and Dallos (2017) highlight the importance of systemically addressing dyadic needs versus delineation of diagnoses citing the overlap of symptoms of ASD and insecure attachment, possibly influenced by trauma and the caregiver experiences of being parented. They call for dyadic and family systems interventions with feedback processes that collectively address identified needs to mitigate the challenges associated with “escalating misunderstanding, disconnection, stress, anxiety, and poor coping” (McKenzie and Dallos, 2017, p. 642).

Social Context

Caregivers and families live within a social context that is not always understanding, appreciative, or supportive—instead, stigma is often a challenge. McKenna Gulyn and Diaz-Asper (2018) examined the literature for causal factors of autism and developed and used a survey instrument that examined beliefs about autism causation to explore the perceptions of blame from non-parents of a child with autism yielding results from 597 people who were recruited through email from a medium-sized liberal arts university community in the United States. The survey measured using 15 statements with which agreement was measured using a Likert scale from which four factors were derived: parenting, supernatural, medical-chemical, and genetics. Respondents represented men and women, whites and non-whites, ages 18 and over, with some having no college experience to having advance degrees, with non-international and international backgrounds. Interestingly parenting—which included emotional trauma and neglect and bad nutrition—was strongly indicated as a causal factor by non-white men with international origins whereas non-whites with lower education endorsed supernatural causes such as “God’s Will/Higher Power.” The Medical-Chemical factor was clearly identified—more so among those with lower education levels—while genetics was very strongly indicated as causal (McKenna Gulyn & Diaz-Asper, 2018). The results of this particular study offer an example of community perceptions related to the etiology of autism and carry implications for the social support afforded to families of infants/toddlers at risk for ASD.

Therefore, whether considering risk and protective factors related to infant/toddler, caregiver, family system, or social context—the importance of identifying and addressing systemic needs is of paramount importance for family stability and development of secure attachment for the infant/toddler—all of which underscores the importance of early detection and diagnosis.

Early Detection and Diagnosis

ASD is classified as a neurodevelopmental disorder (American Psychiatric Association, 2013; ZERO TO THREE, 2016) with features noted in very early childhood—a time when the neurotypical infant/toddler experiences progressive growth within five developmental domains of (1) cognition, (2) physical and motor skills including vision and hearing, (3) communication, (4) social and emotional skills including relationship, trust, coping/frustration tolerance, and self-confidence; and (5) adaptive/age appropriate skills related to self-care. Infants/toddlers who are neurodiverse differ developmentally and in their experiences and often fall behind their peers within these fundamentally important areas of development. Without early intervention, neither the infant/toddler nor the caregiver and other family members have the opportunity to attain full potential.

For example, it is commonly known that children and adults with features of autism spectrum disorder experience the world differently than neurotypicals. Although the presentation and severity of symptoms varies by individual, persons with autism often struggle with communication (verbal, nonverbal, and/or written) and self-expression; may misinterpret or possibly not observe social cues; often have great difficulty making or sustaining eye contact; frequently have strong preferences for some objects, activities, or a specific routine over alternatives—with extreme resistance to change; can range from being super-sensitive to touch to seeming invulnerability to pain; often prefer solitude over activities that involve other people; may be easily overstimulated and unable to regulate physical and emotional response; sometimes experience their bodies differently from neurotypical persons, possibly struggling with movement, coordination, balance and/or fine motor skills; and sometimes have other sensorimotor uniqueness sometimes with differences in hearing—or perhaps preferring or possibly rejecting certain foods, textures, smells, types of fabric (or clothing with tags), softness/roughness, or possibly activity or interaction that might temporarily result in having uncomfortable "messy or sticky hands."

Zwaigenbaum et. al., (2009) addresses some of the challenges of early detection noting the average age of diagnosis is around age four or older with disadvantaged groups despite features of autism emerging before age two. Zwaigenbaum et. al. (2009) draw on both retrospective and prospective studies and calling for increased screening by primary care physicians, noting the DSM is challenging to apply to infants/toddlers. Indeed the publication of DC:0-5™, the *Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood* (ZERO TO THREE, 2016) which is tailored to very early childhood is a welcome addition for diagnosis that includes a diagnostic algorithm for ASD and also “early atypical autism spectrum disorder.” This helps make earlier diagnosis possible allowing the infant/toddler to receive services sooner in an effort to preclude further developmental delays.

Dawson (2008) identified factors that were predictive of ASD as early as 12-months of age while making a case for early intervention suggesting that by leveraging understandings in neuroscience related to brain plasticity coupled with appropriate treatment, in the future it may be possible to prevent autism. Echoing the importance of early detection and implementation of preventative treatment, Jeans, Santos, Laxman, McBride and Dyer (2013) reported on an examination of early predictors in nationally representative data set citing Dawson and also Zwaigenbaum and colleagues (2009) also noting the American Academy of Pediatrics recommended “frequent surveillance for ASD including universal screening at 18 and 24 months” (Jeans et al., 2013; Johnson et al., 2007).

Impacts of Diagnosis

While the impact of the diagnosis in the 0-3 cohort is unlikely to have a direct “felt” impact on the infant/toddler, such is not the case for the caregiver and possibly not for other siblings as well. For example, some mothers may reflect over their own choices and feel responsible—to the point of guilt and self-blame—for the diagnosis. Research indicates reduction in self-blame and acceptance is predictive of better parental adjustment and psychological resilience (Da Paz et al., 2018; McKenna Gulyn & Diaz-Asper, 2018; Tomiyama et al., 2018; Wayment & Brookshire, 2018). There is also the matter of grieving the loss of the “hoped for” child and learning to accept the “received” child (Wayment & Brookshire, 2018). Grappling with these psychological issues (or not) can occur while parenting and co-parenting amidst other life challenges. An Australian study of co-parenting relationships identified the child's ASD diagnosis as negatively impacting the relationship with the co-parent greatly (29%) and slightly (43%) with only 15% of respondents reporting no impact (Sim, Cordier, Vaz, Netto, et al., 2017). The underlying issues are suggestive of caregivers needs to "process" the nature of the diagnosis and its meaning to find acceptance to better attend to the needs of all family members.

Research Informed Programs and Interventions

From a research perspective, program models that address the relationship between caregiver and infant/toddler at risk for ASD are varied in scope and approach. For example, the Early Start Denver Model (ESDM) is a full-featured program that is delivered to the child that is evidence-based and focused on increasing positive parent-child interaction to foster children's social and communication development and parenting skills (Paul, 2011; Rogers & Dawson, 2010; Rogers & Vismara, 2008; Smith & Iadarola, 2015). Additionally, ESDM addresses all five developmental domains and can be delivered in a provider facility or home-based settings with delivery provided by early childhood professionals and/or caregivers. ESDM interventions designed for infants/toddlers at risk for autism target developmental ages of around seven months to approximately 48 months. ESDM uses positive behavioral supports in combination with play and other methods and while involving caregivers in treatment and being attentive to family functioning, does not provide a separate context within which caregivers can come together to find mutual support—nor is family therapy provided (Rogers & Dawson, 2010).

Another attachment-referenced models identified in research that are designed to be delivered to the child included DIR/Floortime™ (Mercer, 2017; Solomon, Necheles, Ferch, & Bruckman, 2007). DIR refers to “developmental, individual-difference, relationship-based approach” (Greenspan & Weider, 2006) and is founded on the premises that children learn through relationship, vary in motor and sensory processing, and that all areas of development are interrelated (Greenspan & Weider, 2006). The model is well-developed, inherently systemic and delivered by professionals and family members, and acknowledges needs of families, yet does not provide a specific framework for caregiver or family support. Interestingly, a study that paired family focused therapy with Floortime, a component of the DIR methodology, showed very favorable results pointing to the importance family therapy (Aali, Amir, Yazdi, & Abdekhodaei, 2015).

Other attachment referenced models identified include: Focused Playtime Intervention (Siller et al., 2014), Pathways Triple-P Positive Parenting Program (Wiggins, Sofronoff, & Sanders, 2009), Parent-Child Interaction Therapy (Armstrong, Deloatche, Preece, & Agazzi, 2015; Hansen & Shillingsburg, 2016; Masse, McNeil, Wagner, & Quetsch, 2016), Video-feedback Intervention to Promote Positive Parenting Adapted to Autism (Poslawsky et al., 2014, 2015), Circle of Security (Fardoulys & Coyne, 2016), and Child Parent Relationship Therapy (Carnes-Holt & Bratton, 2014; Landreth & Bratton, 2006; Lindo, Bratton, & Landreth, 2000). Child Parent Relationship Therapy is a compelling, 10-week program that can be offered in a group setting to teach caregivers-how to interact with their child through filial play to foster secure attachment.

“CPRT has demonstrated positive effects with … sexually abused children; children whose mothers or fathers are incarcerated; children who live in domestic violence shelters; and children diagnosed with learning differences, attachment disorders, pervasive developmental disorders, chronic illness, and adjustment disorders” (Lindo et al., 2000). Each method identified carries strengths and limitations, but none attempt to directly address the needs of the infant/toddler, the caregiver, and the family. Filal therapy has been used effectively with incarcerated mothers to enhance parent-child relationships (Harris & Landreth, 1997).

Other models noted that are delivered to the ASD population that may include caregivers, but without a specific attachment focus include Hanen’s More Than Words (Carter et al., 2011), Responsive Teaching (Baranek et al., 2015), and Social Communication Emotional Regulation and Transactional Support also known as SCERTS (Lopata et al., 2018; Molteni, Guldberg, & Logan, 2013; Yu & Zhu, 2018).

Positive Behavior Support, is an evidence-based method that has been used successfully with young children with autism (Fox & Buschbacher, 2003; Neitzel, 2010) as well as adult ASD populations (McClean & Grey, 2012b) with Hieneman (2015) providing a description of the process and application, McClean & Gray offering a component by component analysis (2012a), and LaVigna & Willis (2012) addressing efficacy. The Prevent Teach Reinforce method is well-documented and researched (Dunlap et al., 2010; Fronapfel, Dunlap, Flagtvedt, Strain, & Lee, 2018; Sears, Blair, Iovannone, & Crosland, 2013) and a skilled clinician can be readily adapt the principles to for the benefit of the caregiver-infant/toddler at risk for ASD.

Contextual Challenges Across the Lifespan

Unfortunately, not only is the etiology of autism without clarity, there is also no known “cure” and the unique manifestations of ASD which vary from person to person can span a lifetime. In adulthood, persons with ASD continue to need support for employment; mental, physical and allied health; transportation, and independent living—yet those living with families reported less service use, higher unmet need, and obstacles to service (Dudley, Klinger, Meyer, Powell, & Klinger, 2019). Lever identified the significance of depression and anxiety in the ASD population throughout adulthood (Lever & Geurts, 2016) and deficits in cognitive and executive function have been identified aging and ASD (P. S. Powell, Klinger, & Klinger, 2017). Though ASD symptoms reflected little change, medical and psychiatric symptoms were noted to increase with age among adults in a residential program, while incidence of behavioral challenges decreased (Lever & Geurts, 2016). A qualitative study that examined the aging processes of lifelong caregivers identified misunderstanding and stigma associated with ASD, the complexity of caregiving roles and responsibilities, and the impact of daily schedules as factors in social exclusion impacting the couple, their other children, friendships, and long-term planning (Marsack & Perry, 2018). The reality of the lifelong nature of an ASD neurodiversity can be challenging for caregivers to fathom, while also pointing to the importance of early diagnosis and intervention for the infant/toddler as well as caregiver and family services that lay the groundwork for development of trust and secure attachment.

Programs Currently Available

In California three distinct and somewhat non-aligned legislative acts address needs and delivery of services for infants/toddlers from 0-3 at risk for autism spectrum disorder and their families: the Lanterman Developmental Disabilities Act, Cal. Welf. & Inst. Code §§4400-4850 (Lanterman) which established the California Department of Developmental Services and the Regional Center system; the California Early Intervention Services Act, 17 Cal. Code of Reg., Public Health, Div. 2, Ch.2. (EISA) and at the federal level, Part C of Individuals with Disabilities Education Act, 20 U.S.C. §§ 1431-1444 (IDEA) specifically addresses Infants and Toddlers with disabilities. While there are challenges in alignment between federal and state legislation and ongoing change to legislation and funding flow, there is general agreement that infants/toddlers ages birth to three who are at risk for autism – and their families require services and support. As California shifts toward better alignment with IDEA, Lanterman and EISA continue to provide frameworks for assessment of needs and delivery of services to infants/toddlers at risk for ASD and to their families to support the developmental needs of the infant/toddler through Early Start programs.

Regional Center of Orange County (RCOC) publishes Purchase of Services (POS) Guidelines that are specific to areas of funding and service (RCOC, 2018) including Early Intervention Services for infants/toddlers from birth to 36 months of age. The POS Guidelines summarize legislation and identify Early Intervention Service criterion beginning with a multidisciplinary assessment of the infant/toddler needs considering five developmental domains: (1) cognitive, (2) physical and motor development including vision and hearing, (3) communication, (4) social or emotional development, and (5) adaptive development. Family needs are considered to the extent they support the child's development. Following assessment, an Individualized Family Service Plan (IFSP) is developed and discussed with caregivers who can then choose to purchase services for the infant/toddler and family from approved RCOC vendors. Therefore, depending on assessed needs and the capacities of providers, infants/toddlers receive services that address needs in the some or all five domains of development with expected outcomes typically targeting the infant/toddler's development and behavior skills. It is common to address some caregiver needs – especially training – to foster the infant/toddler's skill development.

In Orange County, caregivers of infants/toddlers who qualify for services due to developmental delay or disability may select services for the child from an RCOC approved service provider. Some approved service providers offer "in center" programs commonly called "Infant Development" programs that address the infant/toddler's cognitive development; physical and motor development, including vision and hearing; communication development; social or emotional development; or adaptive development needs using multidisciplinary teams comprised of qualified professionals trained as Occupational Therapists, Speech, Language, and Hearing Pathologists, Physical Therapists, Music Therapists, and Child Development Specialists. Some existing programs also provide behavioral services to infants/toddlers—often training the caregiver to use behavioral techniques with their infant/toddler. Based upon assessed need, services may also be provided by member(s) of multidisciplinary teams in-home or other settings.

To better understand the services currently available to infants/toddlers at risk for

ASD and their families in Orange County, the publicly available vendor list for RCOC was first examined to identify providers. Next, Google searches were used to identify provider websites and program descriptions, recognizing the limitations that web-design and web-content may not completely or accurately reflect current program status. Vendor contracts were not examined, therefore, there is potential for missing program offerings that were not identified on provider websites at the time of inquiry (August 28-31, 2018). Existing services provide for individual and group-based treatment with services delivered at provider facilities, in homes, or sometimes in other settings and/or a combination of settings.

Specifically, within the population of Vendorized Providers (n=1525) as of August 28, 2018, providers offering an 805-Infant Development Program (n=56) were identified for further review. Additionally, within the Vendorized Population, all providers with "Autism" in the Provider name that seemed to be programs (other than 805 Infant Development Programs) versus individuals (e.g., not Behavior Specialist, Infant Development Specialist) were selected for review (n=6). During the period of review, attempts were made to: (1) identify a website for each provider; (2) determine whether Applied Behavior Analysis (ABA) an ABA subset, or Positive Behavior Support/Reinforcement (PBS) methodologies are cited within descriptions of Early Intervention Programs; (3) determine whether program descriptions explicitly include or offer caregiver participation; and (4) determine whether programs include services for families. Vendors ultimately removed from cited sample included three providers for which websites were not located and four vendors that did address behavioral issues within their program descriptions.

As reflected in Table 1, in Orange County, a majority of available programs serving infants/toddlers at risk for ASD do involve caregivers and provide behavioral support using ABA with a few using PBS. Vendor references to use of ABA is not at all surprising as behavioral challenges are common with ASD and the principles of ABA, when correctly applied, consistently result in modified behavior. However, ABA does not address the caregiver-infant/toddler relationship.

It is also interesting that only half of the websites reflected family care or involvement, and, in many cases, the specific services offered to the child, caregiver, and family could not be specifically determined. While it is important to acknowledge the limitations inherent to this method of data gathering and analysis, the results suggest the families of infants/toddlers at risk for ASD may not receive sufficient support to best address the needs of the developing infant/toddler. Further, although some existing programs involve caregivers in service delivery and also involve caregiver interaction with the infant/toddler, it is easy to assume that such programs foster improved attachment security—but unless attachment security is defined as a treatment objective or a measured outcome in the caregiver-infant/toddler dyad—the outcome and treatment effect is unknown. It is therefore important for new programs to consider not only how the needs of families and caregivers can be addressed in support of the developing infant/toddler at risk for ASD—but also to measure outcomes and attempt to identify the treatment effect. One provider was noted to reference their program for infants/toddlers with features of ASD to evidence-based research and interventions—specifically ESDM and ABA ("Cornerstone Autism Program," 2017). While that provider, like others on the Vendorized Provider list, identifies the uniqueness of the infant/toddler with ASD and the uniqueness of the family and the centrality of family to services—specific services available to families was not immediately clear.

Table 1. Early Intervention Services Available in Orange County in August 2018

Characteristic	805-Infant Development Program (n=56)		Autism in Provider Name (not 805 Programs) n=6	
Behavior Support				
ABA	31	55.4%	6	100.0%
Positive Only	8	14.3%		
Not Determined	17	30.4%		
Caregiver Involvement				
Yes	42	75.0%	6	100.0%
Not Determined	14	25.0%		
Considers Family				
Yes	28	50.0%	6	100.0%
Not Determined	28	50.0%		

To better understand some of the diversity factors in Orange County, data from the RCOC's Combined Expenditure Report for Fiscal Year 2016-2017, Version 1.6, (Regional Center of Orange County, 2018) were examined. It was noted that 170 infants/toddlers from birth to age 3 received services for Autism. Secondary analysis of these data, as shown in Table 2, reflect services were delivered to families and infants/toddlers from birth to age three in 16 different languages with 78% of services provided in English, 16.7% in Spanish, and 4.1% in Vietnamese. Language data for all eligible families not purchasing services during 2016-2017—4.2% of those eligible for services— are reflected in Table 3 (Regional Center of Orange County, 2018) of which 72.2% were English-speaking, 24.7% were Spanish-speaking, 2.7% were Vietnamese-speaking, and .4% spoke Mandarin-Chinese.

Table 2. Early Intervention Services in Orange County by Language of Service Delivery, 2016-2017

Language	Families (n=5029)	Percentage
Arabic	7	0.1%
ASL (American Sign Language)	4	0.1%
Cantonese Chinese	1	0.0%
English	3922	78.0%
Farsi (Persian)	6	0.1%
French	1	0.0%
Hindi (Northern India)	2	0.0%
Italian	1	0.0%
Japanese	3	0.1%
Korean	9	0.2%
Mandarin Chinese	18	0.4%
Portuguese	2	0.0%
Russian	3	0.1%
Spanish	842	16.7%
Urdu (Pakistan India)	1	0.0%
Vietnamese	207	4.1%

Note: These secondary calculations were made from publicly available data identified within the Total Annual Expenditures and Authorized Services Report for Fiscal Year 2016-2017 obtained through Regional Center of Orange County.

Table 3. Early Intervention Services Not Purchased in Orange County by Language of Service 2016-2017

Language	Families (n=223)	Percentage
English	161	72.20%
Mandarin Chinese	1	0.45%
Spanish	55	24.66%
Vietnamese	6	2.69%

Note: These secondary calculations were made from publicly available data identified within the Total Annual Expenditures and Authorized Services Report for Fiscal Year 2016-2017 obtained through Regional Center of Orange County.

Gap in Services

Legislation and RCOC POS Guidelines affirm the importance of caregivers and families to promote the development of the infant/toddler. From an attachment perspective, caregivers and families can provide a secure base from which the infant/toddler can learn to master developmental tasks. In the survey of program offerings as described on the websites of Vendorized Providers frequent references to caregiver involvement and family support were noted. However, as reflected in Table 1, specific caregiver involvement was not determined for 25% of providers and family support and involvement was not determined for half of the providers. These findings suggest that caregiver and family needs may go unmet, possibly placing the infant/toddler at increased risk for continued delays with unmitigated systemic family stress. In addition, only one of the programs available identified possible affiliation with a model that specifically addresses the relationship between caregiver and infant/toddler.

From an attachment perspective, when program services fail to specifically address relationship needs and attachment security, the infant/toddler and caregiver both remain vulnerable with the infant/toddler less likely to meet developmental milestones and go on to attain full potential. Caregivers, in turn can experience increased parental stress possibly coupled with mental health issues such as anxiety and depression (Derguy, Michel, Katia, et al., 2015; Karst & van Hecke, 2012; Keenan et al., 2016) In addition, without necessary caregiver support the infant/toddler's challenges with regulation persist, potentially escalating caregiver challenges, which then lead to increased social isolation, inability to sustain employment due to caregiving issues, financial insecurity, and partner relationship instability—all of which increase the societal burden of care for families contextualized by ASD—an atypical neurodevelopmental condition that often extends across the lifespan (Derguy, Michel, Katia, et al., 2015; Karst & van Hecke, 2012; Keenan et al., 2016).

Moreover, a retrospective evaluation of a nationally representative sample identified differences in neurotypical children and children subsequently diagnosed with features of ASD at age two, highlighting the importance of early intervention (Jeans et al., 2013). Analysis of autism prevalence data that considered differences in diagnostic criterion over time using three different datasets, reported on data from the California Department of Developmental Services, stating, "prevalence has increased by a factor of 25 from birth year 1970-2012, and by as much as a factor of 1000 from birth year 1931-2012" (Nevison et al., 2018). The Centers for Disease Control and Prevention concluded that one in 59 eight-year-olds in 11 participating states met diagnostic criterion for ASD (Baio et al., 2018).

Therefore, to support the developmental needs of the infant/toddler, caregivers and family needs must also be addressed. Programs that provide caregiver support and education and which promote improved communication and attunement within the family, can foster creation of a secure context within which infants/toddlers further develop and attain full potential. Unfortunately, research and theory-based programs that specifically address these needs are not yet in place in Orange County.

CHAPTER THREE

PURPOSE OF STUDY

Connected Families

Connected Families is a program developed to support infants/toddlers at risk for autism spectrum disorder and their caregivers and families. There are three program components and the caregiver-infant/toddler dyad is the agent of change within attachment, developmental, behavioral, and systems frameworks. The overall program hypothesis is that caregivers and their infant/toddler have the capacities to learn new and apply new skills in a relational context that improves the potential for each to more reliably predict the reaction/response of the other thereby increasing the potential for self-regulation and improved stability in the family.

- First, positive behavior support is used to incentivize desired behavior in the infant/toddler, then a stressor or conflict is added to further develop regulation/tolerance; and finally, the caregiver who has observed and been trained, uses positive behavior support with the child.
- Second a caregiver support group that delivers psychoeducation on attachment, ASD, and child-centered play. In the caregiver support group, caregivers experience an expanded system support where there is the opportunity to "feel felt" and experience a broader sense of community. Caregivers participating in group record their play with the child in the home and bring recordings to the group to share. Caregiver-infant/toddler interactions are deconstructed in group with attention given to the child's unique communication patterns. This allows the

caregiver to attend to the child's unique communication patterns. As interaction sequences become more coherent and predictable to the infant/toddler and the caregiver, the caregiver learns to function as the child's secure base and safe haven resulting with increasing coherent (versus ambiguous) interaction sequences. The improved interaction between caregiver and child offers each the ability better predict interactions offering each a foundation for improved regulation and coherence.

- Third, caregivers and siblings of the infant/toddler are offered family therapy. Family therapy is inherently systemic and structurally informed to foster desired subsystem alignment and address roles and responsibilities along with the challenges facing members of the family. Joining and enactments are used to foster healthy flexibility and cohesion within the family to provide necessary support for the infant/toddler at risk for ASD throughout the stages of development.

Connected Families is designed for implementation as a non-duplicative supplement to existing Early Start Infant Development programs that target the child's attainment of developmental milestones and behavioral improvement. With foundations in developmental, behavioral, attachment, and systems theory—Connected Families is designed to specifically address unmet caregiver and family needs to better support the development of the infant/toddler.

The Connected Families Program Manual identifies specific goals, objectives, methods, and intended outcomes for Positive Behavior Support/Caregiver Training (PBS/CT), Connected Families Caregiver Group (CFCG), and Family Therapy (FT) is included in Appendix A while the assessment measures used within the program—both to guide clinical care and for program evaluation—are included in Appendix B. Taken together, Connected Families will bridge the gap between services now available to infants/toddlers at risk for ASD and provide caregivers and family support through education, connection, and an expanded system of support for caregivers; structural family therapy to rebalance family subsystems, hierarchies, and address roles/responsibilities for family members impacted by an infant/toddler at risk for ASD—and positive behavior support that adds predictability in caregiver response so that infants/toddlers can develop secure base from which they can learn and grow and attain full potential. Therefore, as Connected Families supports the developmental and behavioral achievements of infants/toddlers, facilitates improved connection between caregivers and their infants/toddlers and one another; and addresses needs of the ASD family system—communities become more connected and empowered shifting, and decreasing the lifelong societal burden of care for ASD family members.

Connected Families is a program development that leverages the strengths of the models identified in research to deliver an early intervention and prevention program that addresses the challenges and needs surrounding families of the infant/toddler at risk for ASD within the contexts of developmental, behavioral, attachment, and systemic structural theories targeting increased secure attachment behaviors in the infant/toddler while also addressing child development and behavior, caregiver education and support, and improved family homeostasis to better support the needs of the developing child.

Connected Families informs, strengthens and supports the caregiver-infant/toddler relationship as the agent of change and delivers positive behavioral support to the infant/toddler at risk for ASD with specific attention to the child's attainment of developmental milestones and attachment needs—and trains the caregiver to do the same drawing upon developmental, behavioral, attachment, and structural theories. Second, caregivers are provided with: (1) group support for processing thoughts, emotion, and choices (within the context of caregiver culture and diversity factors) in an atmosphere of respect where there is opportunity to "feel felt" and connect with other group members; (2) attachment-based psychoeducation; and (3) parent-training that addresses development and behavior while specifically considering the infant/toddler's unique style of interaction. To increase caregiver awareness and deepen understandings of attachment with the infant/toddler, help foster improved attunement in the caregiver-infant/toddler dyad and promote cohesion in the group— caregiver-recorded interactions with their infant/toddler will be shown and discussed with the group. Thus, caregivers will have a forum to share their experiences and find ways to strengthen and support each other while acknowledging personal needs, decreasing the likelihood of isolation. Finally, Connected Families provides short-term structurally informed family therapy to assist caregivers, siblings, and the infant/toddler as they interact systemically in roles, subsystems, and hierarchies to identify appropriate boundaries and find balance and the ability adapt throughout psychosocial development.

CHAPTER FOUR

CONCEPTUAL FRAMEWORK

Connected Families is founded upon developmental, behavioral, attachment, and systems frameworks and uses the caregiver-infant/toddler dyad as the agent of change. Three program components foster development of new skills and connection and address unmet caregiver and family needs, thus strengthening the system of support for infant/toddler development.

Developmental Theories

While a complete discussion and criticism of Developmental Psychology is well beyond the scope of this paper, there are specific frameworks and theorists that are important because together they form context for expectations, interactions, interventions and possible outcomes. From a very broad perspective, developmental theories can be classified as having originated from psychoanalytic, cognitive, or learning perspectives (Bee & Boyd, 2007a, p. 21). For example, from a psychoanalytic perspective, Freud identified lifespan *psychosexual* developmental stages (oral, anal, phallic, latency, and genital) that were challenged by Erikson who proposed lifespan *psychosocial* crises in stages associated age and development. Erikson identified these crises as trust versus mistrust, autonomy versus shame and doubt; initiative versus guilt; industry versus inferiority, identity versus role confusion; intimacy versus isolation; generativity versus stagnation; and integrity versus despair (Erikson, 1950, 1982). Infants/toddlers would typically face the dilemma of trust versus mistrust possibly yielding the psychosocial strength of hope; and autonomy versus shame and doubt possibly yielding the psychosocial strength of will (Erikson, 1982, pp. 55–56). Navigation of both stages are grounded in relationship between the infant/toddler and caregiver and have implications for attachment security, behavior, and expression. Viewed systemically, caregivers and siblings also move through psychosocial development in interactive patterns and exchanges, creating additional variables for attachment security, behavior, and expression occurring individually and within dyads and subsystems.

Cognitive child developmental understandings have been heavily influenced by Piaget's work. Piaget provides, yet another developmental framework for understanding the infant/toddler's encounters as an active participant seeking knowledge and understanding using reflex and circular reactions to learn and develop (Bee & Boyd, 2007b, pp. 150, 154) with the Sensorimotor and Preoperational stages most relevant to the infant/toddler (Bee & Boyd, 2007b).

With the exception of Freud's model which was focused on nature alone, both psychoanalytic and cognitive developmental theories consider the influences of both nature and nurture. Learning theories, which are both developmental and behavioral, focus on nurture and are discussed in the context of behavior in the section that follows. Regardless of whether the infant/toddler is neurotypical, understandings and competent use of these important frameworks are often foundational to programs that foster developmental outcomes.

From a developmental perspective, the systemic challenge facing the infant/toddler at risk for ASD and the family system, stems from neurodevelopmental differences that heavily influence the infant/toddler's sensorimotor experience leading to emotional and behavioral challenges—which in turn, without intervention, influences and activates problematic interactional patterns with caregivers and siblings.

Behavioral Theories

According to Winek (2010), behavioral therapy is an early theory that relies on positive and negative behavior reinforcements which include modeling, shaping, and use of the Premack principle (willingness to perform or tolerate an activity that is *not* preferred in exchange for a reward that *is* preferred), to develop new skills and adaptive behavioral responses. Behavioral theory emerged from the Rational Choice and Social Exchange frameworks described by White, Klein, and Martin (2015) which assumes actors are rational, motivated by self-interest, with chosen behaviors hinging upon the concepts of rewards and costs. Bee and Boyd (2007a, p. 21) identify Behavioral Theories with Learning Theories and include Classical Conditioning, Operant Conditioning, and Bandura's Social-Cognitive Theory.

From a Behavioral Theory perspective, the challenges facing the infant/toddler and the family system are inclusive of developmental differences and delays that extend to problem behaviors including restrictive and repetitive behaviors, social-communications symptoms, and sensory impairment requiring caregiver/family accommodation with impact to family functioning (ZERO TO THREE, 2016, pp. 16–17). Thus, the focus of treatment is often focused on behavior.   Customary treatment for infants/toddlers and their caregivers generally includes Applied Behavior Analysis (ABA), a principle-based series of interventions that are based on behavior reinforcement practiced by professional behavioral analysts (Association of Professional Behaviour Analysts, 2017). Unlike standard ABA interventions, Connected Families use of Positive

Behavior Support (PBS) was chosen to foster the caregiver-infant/toddler relationship allowing for dyadic communication congruence unimpeded by punitive reinforcements. The Prevent-Teach-Reinforce method (Dunlap et al., 2010) is school-based and therefore appropriate to older children in a school setting. However Sears (2013) successfully adapted these PBS principles to a home setting involving parents of two boys with ASD to address their problem behaviors with parental involvement. PBS holds great promise over punitive interventions, especially for infants/toddlers struggling with emotional dysregulation and need for comfort from a predictable caregiver (Skelly, 2007).

Thus, Behavioral Theory has important implications for program delivery to ASD infants/toddlers and their caregivers with the understanding that as infants/toddlers move through the stages of psychosocial development—especially during adolescence—relationship with the caregiver can take on a different level of importance. In fact, if caregivers learn to use Behavior Theory to incentivize, punish, and control behavior without also cultivating a positive relationship with their child, there will most certainly be dyadic relationship and behavior challenges during adolescence and young adulthood. The new program will therefore attend to the infant/toddler's developmental needs—partially through existing programs—but with the enhancement of leveraging the principles of Behavior Theory with the distinction of focusing on use of positive, rather than punitive reinforcement, and also draw upon the foundations and principles within Attachment and Structural systems theories.

Attachment Theory

Attachment Theory, which stands as a grand theory of personality development put forth by John Bowlby in three separate volumes (Bowlby, 1973, 1980, 1982; Fletcher & Gallichan, 2016; Simpson, Cassidy, & Shaver, 1999), emerged from evolutionary theory proposed by Darwin in the nineteenth century with importance of relationship at the very heart of the theory. Building on Darwin's foundation of survival with the goal of reproduction, Bowlby suggested that autism came about due to the infant/toddler's inability to predict caregiver response. Bowlby built upon Darwin's foundation which was a proposal well ahead of any exploration of the human genome and its intergenerational expression and long before advances in neuroscience and the concept of neuroception. Discussing the evolutionary base for attachment theory, Simpson, Cassidy, & Shaver (1999) draw on Darwin's work specifying animals are social and therefore uncomfortable when separated and comfortable together because staying in close association provides the greatest protection from danger while living solitary is more likely to result in death.

Also placing a great deal of importance on behavior, Bowlby observed interactions in animals and among people as adults cared for their young and noticed common patterns at separation. The young and vulnerable would first protest and if unanswered would move to despair/despondency with slowed motor skills and silence. Over time, without the caregiver, the young detach and seem to move toward independence and self-reliance. Bowlby linked each response with improved survival outcomes and as setting the stage for a developmental life story and as grounds for attachment style (Simpson et al., 1999).

Bowlby identified phases of attachment beginning at birth and identified fear and exploration as biologically-based behavior systems. Referring to Bowlby's work in 1973, Simpson indicates that during the third phase of attachment which typically occurs between seven months and three years of age, children develop an internal working model of proximity and social interaction based on their experiences with significant others. It is during this phase that children maintain closeness (proximity) to the caregiver and resist separation, and also turn to the attachment figure (caregiver) for comfort and support (safe haven), and depend on the attachment figure as a "secure base" from which the child can launch into and return from nonattachment behaviors such play and exploration. (Simpson et al., 1999).

Bowlby suggested that separation anxiety varies based on interaction in the caregiver-child relationship and Ainsworth's experimentation with mother-child interaction produced attachment classifications of ambivalent, avoidant, and secure (Bretherton, 1992). Therefore, attachment style develops and is carried forward in life with implications for adult relationships potentially including caregiving. Bowlby's development of Attachment Theory highlighted the importance of caregiver attunement and responsiveness to the needs of the child and viewed the nature of interactions within the caregiver-child dyad as a foundation for creating secure attachment (Bowlby, 1973, 1980, 1982). Ainsworth's work with the strange situation procedure has further informed understandings of child-caregiver attachment and provided a basis from which many longitudinal follow-up studies sprung—with varying hypotheses but with "a general expectation that a secure attachment predicts better functioning" also noting the challenges associated with measuring constructs of attachment during development (Thompson, 1999). A synthesis of 40 articles published between 1987 and 2015 addressing attachment in children with ASD noted that while severity of ASD is a factor also pointing out “there is considerable evidence that children with ASD are capable of forming secure, selective attachment relationships with caregivers” (Teague et al., 2017). Additionally, pre- and post-intervention assessments of 18 caregiver-child dyads with older children (children’s mean chronological age 6 years, 11 months; mean developmental age 5 years 10 months at baseline) validated the severity of ASD as a factor in caregiver-child relatedness, concluded caregiver-child interaction at baseline was the best predictor of change (Hobson, Tarver, Beurkens, and Hobson, 2015, p. 753). In a study that considered neuroscientific aspects of attachment and emotion processing in children with ASD, Sivaratnam, Newman, Tonge & Rinehart noted the bidirectionality and interdependencies within formation of caregiver-child attachment “mediated by the severity of the child’s ASD symptomology, the child’s cognitive ability, as well as parental stress and coping styles.” (2015).

Infants/toddlers are most certainly dependent on adult caregivers to meet their basic needs and those at risk for ASD—typically display communication and behavioral challenges that differ from a neurotypical child of the same age. Child communication and behavior challenges impact caregiver stress and may impair the caregiver’s ability to attune to their child. Lack of caregiver attunement prevents the child from developing a “secure base” from which to explore and also a “safe haven” where the necessary comfort is experienced for emotional regulation. These interactions can then lead to the child becoming further isolated, possibly missing important developmental milestones—such as development of an internal working model, resulting further communication deficits and behavioral issues. Thus, for infants/toddlers experiencing ASD—and their caregivers, the circularity of the interaction can become inherently problematic for both without an attachment-based intervention.

Building on Darwin’s foundation and actually advancing understandings of attachment, Panksepp’s studies of animal and human emotions provide new understandings of mammalian experience and expression of emotion at a neurobiological level (Panksepp, 1998). In conjunction with proposing Polyvagal Theory, Porges defines neuroception as the “ways that perception engages and affects neural regulation—is involved in the following behaviors: social engagement, mobilization of fight-flight, play and foreplay, immobilization due to life threat, and immobilization without fear” (Montgomery, 2013, p.90). Porges’ theory specifically considers the experience of an “other” with survival as a foundation.

While a complete discussion of neuroscience and attachment is well beyond the scope of this paper, evolutionary theory provides a foundation for their emergence and convergence and Badenoch provides some linkage noting Landreth’s (1991) work with child-centered play paired with new understandings from neuroscience that allow for the rebuilding of pathways that offer the opportunity for improved regulation under stress (Badenoch, 2008). Although Badenoch is not specifically addressing the challenges facing infants/toddlers with autism, the concepts certainly apply. Considering Porges’ work, the interaction within the caregiver-child dyad in families contextualized by autism spectrum disorder could benefit from attachment-based interventions that foster connection and the ability to experience security.

Taken together, current research points to the importance of attachment theory with specific application to infants/toddlers and their caregivers as a prerequisite to emotional and behavioral regulation. The new program will therefore specifically address the infant/toddler's attachment needs through caregiver education and support that addresses the dysregulation and behavioral challenges that are unique to infants/toddlers at risk for ASD. The new program will additionally draw upon broad systemic frameworks to foster families' abilities to adapt to change.

Systems Theory

Systems theory is vast and expansive and is considered broadly to include the contributions of Bateson who discussed "homeostatic circuits" within the systemic context of biology and evolution (Bateson, 2000). Turning to communication, in their seminal discussion of the organization of human interaction, Watzlawick, Beavin, and Jackson identify family interactions as a system that "is stable with respect to certain of its variables…tend to remain within defined limits" (1967, p. 134) noting Jackson's concept of "family homeostasis" (Watzlawick et al., 1967) which suggests actors repeat known sequences or patterns to maintain stability or status quo despite the need for change. Family systems work therefore addresses the need for change and adaptation, through the challenging the feedback mechanisms and this perspective is endemic to the Positive Behavior Support/Caregiver Training program component while specific systemic models are used within other program components.

For example, one systemic perspective used to conceptualize work within the Family Therapy program component, is the Circumplex Model suggested by Olson (Altiere & von Kluge, 2009; Olson, 2000). Olson's systemic model addresses cohesion and flexibility on two axes with family cohesion spanning from enmeshed to disengaged and flexibility ranging from rigid to overly flexible. This model has particular relevance for caregivers and families of the neurodiverse child as Altiere and von Kluge noted that enmeshed families perceived more social support from family and friends (Altiere & von Kluge, 2009; Olson, 2000). With respect to flexibility, it is well known that structure, consistency, and predictability is important to persons with ASD, yet if the family is too rigid and locked in homeostasis, their abilities to adapt to the changing developmental needs of the infant/toddler will be problematic.

The principles of Structural Therapy, a family systems model, that was developed by Salvador Minuchin in the 1970s using a combination of research and treatment of families at the Wiltwyck School for Boys in New York and the Philadelphia Child Guidance Center (Winek, 2010) are also specifically applied in the Family Therapy program component. More specifically, Minuchin taught that interactions within the family system define the members in relationship to each other noting that repetition creates a transactional pattern that informs or defines family structure (Colapinto, 2016, Minuchin, 1974). As such, Structural theory sees the family as a system with subsystems, hierarchies, roles and rules, and boundaries; and structural techniques include joining, enactments, mapping (Winek, 2010) with the capacity to “get stuck” developmentally thus, benefitting from unbalancing and crisis induction to change patterns of interaction and foster the family’s ability to adapt (Colapinto, 2016).

Therefore, from a Structural perspective, the family system is developmentally stuck, struggling with roles and rules, boundaries, and likely imbalances in hierarchies and subsystems owing to an infant/toddler at risk for ASD. Connected Families draws upon Minuchin’s work as the therapist joins with the family as an agent of change to assist with establishing rules, roles, and boundaries first creating a comfortable and predictable environment where the infant/toddler can achieve the desired responses while the caregiver observes and learns new ways of interacting with the infant/toddler that allow for emotional regulation and connection.

Functional Family Therapy, an evidence-based model, that has been used with families of youth facing a variety of problems, is also an excellent model that is worthy of further exploration for inclusion. Strengths of the model include the scientific foundation, multi-systemic perspective, and well-defined protocol within three phases and the systemic measurements that are endemic to the model (Sexton, 2016). Further, the model relies on the dynamic interactions between the therapist and family as the agent of change making a compelling case for further consideration with families of ASD (Sexton, 2019).

Experiential and play-based methods are systemically founded and are also used within the Caregiver Group to offer a rich context for promoting caregiver change and the ability to adapt to support the needs of the developing infant/toddler. Although the Caregiver Group is inherently systemic, the fourth module—which is itself a standalone filial treatment program that promotes attachment—Child-Parent Relationship Therapy (Landreth & Bratton, 2006)—has been cited by the American Psychological Association "as meeting the criteria for promising or probably efficacious treatment" (Bratton, Landreth, & Lin, 2010, p. 290) and it has been used successfully with parents of children with pervasive developmental disorder (Bratton et al., 2010).

Synthesis

A collective and synthesized perspective of the challenges facing infant/toddler at risk for ASD and caregiver that considers development, behavior, attachment and structural systems must also consider cultural and diversity issues within the family for appropriate program delivery. Cultural and diversity topics are worthy of specific exploration that is beyond the scope of this paper, but conceptualization of the infant/toddler and caregiver must minimally consider whether family culture is collectivist versus individualist and possible implications and meanings of ASD to the family within the culture. Diversity factors such as gender, race, color, age, ancestry, national origin, religion, veteran status, mental/physical disabilities must be also considered and understood in order to effectively and compassionately conceptualize and provide competent care to challenges experienced by caregivers and other family members as they interact with an infant/toddler at risk for ASD. Broadly speaking, understanding and respect for diversity and cultural factors need to be integrated into the treatment planning and service delivery together with the theoretical models of care for the benefit of the infant/toddler, caregiver and other family members.

With these important matters in mind, focus is then turned to integrating the theories previously discussed to define the challenges and needs surrounding the infant/toddler at risk for ASD and caregiver with implications for the family and community. More specifically, ASD is classified as a neurodevelopmental disorder (American Psychiatric Association, 2013; ZERO TO THREE, 2016) with features noted in very early childhood. Infants/toddlers who are neurodiverse often experience sensorimotor differences and use self-expression differently from an infant/toddler with typical development. The atypical infant/toddler is therefore vulnerable to being misunderstood by caregivers; with caregivers likewise vulnerable to increased stress and undermined caregiver confidence. Misunderstanding, stress, and decreased confidence then set up an interactional pattern of behavioral miscuing in the infant/toddler-caregiver dyad which can lead to further and increasingly extreme emotional dysregulation in the infant/toddler while perpetuating caregiver stress. The infant/toddler, unable to regulate and make sense of the world, can fall behind failing to meet typical physiological and behavioral developmental milestones.

It is important to note the availability and significance of existing programs available through California Early Intervention Services Act of 1993 (CCR Title 17 Public Health. Division 2: Health and Welfare Agency -Department of Developmental Services Regulations. Chapter 2: Early Intervention Services, 2015)and the Early Start (Department of Developmental Services, n.d.) initiative that are coordinated through the state's system of Regional Centers. Caregivers of infants/toddlers who qualify for services due to a developmental delay or disability can select services for the child from an approved service provider. Approved service providers offer programs that address cognitive development; physical and motor development, including vision and hearing; communication development; social or emotional development; or adaptive development needs using multidisciplinary teams comprised of qualified professionals trained as Occupational Therapists, Speech, Language, and Hearing Pathologists, Physical Therapists, Music Therapists, and Child Development Specialists. Some existing programs also provide behavioral services to infants/toddlers using Applied Behavior Analysis with the explicit goal of altering behavior in infant/toddler—often training the caregiver to use behavioral techniques with their infant/toddler.

Unfortunately, the programs that are currently available do not explicitly target improved attachment security as an outcome, nor do existing programs explicitly address many of the systemic factors that can limit the effectiveness of treatment. Because infants/toddlers at risk for ASD have differences in communication and behavior, without training that is attentive to attachment issues, caregivers may miss the infant/toddler's attempts to communicate and interact. Missed opportunities and miscuing then contribute to negative interactional patterns that continue to impact the infant/young-child, caregiver, and all other family members—increasing stress, potential for mental health issues, isolation, with increased potential for divorce.

Therefore, Connected Families, a new program and approach using multiple theories is needed to supplement existing programs and support both caregivers and infants/toddlers at risk for ASD—and the family. Connected Families addresses the need for change systemically in all three program components. Each program component is founded in developmental, behavioral, and attachment theories that are systemically applied to alter homeostasis and foster caregivers' and families' abilities to adapt to the changing needs of the developing infant/toddler. Within each program component, the therapist systemically fosters development, behavior change, and relationship acting as a "secure base" and "safe haven" that allows for the exploration of new ideas and development of competencies—and for reassurance, comfort and soothing support when needed. By improving interaction in the caregiver-infant/toddler relationship and increasing caregiver support and interaction skills, attending to the infant-young/child's developmental and behavioral needs, and promoting healthy adaptation within the family system, Connected Families empowers all family members to reach full potential and meaningfully engage in life.

CHAPTER FIVE

METHODOLOGY

The Connected Families program is designed for implementation as a nonduplicative, integrated supplement to existing California Early Start (Infant Development/Infant Stimulation or Global) programs which target the infant/toddler's (from birth to 36 months) attainment of developmental milestones and behavioral improvement. With foundations in developmental, behavioral, attachment, and systems theories—Connected Families is designed to specifically address unmet caregiver and family needs to better support the development of the infant/toddler at risk for autism spectrum disorder (ASD) targeting increased secure attachment interaction in the caregiver-infant/toddler dyad and improved healthy family adaptability to better support the infant/toddler's developmental needs. Using the caregiver-infant/toddler dyad as the agent of change, Connected Families corrects and stabilizes ambiguous interaction sequences that are believed to result from miscuing that stems from the infant/toddler's inherent dysregulation coupled with the caregiver's expectation of a neurotypical response leading to increased caregiver stress and lack of caregiver confidence (Derguy, Michel, Katia, et al., 2015; Karst & van Hecke, 2012; Keenan et al., 2016). As a new early intervention and prevention program suite, Connected Families provides caregiver education specific to autism and positive behavior support together with caregiver support and family therapy to better address the challenges and needs surrounding families of the infant/toddler at risk for ASD.

Program Overview

Connected Families is a program suite comprised of three distinct components: Positive Behavior Support/Caregiver Training (PBS/CT); Connected Families Caregiver Group (CFCG); and Family Therapy (FT) that are supported by a Logic Model. In the PBS/CT component, the therapist uses techniques including reinforcement and shaping to foster desired behaviors and the infant/toddler relationship with the therapist. Next the therapist introduces tension as infants/toddlers master new skills including improved ability to regulate emotion and behavior; then as the infant/toddler masters these skills, prompts can be faded as the relationship with the therapist motivates behavior and regulation. As the infant/toddler consistently attains 75% of goals the with caregiver shadows the therapist working with the child and later works one on one with the child as the therapist provides coaching to the caregiver (K. G. Shanahan, personal communication, April 15, 2019).

The second program component is the Connected Families Caregivers Group (CFCG), a small, closed group of not more than 10 participants per therapist which meets once weekly and includes four 10-week modules where group cohesion and support is fostered. Participants can elect to opt-in to the group at each module break. The content of Module I experientially addresses caregiver and family needs, processes and strategies including caregiver perspectives about their child, emotional responses and recognition of need, the importance of self-care and of a sense of community. Module II is also experiential and addresses the neurodiversity of autism throughout development and across the lifespan as well as foundations of attachment and meanings of autism for the family. Module III explores parenting models as a foundation for relationship and development and experientially explores positive behavior support between caregivers and their infant/toddler. Module IV is a complete implementation attachment-based filial therapy as conceived by Bratton, Landreth, Kellam, and Blackard in the *Child-Parent Relationship Therapy (CPRT) Treatment Manual: A 10-Session Filial Therapy Model for Training Parents* (2006). Module IV requires therapist credentialing before applying the model, then additional credentialing to teach the model to the caregivers; however, it has been applied with ASD children and their caregivers (Beckloff, 1997; Duffy, 2008) and was chosen explicitly because of the model's focus on developing attachment (Duffy, 2008).

Family Therapy is the third program component, which draws extensively on family systems and experiential frameworks to foster the families' abilities to adapt to the changing needs of the infant/toddler throughout development and to better attend to the needs of the whole family. More specifically as previously described systemic work draws from the contributions of Minuchin (Structural Family Systems), Olson (Circumplex Model), Sexton and Alexander (Functional Family Systems), and Bowen with humanistic experiential influences.

Participation, Implementation & Assessment

Connected Families participants are referred to Early Start programming and choose a specific site and program through Regional Center of Orange County based on the infant/toddler's identified needs as described in Chapter One. Connected Families coordinates services, including the Intake Process with Early Start services. Participation in Connected Families is initially limited to caregivers and families of infants /toddlers at risk for ASD without accompanying medical fragility. Caregivers and families must be willing and able to commit their time for completion of the program requirements which includes attendance, fostering the development of new skills within the infant/toddler, learning and applying new caregiver skills, and adaptation to development and change within the family system. Additionally, caregivers must have the ability to physically interact with their infant/toddler and exhibit the desire and capacity to be emotionally available to the infant/toddler and be able to spend focused time with the infant/toddler for a minimum of 30 minutes. To protect the child from attachment injuries, caregivers who have perpetrated abuse on the infant/toddler without rehabilitation, with serious psychopathology, or unmitigated addictions when identified will be referred to a higher level of care either as a prerequisite or corequisite to program participation. A higher level of care can include referrals for psychiatric and/or medical evaluation, individual psychotherapy, and/or participation in 12-step or other recovery models when indicated. Program staff working with caregivers will have appropriate referral sources immediately available to share with caregivers as appropriate.

As Connected Families resources are limited, not all caregiver-infant/toddler dyads interested in the program can be served at the same time; therefore, a waitlist will be used with waitlisted infants/toddlers continuing to receive customary care through their Early Start program. With this structure in place from the beginning, the Connected Families program suite can undergo necessary change based on formative evaluation—considering actual versus expected outcomes for each program component. As program components are stabilized—the infrastructure is stable, yet sufficiently flexible to adapt to research needs using a quasi-experimental design that compares Connected Families participants pre-test and post-test with those waitlisted, but participating Early Start programming which is treatment as usual (Campbell & Stanley, 1963).

Therefore, since evaluation and research are anticipated following program implementation, controls necessary for case management are required along with controls that allow for de-identifying data that can be subsequently analyzed in aggregate. This provides a foundation for care as well as possible human studies research that can only be conducted following the approval of the Institutional Review Board.

As suggested a variety of tools are used for purposes of initial assessment, case management, program evaluation—and possibly future research. In general, baseline or pre-treatment assessments are used for case conceptualization and assistance in developing treatment goals. Progress notes are maintained throughout the duration of each program component for purposes of case management.

Additionally, time-series instruments also offer important case management data with respect to caregiver depression and anxiety, possibly indicating a need for a different level of care—or even potential safety issues for the infant/toddler. From a program evaluation perspective, time-series instruments provide perspectives of "within program" experiences and with proper controls allow for the ability to evaluate shifts as participants move through each program component possibly lending perspectives about differences in treatment effect between program components. For example, it would be interesting to know whether caregiver depression and anxiety vary within each program component—and it would also be interesting to understand whether one program component accomplishes this more frequently, or more rapidly than others. Mid-point measures are used primarily for program evaluation and allow for better understandings of whether the program component is achieving the desired outcomes.

Finally, post-treatment measurements are also used for case management and program evaluation. From a clinical perspective, when post-treatment measures reflect needs for additional services, appropriate referrals can be provided. Additionally, post-treatment measures offer important perspectives about whether program outcomes were attained as pre-treatment results can be compared with post treatment results.

As indicated, in order to use assessment data for case management, program evaluation, and future research a sound control environment that provides for confidentiality and protection of participants is needed. All Connected Families program staff are required to complete and maintain compliance with Federal Policy for the Protection of Human Subjects also known as or the Common Rule (HHS regulations, 45 CFR part 46) before and throughout the program. Additionally, an IRB approval is required before any program data can be used for research purposes and a Data Management Plan shall be included with the IRB application. The Data Management Plan specifies the role of the Document Custodian, who has no program implementation or evaluation responsibilities and who has no responsibility for clinical care; rather the Document Custodian functions as a gatekeeper to maintain program data that can be meaningfully analyzed while deidentified. Case management staff maintain clinical records including all assessment inventories in the clinical file and also provide a copy of each assessment inventory to the Document Custodian. The Document Custodian ensures the instrument is dated, correlated with a program component, and annotated to indicate whether it is pre-treatment, time-series, mid-treatment, or post-treatment. The Document Custodian then assigns a unique identifier for each caregiver-infant/toddler pair and family constellation.

The unique identifier is placed on Document Custodian's copy of the assessment instruments and data that could identify specific persons (e.g., all non-public personally identifiable information) is redacted before the instrument is stored or shared with the evaluation team, thus resulting in de-identifying data used for evaluation or research. The master list of unique identifiers is securely maintained and inaccessible to case management the evaluation team, and researchers. This arrangement allows for evaluation within and between programs without identifying participants and also provides a means of preserving deidentified data that can be used in research.

With respect to specific assessments, all infants/toddlers are initially assessed at intake by a multidisciplinary team in the Early Start program addressing all five developmental domains: (1) cognitive; (2) physical and motor development including vision and hearing; (3) communication; (4) social or emotional development; and (5) adaptive development using a combination of standardized inventories, observation, and self-report measures provided by caregivers. Connected Families coordinates care with the Early Start program for each infant/toddler and thus is able to leverage these measures for use as baseline assessments for the infant/toddler. In addition, Connected Families will use a series of assessments for the control and treatment groups for purposes of understanding and comparing baseline and post-treatment caregiver attachment style, use of empathy, depression, anxiety, and stress—and the infant/toddler's attachment interaction patterns. Time-series measures will be introduced at multiple points in time within Connected Families program components to support future evaluation efforts that address the validity of the model and delivery (Chen, 2015, Chapter 10). The Connected Families Logic Model at Table 4 identifies the instruments used within the program. The

Program Manual at Appendix A specifically identifies the program materials including assessments and functions as a guide for program implementation and operation—also providing a foundation for program evaluation. The assessment measures themselves are located at Appendix B.

Evaluation Methods

The Overall Evaluation Plan is presented in two parts including best practices, identification and description of key stakeholders, purpose of the evaluation and the logic model. Generally speaking, an early formative evaluation should follow best practices and engage and meet the needs of key stakeholders while also considering program adherence to the logic model and identifying program results.

Best Practices

The Centers for Disease Control and Prevention Program Performance and Evaluation Office provides a framework for evaluation involving six primary steps as follows: "(1) Engage Stakeholders; (2) Describe the Program; (3) Focus Evaluation Design; (4) Gather Credible Evidence; (5) Justify Conclusions; and Ensure Use and Share Lessons" (Centers for Disease Control and Prevention, 2011, p. 4). The framework identifies four standards that apply to every phase of evaluation including, "Utility, Feasibility, Propriety, and Accuracy" (Centers for Disease Control and Prevention, 2011, p. 4).

Given the formative nature of Connected Families, and drawing upon the standard of utility, a utilization-focused evaluation as described by Patton can be important to program administrators, staff, and participants, possibly resulting in adjustments to enhance implementation and outcomes (Patton, 2012, p. 132). From a theory-driven perspective, a constructive outcome evaluation could help identify strengths and weaknesses within program components in relationship to expected outcomes (Chen, 2015, p. 12) or possibly an integrated process/outcome evaluation that considers program theory, qualitative and quantitative data analysis as a whole program with individual components with linkages to change and outcomes (Chen, 2015, pp. 328–329) to validate the model and identify necessary improvements (Chen, 2015, p. 305). Involvement of key stakeholders in planning the evaluations can shape the purpose, scope, breadth, and depth of the evaluation using a best practices framework, while also offering an opportunity to better identify changes needed to foster improvement in outcomes for program participants. The Program Manual, at Appendix A provides materials that can be useful for initial evaluation, but more importantly, a framework for consistent, well-documented program implementation that is founded in theory while targeting specific and measurable outcomes.

Key Stakeholders

As a formative program, Connected Families has multiple stakeholders. Primary stakeholders include multidisciplinary program staff comprised of mental health professionals; speech, language, and hearing pathologists; occupational therapists; physical therapists; music therapists; behavioral therapists; and other early interventionists involved with Early Start program delivery along with Connected Families clinical and administrative program staff. In addition, the infants/toddlers and their caregivers and families served within the program are primary stakeholders. Other key stakeholders include Regional Center staff such as client service coordinators, psychologists, and multi-disciplinary personnel who conduct initial assessment, provide referrals to the program, and monitor progress of program participants. When considering specific involvement in the evaluation process, it is important to include members of each stakeholder group, with attention to diversity factors.

Program personnel, Regional Center personnel, and other stakeholders with interests in a theory-driven approach to outcome evaluation includes researchers and developers of models used in program design and implementation as well as designers of assessment measures used within the program (Chen, 2015). From socio-ecological and longitudinal perspectives, members of the community are also stakeholders as the intended impact is alleviation of the societal burden of care for caregivers and families of infants/toddlers at risk for ASD. Therefore, the program development and Program Manual will need to provide sufficient detail and controls over implementation for future evaluation.

Purpose

The identified needs and interests of key stakeholders will drive the purpose of the Connected Families Evaluation Plan the considering phase of implementation and need to validate the model along with possibly addressing: (1) the extent to which program goals are met; (2) the nature and extent to which internal and external factors bearing on outcomes drive the need for change to achieve program success —and (3) issues of transparency and accountability related to the use of funds in a non-profit setting (Centers for Disease Control and Prevention, 2011).

When considering the extent to which program goals are met, it is important to fully develop an evaluation plan that considers the formative status of the Connected Families model and the need to collect and appropriately analyze data to determine any adjustments needed to achieve desired outcomes while also validating the program model. Adherence to the model, deviation from the model, and modification of the model must therefore be specifically identified when gathering data, managing, and monitoring the program in keeping with the comprehensive Program Manual.

Logic Model

The Logic Model for Connected Families is included as Table 4 and identifies intended Program Inputs, Processes (Activities), Outputs (Participation), Short- and Long-Term Outcomes and Impact that provides a framework for development of the Program Manual as well as a foundation for future program evaluation. Connected Families is planned for delivery in a fully-equipped Orange County Early Intervention Center staffed by a team of multidisciplinary professionals representing mental health; physical, occupational, and music therapy; speech, language and hearing pathologists; behavioral specialists; and other early interventionists. Although not specifically depicted as a part of the Logic Model, the infant/toddler's Early Start program with which Connected Families coordinates treatment and care addresses the developmental needs of qualified and referred developmentally delayed and disabled infants from birth to 36 months within five developmental domains: (1) cognitive; (2) physical and motor development including vision and hearing; (3) communication; (4) social or emotional development; and (5) adaptive development (self-care) including the infants/toddlers participating in Connected Families programming. Integration of skill building—which includes emotional regulation and behavior— across developmental domains is within the very nature of Infant Development programs creating opportunity to further integration of Connected Families for infants/toddlers at risk for ASD with their caregivers. Therefore, the Logic Model contains three core Connected Families program components and identifies the collective expected outcomes.

The caregiver and infant/toddler comprise the unit of treatment and their relationship is leveraged as the agent of change within Connected Families and it is therefore important to first discuss their initial baseline assessment. The Program Manual at Appendix A addresses this process in detail, however, the assessment itself is comprised of (1) a three-hour Behavior and Relationship observation by a skilled mental health professional with expertise in early child development as the infant/toddler and caregiver move through the Early Start program; (2) an extensive caregiver interview that captures developmental and trauma history; and (3) caregiver completed inventories on behalf of the infant/toddler.

Table 4. Connected Families Logic Model: An Early Intervention and Prevention Program for Families of Infants/Toddlers at Risk for Autism Spectrum Disorder

Inputs	Process	Outputs	Outcomes		Impact
	(Activities)	(Participation)	Short-Term	Long Term	
Caregivers and their Infant/Toddler at risk for Autism Spectrum Disorder (ASD) are referred through Regional Center, insurance, or are self-referred (private pay). Coordination with existing external multidisciplinary team comprised of mental health professionals; physical, occupational, and music therapists; and speech, language, and hearing pathologists, and early interventionists. The Therapy Center is equipped with readily available, age appropriate toys and other materials that are used to promote the development of gross and fine motor skills, speech, language, hearing, and feeding skills, and social and behavioral interactions and audio//video equipment. Assessment instruments including DECA I/T, CBCL, PSI-4-SF, BDI, BAI, SSI, and TAS-45, FACES IV, GSRS, SRS, & ORS.	1. Conduct multi-disciplinary baseline assessment of child's developmental needs; assess Caregiver baseline attachment style; and assess baseline Caregiver-Infant/Toddler interactions. 2. Provide developmental services to the child. 3. Provide psychoeducation related to attachment, PBS, and ASD in Caregiver Group fostering connections between Caregivers and increased attunement between Caregivers and their Infants/Toddlers. 4. Deliver PBS interventions to the Infant/Toddler, introducing tension as child learns, complies and is able regulate. 5. Provide family therapy to rebalance subsystems, promote healthy role responsibilities, communication skills and foster families' abilities to adapt.	85% of Caregivers experience mutual support in the Caregiver Group. 85% of Caregivers show increased awareness of their own attachment style and patterns of interaction. 85% of Caregivers become more aware of their child's unique bids for connection and communication patterns. 85% of Caregivers are able to implement positive behavior support with the Infant/Toddler. 85% of Caregiver-Infant/Toddler dyads demonstrate improved communication (e.g., less ambiguity and more direct/verbal) and interactions are congruent with less frequent miscuing).	80% of Caregivers show increases in attunement with the Infant/Toddler. 80% of infants/ toddlers respond appropriately to positive behavior support and show improvement in frustration tolerance 80% of Infants/Toddlers exhibit increased incidence of secure attachment behaviors such as relying on the Caregiver as a "secure base" for exploration and as a "safe haven" when needing comfort 80% of Caregivers are confident of their abilities to capably attend to the child's attachment and developmental needs and are able to self-soothe and ask for help when necessary.	70% of Caregivers show evidence awareness of needs and resources and are willing and able to access support. 70% of Caregivers report less parenting stress. 70% of Caregivers report less depression and anxiety. 70% of Caregivers report improvement in the ability to adapt to the changing needs of infant/toddler during development and better attend to the needs of the whole family.	60% of Families of infants/toddlers at risk for ASD are better able to support each other—both inside the family—and in a broader system of support—increasing potential for all family members to meaningfully engage in work, school, and play across the lifespan; thus, decreasing the impact of stress and likelihood of isolation and lessening the societal burden of care.

Table 5 reflects the inventories completed by the caregiver on behalf of the child at baseline, and again at the conclusion of the program.

Table 5. Measures to Evaluate Infant/Toddler Needs and Change.

Informant	Instruments	Assessment Frequency	Factors Assessed
Caregiver, Teacher	CBCL 1.5-5 with LDS 18-35 mos.	Pre & Post	Syndromes (Emotional Reactivity, Anxious/Depressed, Somatic Complaints, Withdrawn, Sleep Problems, Attention Problems, Aggressive Behavior), Internalizing, Externalizing, Total Problems, Stress, DSM Oriented Scales (Depressive, Anxiety, Autism Spectrum, Attention Deficit/Hyperactivity, Oppositional Defiant), Language Development
Caregiver, Teacher	DECA I/T	Pre & Post	Attachment/Relationships, Initiative, Self-Regulation, Total Protective Factors

Note: The table depicts baseline Infant/Toddler assessments that are administered before participation in Connected Families at Intake for PBS/CT. The instruments are used again "post" treatment at or near the end of Caregiver completion of Module III of the Connected Families Caregiver Group.

As discussed and indicated in Table 5, Connected Families partially identifies infant/toddler needs during the Intake using the Devereux Early Childhood Assessment for Infants and Toddlers (Mackrain & LeBuffe, 2018; G. Powell, Mackrain, & Lebuffe, 2007) commonly referenced as the DECA I/T, and the Child Behavior Checklist with Language Development Scale (Achenbach, 2018; Achenbach & Rescorla, 2000), commonly referred to as the CBCL-LDS as collected at intake (baseline) through the Early Start program or through Connected Families. Both measures must be completed by the caregiver, and it is preferred that they are also completed by a teacher in addition if at all possible as another perspective on the infant/toddler. The CBCL-LDS is psychometrically strong and has been demonstrated to accurately characterize ASD (Pandolfi, Magyar, & Dill, 2009) provide specific and valuable information about the strengths and areas of growth for each infant/toddler that are used to guide treatment within Early Start program as well as in Connected Families.

With respect to psychometrics on the DECA I/T, internal reliability for Total Protective factors ranged from $\alpha = .90$-.94 and $\alpha = .93$-.94 for parent and teacher raters respectively with Initiative and Attachment/Relationship factors on the DECA-I ranging from $\alpha = .80$ to .93 and Initiate/Self-Regulation and Attachment/Relationship factors on the DECA-T ranging from $\alpha = .79$ to .93 on the DECA-T (G. Powell, Mackrain, & Lebuffe, 2007) However, when parent and teacher ratings of the DECA I/T were examined for reliability and validity confirming earlier findings for Total Protective factor, but exposing validity challenges among the other scales due to possible overlap, thus recommending revisiting the DECA I/T or using it alongside another instrument (Barbu, Levine-donnerstein, Marx, & Yaden, 2012). Yet, the DECA I/T is but one of the instruments used as a baseline measure and post measure—offering opportunity for comparison to determine outcomes and to overcome possible deficiencies Connected Families coordinates services—including intake with Early Start programming where additional assessments are shared. Further, the infant/toddler is also observed over a three-hour period during participation in Early Start programming to help establish goals of treatment within Connected Families.

Progress notes for infants/toddlers maintained throughout duration of treatment for purposes of case management and the DECA I/T and CBCL-LDS are administered again and at conclusion of services (post) for comparison with baseline with results evaluated collectively identify program outcomes. Additionally, as part of the Intake, the therapist consults with the Early Start program staff and obtains results of their multidisciplinary assessment for inclusion in the Connected Families PBS/CT Intake Summary that is used to develop a treatment plan.

Because Connected Families leverages the caregiver-infant/toddler dyad as the agent of change, it is important to also understand caregiver baseline function and identify outcomes. Table 6 reflects the instruments used to evaluate caregiver needs and change. For example, Parenting Stress Index™-4-Short Form (PSI-4-SF), a 36-item self-report measure with child and parent domains/subscales one of which is Parental Attachment. Reliability coefficients range from $\alpha = .78$ - .88 and $\alpha = .75$ - .87 for the child and parent domain/subscales respectively (Abidin, 2012). The PSI-4-SF provides an opportunity to measure stressors impacting parenting responsibilities at intake and again post-treatment including a glimpse of attachment that may be useful for further inquiry during the intake. A specific measure of caregiver attachment style as it relates to parenting has not yet been identified, yet it is recognized that this is an important variable that requires consideration for both clinical care and program outcomes.

The Beck Depression Inventory has demonstrated reliability of $\alpha =$.92 -.93 (Beck, Steer, & Brown, 1996) with the Beck Anxiety Inventory at $\alpha =$.92 -.94 (Beck & Steer, 1993). These instruments will be used as time series measures throughout all program components to monitor caregiver mood, beginning at intake, during infant/toddler and caregiver participation in PBS/CT, caregiver participation Connected Families Caregiver Group, and at various points during family therapy. The Social

Support Index (SSI) measures the degree to which families find support in community with reliability at $\alpha = .83$ (McCubbin, Patterson, & Glynn, 1982). The SSI is therefore used to gain understandings about the caregivers' pre-, mid-, and post-sense of support and community interaction. As previously indicated, each of these instruments are used with clinical application and will also be used for program evaluation and for purposes of research following approval of the Institutional Review Board.

Table 6. Self-Report Measures to Evaluate Caregiver Needs and Change.

Instruments	Assessment Frequency	Factors Assessed	Psychometrics
Parenting Stress Index^{TM}, Fourth Edition, Short Form	Pre, Mid, Post	Caregiver parenting stress	$\alpha = .78 - .88$ (child); $\alpha = .75 - .87$ (parent)[a]
Beck Depression Inventory (BDI)	Pre, TS, Post	Caregiver Depression	$\alpha = .92 - .93$[b]
Beck Anxiety Inventory (BAI)	Pre, TS, Post	Caregiver Anxiety	$\alpha = .92 - .94$[c]
Social Support Index (SSI)	Pre, Mid, Post	Caregiver social support	$\alpha = .82$[d]

Note: The table depicts baseline Caregiver assessments before participation in Connected Families at Intake of PBS/CT. Time series instruments are used to measure caregiver mood shift throughout PBS/CT, during Connected Families Caregiver Group, and throughout participation in Family Therapy. Post measures are administered at or near the end of Family Therapy. [a](Abidin, 2012), [b](Beck et al., 1996), [c](Beck & Steer, 1993), [d](McCubbin et al., 1982).

As depicted in Table 7, caregiver and infant/toddler interactions are measured at baseline at the outset of participation in the Connected Families Caregiver Group using the TAS-45 (Toddler Attachment Sort-45), an observational measure of toddler attachment conducted in a natural setting with good psychometric properties (Andreassen C & Fletcher P, 2007; Spieker, Nelson, & Condon, 2011; Tryphonopoulos & Letourneau, 2014). This is done after PBS/CT for several reasons: first the intake process is lengthy and involved and there is no need to increase caregiver burden by asking for an additional assessment; second, in PBS/CT there is an introduction to relational interaction with skill building for both the infant/toddler and the caregiver; but perhaps most importantly, it is within the CFCG the caregiver is specifically introduced to the challenging intersectionality of ASD and attachment and provided with opportunities to foster the increase of secure attachment interactions with their infant/toddler.

Table 7. Measures to Evaluate Family Interaction Needs and Change.

Unit of Assessment	Informant	Instruments	Assessment Frequency	Factors Assessed	Psychometrics
Caregiver-Infant/Toddler Dyad	Trained observer/coder	TAS-45	Pre, Post	Attachment security, dependency	r=.83 for security; r=.92 for dependency[a]
Family	Self-report	FACES-IV	Pre, Mid, Post	Family cohesion and adaptability using six scales	$\alpha = .77 - .89$[b]

Note: The table depicts baseline Caregiver assessments before participation in PBS/CT. The mid-point FACES-IV assessment is administered at the beginning of Family Therapy. Post measures are administered at or near the end of Family Therapy. [a](Spieker et al., 2011), [b](D. Olson, 2011)

Also, as depicted in Table 7, caregivers complete the baseline FACES-IV measure at the beginning and at the end of Family Therapy. FACES-IV was chosen because it can increase program staff understandings about caregiver perceptions of their family's cohesion and flexibility—two very important factors in the family's ability to adapt to the changing needs of the neurodiverse infant/toddler throughout development and as well as possibly being important with respect to parenting stress, caregiver mood, and the family's ability to meet the needs of the whole family. Olson described development and validation the FACES IV instrument including confirmatory factor analysis and identified of Cronbach alpha range of .77 to .89 for the six scales (D. Olson, 2011).

Finally, treatment efficacy is important for both case management and program evaluation purposes. Therefore, to gather participant perspectives related to treatment efficacy, as reflected in Table 8, the Session Rating Scale (SRS) and the Outcome Rating Scale (ORS) will be used to better understand family member views and the results of family therapy, whereas the Group Session Rating Scale (GSRS) is used to measure group therapy alliance throughout caregiver participation in CFCG. Each measure of treatment efficacy has strong psychometrics (Campbell & Hemsley, 2009; Duncan et al., 2003; Miller, Duncan, J., Sparks, & Claud, 2003; Quirk, Miller, Duncan, & Owen, 2012).

Table 8. Self-Report Measures to Evaluate Treatment Efficacy.

Instruments	Program Component(s)	Assessment Frequency[a]	Factors Assessed	Psychometrics
Group Session Rating Scale (GSRS)	Connected Families Caregiver Group	TS	Group Therapy Alliance	$\alpha = .86. - .90$ [b]
Session Rating Scale (SRS)	Family Therapy	TS	Therapeutic Alliance	$\alpha = .93$[c]
Outcome Rating Scale (ORS)	Family Therapy	Pre, TS, Post	Personal well-being; Family/close relationships; Work, school, friendships; General sense of wellbeing	$\alpha = .90$[c]

Note: The table depicts baseline Caregiver assessments before participation in Connected Families of PBS/CT. [a]Time series instruments are used to measure caregiver mood shift during PBS/CT, CFCG, and Family Therapy. Post measures are administered at or near the end of Family Therapy. [b]Quirk, Miller, Duncan & Owen (2012), [c]Campbell and Hemsley (2009).

Therefore, as indicated in Table 4, program outputs are identified in the Logic Model as intermediate results of program participation and are estimated at 85% as indicated in the Logic Model. Specifically, it is expected that 85% of caregivers will: (1) experience mutual support in the caregiver group; (2) show increased awareness of their own attachment style and patterns of interaction; (3) become more aware of their child's unique bids for connection and communication patterns; (4) be able to implement positive behavior support with their infant/young child; and (5) demonstrate improved communication with the infant/young child that is more congruent with less frequent miscuing. Caregiver experience of mutual support is measured through the Group Session Rating Scale. Other caregiver outcomes are measured using through analysis of the Weekly Summary, which provides a de-identified, quantitative perspective of caregiver progress.

In addition, the Logic Model identifies short-term and long-term outcomes with short-term gains targeting 80%. More specifically, with respect to short-term outcomes, it is expected that 80% of caregivers will show increases in attunement with their infant/young child and are confident of their abilities to capably attend to the child's attachment and developmental needs while maintaining the capacity to self-soothe and ask for help when necessary. Other short-term outcomes specific to the infant/young child include the expectations that 80% of infants/young children will respond appropriately to positive behavior support, show improvement in frustration tolerance, and show increased incidence of secure attachment behaviors with the caregiver. While measurement of short-term outcomes is expected to involve a combination of time-series assessment measures, observation from program staff, specific instruments need to be identified and included in the Program Manual to support implementation and evaluation.

As depicted in the Logic Model, long-term gains for the caregiver at 70% and include: (1) caregivers show awareness of needs and resources and are willing and able to access support; (2) caregivers report less parenting stress; (3) caregivers report less depression and anxiety; and (4) caregivers report healthier homeostasis in the family system. Measurement of long-term outcomes can be accomplished using a combination of time-series assessments and post-tests related to caregiver depression, anxiety, and stress and perhaps a retrospective posttest designed to provide increased understanding of caregiver perspectives of the program and process overall as they finish the program.

Program impact can be measured somewhat as participants finish the program possibly through surveys and through corroboration of the family therapist using deidentified data that indicates whether family members: (1) show improvement in their ability to support each other; (2) have an adequate system of support and are not isolated; and (3) are meaningfully engaged in work, school, and play.   Such a snapshot at the end of the program is not a substitute for longitudinal evaluation which will require follow-up with caregivers and families over time—perhaps using qualitative methods to better understand their lived experiences. The Program Manual at Appendix A includes survey forms the therapist can use to better understand participants program experiences as they finish the program. In addition, the Program Manual will identify a series of questions that can be used qualitatively at program exit for longitudinal evaluation of program impact.

CHAPTER SIX

PROJECT OUTCOME

The Connected Families program suite is comprised of three distinctive service components each of which will be described within this section and articulated within the Program Manual in Appendix A. As previously discussed, Connected Families strengthens and leverages the caregiver-infant/toddler relationship to foster increased attunement, connection, and capacity for emotional regulation—setting the stage for the infants'/toddlers' attainment of skills while decreasing caregiver stress and improving overall family function while being specifically attentive to cultural and diversity issues and globally responsive to the infant/toddler developmental issues.

In the first program component, Connected Families delivers positive behavioral interventions to the infant/toddler with specific attention to the child's attachment needs and trains the caregiver to do the same drawing upon behavioral and structural theories. Second, and at the heart of the Connected Families program suite, through the Connected Families Caregiver Group, caregivers are provided with: (1) group support for processing thoughts, emotion, and choices (within the context of caregiver culture and diversity factors) in an atmosphere of respect where there is opportunity to "feel felt" and connect with other group members; (2) attachment-based psychoeducation that specifically addresses the caregiver-infant/toddler relationship; and (3) parent-training that specifically considers the infant/toddler's unique style of interaction. Finally, family therapy provides opportunities for families to develop new interactional skills that systemically address the needs of the entire family, challenge maladaptive homeostasis, and provide a secure foundation of support capable of sustaining for the bio-psychosocial-spiritual development of infant/toddler across the lifespan.

All Connected Families program components draw from research-based methods and approaches and are designed for implementation with baseline, time series, and outcome measures. Each program component can be implemented as a standalone component or in conjunction with other program components, yet the perspective of this section is a full implementation of each program component in coordination with or alongside an existing Early Start, Infant Development/Stimulation program.

Two of the Connected Families programs are highly individualized and intensive: (1) positive behavior support delivered to the infant/toddler and caregiver training; and (2) family therapy. These program components are specifically tailored to the needs of each caregiver-infant/toddler dyad and family respectively, though each program component carried out according to the Program Manual in Appendix A. The Connected Families Caregiver Group uses a modularized curriculum that is also included in the Program Manual in Appendix A.

Positive Behavior Support/Caregiver Training

Program goals for the infant/toddler in the Positive Behavior Support/Caregiver Training (PBS/CT) program component include: (1) increased incidence of developmentally appropriate social-emotional and behavioral responses; and (2) demonstrated increase in frustration tolerance. Program goals for the caregiver include: (1) ability to identify positive behavior support techniques; (2) increased ability to apply positive behavior interventions; and (3) possible change in caregiver stress, depression, and anxiety levels. As discussed earlier, baseline, time-series, and outcome measures are used to evaluate program effectiveness with baseline measures also used to establish goals at the individual/dyadic level for the infant/toddler and caregiver. Positive behavior interventions such as reinforcement, shaping and fading of prompts are used with the infant/toddler without using punishment. The infant/toddler initially modifies behavior to gain access to a preferred activity or object, but as treatment progresses, the infant toddler learns to respond to praise and affirmation from the therapist—and ultimately the caregiver. Connected Families programs do not use punishment to motivate change, because punishment can impair development trust and a felt sense of security with the therapist and caregiver and possibly exacerbate incongruent or ambiguous interaction sequences thereby undermining secure attachment interactions.

Specific goals for each infant/toddler and the caregiver as well as the dyad are established, discussed with the caregiver, and documented using baseline assessment measures. Within this program component, the infant/toddler works one on one with the therapist during participation in an Early Start program to meet behavioral and relationship goals. The caregiver has respite from caregiving responsibilities during the first phase of treatment and during the second phase begins shadowing the therapist who continues working with the infant/toddler. Although a mild adjustment is expected initially due to the presence of two authority figures with different interaction styles, the infant/toddler eventually adapts and the caregiver learns the language and methods used by the therapist. In the third phase of treatment, the caregiver leads the child with the therapist coaching. As treatment progresses, the caregiver shadows the therapist during work with the infant/toddler as a silent, yet present and learning observer. Treatment progresses next to the caregiver working directly with the infant/toddler as the therapist coaches the caregiver and encourages congruent and consistent dyadic interactions. Caregivers are also directed to published materials that can further support and facilitate their development of skills and understandings related to autism, positive behavior support, and parenting. In addition, throughout PBS/CT, the therapist is attentive to and supportive of caregiver needs and will make referrals to supportive services as appropriate including other program components such as Connected Families Caregiver Group and Family Therapy.

Connected Families Caregiver Group

Program goals for the Connected Families Caregiver Group (CCSG) include: (1) caregiver experience of mutual support within the group experience; (2) increased caregiver awareness of their own interaction patterns and attachment style; (3) increased caregiver awareness of their infant/toddler bids for connection and communication patterns; (4) improved dyadic communication and attunement between the caregiver and infant/toddler with less ambiguity and miscuing; (5) increased use of positive behavior support techniques; (6) improved caregiver confidence; and (7) increases in secure attachment interactions between the infant/toddler and caregiver.

The CCSG program component provides a weekly 60-minute, closed caregiver support group over 40 weeks within four program modules. Group size is limited to no more than 10 caregivers per therapist. Each module carries the inherent goal of fostering insight within each caregiver and connection between group members The modules need not be completed sequentially, yet are identified as Modules I, II, III, and IV within the Program Manual.

Module I experientially considers caregiver and family needs, processes and strategies s. In this module, the caregivers have the opportunity to acknowledge and process some of their emotional responses and acknowledge the importance of self-care. Within this module, there is also interaction around family patterns and community experiences.

Module II content offers perspectives on the challenges of creating secure attachment within the neurodiverse child. Drawing upon recent research—presented in a relatable way—caregivers can realize that they are not alone in their struggle to maintain connection with their infant/toddler. Additionally, group members engage with each other about the neurodiversity of autism from a developmental perspective that extends across the lifespan.

The focus of Module III is learning, understanding, and applying parenting skills and positive behavior support strategies with the neurodiverse infant/toddler. Within this module, caregivers record and share their interactions with the infant/toddler and receive supportive feedback and encouragement from the therapist and from each other.

Module IV, while fully developed and previously published requires further training before implementation. More specifically, once proper credentialing is in place, Module IV implements the complete *Child Parent Relationship Therapy Treatment Manual: A 10-Session Filial Therapy Model for Training Parents* by Bratton, Landreth, Kellam, and Blackard with possible adaptation to the age of the infant/toddler in a two-hour group format. CPRT (Bratton, Landreth, Kellam, & Blackard, 2006) requires homework between sessions including, but not limited to caregiver recorded video of play sessions that are shared in the group. This is an intensive filial therapy-based module that trains caregivers to play, encourage, and build attachment in the caregiver-infant/toddler dyad. Module IV incorporates the assessment instruments that are part of the CPRT (Bratton et al., 2006) program to evaluate outcomes within the program module.

As with the PBS/CT program, CCSG participants are also directed to published materials that can further support and facilitate new understandings and skills for meeting the attachment, developmental, and behavioral needs of the neurodiverse infant/toddler while attending to personal caregiver needs within the context of the family system.

Throughout the duration of CCSG, therapists are attentive to individual process and progress, group cohesion and dynamics, and monitor the need for additional supportive services. Appropriate referrals are made for individual and family therapy and possibly other services to continue to strengthen caregivers and families in order to bolster support for the infant/toddler.

Family Therapy

Program goals for Family Therapy (FT) include disruption of maladaptive homeostasis, rebalance subsystems (executive and child as necessary), promotion of healthy role responsibilities, and development and implementation of adaptive coping and communication skills to create an environment of support that can sustain the neurodiverse infant/toddler at all stages of psychosocial and physiological development.

Within FT, the therapist works with individual family units using a systemic approach that draws from structural and humanistic perspectives. Goals for the unit of treatment—the family—are established based on presenting family dynamics with specific consideration to diversity factors that influence the family's ability to provide a stable and supportive environment for the infant/toddler. Specific areas of attention include fostering a sense of family culture and identity that extends beyond ASD, where needs of all family members can be considered—especially the need for social and community involvement. Specific goals discussed with the family and documented and time series assessment measures are used to evaluate program outcomes. A fuller description of the FT program component is provided in the Program Manual in Appendix A.

As with the PBS/CT and CCSG participants are also directed to published materials that can further support and facilitate new understandings and skills for meeting the attachment, developmental, and behavioral needs of the neurodiverse infant/toddler while attending to personal caregiver needs within the context of the family system.

Throughout the duration of FT, therapists are attentive to individual process and progress, family dynamics and progress, and monitor the need for additional supportive services. Appropriate referrals are made for individual and possibly other services to continue to strengthen caregivers and families in order to bolster support for the infant/toddler.

CHAPTER SEVEN

SUMMARY AND APPLICATIONS

As discussed earlier, studies show that children with secure attachment have better outcomes across the lifespan (McKenzie & Dallos, 2017; Sroufe, 2005) and recent research demonstrates that children at risk for autism spectrum disorder (ASD) have the need and capacity for secure attachment (Beurkens, Hobson, & Hobson, 2013; McKenzie & Dallos, 2017; Teague, Gray, Tonge, & Newman, 2017). Yet, fostering secure attachment in an infant/toddler at risk for ASD can be particularly challenging due to the ambiguous, negative interactional patterns (Cortina & Liotti, 2010; Fonagy et al., 1991; Teague et al., 2017) that result when emotional dysregulation patterns of the infant/toddler undermine caregiver confidence and the caregiver's ability to respond to the child's needs. These patterns set the stage for ongoing miscuing in the caregiver-infant/toddler dyad further reducing the likelihood of attunement and the development of trust, with missed opportunities for soothing, support, and overall development. These challenges directly impact the caregiver and the infant/toddler as well as other members of the family and persons with whom the family interact in multiple contexts. Without intervention the caregiver and family system upon which the infant/toddler is dependent is vulnerable to stress, anxiety, depression, and isolation.

While the etiology of ASD is at the heart of many ongoing studies, uncertainty remains; however, correlations have been made with broad agreement that there are familial (genetic), environmental (toxins), and possible nurturing factors. What is perhaps important to notice is caregiver perceptions about the etiology of ASD, and their possible contributions to risk factors necessarily impact the dyadic relationship and the family overall (Da Paz et al., 2018; Falk et al., 2014; McKenna Gulyn & Diaz-Asper, 2018). Despite the risk factors and challenges associated with ASD, attachment security has been identified as a protective factor in the child's social-emotional development (Teague et al., 2017, 2018).

When programs fail to specifically address relationship needs and attachment security, the infant/toddler and caregiver both remain vulnerable with the infant/toddler less likely to meet developmental milestones and go on to attain full potential. Caregivers, in turn can experience increased parental stress possibly coupled with mental health issues such as anxiety and depression (Derguy, Michel, Katia, et al., 2015; Karst & van Hecke, 2012; Keenan et al., 2016). In addition, without necessary caregiver support the infant/toddler's challenges with regulation persist, potentially escalating caregiver challenges, which then lead to increased social isolation, inability to sustain employment due to caregiving issues, financial insecurity, and partner relationship instability—all of which increase the societal burden of care for families contextualized by ASD—an atypical neurodevelopmental condition that often extends across the lifespan (Derguy, Michel, Katia, et al., 2015; Karst & van Hecke, 2012; Keenan et al., 2016).

Therefore, to support the developmental needs of the infant/toddler, caregivers and family needs must also be addressed. Programs that provide caregiver support and education and which promote improved communication and attunement within the family, can foster creation of a secure context within which infants/toddlers further develop and attain full potential. Unfortunately, programs that are specifically designed to address the caregiver-infant/toddler relationship have not been identified in Orange County.

The Connected Families program is designed for implementation as a non-duplicative supplement to existing Early Start Infant Development programs that target the child's attainment of developmental milestones and behavioral improvement. With foundations in developmental, behavioral, attachment, and systems theory—Connected Families is designed to specifically address unmet caregiver and family needs to better support the development of the infant/toddler. Unlike existing Early Start services in Orange County that target behavioral outcomes, Connected Families specifically targets improvement in the caregiver-infant/toddler relationship with increases in: (1) caregiver confidence and awareness of their child's unique bids for connection; (2) congruent dyadic communication and attunement; and (3) secure attachment behaviors.

Within the Connected Families program, specific needs of the infant/toddler are identified and met and caregivers are trained and coached to attend to their child's unique bids for connection and communication patterns while applying positive behavior support. Thus, the potential for ambiguity and miscuing is mediated and both the caregiver and infant/toddler have increased predictability within their relationship and expanded capacity for soothing, down-regulating strong emotion, experiencing comfort, and felt connection. Additionally, caregivers who receive needed support within the caregiving community and are able to grasp the importance of attending to their own needs in order to continue function as a secure base for their child throughout development. Finally, Connected Families embraces, supports, and fosters families' abilities to adapt to the infant/toddler's neurodiversity issues throughout development while magnifying the importance of meeting the needs of all family members. Taken together, Connected Families programs bridge the gap in services to caregivers and families laying a supportive foundation for the infant/toddler to continue development and attain full potential, with caregivers and families engaging in community and social contexts versus isolation, thereby lessening the societal burden of care.

Although a measure of the child's attachment style has been identified, caregiver attachment style is an important variable within the program, yet a suitable measure that is focused on parenting versus romantic partner has not been identified, thus representing a program limitation. Additionally, the current version of the Program Manual does not include documents that are needed to administer the program including intake documents, handouts and presentations for CFCG. These limitations have the potential to impact program implementation and delivery as well as evaluation and therefore must be addressed in advance of implementation.

As designed, the Connected Families program suite can be implemented component by component, or as a collective. Connected Families can be implemented alongside an existing Early Start program or perhaps in Regional Center settings that draw from a wide geographic area where Early Start, Infant Development/Stimulation services are delivered separately. With a Regional Center implementation, there is need to exchange information and coordinate care with the Early Start programs. With a Regional Center implementation, program evaluation issues may become complex due to possible variations between the Early Start protocols. For example, baseline assessment measurements may be required for both the Early Start and again at the Connected Families program based at Regional Center. Evaluation limitations therefore arise due to differences in measurement timing and administration with the informant likely gaining experience with the assessment material and feedback process—both conditions with the potential to skew baseline results for the unit of treatment and for program evaluation purposes overall. These limitations can be controlled or minimized when Connected Families is implemented alongside an existing Early Start program.

Among the advantages to implementation alongside an existing program are the coordinated, synergistic effects of shared staffing, assessment tools, service delivery, as well as coordination of care and collection of evaluation information within a single location—both potential benefits to the infant/toddler, caregiver, family as well as the service provider. A possible disadvantage of an integrated implementation strategy may be limitations on program visibility and accessibility to the broad service areas covered by a Regional Center.

Connected Families program components or the full suite of programming, can provide a rich environment for research, but only after obtainment of approval of the Institutional Review Board and obtainment of appropriate consents from participants. For example, if Connected Families is implemented alongside an existing Early Start program, it is possible to use assessment measures from the Early Start program as a control group as these infants/toddlers receive treatment as usual. Connected Families participants would constitute the "treatment group" and comparison could then be made between the two groups. This research then, could extend beyond program evaluation and move in the direction of validating the model of treatment.

Development of a solid infrastructure to support ongoing programming is the logical next step for Connected Families. This necessarily includes: (1) identification of an appropriate, validated adult attachment style measurement that addresses the caregiver-child relationship; (2) development of a program budget, intake and informed consent documents, handouts and presentations necessary to support all program components; (3) submission of the application for Human Studies Research to the Institutional Review Board; (4) identification of a program site and program personnel; and (5) coordination of contracts and vendorization.

As a mental health profession, marriage and family therapy is focused on relationship improvement and satisfaction—a value and perspective that foundational to Connected Families. More specifically, for caregivers and families of infants/toddlers at risk for ASD, the importance of predictable, stable, and safe relationships between the caregiver-infant/child, within the caregiving community, and among families is at the heart of all Connected Families programs with services delivered through the contributions and skills of marriage and family therapists. Connected Families programs are therefore distinctive from programs that focus primarily on behavior or behavioral outcomes and provide new opportunities for marriage and family therapists to engage in new settings with the opportunity to apply skills for the benefit of children, families, and communities.

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APPENDIX A

TREATMENT MANUAL

Connected Families

...care for the whole family

A Program Development Supporting Caregivers & Families of Young Children at Risk for Autism

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Doctor of Marital & Family Therapy (DMFT) Degree
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This program is written in support of and dedicated to
Kathleen Gabriela Shanahan—
a servant leader, brilliant therapist, an exceptional human being—
And to the many special needs children that she serves.

Connected Families Program Manual

Overview

Introduction

Connected Families offers three program components that function independently, yet are supportive of each other, for infants/toddlers at risk for autism together with their caregivers and families. Program components include: Positive Behavior Support/Caregiver Training (PBS/CT); Connected Families Caregiver Group (CFCG); and Family Therapy (FT). As designed, Connected Families can be implemented alongside an Early Start program as a non-duplicative, supplementary service or as a separate program suite that coordinates with the neurodiverse child’s Early Start program

The program can be implemented by mental health professionals with understandings of child development and attachment, behavioral, and systems theories. The clinician’s ability to work within the collective theories for the benefit of the child, caregiver, and family is important to clinical and program success. Administrative support program staff carry responsibilities for scheduling, billing, and independent custody of deidentified documents used for evaluation and potentially for research.

Connected Families is theory-based and designed with a logic model that defines expected program outcomes. Therefore, within the Program Manual, there instructions for collecting various assessment inventories pre-treatment (“pre”), mid-treatment (“mid”), time-series (“TS”), and post-treatment (“post’) to allow for program evaluation overall and within each program component. Evaluation of data collected from these instruments, though not included in the Program Manual, is an important part of validating treatment fidelity and program effectiveness while also offering the possibility of making changes to the program over time. Additionally, following approval of the Institutional Review Board (IRB), Connected Families program data could be collected, analyzed, and used in research. Obtaining IRB approval is therefore prerequisite to program implementation.

Contents

I. Positive Behavior Support/Caregiver Training

PBS/CT Program Description

Introduction

Positive Behavior Support/Caregiver Training (PBS/CT) is a one on one program that considers the child's needs within the five developmental domains of cognition, physical and motor development including vision and hearing, communication, social-emotional development, and adaptive functioning—all of which are expressed behaviorally. The foundation for the behavioral work with the child is Positive Behavior Support (PBS) underpinned by an authoritative parenting model. Connected Families does not promote or endorse punishment as an adaptive motivator; however, natural and logical consequences are used within the learning process. PBS is distinctive from Applied Behavior Analysis (ABA) though some methods and techniques may align with ABA. PBS was chosen in lieu of ABA in order to foster positive and predictable interactions within the caregiver/child relationship that allow both the caregiver and child to better attune to each other, regulate their responses with one another, and promote the child's ability to develop a secure base with the caregiver.

This program component draws from developmental, behavioral, attachment, and systems theories and is based on the methods developed by Kathleen Gabriela Shanahan. The program is designed for implementation by mental health professionals with experience in early childhood development (ages 0-3), infant/toddler mental health, Early Start programming methods, PBS, and the ability to work collaboratively with a multidisciplinary team including occupational and physical therapists, speech/language and hearing specialists and other early interventionists. The PBS/CT program manual reflects our collaboration and summarizes some of our clinical communication during 2017-2019. Additionally, the methods are adapted from Dunlap, Iovannone, Kincaid, Wilson, Christiansen, Strain and English (2010).

Contents

Continued on next page

Program Goals

PBS/CT addresses the needs of the child within the five developmental domains and provides training to the caregiver. Program goals for the infant/toddler in PBS/CT include: (1) increased incidence of developmentally appropriate social-emotional and behavioral responses; and (2) demonstrated increase in frustration tolerance.

Caregiver goals include: (1) ability to identify positive behavior support techniques; (2) increased ability to apply positive behavior interventions; and (3) improvements in in caregiver stress, depression, and anxiety levels.

Dyadic goals for the caregiver and child include improved communication and increased incidence of congruent interaction sequences.

Informed Consent

Informed Consent is an ongoing process that occurs throughout treatment. Valid, and authorized signed Informed Consent for Treatment documents are required before Intake and Assessment, Defining Program Goals, or Treatment. For divorced, separated, step, and blended families and for children in foster care, it is important secure Informed Consent for Treatment from all responsible parties before Intake and Assessment.

At such time that research might be done using data collected within the program, Informed Consent for Research forms approved by the Institutional Review Board (IRB) must also be signed and collected from all persons authorized to consent.

For purposes of coordinating care, we must also have on file signed a Release for Exchange of Information with: (1) the child's pediatrician/medical doctor; (2) the Early Start global program personnel; (3) the CSC at Regional Center; and (4) Connected Families group and family therapists or other therapist providing treatment to the child, caregiver, or family as appropriate.

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Intake and Assessment: Observation

As part of the intake and assessment process, the treating therapist will conduct a **Behavior and Relationship Observation** of the child and caregiver during their participation in a global program environment. Over a three-hour period as the child rotates through activities that address all five developmental domains with their caregiver participating, the therapist will note and identify caregiver/child interaction, developmental issues, and identifying patterns.

Personal communication with K. G. Shanahan (April 1, 2019) reflects that during the initial observation of the caregiver/child pair, the therapist is attentive to the:

- Child's preferences and areas of struggle or disinterest.
- Relationship patterns between the child and caregiver noting that some children avoid interaction and actively pull away; others are passive in their interaction style with caregiver and environment.
- Child's ability to self-regulate.
- Caregiver's ability to connect with their child's social-emotional needs and contain their own reactions and adaptively respond.
- Caregiver/child attachment style.
- Child's tendency for fixation on shapes/objects.
- Child's ability to sit and sustain attention to task.
- Things that motivate and engage the child. Examples include praise, extrinsic rewards such as food prompts (Cheerios, pretzel), using a preferred play item, or getting a sticker.
- Looking at transitions and adaptation to change (engage with caregiver/noticing facial affect).
- Antecedents to maladaptive reactions, attempts to respond/redirect the child, and child's response to redirection
- Child's learning style and preferences
- Child's language development for purposes of communicating adaptive needs.

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Intake and Assessment Observation continued

Conditions noted during the observation are documented on Intake Observation Results which is placed in the child's file. A written summary of the *Behavior and Relationship Observation* is included as part of the Evaluation Results on the **Connected Families PBS/CT Intake Summary**.

Intake also includes a **Caregiver Interview** with the therapist about the child's medical, trauma, and developmental history and about any concerns the caregiver currently has regarding the child considering cognition; physical and motor development including vision and hearing; communication; social-emotional development; and adaptive functioning. The therapist maintains a clinical record that reflects caregiver perspectives based on the interview that is placed in the child's file. In addition, relevant information, including a written summary of *Caregiver Concerns about the Child's Development* are recorded in the **Connected Families PBS/CT Intake Summary.**

Also, on behalf of their child, caregivers must complete the **Child Behavior Checklist 1.5- 5 years (CBCL) with Language Development Survey 18-35 months. (LDS)** (Achenbach, 2018)and either the **Devereaux Infant (DECA I)** (Powell, Mackrain, & LeBuffe, 2007)for children 1-18 months of age or **Devereaux Toddler (DECA T**) (G. Powell, Mackrain, & LeBuffe, 2007) for children 18-35 months of age. The therapist scores each instrument according to instructions and records a written summary of the results in the appropriate location of the **Connected Families PBS/CT Intake Summary** for both the *CBCL with LDS* and the *DECA I/T.*

Also, as part of the Intake, the caregiver on their own behalf, also completes the **Parenting Stress Index, Fourth Edition, Short Form**(Abidin, 1983); **Beck Depression Inventory** (Beck et al., 1996); and **Beck Anxiety Inventory** (Beck & Steer, 1993). The therapist will score each item, charting results that identify clinical and subclinical ranges child's file. Original documents will be maintained in the child's file with a copy provided to the Document Custodian. Any and all evidence of potential safety issues (e.g., suicidality) are to be immediately and directly addressed according to ethical standards of care.

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Intake and Assessment Observation continued

It is very important to ensure the date of assessment is captured on ALL inventories for the child and caregiver. It is also very important that the therapist record PRE at the top of each inventory for ALL INTAKE ASSESSMENTS as this provides ease of processing for program evaluation.

Importantly, the therapist will also consult with global program staff involved in the child's multidisciplinary assessment and obtain results for inclusion in the **Connected Families PBS/CT Intake Summary.** The final step of the Intake Process is completion of all sections of the Connected Families PBS/CT Intake Summary including axial diagnoses based on the **DC: 0-5™**, *Clinical Summary*, *Recommendations*, and *Suggested PBS/CT Goals* (ZERO TO THREE, 2016).

Treatment Goals

Treatment goals for the child/caregiver pair flow directly from the **Connected Families PBS/CT Intake Summary**. Conditions identified are carried forward and included in **the Positive Behavior Treatment Strategies and Plan** which is discussed with the caregiver at length to gain buy-in and arrive at consensus. It is very important to have caregiver buy-in and consensus, before moving into the treatment phase of the program.

Recordkeeping

For purposes of case management, the **Informed Consent for Treatment**, **Caregiver Personal Data Sheets** and **Child Personal Data Sheets**, clinical notes, the **Connected Families PBS/CT Intake Summary** and supporting documents, **Positive Behavior Treatment Strategies & Plan**, progress notes for the child and caregiver and all child and caregiver assessment inventories are placed in the child's file**. Throughout PBS/CT, dated copies of all assessment inventories marked pre, mid, or post are also forwarded to the Document Custodian**.

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Recordkeeping, continued

The **Document Custodian** who is not involved with the treatment assigns a unique number to the child/caregiver pair at Intake. Copies of all assessment inventories for the child and caregiver are submitted to Document Custodian. The Document Custodian places the unique number assigned to the child/caregiver pair on the assessments upon receipt after removing or redacting information that would identify the pair. Information that would identify either the child or caregiver will therefore be securely destroyed allowing for future collective, deidentified data analysis. Thereafter, the deidentified copies of each assessment are securely maintained by the Document Custodian pending input to SPSS to for program evaluation and, only after IRB approval and with appropriate consent, for research.

Treatment goals for the child/caregiver pair are determined based on the results of observation, caregiver input and responses on assessment measures completed at intake, and collaboration with Early Start multidisciplinary program staff. When relevant and possible, the perspectives of the child's nanny, childcare, and preschool staff are also sought and considered. The child's treatment goals will be identified considering other assessments and will be documented on the Positive Behavior Treatment Strategies & Plan. The Treatment Plan Summary is inclusive of the Positive Behavior Treatment Strategies & Plan and also includes richer and thicker descriptions of the child's functioning in all five developmental domains as compared with a neurotypical child and includes the child's chronological age and calculated developmental age.

Caregiver training in Positive Behavior Support techniques and skills is specifically addressed within PBS/CT. Unique characteristics of the caregiver will be considered and addressed to the extent possible within the program. Caregivers can also participate in other Connected Families program components, possibly including the Connected Families Caregiver Group and Family Therapy for additional supportive services. Though not specifically part of the Connected Families program suite, caregivers might also be referred for Individual psychotherapy or outside supportive services as appropriate and necessary.

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PBS/CT Program Description, Continued

Positive Behavior Support: Adapting *Prevent, Teach, Reinforce* Program Materials

Connected Families PBS/CT works with the neurodiverse child adapting positive behavior support principles to the child's developmental age. These principles are taken from a program developed for school-age children *Prevent, Teach, Reinforce: The School-Based Model of Individualized Positive Behavior Support* written in 2010 by Dunlap, Iovannone, Kincaid, Wilson, Christiansen, Strain, and English who state, "*among the ABA principles used by PTR are functional behavioral assessment (FBA) procedures, reinforcement of desired alternative behaviors, shaping of new behaviors, fading of prompts and reinforcement, and contingency management*."

Positive Behavior Treatment Methods

Using the principles identified, considering the child's assessed needs and development, goals specific to the child and caregiver are identified on the Positive Behavior Treatment Strategies & Plan that guides all phases of treatment.

As a program, PBS/CT expects the treating therapist to very familiar with early childhood development for neurotypical and neurodiverse children. Additionally, the threating therapist must also be well-equipped to deliver positive behavior support to the child using the methods identified by Dunlap, et.al.

For example, to properly assess and treat the child, the therapist will need to conduct a functional behavioral analysis to better understand conditions (e.g., actions/inactions, environment, time of day, location, the presence/non-presence of people or objects, etc.) or circumstances such as transitions that are antecedent to challenging behavior. Additionally, it is important for the therapist to notice potential benefits or gains for the child related to their challenging behavior. This process allows for the development of hypotheses about reasons for challenging behaviors.

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Positive Behavior Treatment Methods continued

Once identified, the therapist uses additional techniques such as initially redirecting attention to an appropriate or preferred activity, motiving desired behaviors, and helping the child master new behaviors step-by step. As the child masters desired behaviors, tension or mild conflict is introduced allowing the child to build frustration tolerance when expectations are not immediately met. As indicated previously, Connected Families does not endorse the use of punishment. However natural and logical consequences provide a context for learning. An authoritative parenting model underpins our methodologies and a goal of care is to increase congruent interaction sequences between caregiver and child. Neurodiverse children need predictability and structure and can become confused by a caregiver who is warm and friendly (sometimes to the point of overstimulating the child) one moment, and angry and punishing the next. Overall goals for the child/caregiver pair are identified in the **Positive Behavior Treatment Strategies & Plan**. The Positive Behavior Treatment Strategies & Plan used in PBS/CT and the sample that follows is based on Dunlap, et. Al. (2010).

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Sample Positive Behavior Treatment Strategies & Plan

Challenging Behavior: Avoidance

Avoidance is defined as a maladaptive coping mechanism to avoid dealing with a non-preferred or stress inducing activity, environment or object.

Onset: When Child encounters non-preferred stimuli and pulls away or attempts to distance himself

Offset: When Child leans in and engages with non-preferred stimuli

Function of the Challenging Behavior: To avoid, escape or terminate non-preferred stimuli including instruction, task, people, and objects.

Consequences of Challenging Behavior on the Parent-Child Relationship: *Misunderstanding, stress, and decreased competence set up an interactional pattern of behavioral miscuing in the infant/young child-caregiver dyad which can lead to further and increasingly extreme emotional dysregulation in the infant/young child while perpetuating parental stress. The infant/young child, unable to regulate and make sense of the world, can fall behind failing to meet typical physiological and behavioral developmental milestones.*

Overall Treatment Goals: Decrease non-compliant/avoidant behavior and increase cooperative/ engaged behavior.

Prevent Strategy:

- Use visual supports, schedules and routines
- Use visual supports such as picture schedule to help child predict what comes next
- Use transition songs to assist Child with expected behavior and predictability

Implement a 5:1 ratio of positive to negative or neutral attention for completion of expected behavior such as transitioning from group to group and completing any and every part of a task.

- Caregiver will position themselves in such a way that Child can see their face and caregiver can see Child’s face to increase attunement.
- Caregiver will use developmentally appropriate language when providing instruction
- Caregiver will provide pressure to Child’s body to assist with relaxation and grounding
- Caregiver will provide consistent and clear instruction and follow through with communicated expectations. Use behavioral rehearsal after providing child with a single opportunity to follow through with instruction.
- Caregiver will notice signs of frustration (pulling away, changes in facial affect, tense body).
- Provide child with assistance and decrease his task expectations.

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PBS/CT Program Description, Continued

Sample Positive Behavior Support Strategies & Plan, continued

Teach Strategy: Teach Communication Skills

- Child will communicate his basic needs using sign or words before receiving preferred items.
- Child will make the choice to engage with designated stimuli
- Teach treatment strategies to caregiver
- Teach caregiver to assist Child with behavioral rehearsal of expected behavior if he does not engage after a single instruction has been provided.

Reinforce Strategy:

- Reinforce desirable behaviors. Remove reinforcement for challenging behaviors
- Reinforce child's efforts to communicate his needs
- Ignore avoidant behaviors and redirect to expected/ replacement behaviors
- Establish a clear boundary when avoidant behaviors occur and redirect to follow through with initial instruction.

Treatment Phases

Active work with the child/caregiver pair involved three distinct phases. Initially the child and therapist work together offering the caregiver respite time from caregiving responsibilities. When the child is consistently meeting 75% of their goals, the therapist invites the caregiver into the sessions as a shadow to increase familiarity with new ways of interacting with the child. In the final phase, the caregiver works directly with their child as the therapist coaches the caregiver and observes child behavior, caregiver choices, and pair interactions.

Phase 1: Child & Therapist / Caregiver Respite

During this first phase of treatment with the child, the therapist works alone with the child allowing the caregiver some respite time away from caregiving duties. The therapist has different expectations and patterns of interaction from the caregiver and family. This environment allows for change, the development of new skills and ways of interacting based on the new relationship between the neurodiverse child and therapist.

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Phase 1: Child & Therapist / Caregiver Respite continued

When children come into treatment, often their caregivers and families do not know the child's capabilities and may not expect the child to adapt. The caregiver and family mindset may be unacknowledged and/or outside of awareness yet limit the child's growth. Therefore, in this phase of the program, children are challenged to do their best and to respond within a positive feedback loop that encourages mastery of new challenges.

Elapsed time is for the first phase of treatment is usually three weeks or until the child has reached 75% mastery working a minimum of three and sometimes as many as five days per week each one on one (therapist and child) for a three-hour block of time. During this time the child is led through transitions for all five developmental domains for a minimum of 27 total hours. Time varies based on individual needs and may require as much as 45 hours over a three-week period (K.G. Shanahan, personal communication, April 1, 2019). The child's progress is documented within progress notes which are placed in the child's file.

Throughout this phase—on the "middle" day of each treatment week, caregivers complete the **Beck Depression Inventory** (Beck et al., 1996)and **Beck Anxiety Inventory**(Beck & Steer, 1993). The therapist monitors for change and potential safety issues intervening according to ethical standards. Originals are dated with "TS" (for time series) and "PBS/CT" written at the top of the first page. Original documents are placed in the child's file with a copy to the Document Custodian.

Phase 2: Child & Therapist / Caregiver Shadowing

During Phase 2, the caregiver shadows the therapist working with their child –which allows the caregiver to experience the child's growth and success and to specifically notice how the therapist continues to use positive behavior support to motivate desired responses and foster relationship with the child.

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PBS/CT Program Description, Continued

Phase 2: Child & Therapist / Caregiver Shadowing continued

At the beginning of Phase 2, caregivers observe the child's live interaction with the therapist for at least two sessions using the audio/video link. This requirement allows the caregiver to become familiar with the nature of treatment and therapist/child interaction before physically entering the therapy room.

Children respond differently when their caregiver is in the room with the therapist and may struggle to follow the therapist's lead when the caregiver is present. This does not represent regression, rather it represents the child's confused response to having more than one authority figure, each with different expectations and patterns of interaction with the child. The therapist continues to work directly with the child while asking the caregiver to observe and notice the techniques used to motivate the child from a background or shadowing position.

Gradually, the child becomes accustomed to having the caregiver present, yet silent and will thus turn attention to the therapist's direction eventually learning to consistently make adaptive responses.

Throughout this phase—on the "middle" day of each treatment week, caregivers complete the **Beck Depression Inventory** (Beck et al., 1996) and **Beck Anxiety Inventory** (Beck & Steer, 1993). The therapist monitors for change and potential safety issues intervening according to ethical standards. Originals are dated with "TS" (for time series) and "PBS/CT" written at the top of the first page. Original documents are placed in the child's file with a copy to the Document Custodian.

Phase 3: Child & Caregiver / Therapist Coaching & Observing

At the beginning of Phase 3, the caregiver and child work directly together on the child's goals with the therapist providing coaching for child/caregiver interaction. Thus, caregivers learn positive behavior support skills. At first, coaching may be frequent and direct allowing the caregiver to learn and apply new techniques. As caregivers become more skilled and confident working with their child, the therapist can take more of an observer role. During Phase 3, caregivers are especially encouraged to practice their positive behavior support skills at home and in other settings with their child. Caregivers can consult with the therapist during this time about unexpected outcomes with their child.

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Phase 3: Child & Caregiver / Therapist Coaching & Observing, continued

Throughout this phase—on the "middle" day of each treatment week, caregivers complete the **Beck Depression Inventory** (Beck et al., 1996)and **Beck Anxiety Inventory** (Beck & Steer, 1993). The therapist monitors for change and potential safety issues intervening according to ethical standards. Originals are dated with "TS" (for time series) and "PBS/CT" written at the top of the first page. Original documents are placed in the child's file with a copy to the Document Custodian.

Termination, Referrals & Supports

Termination of treatment is appropriate when child and caregiver goals have been substantially met. Specifically, the child demonstrates: (1) increased incidence of developmentally appropriate social-emotional and behavioral responses; and (2) increase in frustration tolerance. Likewise, the caregiver has: (1) demonstrated the ability to identify positive behavior support techniques; (2) shown increased ability to apply positive behavior interventions; and (3) experienced improvements in in caregiver stress, depression, and anxiety levels. In addition, communication and interactions between the caregiver and child are more congruent and positive.

During the termination process, the caregiver on their own behalf, completes the **Parenting Stress Index, Fourth Edition, Short Form** (Abidin, 1983, 2012); **Beck Depression Inventory** (Beck et al., 1996); and **Beck Anxiety Inventory** (Beck & Steer, 1993). The therapist will score each item, charting results that identify clinical and subclinical ranges child's file. Original documents are marked "**Post**" and will be copied with the copy provided to the Document Custodian and the original maintained in the child's file. Any and all evidence of potential safety issues (e.g., suicidality) are to be immediately and directly addressed according to ethical standards of care. **Connected Families does not terminate treatment where an existing safety issue is identified**.

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PBS/CT Program Description, Continued

Termination, Referrals & Supports: continued

Part of the termination process includes review of successes and challenges from the perspective of the child/caregiver as well as the treating therapist as well as planning for next steps.

At this time, it is important to predict success with a few stumbles—perhaps using the metaphor of the child learning to walk. Referrals to other Connected Families programs will be considered and provided where appropriate. In addition, referrals will be made outside Connected Families based on need. Schedules permitting, Connected Families clients are always welcome to return at a later time if needed.

Measurement of Treatment Outcomes

Caregiver depression and anxiety levels are monitored throughout the duration of treatment for purposes of case management and can be evaluated in aggregate to measure actual program outcomes for comparison with expectations within the logic model. Similarly, the infant/toddler's treatment progress is monitored and recorded in progress notes.

II. Connected Families Caregiver Group

Connected Families Caregiver Group Program Description

Introduction

The **Connected Families Caregiver Group (CFCG)** program component is designed for implementation relying on mental health professionals with skills and experience in cognitive-behavioral, insight-oriented, experiential, and systemic group therapy combined with knowledge of PBS, attachment, parenting issues, and ASD. Through CFCG caregivers enjoy the opportunity to interact with each other in a group setting as they learn about autism and identify their own needs, develop new skills, improve relationships with their children, and experience an expanded system of support. More specifically, CFCG is a caregiver group that meets throughout the year with content broken into 10-week modules with each group meeting in Modules I-III lasting -60 minutes and Module IV lasting 120 minutes. Participants are asked to commit to the group one module at a time and modules need not be completed sequentially. Modules include:

- Caregiver and family needs, processes, and strategies
- Attachment and the neurodiversity of autism across the lifespan
- Parenting and positive behavior support
- Child Parent Relationship Therapy: A 10-Session Filial Therapy Model for Training Parents (Bratton et al., 2006)

The group meets once weekly and sessions are topical with group processing, possibly including an activity that relates directly to the content presented. Caregivers are encouraged to maintain good boundaries and speak only on behalf of themselves within the group without attempting to "fix" another participant. Children are not permitted to attend the group.

Contents

Continued on next page

Program Goals

Program goals for the Connected Families Caregiver Group (CFCG) include: (1) caregiver experience of mutual support within the group experience; (2) increased caregiver awareness of their own interaction patterns and attachment style; (3) increased caregiver awareness of their infant/toddler bids for connection and communication patterns; (4) improved dyadic communication and attunement between the caregiver and infant/toddler with less ambiguity and miscuing; (5) increased use of positive behavior support techniques; (6) improved caregiver confidence; and (7) increases in secure attachment interactions between the infant/toddler and caregiver.

Unit of Treatment: Group

The group is the unit of treatment for the Connected Families Caregiver Support Group, yet individuals are members of the group. Each group is comprised of no more than 10 members who stay together in a “closed group” setting over a 10-week period. During the 10-week period, group work will focus on one of the four modules delivered within the program.

Although the Group is the unit of treatment, the Informed Consent process and the Intake & Assessment processes occur at individual and group levels. Also, while there is a “a group progress note” is generated for each meeting, the group note is tailored for each caregiver and kept in the caregiver group record.

Also, in the fourth module, the Caregiver will interact directly with their Child and will show videos of caregiver/child interaction within the group. For this reason, although children are not permitted to attend group, it is important to ensure a valid Consent for Treatment is also on file for the child from all responsible/authorizing caregivers.

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Informed Consent

Informed Consent is an ongoing process that occurs throughout treatment. Valid, and authorized signed Informed Consent for Treatment documents are required before Intake and Assessment, Defining Program Goals, or Treatment.
For divorced, separated, step, and blended families and for children in foster care, it is important secure Informed Consent for Group Treatment from all responsible parties before Intake and Assessment. At the first group meeting, the therapist will review limitations of confidentiality (e.g., mandated reporter for child, dependent/elder adult abuse; danger to self or other; worker's compensation cases; litigation where mental health issues are asserted as germane to the case). Additionally, as the therapist will verbally review the importance of keeping matters that occur within the group—within the group and not shared with outsiders. The therapist will commit to maintaining confidentiality as a professional yet cannot guarantee that all group members will abide by this request. **Standards for Group Interaction** will also be reviewed and those desiring to comply and stay in the group sign pledging their agreement in support of group safety.

For purposes of coordinating care, we must also have on file signed a Release for Exchange of Information with: (1) the child's pediatrician/medical doctor; (2) the Early Start global program personnel; (3) the CSC at Regional Center, and (4) Connected Families PBS/CT child/caregiver therapist and family therapist or as well as any other therapists involved in treatment of the child, caregiver, or family as appropriate.

At such time that research might be done using data collected within the program, Informed Consent for Research forms approved by the Institutional Review Board (IRB) must also be signed and collected from all persons authorized to consent.

Continued on next page

Intake and Assessment

Initial intake for CFCG includes a **Caregiver Interview** with the therapist. The purpose of the interview is three-fold: first, it is important to determine whether the caregiver has the willingness and capacity to commit to the 10-week group; second it is important to for the therapist to gain understandings of caregiver history and attachment; perspectives about their child; attitude toward self-care, and nature supportive services needed. If/when there are indications of serious psychopathology or lack of readiness for the group, Connected Families will suggest a higher level of support for the caregiver either in keeping with the group, or perhaps as a pre-requisite to group participation. An example of this would be individual psychotherapy. The therapist maintains a clinical record that reflects caregiver perspectives based on the interview that is placed in the caregiver's group file.

In addition, therapist will observe the caregiver/child in home and complete the **Toddler Attachment Sort-45 (TAS-45**) to identify the child's baseline attachment style and caregiver interaction. Caregivers must complete the **Social Support Index (SSI)**, **Beck Depression Inventory (BDI)**(Beck et al., 1996), and **Beck Anxiety Inventory (BAI)** (Beck & Steer, 1993) as baseline measurements for CFCG. The therapist scores each instrument according to instructions. Original documents will be maintained in the caregiver's group file with a copy provided to the Document Custodian. Any and all evidence of potential safety issues (e.g., suicidality) are to be immediately and directly addressed according to ethical standards of care.

It is very important to ensure the date of assessment is captured on ALL inventories for the child and caregiver. It is also very important that the therapist record PRE at the top of each inventory for ALL INTAKE ASSESSMENTS as this provides ease of processing for program evaluation.

Importantly, the therapist will also consult with the child/caregiver **Connected Families PBS/CT** therapist to coordinate care. When the caregiver moves into **Family Therapy**, the group therapist will collaborate for the benefit of the child's family unit and support system.

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Recordkeeping

For purposes of case management, the **Informed Consent for Treatment, Caregiver and Child Personal Data Sheets**, clinical notes, the **Treatment Plan Summary**, **Progress notes** for the child and caregiver and all child and caregiver assessment inventories are placed in the caregiver's group file. Dated copies of all assessment inventories marked pre, mid, or post are also forwarded to the Document Custodian.

The Document Custodian who is not involved with the treatment assigns a unique number to the child/caregiver pair at PBS/CT Intake. The unique pair number is placed on copies of all assessment inventories for upon receipt after removing or redacting information that would identify the caregiver or child/caregiver pair. Information that would identify either the child or caregiver will therefore be securely destroyed allowing for future collective, deidentified data analysis. Thereafter, the deidentified copies of each caregiver assessments can be used as source documents for input SPSS to for program evaluation and, only after IRB approval, for research.

Measurement of Treatment Outcomes

Caregiver depression and anxiety levels are monitored throughout the duration of treatment for purposes of case management and can be evaluated in aggregate to measure conformance of actual program outcomes to expectations within the logic model. CFCG treatment efficacy and cohesion within the group are evaluated throughout treatment for purposes of case management using **Group Session Rating Scales** (Quirk et al., 2012) and **Outcome Rating Scales** (Miller et al., 2003). These data are also deidentified, aggregated, and further analyzed to evaluate caregiver perceptions of treatment efficacy and caregiver experience of mutual support within the group experience.

Progress notes will identify changes in caregiver awareness of: (1) their own interaction patterns and attachment style; (2) their infant/toddler bids for connection and communication patterns; (3) improved dyadic communication and attunement between the caregiver and infant/toddler with less ambiguity and miscuing; (4) increased use of positive behavior support techniques; (5) improved caregiver confidence; and (6) increases in secure attachment interactions between the infant/toddler and caregiver. De-identified **Weekly Summaries** that identify caregiver status/progress based on a Likert scale are provided to the Document Custodian and evaluated in aggregate to determine program outcomes.

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Connected Families Caregiver Group Program Description, Continued

Approach

Because the CFCG is designed to address needs of a diverse caregiver community, the modules are designed to address broad areas with the understanding that each group—and the participants of the group—are unique and therefore may have greater interest in some themes and methods than others. For this reason, sessions address specific content with questions and activities suggested. Activities may be done during group time or as homework, but “in group” is preferred to build connection between participants. The therapist may choose to include some, none, or all of the suggested questions and activities within each session to adapt to and accommodate the needs of the group members. It is expected that progress notes will reflect the nature of group experience including questions, activities, and interventions used. Significant deviations from the material must be identified in writing and provided to the Program Manager to allow an opportunity to consider evaluation implications as well as possible change to program content or methods.

Orientation

Before the start of each new Module, an Orientation session is held to welcome newcomers. This session provides an opportunity to introduce the nature and structure of the group and collect any remaining documentation. This is a good time to field questions and address housekeeping issues including Standards for Group Interaction.

Portfolio of Progress

Sessions within the modules contain experiential caregiver activities that are designed to foster increased awareness and insight as well as provide a forum for sharing perspectives among group members. The experiential work for each caregiver will be included photographically in the clinical record with original caregiver art maintained each Caregiver’s Portfolio of Progress.

Reference Books

References that may be useful for caregivers in the program include:

Active Parenting by Michael H. Popkin (Popkin, 1993)
Ages & Stages: A Parent’s Guide to Normal Child Development by Charles E. Schaefer and Theresa Foy DiGeronimo (Schaefer, DiGeronimo, 2000)
Not What I Expected: Help & Hope for Parents of Atypical Children by Rita Eichenstein (Eichenstein, 2015)
Parenting from the Inside Out by Daniel J. Siegel (Siegel, D. J., Hartzell, 2003)
Parenting with Love & Logic by Foster Cline & Jim Fay (Cline, F., Fay, 2006)
The Whole Brain Child by Daniel J. Siegel and Tina Payne Bryson (Siegel, D. J., Bryson, 2012)

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Connected Families Caregiver Group Program Description, Continued

Module I: Caregiver and family needs, processes & strategies	Module I content experientially addresses caregiver and family needs, processes and strategies with the intention of fostering insight within each caregiver and connection between group members. Issues that are specifically addressed in this module include the caregivers' emotional response and highlights the importance of self-care for the caregiver. Finally, there is interaction around family patterns and community experiences.
Module II: Attachment and the neurodiversity of autism across the lifespan	Module II content offers perspectives on the challenges of creating secure attachment within the neurodiverse child. Drawing upon recent research but presented in a relatable way—caregivers can begin to realize they are not alone in the struggle to maintain connection with their child. There is discussion about the neurodiversity of autism from a developmental perspective that extends across the lifespan.
Module III: Parenting and positive behavior support	Module III content is focused on learning, understanding, and applying parenting skills and many positive behavior support strategies with the neurodiverse child. In this module, caregivers can get feedback from the therapist and each other.
Module IV: Child Parent Relationship Therapy	Module IV content is an implementation of the complete CPRT treatment protocol as conceived by Bratton, Landreth, Kellam, and Blackard in a standalone treatment manual. This attachment-based filal therapy model requires the credentialing of the treating therapist which is not yet in place. This evidence-based approach teaches caregivers how to create a special playtime with their child and record the experience to share with the group. The group offers encouragement and feedback to the caregiver noting strengths. This module includes assessment instruments which shall be used to measure outcomes.
Termination, Referrals & Supports	Groups run for a pre-determined period of time: 10 weeks per module with caregivers making a commitment one module at a time. Referrals and supports are considered throughout the duration of the group. At the end of each module, a Quality Assessment Survey is provided to caregivers for their feedback about their experiences in the group. "Post-treatment measures are collected at the end of Module III as Module IV has independent assessment instruments.

Connected Families Caregiver Group Module I

Overview

Module I content experientially addresses caregiver and family needs, processes and strategies with the intention of fostering insight within each caregiver and connection between group members. Issues that are specifically addressed in this module include the caregivers' emotional response and the importance of self-care for the caregiver. Finally, there is interaction around family patterns and community experiences.

Session	Description
1	Introductions & The Family Portrait
2	Welcome to Holland or Beirut or Wherever We Are
3	Parenting: An Experience Like No Other
4	Caregiver Life Experiences
5	The Person of the Caregiver
6	Hiding in Plain Sight
7	Caregiver Needs
8	Feelings, Interactions & Communication
9	Family Patterns
10	Community Experiences

Continued on next page

Session 1

Introductions & the Family Portrait

To the therapist: **The goal for this session is to introduce the group and help members begin connecting with their idea of "family" and with each other.** This can be a very busy session. Depending on the energy in the room and space/materials available the activity could be done concurrent with the discussion. The activity could be done as homework, but often caregivers have little time for themselves to complete homework.

Content & Process: As this is the first session together, the therapist introduces themselves and before starting discussion will verbally readdress matters of Informed Consent including limits on confidentiality and expectations of confidentiality in the group. It is also important to quickly review the Standards for Group Interaction and ask all group members to agree to keep matters shared within the group inside the group. After introducing the overall content covered within the module, we allow time for group members to introduce themselves. It would be helpful if each person can share their first name and a little about themselves and their child and perhaps what they hope to gain from participating in the group.

Once housekeeping matters are completed, the therapist can reference to the TV show, "This is Us," a show about a multi-generational family that remains connected across time despite the ebb and flow of life which includes a few tragedies. The series is set in the here and now—much like we live our own lives—but includes "flashbacks" to points in time that shaped memory, experience, and thinking and feelings for the family. As we begin to work together, it is important to know that where we are today has everything to do with where we have been in our journeys—and the choices made today have a powerful impact on the future of our lives and those of our children.

Questions for group process:

(1) What are some of the things that shape your experience as a caregiver (e.g., culture, race, religion, family history, my/others expectations, abilities, etc.)?
(2) What are the most important things to you as your child's caregiver?
(3) What goals have you set for yourself?

Activity: *Either reflect on a family portrait through writing or drawing OR create a family portrait using any medium. Share a little about what this experience was like for you and perhaps something that you discovered in the process.*

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Session 2

Welcome to Holland

To the therapist: **The goal of this session is to help caregivers begin to consider and process their thoughts and feelings about their child.** You may need to provide some definitions for feeling words—or even pictures. Words and tears are both important and both can flow once the therapeutic alliance and safety are in place. Depression and anxiety are real, and community is vital. It is not good to be alone. Use the self of the therapist with empathic attunement, encouragement, and reframing as needed and be with each participant.

Content & Process: Few caregivers knew in advance the emotional journey that accompanies loving and supporting a special needs child. There are MANY diverse experiences; but a poem written by Emily Perl Kingsley provides one metaphor for the experience (Massanari, J. D., Massanari, 2008). As you watch the video, listen, or read the words--try to tap into your own thoughts and emotions and notice what resonates with you—and maybe even things that don't. Remember this is one person's experience—and you have your own.

Video Link: Welcome to Holland (Beccera, 2017)	Sent request to author to reproduce poem in Program Manual 5/3/19 (Kinglsey, 1987)

Questions for group process:

- What is your emotional response to the poem or video (e.g., happy, mad, depressed, anxious, sad, glad, guilt, shame, grief, joy, thankfulness, hope)?
- What are some of the things that are different about your life, your family, and your child that you couldn't expect?
- What do you tell yourself about the differences? How do the differences impact your day-to-day activities and choices?
- Looking at the group as part of your community, what do you need most as far as support?

Activity: reflect on the video/poem and write (journal) or draw your response to one or the other or both. Share a little about what this experience was like for you and perhaps something that you discovered in the process.

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Session 3

Different is…

To the therapist: **The goal of this session is for caregivers to being to consider the expectations they have for themselves and their child and to foster connection between group members.** In this session, caregivers have the opportunity to discuss "differences" and the meaning of different for themselves and for their child. Depending on the group, this could be a superficial discussion or a deep and thought-provoking discussion. Hold space as needed for whatever emerges and know that your presence and empathy matter as you move the discussion along and give everyone an opportunity to have a voice. Notice how the group operates as a system—facilitate support and connection between group members.

Content & Process: Parenting is an experience like no other and there are many "experts" who may tell you what you should be doing. There are so many places where this can happen. The grocery store, the park, maybe even in your own neighborhood—or in your own family. While there are many parenting models—and we'll talk about those in another module—it's important to know that no two children are the same. Period. Each child is unique and brings opportunities and challenges into the family. But being labeled "different" can mean a lot of very different things. Being different is not bad. Being different is not being "like" the others. Different is…: tragic, beautiful, significant, devastating, wonderful, brilliant, exhausting, heartbreaking, elusive, breathtaking, beyond description, valuable, precious, unique. Different is sometimes hard to accept and act on; often misunderstood; but not flawed, and certainly not unloved.

Questions for group process:

- What does "different" mean in your family when it comes to your child?
- Where are you today with the "differences" in your child?
- Are there some settings where you notice the differences more than others? What are those and how do they impact you as a caregiver? What do you tell yourself in those situations: (a) about yourself; (b) about your child; (c) about your family; and/or (d) about the future?

Activity: reflect on your expectations and experiences with your child and either sketch or write about an important or interesting event or experience—good, bad, or indifferent. Share a little about what this experience was like for you and perhaps something that you discovered in the process.

Continued on next page

Session 4

Life Experiences

To the therapist: **In this session, the goal is to help caregivers begin to explore dimensions of themselves as they maintain caregiving responsibility for a child at risk for ASD.** During discussion, notice the strengths within each caregiver and provide encouragement and affirmation that fosters a survivor/challenger/conqueror mindset versus victimhood. It may be helpful to familiarize yourself with superheroes and other characters to help with discussion. Notice and facilitate actions each caregiver can take to notice themselves and their child and advocate for both.

Content & Process: There's what happens—and what we do with what happens. Things happen in life that are not according to our plans and choices and how we respond matters. The victim mindset says, "this has happened and now I don't have choices." The survivor mindset notices there is always choice—at the very least "to choose one's attitude in any given set of circumstances" (Frankl, 1984, p. 86). Yet, trying to keep up appearances in the face of misunderstanding and judgment is both exhausting and impossible. Sometimes the best and most important choice is showing up. Another important fact is that the truth will set you free—mostly. I say mostly, because sharing the truth with an unsafe or unsupportive person doesn't work—but sharing it in your tribe that understands can be liberating. As you consider the many dimensions of who you are—you're not only a caregiver. You are a person operating in many family and community roles and responsibilities. You have a body, a mind, a spirit, culture and society. You may work or participate in spiritual or religious community.

Questions for group process:

- What do you hope people see when they look at you? Consider your roles/responsibilities, vocation, family, spirituality, health.
- When you think about how you see yourself,
- When you think about people who have great strength and your own experience, what is the quality or person with whom you identify and why?

Activity: Create a *<u>self</u>**-portrait using any medium, including a collage that reflects the dimensions of your life experience. This is your experience of you, not necessarily what others see. Share something you feel, think, or have discovered while doing this activity.*

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Session 5

Looking Closer inside the Person of the Caregiver

To the therapist: **The goal of this session is to help caregivers explore their expectations of themselves and to foster connection between group members**. This session systemically draws from cognitive-behavioral theory and provides participants the opportunity to explore personal thoughts and emotions with respect to their caregiving roles. Notice what is said and unsaid and if people hold themselves (or others) to unrealistic standards. As you foster safety and hold space for group process, your Presence matters and helps people connect with themselves and each other. Use empathy and compassion, especially when vulnerable emotions are shared. Use reframing, redirection, perhaps components of cognitive restructuring, and scaffolding as needed to shift perspectives and maintain necessary focus.

Content & Process: Systems of belief (schemas) that provide an infrastructure for experiences, thoughts, emotions, and choices.
Words spoken by others or even our own self-talk can trigger challenging thoughts and emotions like guilt *(I did something wrong or I didn't do something that I should have done)* or shame *(I AM wrong, defective, bad)*: inappropriate, irresponsible, inadequate, incompetent, ineffective….there are MANY words in this category.
We all have triggers and noticing them is an important first step to mastering self-control in a sea of chaos. It's not wise to make decisions based solely on emotion, or only on logic; the ability to "sit with" both/and when making choices can allow us to consider the bigger picture.

Questions for group process:

- What are some of the things you say to yourself about yourself as your child's caregiver?
- What emotions or feelings do you experience as a caregiver to your child? Consider feelings for/about your child or children; partner; parents and in-laws; extended family.
- What are examples of "double-binds" that you have placed on yourself—or that others have placed on you?

Activity: Using a plain brown bag, decorate the outside with what you hope people see/say/think of you as a caregiver; on the inside, place objects or words that represent things that you want to remain unseen. We'll work with the same bag next week, so leave it in the Center in a secure location.

Continued on next page

Session 6

Hiding in Plain Sight—

To the therapist: **The goal of this session is to allow caregivers to tap into how vulnerable emotions (acknowledged or not) might be keeping them from experiencing community and to prompt reaching out and connecting within the group.** In this session, the focus is on the vulnerable emotion of fear and how hiding can keep us from experiencing community, connection, and calm. The "fear cocktail" can be interwoven with shame and guilt (especially false guilt) and misunderstanding that can further isolation.

Content & Process: Fear is a powerful motivator; but doesn't always produce the best results. Sometimes we hide believing that by hiding we are safe when we are actually in plain sight. My cat Simba, though a bold fighter, had a traumatic experience as a kitten and it all started when someone rang the front doorbell. Halloween is awful for him, and he hides looking for safety, not knowing he's in plain sight. This is his Halloween costume every year. Despite his fierceness and desire to be "king," Simba needs understanding and a gentle touch to bring him out of hiding. And when he comes out of hiding, he finds comfort, and connection and a sense of belonging and safety that helps him calm down. Living by the mantra, "*Don't ask, don't tell, don't trust, don't feel*" is a prescription for going solo and not getting support. Some of the gifts we can offer each other are holding space without judging or fixing, showing empathy, understanding, offering connection, a sense of caring and belonging. To pour yourself out as a caregiver, you need a way to recharge. You can't pour from an empty glass.

Questions for group process:

- What are some of the things you might be hiding about yourself (e.g., body issues: care, feeding, exercise, sleep; need for balance between caregiving, work, and play; spiritual/religious needs; cultural and social participation; need for understanding and a system of support)?
- If you feel comfortable sharing, what role does "fear" play in hiding?

*Activity: Let's revisit the plain brown bag from last week. When you look inside, of your own bag, what do you see? Are there more unseen emotions and needs that belong inside? Place them there now! Is there one thing that you put **inside** your bag that you are willing to share?*

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Session 7

My Needs?

To the therapist: **The primary goal of this session is to provide caregivers with specific time to consider and contemplate their own needs. A closely affiliated goal is for group members to experience this as a joint/shared activity where they collectively identify their needs and discuss whether their needs are met.** This session is rather broad, so having some visual supports that help caregivers consider the bio-psycho-social-spiritual dimensions of themselves throughout process and activity might be helpful.

Content & Process:

Caring for another person can be both rewarding and consuming but giving without also receiving is not sustainable. Metaphor: You cannot pour from an empty glass. All of us have needs in many areas including: biological/physiological; psychological—mental and emotional; social—family, friendships, relationships; and spiritual—transcendence, meaning-making, possibly religious. When you consider your child(ren) and what you do to provide care and then look at the things that could fill you up—do you find a balance? Many special needs families struggle a great deal in this area. Sometimes people change careers or stop working to accommodate the schedule demands and support the needs of their child(ren). Often relationships with family and friends change. It may be easy to isolate, rather than engaging in community or taking your child with you to a public setting such as a store or a religious observance. Your journey with your child needs to last many years—and therefore you—the caregiver—need to be nurtured and supported in the process.

Questions for group process:

- What are some of the rewards and challenges in your caregiver role to your child?
- As you stand back and look at “what you pour out” what is in place – or needs to be put in place to “fill you up”?
- How can the group support you as you explore ways to meet your own needs?

Activity: Using magazines, or your own sketches, create a collage that reflects some of your NEEDS. Consider the roles that you have in your life--e.g., family, school, work, religious/spiritual, physical, home, as a caregiver--find objects that represent those NEEDS.

Continued on next page

Session 8

Feelings, interactions, and communications

To the therapist: **During this session, the goal is to introduce more difficult emotions such as guilt, shame, grief/loss and sadness and provide the opportunity for caregivers to discuss their own difficult emotions and patterns of interaction and communication with their child. An additional goal is fostering connection between the group members**. This theme will carry forward for two more sessions and be applied to the family and community. This can be a heavy session and it is important to provide congruent, empathic support as members share. The depth of sharing is likely to vary based on perceived safety within the group, caregiver characteristics, and external factors. If/when group members may wish to voluntarily exchange contact information for outside support. Journaling is highly recommended.

Content & Process: As caregivers explore their own experiences and needs, it is very common for difficult emotions to come up. Today, we begin to discuss some of the more challenging of the difficult emotions: guilt, shame, grief/loss, and sadness. Like all people, caregivers can experience these emotions all together and it's hard to sometimes tease them apart. So, we begin with some definitions. Within Connected Families we define "guilt" as a matter of fact that is associated with behavior: something that should not have been done was done OR something that should have been done was not done. Additionally, we define "shame" as "I am bad" which is therefore associated with character and sense of person. Grief and loss are normal within the experiences of life and is a process that must be honored. There is no right or wrong way to process grief and loss, nor does it follow a defined time period. Sadness is an emotion that accompanies grief/loss and disappointment that can just feel heavy—or like being covered with a wet blanket. Sometimes it can be difficult to figure out whether a person is feeling guilt or shame—or maybe both. All of these difficult feelings are normal. But like in the Disney movie, *Inside Out*, the ability to recognize, acknowledge, and move through difficult emotions makes the positive emotions like joy, happiness, gladness and even hope possible. This week we focus on your relationships as a caregiver with your child. In the next two weeks we will focus on other relationships.

Questions for group process:

- As you reflect on the definitions that were shared for some of the difficult emotions that all people experience, which one(s) do you recognize from your own experience as a caregiver?
- When you consider the challenges that your child faces, what emotions come up for you?
- How can the group come alongside you as a community of hope as you honor the emotional challenges you face?

Activity: Using crayons, markers, paint, or chalk create a drawing that represents your challenging emotions as a caregiver to your child. You might want to represent emotions with different colors for example.

Continued on next page

Session 9

Family patterns

To the therapist: **During this session, the goal is to introduce more difficult emotions such as guilt, shame, grief/loss and sadness and provide the opportunity for caregivers to discuss their own difficult emotions and patterns of interaction and communication with their child and family. An additional goal is fostering connection between the group members**. This theme began last session will carry forward for another session and be applied to the community. This can be a heavy session and it is important to provide congruent, empathic support as members share. The depth of sharing is likely to vary based on perceived safety within the group, caregiver characteristics, and external factors. If/when group members may wish to voluntarily exchange contact information for outside support. Journaling is highly recommended.

Content & Process: As caregivers explore their own experiences and needs, it is very common for difficult emotions to come up. Today, we continue to discuss some of the more challenging of the difficult emotions: guilt, shame, grief/loss and sadness. Like all people, caregivers can experience these emotions all together and it's hard to sometimes tease them apart. So, we begin with some definitions. Within Connected Families we define "guilt" as a matter of fact that is associated with behavior: something that should not have been done was done OR something that should have been done was not done. Additionally, we define "shame" as "I am bad" which is therefore associated with character and sense of person. Grief and loss are normal within the experiences of life and is a process that must be honored. There is no right or wrong way to process grief and loss, nor does it follow a defined time period. Sadness is an emotion that accompanies grief/loss and disappointment that can just feel heavy—or like being covered with a wet blanket. Sometimes it can be difficult to figure out whether a person is feeling guilt or shame—or maybe both. All of these difficult feelings are normal. But like in the Disney movie, *Inside Out*, the ability to recognize, acknowledge, and move through difficult emotions makes the positive emotions like joy, happiness, and gladness possible. This week we focus on your relationships as a caregiver with your child and family. In the next session we will focus on other relationships.

Questions for group process:

- As you reflect on the definitions that were shared for some of the difficult emotions that all people experience, which one(s) do you recognize from your own experience as your child's caregiver with or in your family? (Note: This can be immediate or extended.)
- When you consider the family challenges facing you and your child, what emotions come up for you?
- How can the group come alongside you as a community of hope as you honor the emotional challenges you face?

Activity: Using crayons, markers, paint, or chalk create a drawing that represents your challenging emotions as a caregiver to your child with your family. You might want to represent emotions with different colors for example.

Continued on next page

Session 10

Community experiences

To the therapist: **During this session, the goal is to introduce more difficult emotions such as guilt, shame, grief/loss and sadness and provide the opportunity for caregivers to discuss their own difficult emotions and patterns of interaction and communication with their child and community. An additional goal is fostering connection between the group members.** This can be a heavy session and it is important to provide congruent, empathic support as members share. The depth of sharing is likely to vary based on perceived safety within the group, caregiver characteristics, and external factors. If/when group members may wish to voluntarily exchange contact information for outside support. Journaling is highly recommended.

Content & Process: As caregivers explore their own experiences and needs, it is very common for difficult emotions to come up. Today, we continue to discuss some of the more challenging of the difficult emotions: guilt, shame, grief/loss and sadness. Like all people, caregivers can experience these emotions all together and it's hard to sometimes tease them apart. So, we begin with some definitions. Within Connected Families we define "guilt" as a matter of fact that is associated with behavior: something that should not have been done was done OR something that should have been done was not done. Additionally, we define "shame" as "I am bad" which is therefore associated with character and sense of person. Grief and loss are normal within the experiences of life and is a process that must be honored. There is no right or wrong way to process grief and loss, nor does it follow a defined time period. Sadness is an emotion that accompanies grief/loss and disappointment that can just feel heavy—or like being covered with a wet blanket. Sometimes it can be difficult to figure out whether a person is feeling guilt or shame—or maybe both. All of these difficult feelings are normal. But like in the Disney movie, *Inside Out*, the ability to recognize, acknowledge, and move through difficult emotions makes the positive emotions like joy, happiness, and gladness possible. This week we focus on your relationships as a caregiver with your child living in a community.

Questions for group process:

- As you reflect on the definitions that were shared for some of the difficult emotions that all people experience, which one(s) do you recognize from your own experience as your child's caregiver within community (e.g., neighbors; work/school; church, synagogue, mosque, temple; or marketplace)?
- When you consider the community challenges facing you and your child, what emotions come up for you?
- How can the group come alongside you as a community of hope as you honor the emotional challenges you face?

Activity: Using crayons, markers, paint, or chalk create a drawing that represents your challenging emotions as a caregiver to your child in community. You might want to represent emotions with different colors for example.

Connected Families Caregiver Group Module II

Overview

Module II content offers perspectives on the challenges of creating secure attachment within the neurodiverse child. Drawing upon recent research but presented in a relatable way—caregivers begin to realize they are not alone in the struggle to maintain connection with their child. There is discussion about the neurodiversity of autism from a developmental perspective that extends across the lifespan. Caregivers have the opportunity to share "connection" videos of their child.

Session	Description
1	Pictures of autism as a neurodiversity: early years
2	Attachment talk: secure bases and safe havens
3	The research says autism and attachment are a good, but challenging mix
4	What I tell myself (and my child) matters
5	Offering connection
6	Sharing experiences
7	Staying connected: pictures of autism as a neurodiversity: childhood & adolescence
8	Pictures of autism as a neurodiversity: adulthood
9	Communities supporting autism as a neurodiversity
10	The meanings of autism in our family

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Session 1

Pictures of autism as a neurodiversity: early years

To the therapist: **Goals of this session include introduction of group members to each other and to the group format as well as opening discussion about the neurodiversity of autism.** It is likely that the theme of ambiguous loss might emerge. Make notes of what people expect from the group. Use empathic attunement and affirm when possible as each caregiver shares while fostering connection among group members.

Content & Process: As this is the first session together, the therapist introduces themselves and before starting discussion will verbally readdress matters of Informed Consent including limits on confidentiality and expectations of confidentiality in the group. It is also important to quickly review the Standards for Group Interaction and ask all group members to agree to keep matters shared within the group inside the group. Additionally, the therapist briefly reviews the overall content covered in Module II; then, allows time for group members to introduce themselves. It would be helpful if each person can share their first name and a little about themselves and their child and perhaps what they hope to gain from participating in the group.

Providing care for a special needs child can be demanding and rewarding for most people and when it comes to autism—it's a spectrum that can span from mild to severe. There's no "one" picture of ASD and you have made a wise choice to get early support for your child—and for yourself as well. Researchers don't know exactly what causes autism—but there are familial/genetic and environmental factors. We also know that those on the spectrum are neurodiverse—that is, the brain, nervous system, and even gut bacteria are different than neurotypicals. Biology is involved here—it's not just about the child having a strong will or behavioral issues—and caregivers have hopes and dreams that involve relationship experiences with their child. No doubt, caring for your child is different from what you expected, but you are taking bold steps for yourself and your child that matter.

Questions for group process:

- When you think about your own encounter with neurodiversity, what comes up for you? What longings do you have for your child? For yourself with your child?
- What has shaped your experiences with neurodiversity? What messages have you encountered and which ones do you embrace for yourself?
- How are you doing with the "differences" of neurodiversity and what do you most need now?
- What does neurodiversity say to you? What would you like to say back to neurodiversity?

Activity: As you reflect on your child today, create a drawing that represents your own encounter with neurodiversity. Reflect what this experience is like for you. Use colors and shapes to bring perspective to your experience.

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Session 2

Attachment talk: secure bases and safe havens

To the therapist: **A goal of this session is to introduce the concept of attachment and the idea of a "secure base" and "safe haven."** In this session, Bowlby's concepts of the secure base and safe haven are introduced(Simpson et al., 1999), and caregiver have the opportunity to discuss interaction patterns with their child. Normalize imperfection and the learning experience, offer support, encouragement, and comfort as caregivers discuss their experiences and help caregivers connect with each other. During this work, the therapist operates as the secure base and safe haven as group members explore and seek comfort.

Content & Process: When we talk about attachment we are drawing from a large body of research and publication that spans decades—all of which indicates that having "**secure attachment**" is a good thing and produces the best outcomes in life. Connected Families programs all promote "secure attachment" between the child and caregiver—and it's something that can develop early in life. As a caregiver, you can become the "**secure base**" and the "**safe haven**" for your child. How is this supposed to work, you might ask? Let's take an example that might be familiar. Imagine being at a baby shower with a bunch of mothers and their toddlers. The environment is new to the toddlers and the moms are seated; some are holding their toddlers and some toddlers are near mom's knees. After a bit, one of the toddlers will stray a bit to explore while looking back at mom – his *secure base*. Her continued safe presence offers the security to explore. The toddler will return to her time and again during exploration. But then something unexpected happens. Perhaps while exploring, there is an unexpected loud noise that is frightening. The toddler runs back to his mother—her presence and offer of comfort and connection now function as a "safe haven." Although this is a neurotypical example, neurodiverse children are capable of secure attachment. It might look different, but your role as a caregiver is so important!

Questions for group process:

- As you think about your child and the example given, can you think of examples of your child looking to you as a secure base or safe haven? If you can think of an example, what are some of the differences in the way your child explores or seeks soothing? If you cannot think of an example, like this—what does your child do and how do you respond when your child is overwhelmed or afraid?
- Are you willing to share what your caregiver experience is like in this process? What skills do you need to develop and what skills does your child need to develop? How can the group support you in this process?

Activity: Either create a drawing or journal about what it means to you to be a consistent safe presence for your child—offering a secure base and a safe haven.

Continued on next page

Session 3

The research says autism and attachment are a good, but challenging mix

To the therapist: **The goal of this session is to introduce the importance of secure attachment and the some of the challenges associated with developing secure attachment in the neurodiverse child.** This session builds from mini introduction to attachment from last time. Caregivers may have increased awareness of their parts in the interactional sequences. Continue to provide a calm, non-anxious presence that encourages and supports with empathic attunement, reframing and redirecting as needed while fostering connection within the group.

Content & Process: Last time we introduced the idea of the caregiver as a "secure base" and as a "safe haven" for the child and we gave an example. Your lived experience with your child may be very different and that is okay. In fact, it can be pretty challenging to understand some of the differences between autism and attachment behaviors and even the experts recognize that (McKenzie & Dallos, 2017; Teague et al., 2017, 2018)! For example, you have a relationship with your child and your child with you. It's hard for caregivers to stay plugged in and engaged when the child doesn't make eye-contact or pulls away or tantrums when over stimulated—or when they might seem lost in space. This is one of the reasons it's so important for you to stay in touch with yourself and have the support you need. In short, to show up for your child—you need to be able to show up for you first.

Questions for group process:

- As you think about your interactions with your child, what are some of the things that challenge you as a caregiver? For example, are your child's reactions sometimes confusing and frustrating?
- Is there one thing, that if it changed—it would help you stay attuned to your child? If so, how would that change help you?

Activity: Draw a picture of a difficult, but typical interaction with your neurodiverse child. Share one thing that you have noticed about yourself and your child through this process.

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Session 4

What I tell myself (and my child) matters

To the therapist**:** **The goal of this session is to help caregivers bring into conscious awareness their own self-talk and possibly negative narratives that might keep them stuck in ambiguous/negative interaction patterns or possibly disconnecting from the child**. Maintain calm, non-anxious, non-judgmental presence and provide encouragement and constructive feedback while fostering connection between group members. Notice that you are modeling for the caregivers how to interact with their child.

Content & Process: In the last session we mentioned the importance of showing up for yourself in order to show up for your child. This can be particularly difficult for many reasons—and the first one is widely recognized in the research. Interactions between a neurodiverse child and caregiver are confusing and often contain many mixed messages! This makes it really hard for some caregivers to feel confident and capable. Other reasons that might make it difficult to show up for yourself include history of trauma that hasn't been resolved, difficult experiences of being parented, or other life experiences that impact your self-confidence or self-esteem—and those things can be addressed in individual therapy. Another common issue is the fatigue that accompanies caregiving. Let's consider the confusing interactions and how those happen between you and your child.

Question for group process:

- Think about an incident with your child where there was confusing interaction between the two of you. Briefly share what happened and what you told yourself about what happened (e.g., why it happened, how it happened, what it says about the child, what it says about you, what it says about the relationship, what it says about the future).
- What do you need to do to give yourself grace—the permission to fail and to get up and try again?

Activity: Look back at the sketch you made last session of the interaction with your child or sketch out a new one. Highlight what happens in the interaction that is confusing. Share part of what happens with you as a caregiver when you are confused by your child.

Continued on next page

Session 5

Offering connection

To the therapist: **One of the goals of this session is increased group cohesion/safety and interaction as members can offer a "cup of water" to each other—perhaps sharing an important resource with the group.** This session draws together many of the concepts addressed within the module and encourages caregivers to seek support for themselves in order to offer a consistent safe presence for their child.

Content & Process: We have been talking about some of the communication challenges with the neurodiverse child and last time the focus was on how caregivers respond when interactions are confusing. As a caregiver, your own needs for connection and support cannot be met by your child. Instead, caregivers need peer adult relationships that offer support for the person of the caregiver. From an attachment perspective, caregivers need their own "secure bases" and "safe havens." Drawing from the metaphor used earlier, you need to fill your own cup before you can pour out for your child. And this is very difficult to do while parenting a neurodiverse child. This group should be a place where caregivers find and offer each other acceptance, support, and connection. This benefits all of us and the children as well. There may be other places where you find "connection." Notice those areas of support and the quality of connection offered as well as what you give in return. When it comes to your child, our focus is on relationship. Your child may or may not respond as you prefer, and the choices that you make to stay connected whether disappointed or celebrating success is important to your child's success and to your own well-being.

Questions for group process:

- As you consider your own needs for connection and support—so you can be that secure base/safe haven for your child, how and where are you engaged in this process for yourself?
- In what areas do you feel a need for increased support and understanding (e.g., financial, family, education, childcare, etc.) and what resources are you familiar with that may benefit other group members?

Activity: Either journal or sketch a picture of how you would like to maintain connection with your child despite a challenging interaction.

Continued on next page

Session 6

Sharing experiences

To the therapist: **Goals of this session include increasing awareness of the issues that impact all caregivers supporting neurodiverse children while prompting the perspective that caregiving is a marathon, not a sprint.** In this session some of the challenges are identified, but there are many MORE. Through this discussion, caregivers can discover more that they have in common. As you lead discussion, notice how people are connecting with each other. Also, as people share, they may mention resources and it would be beneficial to keep track of new ones (see Session 9!)

Content & Process: As we continue to consider how we can be present for ourselves, one another, and our children it is also important to acknowledge some of the difficulties that we encounter as caregivers. We have talked about communication difficulties with potential to impact our own relationships with our child(ren). We haven't directly mentioned that the communication and behavioral issues can also lead to other issues like: difficulty finding adequate childcare, decreases in community involvement, significant time/schedule stress, challenges related to employment and finance, difficulty with sibling relationships, and overall increases in family stress possibly including distancing of friends and family members. Often there is stigma associated with neurodiversity and people without information or understanding may communicate their judgment which is not helpful. With early intervention, there is hope for positive outcomes—but neurodiversity is a lifelong experience, so it is important for caregivers to maintain a steady pace to go the distance—more like running a marathon as opposed to a sprint.

Questions for group discussion:

- When you consider the "marathon vs. sprint" metaphor and the challenges you experience, what is most concerning and why?
- What is your greatest need as a caregiver (e.g. consider bio-psycho-social-spiritual) to your neurodiverse child? To other family members? To friends? Within community?
- Where do you experience hope or a sense of being held, filled up, or supported?

Activity: Consider the challenges you face, the skills you now possess, and the community of support in which you are invested. Journal or draw/sketch a picture that reflects you as you face your challenges with all the resources and strengths available to you. Notice whether you are tapped into and engaged in all the available resources.

Continued on next page

Session 7

Staying connected: pictures of autism as a neurodiversity: childhood & adolescence

To the therapist: **The goal of this session is to engage caregivers around the topic of their child's neurodiverse development throughout childhood and adolescence**. This perspective lends importance to early intervention, perseverance, and relationship.

Content & Process: Caring for a neurodiverse child can be a challenging and rewarding experience and we have talked about the importance of seeing your caregiving responsibilities like a running a marathon compared to a sprint. It's also important to consider some of the things ahead as your child continues to develop. Early intervention is a good thing that can really help with symptoms, but there will probably be some challenges that remain. For example, although early intervention may resolve many issues, some neurodiverse children prefer being alone and avoid social interaction. The child may have a really hard time reading social cues or keep talking about things that are interesting only to themselves without noticing the other person isn't interested. This can negatively impact friendships and sometimes lead to the vulnerability of being bullied. Staying open and connected with your child/adolescent is important at all ages and stages of development.

Questions for group process:

- When you think about your child growing up—through the elementary years and into adolescence, what comes to mind?
- What expectations do you have for yourself as your child matures?
- What concerns do you have as you imagine your child as an adolescent?

Activity: Either journal about your thoughts and emotions in response to your child as an adolescent OR sketch/draw something that reflects your current perspective as you imagine your child as an adolescent.

Continued on next page

Session 8

Pictures of autism as a neurodiversity: adulthood

To the therapist: **The goal of this session is to offer hope and perspective to caregivers and to help them envision their child as an adult.**

Content & Process: Caregivers sacrifice so much to invest in their child's present and future sometimes never imagining their child as an adult. As we've talked about before there is no one face of neurodiversity. Instead there are many faces and variations of adult neurodiversity. If you do a Google search of "famous people with autism" you will find a list of people who influenced the world for good through art, music, comedy, poetry, science, mathematics, invention, politics, scholarship, business, and writing. People are differently abled and uniquely gifted. As you continue to pursue relationship with your child, you will discover their strengths and unique shaping and may also find some new strengths and abilities in yourself during the process.

Questions for group process:

- As you think about your child now, what are some of the strengths that you notice and what interests them?
- As you consider your child's current development and interests, what steps can you take to stay connected and foster your child's curiosity and growth?
- What are some of the things that concern you about your child growing into adulthood?
- Are you connected with your own system of support that can help you walk through the developmental process with your child? If this is an area of growth for you, what changes do you need to make?

Activity: Based on your relationship with your child and noticing your child's interests and strengths, draw or journal about your child's future as an adult. Share something that you notice in yourself as you complete this exercise.

Continued on next page

Session 9

Communities supporting autism as a neurodiversity

To the therapist: **The goal of this session is to identify supportive communities that offer resources and to facilitate connection within the group.** (In this session you may draw from some of the resources mentioned in Session 6 as well as the suggested material.)

Content & Process: Over the last few weeks we've covered a lot of ground. We've talked about neurodiversity and attachment and the importance of attending to your needs as caregivers and approaching the caregiving role like running a marathon. It takes a lot of training, practice and steady pacing to go the distance and reap the rewards of having a good relationship with your child through adolescence and into adulthood. We also mentioned some of the challenges that lots of people encounter related to neurodiversity: caregiver fatigue/exhaustion; difficulty finding adequate childcare; and schedule, work/career, friend/family and social impacts. Today we want to focus on some of the resources that you might find helpful and supportive. You're all familiar with Early Start for 0-3 but may not know that at 36 months interventions are coordinated through the schools. We can help you prepare for that transition at the right time. The Organization for Autism Research provides helpful guides for families, self-advocacy, and employment. Other organizations include Autism Speaks, the Color of Autism, and the Autism Society. There are many other resources.

Questions for group process:

- As you reflect on your child's needs and your needs as a caregiver considering the challenges you now face, what type of resource do you need most? Is it available to you and can you share with the group?
- What if your most significant unmet need as a caregiver? For your child? For your family? Within your social/cultural context?

Activity: As a group, put together a listing of resources that have been beneficial to you and share with each other how you found the resource and how it has been helpful.

Continued on next page

Session 10

The meanings of autism in our family

To the therapist: **The goal of this session is to allow the caregiver to integrate the material presented and apply it specifically within their family context.** Making meaning of autism for the family acknowledges strengths and challenges and choices that can be made. In this session, it is important to focus on strengths and a survivor mentality while acknowledging challenges.

Content & Process: As we reflect on our discussions and progress over the last few weeks, it is important to think about the meanings of the neurodiversity of autism in our family. This may relate to your own growth and perspectives; your child's strengths, challenges; neurodiversity in adolescence and adulthood; caregiver/child attachment security; family or community support, or other areas. Imagine casting a very wide net over neurodiversity and all it can mean. Then consider your relationship with your child and your family and notice what emerges.

Questions of group process:

- What is a strength that you are aware of today that has been developed or brought to your attention because of your encounter with neurodiversity?
- As you watch your child, what do you long for and what can you do, if anything, to satisfy the longing?
- When you listen to other members of the group, what strengths do you notice?
- Can you find any gratitude for the gifts within neurodiversity?

Activity: Today's activity is an opportunity to support each other. As you reflect back over the last 10 weeks, you might recall something that was said that challenged you to go deeper or to take responsibility. Look around the group and notice each person. Quietly, on a 3x5 card, for each person write down something that you appreciate or see as a strength in that person. You need not put your name on the card—only the name of the caregiver being addressed. Place a card in the caregiver's envelope as it is passed around at the end of our time together.

Connected Families Caregiver Group Module III

Overview

Module III content addresses parenting challenges and positive behavior support strategies with the neurodiverse child. In this module, caregivers can get feedback from the therapist and each other. Caregivers have the opportunity to share their use of PBS strategies and connection with their child.

Session	Description
1	Parenting models: so many possibilities
2	Foundation for relationships, learning, adapting, development
3	The way a child is parented matters
4	Relationship, yeah. But what about behaviors?
5	Distinctives of Connected Families PBS
6	Talk about tools
7	Time to Practice: Role Play Together, Then Take it Home!
8	Sharing the struggle and learning: group feedback & support
9	Sharing the struggle and learning: group feedback & support
10	Sharing the struggle and learning: group feedback & support

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Session 1

Parenting models: so many possibilities
To the therapist**: Goals of this session include introduction of group members to each other and to the group format as well as opening discussion about parenting models**. Make notes of what people expect from the group. Use empathic attunement and affirm when possible as each caregiver shares while fostering connection among group members.

Content & Process: As this is the first session together, the therapist introduces themselves and before starting discussion will verbally readdress matters of Informed Consent including limits on confidentiality and expectations of confidentiality in the group. It is also important to quickly review the Standards for Group Interaction and ask all group members to agree to keep matters shared within the group inside the group. Next, the therapist shares an overview of the module content; then allows time for group members to introduce themselves. It would be helpful if each person can share their first name and a little about themselves and their child and perhaps what they hope to gain from participating in the group.

There are several different models of parenting. From a very broad perspective some of the models are Authoritarian, Authoritative, Dismissive/Indifferent, and Permissive/Indulgent. Authoritarian and authoritative styles are often confused with each other—and both have high expectations for the child; but the authoritative parenting style is child-centered and accepting of the child whereas the authoritarian model tends to be parent centered and rejecting of the child. In contrast permissive/indulgent and dismissive/indifferent styles expect little of the child with the permissive/indulgent style being child-centered and the dismissive/indifferent type being parent centered and neglectful. Within these broad camps are many published models. In keeping the research, Connected Families supports Authoritative models that have expectations of the child that are child-centered within a relational context. The *Active Parenting* model (Popkin, 1993) and *Parenting with Love and Logic* (Cline, F., Fay, 2006) are good examples of authoritative models and both have publications that can be useful to caregivers during different periods of child and adolescent development. That said, we have all been “parented” and that experience—whether or not acknowledged-- can inform our own parenting styles. Parenting can also be culturally bound, and we acknowledge this at the start.

Questions for group discussion:

- Do you think that finding a good parenting model is important, or would you rather figure it out as you go? Help us understand your response.
- When you consider your own approach to parenting, what influences your choices, and have you settled into an approach that works for you and fits your culture?

Activity: Fold a sheet of paper in half. On one half of the paper draw a picture that represents your childhood experience of parenting. On the other half of the paper, draw a picture that reflects how you would like to parent your child. Share a thought or two about this experience.

Continued on next page

Session 2

Foundation for relationships, learning, adapting, development

To the therapist: **The goal for this session is increased awareness among members of the group of how their experiences of being parented in childhood may now inform their parenting model.** This session ties together parenting models and attachment looking forward to positive behavior support in the future.

Content & Process: In our last session we touched on parenting models in a really broad way and also worked with the idea that we have all been parented—something that definitely influences the expectations we have of ourselves as caregivers – and the expectations we have of our child(ren). Many a parent has uttered the words, "*Never will I ever parent the way I was parented*" only to find that with the best of intentions, it is incredibly easy to reproduce patterns that have been learned and are so well known it can be as if our parent is standing there directing as we parent our child. For some of us, this leads us to new ways of learning and being—to find some new skills. Connected Families operates from the perspective that relationship between the caregiver and child matter and will eventually outlast child and adolescent development. When caregivers are able to consistently apply a parenting model that is loving and respectful, trust and attunement can be fostered in the relationship. The caregiver-child relationship allows for support throughout psychosocial development and also forms a foundation for the child's future relationships in adulthood.

Questions for group process:

- When you look at your own experience of being parented, what happened when you made a mistake? Did something wrong (perhaps intentionally)?
- When you were a child, were there times that you needed and received comfort and if so, what did that look like?
- When you consider the ways that you were parented, what do you appreciate? What do you want to change in your own parenting?

Activity: Think about a time when your child experienced distress and needed comfort. As you now consider what comfort can look like, sketch a picture of how you would like to offer comfort to your child.

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Session 3

The way a child is parented matters….
To the therapist: **The goal of this session is to foster increased caregiver awareness of how parent/child interactions can promote desired behaviors and relationship in contrast to models that tend to be parent centered**. Listen carefully as some caregivers will have emotional reactions and may need additional support as they work with new information

Content & Process: We have been discussing different models and experiences of parenting and today we'll discuss authoritative parenting with Positive Behavior Support (Dunlap et al., 2010). In general, an authoritative parenting model allows caregivers and children to have a voice, with the caregiver in a leadership role. Mutual respect and choice are at the heart of authoritative models that are based on the belief that behavior is goal oriented. Therefore, a child's behavior indicates a lot about what the child is feeling, thinking, and experiencing—and what the child wants or needs (or doesn't!). As an authoritative caregiver, you can set expectations and structure time, communication, and activities that help the child understand what is expected.

Draw upon some of the skills you learned in PBS/CT. You learned that it is very important to use language that is developmentally appropriate, get down on their level, and sometimes to use your own body to help their body do what is needed. For example, you might say, "Sit, please" or "On floor" and demonstrate what you expect with your own body while leading them through the process. This method allows the child to predict what is expected and it provides support for doing what is expected. When the child is resistant, we continue to say what is expected and positively redirect the child for success rather than confuse the matter by talking about what's not expected.

Questions for group process:

- How does an authoritative parenting model with positive behavior support sit with you today? You probably already have some PBS skills and may already use an authoritative model or have heard enough to at least consider it. Maybe you're still on the fence or even convinced it won't work for you. What guides your thinking?
- Can you share a brief experience where you have tried to use even part of an authoritative model? What worked and what didn't?
- Is there anything that holds you back? How can the group support you in your parenting role?

Activity: Reflect on your relationship with your child. As you consider some of the challenges that you face together, draw a picture that shows what you think your child's challenging behaviors are saying. Notice the thoughts and emotions that are stirred as you complete this activity and share something with the group if you like.

Continued on next page

Session 4

Relationship, yeah. But what about behaviors?

To the therapist: **The goal of this session is to introduce caregivers to parent-child cycles of interaction and notice how parent impacts the child and vice versa. A secondary goal is increased group cohesion.** This is a very interactive session for all group members and the goal is to acquaint caregivers with parent/child interaction cycles and provide an example of how each person's behavior, thoughts, and emotions affect the other. In this session it is very important to demonstrate the differences between positive and negative feedback loops between the child and caregiver. You will also need guide and structure the activity and lead discussion while fostering connections within the group. Help caregivers with self-soothing techniques.

Content & Process: Understandably challenging behaviors can be a huge factor for caregivers and the child. When the child is overstimulated, withdrawn, or aggressive it is very easy for the caregiver to feel the same way. In fact, we know from neurobiology that mirror neurons can create a strong shared experience—good or bad—between caregiver and child. Holding onto your own perspective while parenting isn't always easy especially as we try to change is the confusing and negative interaction cycles. It's important to hear your child's voice and understand their view as you have your own voice and perspective. Developing skills to compartmentalize your experience can be very helpful for you as a caregiver. Compartmentalizing can be like noticing your own reaction and putting that reaction in a container for you to process later—rather than letting your reaction spill over in the interaction with the child. Instead of punishing, natural consequences can foster the child's learning to self-regulate—but it is important to pay attention to safety issues and knowing how to respond best has to consider the purpose—or payoff—for the child's challenging behavior. Consistent use of this model can foster the development of self-esteem, responsibility, and cooperation—qualities that are for good the relationship. It will take time and practice for you and your child to learn new ways.

Activity: The therapist will lead this exercise. As a group identify a parenting challenge that typically occurs with your child. Diagram the parent-child cycle (use Popkin, p. 71 as reference) identifying what (1) child does; (2) parent thinks; (3) parent feels; (4) parent does; (5) child thinks; (6) child feels; and (7) child does. As a group, try to identify the goals (payoffs) of the child's challenging behaviors.

Questions for group process:

- Can you share a brief experience where you have tried to use even part of an authoritative model? What worked and what didn't?
- Is there anything that holds you back from trying an authoritative approach? How can the group support you in your parenting role?
- What steps can you take to self-soothe and remain calm when your child is upset?

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Session 5

Distinctives of Connected Families PBS

To the therapist: **Goals for this session are increased caregiver understandings of the reasons for the child's challenging behavior and improved awareness/ability to respond without unwittingly reinforcing challenging behaviors.** Discussion is drawn from Popkin (1993, p. 67) where child-parent interactions are explicitly addressed. Though this session is heavy with psychoeducation, it is also important to help caregivers with self-soothing techniques.

Content & Process: In discussing *Active Parenting* (1993), Popkin identifies basic goals of the child's relational needs as: contact, power, protection, and withdrawal. The child may negotiate these needs using positive or negative approaches. For example, Popkin identifies the child's negative approaches as: undue attention seeking, rebellion, revenge, and avoidance correlated with goals of gaining contact, power, protection, or withdrawal. Though Popkin (1993) isn't writing specifically for a neurodiverse audience, the parent's typical feelings associated with the child's negative choices include irritation, anger, hurt, and a sense of helplessness. Know that these feelings are normal and use them to help you better create a hypothesis that helps you manage your own response and ability to attend to your child in a positive manner. As you learn to compartmentalize your own reactions and respond to your child, it is also necessary to identify some of the events and triggers that result in their child's challenging behavior, and to form a hypothesis about the reasons for the behavior so you respond in a way that directs the child to the desired behavior. Popkin (Popkin, 1993) suggests actions you can take to foster the desired response from your child whether the child's approach is positive or negative.

Activity: Reflect on a recent behavior challenge with your child and sketch it out using the parent/child cycle we talked about last week. Identify the child's goal, your feelings (in the moment) and consider your response. Is there something that you need to do differently?

Continued on next page

Session 6

Talk about tools

To the therapist: **The goal of this session is for caregivers to increase their understandings and ability to apply of Positive Behavior Support techniques.** This session is focused on review of the application of PBS tools/techniques to the neurodiverse toddler through adaptation and application of the Prevent, Teach, Reinforce methods (Dunlap et al., 2010).. Note: Most caregivers should have some familiarity with the tools from participation in the PBS/CT program; therefore, this session might involve some troubleshooting. Assist caregivers in identifying a vignette and role-play through which they apply skills.

Content & Process: Most of you likely remember some of the positive behavior tools from PBS/CT so today might be a review. We have adapted a school-based model of individualized PBS developed by Dunlap with others: Prevent, Teach, Reinforce. In Connected Families we use **Prevent** to identify and remove events and triggers that can result in challenging behavior. Using the **Teach** strategy the child learns new skills and replacement behaviors through verbal instruction, behavior demonstration/modeling, task-division, providing age appropriate choices, consistency, repetition, and through connection and attunement of the therapist and caregiver with the child's emotional state while offering support for new behaviors without allowing for unwanted/ineffective patterns. As the child masters new skills, conflict is introduced to ensure mastery of skills and regulation tolerance. The **Reinforce** strategy involves use of positive incentives including praise and comfort to foster adaptive behaviors (K. G. Shanahan, personal communication, May 4, 2019).

Activity As a group, identify a challenging pattern of behavior that is a frequent problem. For this exercise, you may need to use task division (breaking the task down into smaller steps) for yourselves to identify a specific issue. Divide into groups with one person acting as the child and the other acting as the caregiver and apply some of the tools. Seek assistance of the therapist as needed. Share something you learned from this experience. Ask questions as needed.

Continued on next page

Session 7

Time to Practice: Role Play Together, Then Take it Home!

To the therapist: **The goal of this session is application of PBS techniques using a vignette, increasing caregiver skills with the PBS method. A secondary goal is group cohesion. Another important goal is setting up the video presentations for next week.** This is a very interactive session that involves role-play between group members as they learn to apply positive behavior skills and get **positive** feedback from the therapist. As a systemic therapist you are instructing and modeling. **NOTE**: Before ending this session, give instructions for video recording and set up the schedule for sharing for the next three weeks. Encourage ALL group members to begin recording this week regardless of whether they are scheduled to share.

Content & Process: In the last few weeks we've talked about parenting models and the need we all have for comfort and relationship. We've discussed behavioral issues and how positive behavior support can be used to incentivize desired behaviors and relationships—and some of the tools that can be used. Today we have an opportunity to practice with each other using role-play. If you're already working with positive behavior support at home, you're probably ahead of the game. If not, we're here to support you as you develop some new ways of interacting with your child.

Vignette: Tommy is 13 months old and has been walking for two months. He has few language skills and enjoys playing with bubbles, but often doesn't respond to his name and has difficulty staying in his chair during snack time at the Center. His caregiver is learning to apply positive behavior support with the help of staff.

Activity: Get knee to knee with a partner and decide who will be the child and who will be the caregiver. Try out the skills. Ask for help when needed. Trade roles when you finish.

Questions for group process:

- What did you learn/notice during the role play?
- Where do you need support or growth?

Continued on next page

Session 8

Sharing the struggle and learning: group feedback & support

To the therapist: **The goal of this session is to offer positive, constructive feedback and support to group members who courageously show video recordings of their interactions with the child allowing the caregiver to learn.** Provide encouragement, support and assistance with skill-building as needed and encourage group interaction.

Content & Process: Three or four group members will present short videos of caregiver/child interaction. The video may reflect epic success or fail or something in-between—it's caregiver choice about what they want to show. The presenting caregiver should share something about the context of the recording (e.g., where, when, and why this segment was chosen and the caregiver's own experience of doing the video of themselves with their child) and the type of feedback they would like to have from the group and therapist. Depending on the feedback requested, the group can deconstruct caregiver/child interactions to notice cycles, communication patterns, and opportunities for engagement. The therapist and group members can offer support and assistance with skill-building in the context of mutual learning.

Questions for group process:

- What strengths did you observe with the caregiver? Child? In the caregiver/child interaction?
- How can you offer encouragement, support, and connection to the caregiver?
- As you watched the caregivers/children interact in the videos was there anything that you saw that is helpful to you as you apply new skills in relationship with your child?

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Session 9

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Family Therapy Program Description

Introduction

The **Family Therapy (FT)** program component is provided by mental health professionals skilled and experienced in systemic work within family systems using concepts from Bowen, Minuchin, and filial therapy (Bratton, Landreth, Kellam, and Blackard, 2006). FT is designed to assist caregivers and families in their abilities to provide a stable and supportive environment for their child. Work with families is tailored to the uniqueness of each family and considers the child's neurodiversity together with other diversities within the family context including health and abilities, cultures, gender and sexuality, and spirituality and religion. With the understanding that "normal" is a setting on an appliance like a washer or dryer, family therapy programs seek understandings of what is desired and appropriate for families from the perspective of the families themselves. While neurodiversity can certainly influence family dynamics, it is unwise to create a family identity that is confined to neurodiversity. Therefore, it is important to acknowledge the needs of all family members and for each family member to experience a system of support in order to offer a secure base for the neurodiverse child.

Contents

Continued on next page

Program Goals

As a program, Family Therapy goals include disruption of maladaptive homeostasis, rebalance subsystems (executive and child as necessary), promotion of healthy role responsibilities, and development and implementation of adaptive coping and communication skills to create an environment of support that can sustain the neurodiverse infant/toddler at all stages of psychosocial and physiological development. Application of program goals with each family must consider family dynamics and diversity factors and be respectful of and adapt to individualist and collectivist cultural perspectives as appropriate for each family.

Unit of Treatment: The Family of the Neurodiverse Child

Family Therapy defines the "family" as the unit of treatment. This includes the caregiver(s), the neurodiverse child, siblings, and possibly others living in the home. The therapist works with each family using a systemic approach that draws from structural and humanistic perspectives. Goals for the unit of treatment—the family—are established based on presenting family dynamics with specific consideration to diversity factors that influence the family's ability to provide a stable and supportive environment for the neurodiverse child. Specific areas of attention include fostering a sense of family culture, connection, and identity that extends beyond ASD, where needs of all family members can be heard and considered—especially the need for social and community involvement. An area of emphasis within family therapy involves identifying and addressing unmet caregiver needs, especially the need for self-care and community involvement that fuels and helps sustain the caregiver.

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Informed Consent, Intake & Assessment

Informed Consent is an ongoing process that occurs throughout treatment. Valid, and authorized signed Informed Consent for Treatment documents are required before Intake and Assessment, Defining Program Goals, or Treatment. For divorced, separated, step, and blended families and for children in foster care, it is important secure Informed Consent for Treatment from all responsible parties before Intake and Assessment. For purposes of coordinating care, we must also have on file signed a Release for Exchange of Information with: (1) the child's pediatrician/medical doctor; (2) the Early Start global program personnel; (3) the CSC at Regional Center, and (4) Connected Families PBS/CT child/caregiver therapist and group therapist or as well as any other therapists involved in treatment of the child, caregiver, or family as appropriate. At such time that research might be done using data collected within the program, Informed Consent for Research forms approved by the Institutional Review Board (IRB) must also be signed and collected from all persons authorized to consent.

The Intake Process for Family Therapy requires completion of Personal Data Sheets (either Child or Adult depending on age) for each family member along with obtaining valid and signed, written Informed Consent for Treatment documents from all members of the family. It is important to note that when dealing with step, blended, separating, or divorcing families that consent from the children's "other parent" may be required before services can begin.

For purposes of program evaluation, at the outset of Family Therapy, caregivers will complete the "pre" treatment FACES IV Inventory (Olson, 2010), the Social Support Index (McCubbin, Patterson, and Glynn, 1982), and the Parenting Stress Index^{TM}, Fourth Edition, Short Form (Abidin, 1983, 2012). These measures are also used as "post" measure and are therefore completed at the end of treatment. Throughout treatment caregivers will also complete Session Rating Scale (Duncan et al., 2003), Outcome Rating Scale (Campbell & Hemsley, 2009) as measure of treatment efficacy. Caregiver depression and anxiety can be monitored throughout treatment using the Beck Depression Inventory (Beck et al., 1996) and Beck Anxiety Inventory (Beck & Steer, 1993).

Family Therapy is offered within the context of other Connected Families programs and the Release for Exchange of Information can be used to allow for the sharing of documentation including treatment goals and progress notes with other program staff for the benefit of the child, caregiver, and family. If/when the research is being conducted following approval of an Institutional Review Board, it is also imperative to collect signed Informed Consent documents for Research that were approved by the Institutional Review Board from family members.

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Informed Consent, Intake & Assessment continued

As part of the Intake process with families, the therapist will verbally highlight limits of confidentiality as part of the ongoing informed consent process including leading discussion that is understandable to family members about therapist's responsibilities as a mandated reporter for child and dependent adult/elder abuse. The therapist will also interact with the family to create an experiential genogram (Gil, 2003) that shows members of the family for at least three generations. In this activity, the genogram can be drawn out on a large piece of butcher paper. The children may select an object that represents each family member and share their reasons for associating the chosen object with the person. The therapist will thicken this experience for the neurodiverse child and other family members by asking questions that help children share their view of the person within the family noting themes that relate to power and authority, aggression, illness, ASD, death/loss, substances, work, religion/spirituality, celebration, peace and calm. Additionally, the therapist will notice possible intersectionalities of themes noting congruence and incongruence.

During these initial times together, the therapist is also noticing and inquiring about family roles as well as customs and traditions that operate within the family and maintaining openness and respectful curiosity about areas of struggle. The therapist specifically asks how the family celebrates special occasions such as birthdays or holidays as well as how the family interacts during times of stress or struggle. In this way, the therapist is gaining perspective on what "normal" is like for the family and noticing communication patterns. For example, it is important to notice whether all family members have a voice or only some and it is important to see the energy in the family and how the family works together or doesn't. The therapist is specifically noticing how attention is drawn to or away from the neurodiverse child and evaluating function and alignment of the executive and child subsystems within the family. Treatment goals for the family then flow from the Intake Process.

Continued on next page

Recordkeeping

For purposes of case management, the Informed Consent for Treatment, Caregiver and Child Personal Data Sheets, clinical notes, the Treatment Plan Summary, progress notes for the family and all child and caregiver assessment inventories are placed in the child's file. Dated copies of all assessment inventories marked pre, mid, or post are also forwarded to the Document Custodian.

The Document Custodian who is not involved with the treatment assigns a unique number to the child/caregiver pair at Intake. Copies of all assessment inventories for the child and caregiver are submitted to Document Custodian. The Document Custodian places the unique number assigned to the family on the assessments upon receipt after removing or redacting information that would identify the pair. Information that would identify any member of the family will therefore be securely destroyed allowing for future collective, deidentified data analysis. Thereafter, the deidentified copies of each caregiver assessments can be used as source documents for input SPSS to for program evaluation and, only after IRB approval, for research.

Defining Treatment Goals

Treatment goals for the family emerge through Intake and Assessment and are established in collaboration with the family. Although variations are expected due to diversity factors and the uniqueness of each family, overarching goals of treatment include: strengthening the caregiver and caregiver dyad when applicable, unbalancing and rebalancing the executive and child subsystems in support of the family and their ability to attend to the needs of the neurodiverse child; facilitating interaction patterns that build connection between family members where the needs of the whole family are addressed; fostering an expanded system of support; encouraging community engagement, and developing the capacity to adapt to the needs of the neurodiverse child's needs throughout development without allowing the neurodiversity to define the family. Additionally, for those families with members participating in other Connected Families programs, a primary goal of family therapy is gaining family support for the gains achieved in PBS/CT and CFCG. Thus, the ineffective homeostasis is challenged, and the family learns to effectively adapt for mutual benefit and in support of the neurodiverse child.

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Treatment Methods & Duration

Family Therapy is a short-term, yet intensive process that requires the participation of family members living in the home with the neurodiverse child for one hour per week over a period of at least 12 weeks. Treatment modality will vary based on family needs and specific goals of treatment.

Treatment methods (modalities) draw initially from Bowen using a genogram to understand intergenerational relationship patterns specifically identifying instances of cutoff, trauma/abuse, abandonment, and addiction as well as relationship conflict and closeness. Using a Bowenian lens, we are assessing and working with differentiation and triangles within the family system. The genogram is also used to explore and better understand family culture and diversity factors and patterns of expression. The experiential genogram exercise (Gil, 2003) leverages a Bowenian frame to experientially give voice to and understand the perspectives of each family member.

Structural techniques such as “joining, unbalancing, and enactments” are also used in family therapy as a means of facilitating adaptive change within the family subsystems (couple, child, parent/child)--challenging maladaptive homeostasis and fostering positive adaptation of family member roles and responsibilities. Structural techniques offer a framework that allows the family to address the impact of the child’s social-emotional and behavioral problems within the family whether at home or in other settings. Structural therapy can be used to shift family dynamics possibly shifting cohesion and flexibility factors allowing the family to adapt to the changing needs of the child.

Filal therapy will also be used to build relationships between caregivers and children. Additionally, use of Functional Family Therapy, an evidence-based, phased approach can be used to explore behavior problems from a multi-systemic perspective. Functional Family Therapy has been used successfully with families facing challenging adolescent behavior, and it may easily adapt to this population (Sexton, 2016). However, the modality is worthy of mention, but cannot be yet fully articulated for this population.

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Measurement of Treatment Outcomes

Caregiver depression and anxiety levels are monitored throughout the duration of treatment for purposes of case management and can be evaluated in aggregate to measure conformance of actual program outcomes to expectations within the logic model.

Treatment efficacy for Family Therapy is evaluated throughout treatment for purposes of case management using Session Rating Scales (Duncan et al., 2003) and Outcome Rating Scales (Campbell & Hemsley, 2009; Miller et al., 2003). These data are also deidentified, aggregated, and further analyzed to evaluate family perceptions of treatment efficacy.

Program outcomes of change in perceived social support and family cohesion and adaptability can be evaluated using the caregiver supplied data on the Pre and Post Social Support Index and FACES IV (Olson, 2010) inventories.

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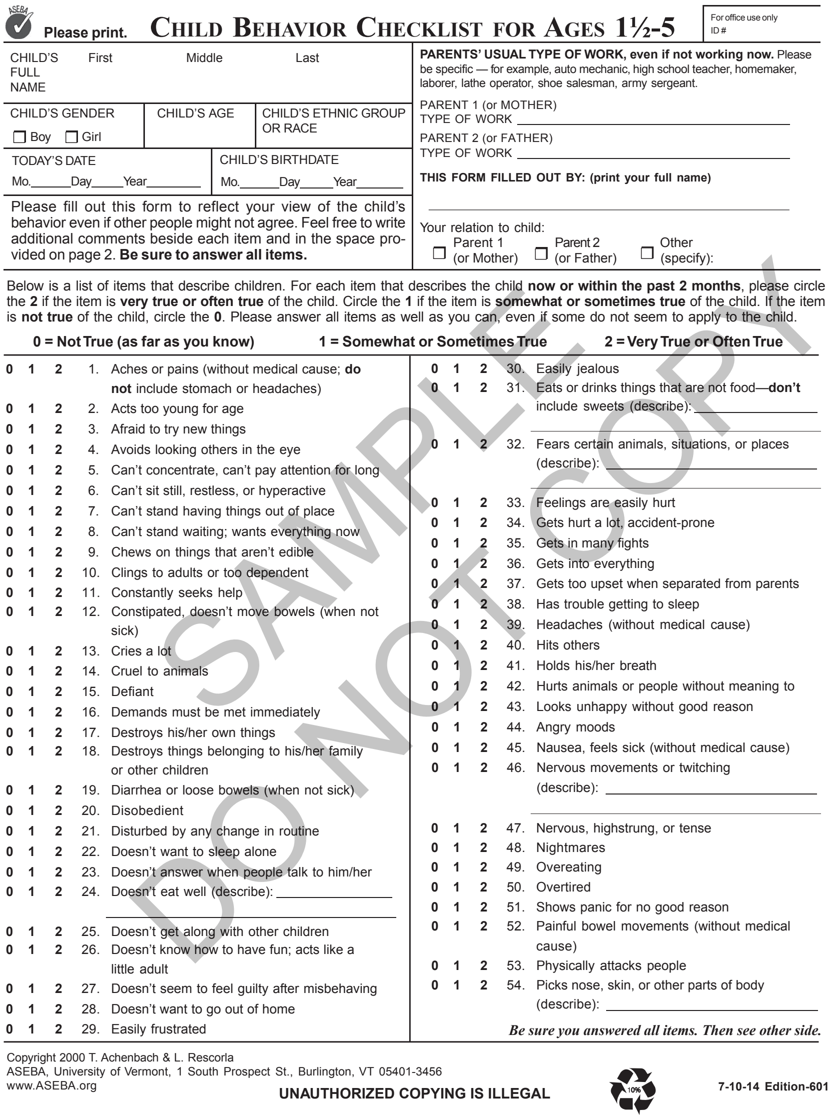
APPENDIX B

EVALUATION MEASURES

Measures to Evaluate Infant/Toddler

Child Behavior Checklist for Ages 1 ½ - 5 (page 1)



Please print. CHILD BEHAVIOR CHECKLIST FOR AGES 1½-5

For office use only
ID #

CHILD'S FULL NAME First Middle Last

CHILD'S GENDER ☐ Boy ☐ Girl

CHILD'S AGE

CHILD'S ETHNIC GROUP OR RACE

TODAY'S DATE Mo.______Day_____Year________

CHILD'S BIRTHDATE Mo.______Day_____Year_______

Please fill out this form to reflect your view of the child's behavior even if other people might not agree. Feel free to write additional comments beside each item and in the space provided on page 2. **Be sure to answer all items.**

PARENTS' USUAL TYPE OF WORK, even if not working now. Please be specific — for example, auto mechanic, high school teacher, homemaker, laborer, lathe operator, shoe salesman, army sergeant.

PARENT 1 (or MOTHER) TYPE OF WORK ____________________________

PARENT 2 (or FATHER) TYPE OF WORK ____________________________

THIS FORM FILLED OUT BY: (print your full name)

____

Your relation to child:
☐ Parent 1 (or Mother) ☐ Parent 2 (or Father) ☐ Other (specify):

Below is a list of items that describe children. For each item that describes the child **now or within the past 2 months**, please circle the **2** if the item is **very true or often true** of the child. Circle the **1** if the item is **somewhat or sometimes true** of the child. If the item is **not true** of the child, circle the **0**. Please answer all items as well as you can, even if some do not seem to apply to the child.

0 = Not True (as far as you know) 1 = Somewhat or Sometimes True 2 = Very True or Often True

0 1 2 1. Aches or pains (without medical cause; **do not** include stomach or headaches)
0 1 2 2. Acts too young for age
0 1 2 3. Afraid to try new things
0 1 2 4. Avoids looking others in the eye
0 1 2 5. Can't concentrate, can't pay attention for long
0 1 2 6. Can't sit still, restless, or hyperactive
0 1 2 7. Can't stand having things out of place
0 1 2 8. Can't stand waiting; wants everything now
0 1 2 9. Chews on things that aren't edible
0 1 2 10. Clings to adults or too dependent
0 1 2 11. Constantly seeks help
0 1 2 12. Constipated, doesn't move bowels (when not sick)
0 1 2 13. Cries a lot
0 1 2 14. Cruel to animals
0 1 2 15. Defiant
0 1 2 16. Demands must be met immediately
0 1 2 17. Destroys his/her own things
0 1 2 18. Destroys things belonging to his/her family or other children
0 1 2 19. Diarrhea or loose bowels (when not sick)
0 1 2 20. Disobedient
0 1 2 21. Disturbed by any change in routine
0 1 2 22. Doesn't want to sleep alone
0 1 2 23. Doesn't answer when people talk to him/her
0 1 2 24. Doesn't eat well (describe): ________________
0 1 2 25. Doesn't get along with other children
0 1 2 26. Doesn't know how to have fun; acts like a little adult
0 1 2 27. Doesn't seem to feel guilty after misbehaving
0 1 2 28. Doesn't want to go out of home
0 1 2 29. Easily frustrated
0 1 2 30. Easily jealous
0 1 2 31. Eats or drinks things that are not food—**don't** include sweets (describe): ________________
0 1 2 32. Fears certain animals, situations, or places (describe): ________________
0 1 2 33. Feelings are easily hurt
0 1 2 34. Gets hurt a lot, accident-prone
0 1 2 35. Gets in many fights
0 1 2 36. Gets into everything
0 1 2 37. Gets too upset when separated from parents
0 1 2 38. Has trouble getting to sleep
0 1 2 39. Headaches (without medical cause)
0 1 2 40. Hits others
0 1 2 41. Holds his/her breath
0 1 2 42. Hurts animals or people without meaning to
0 1 2 43. Looks unhappy without good reason
0 1 2 44. Angry moods
0 1 2 45. Nausea, feels sick (without medical cause)
0 1 2 46. Nervous movements or twitching (describe): ________________
0 1 2 47. Nervous, highstrung, or tense
0 1 2 48. Nightmares
0 1 2 49. Overeating
0 1 2 50. Overtired
0 1 2 51. Shows panic for no good reason
0 1 2 52. Painful bowel movements (without medical cause)
0 1 2 53. Physically attacks people
0 1 2 54. Picks nose, skin, or other parts of body (describe): ________________

Be sure you answered all items. Then see other side.

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www.ASEBA.org

7-10-14 Edition-601

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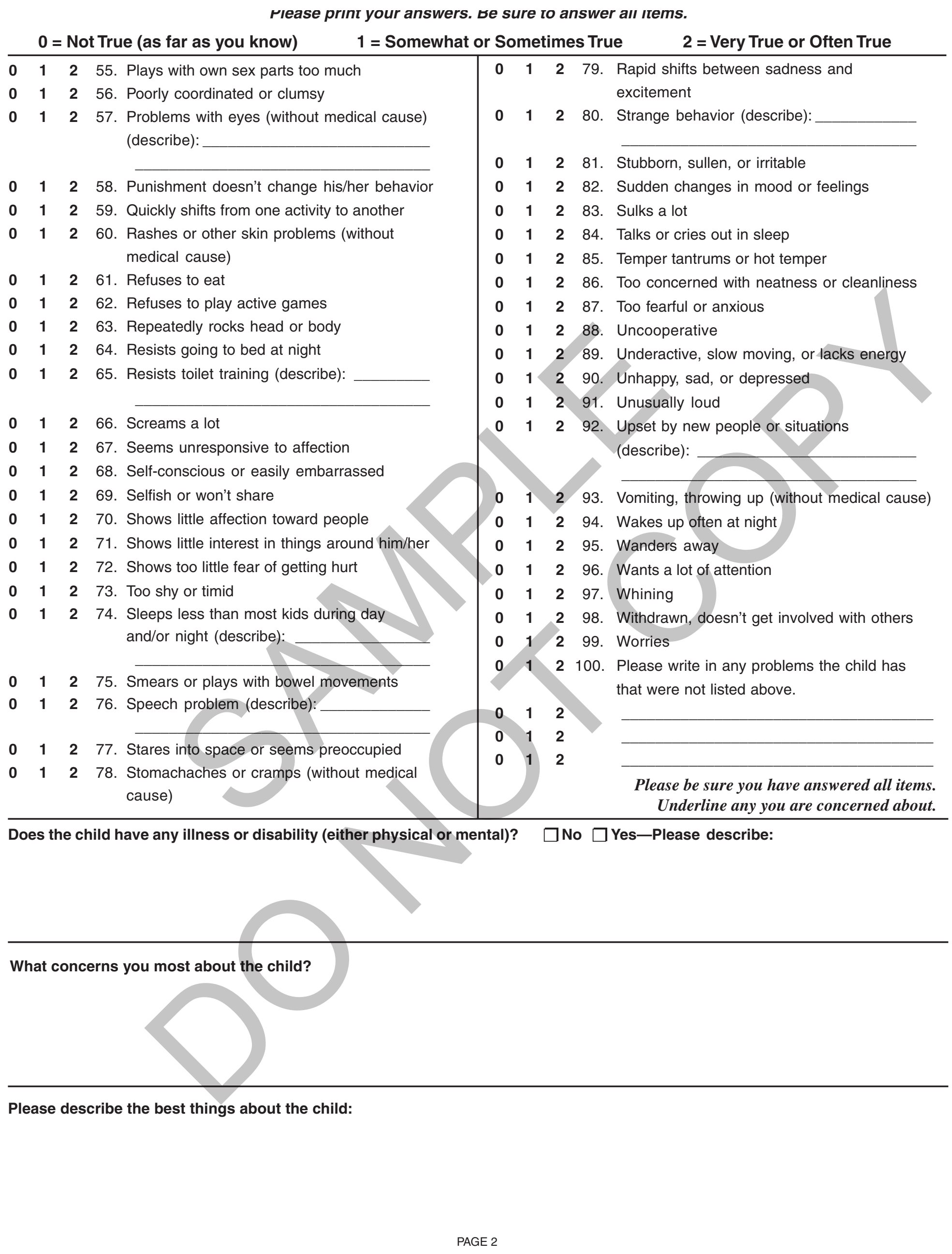
Child Behavior Checklist Ages 1 ½ -5 (page 2)



Please print your answers. Be sure to answer all items.

0 = Not True (as far as you know) **1 = Somewhat or Sometimes True** **2 = Very True or Often True**

0 1 2 55. Plays with own sex parts too much
0 1 2 56. Poorly coordinated or clumsy
0 1 2 57. Problems with eyes (without medical cause) (describe): ______________________________
____
0 1 2 58. Punishment doesn't change his/her behavior
0 1 2 59. Quickly shifts from one activity to another
0 1 2 60. Rashes or other skin problems (without medical cause)
0 1 2 61. Refuses to eat
0 1 2 62. Refuses to play active games
0 1 2 63. Repeatedly rocks head or body
0 1 2 64. Resists going to bed at night
0 1 2 65. Resists toilet training (describe): _________
____
0 1 2 66. Screams a lot
0 1 2 67. Seems unresponsive to affection
0 1 2 68. Self-conscious or easily embarrassed
0 1 2 69. Selfish or won't share
0 1 2 70. Shows little affection toward people
0 1 2 71. Shows little interest in things around him/her
0 1 2 72. Shows too little fear of getting hurt
0 1 2 73. Too shy or timid
0 1 2 74. Sleeps less than most kids during day and/or night (describe): ______________
____
0 1 2 75. Smears or plays with bowel movements
0 1 2 76. Speech problem (describe): ____________
____
0 1 2 77. Stares into space or seems preoccupied
0 1 2 78. Stomachaches or cramps (without medical cause)
0 1 2 79. Rapid shifts between sadness and excitement
0 1 2 80. Strange behavior (describe): ____________
____
0 1 2 81. Stubborn, sullen, or irritable
0 1 2 82. Sudden changes in mood or feelings
0 1 2 83. Sulks a lot
0 1 2 84. Talks or cries out in sleep
0 1 2 85. Temper tantrums or hot temper
0 1 2 86. Too concerned with neatness or cleanliness
0 1 2 87. Too fearful or anxious
0 1 2 88. Uncooperative
0 1 2 89. Underactive, slow moving, or lacks energy
0 1 2 90. Unhappy, sad, or depressed
0 1 2 91. Unusually loud
0 1 2 92. Upset by new people or situations (describe): ________________________
____
0 1 2 93. Vomiting, throwing up (without medical cause)
0 1 2 94. Wakes up often at night
0 1 2 95. Wanders away
0 1 2 96. Wants a lot of attention
0 1 2 97. Whining
0 1 2 98. Withdrawn, doesn't get involved with others
0 1 2 99. Worries
0 1 2 100. Please write in any problems the child has that were not listed above.
0 1 2 ______________________________
0 1 2 ______________________________
0 1 2 ______________________________

Please be sure you have answered all items.
Underline any you are concerned about.

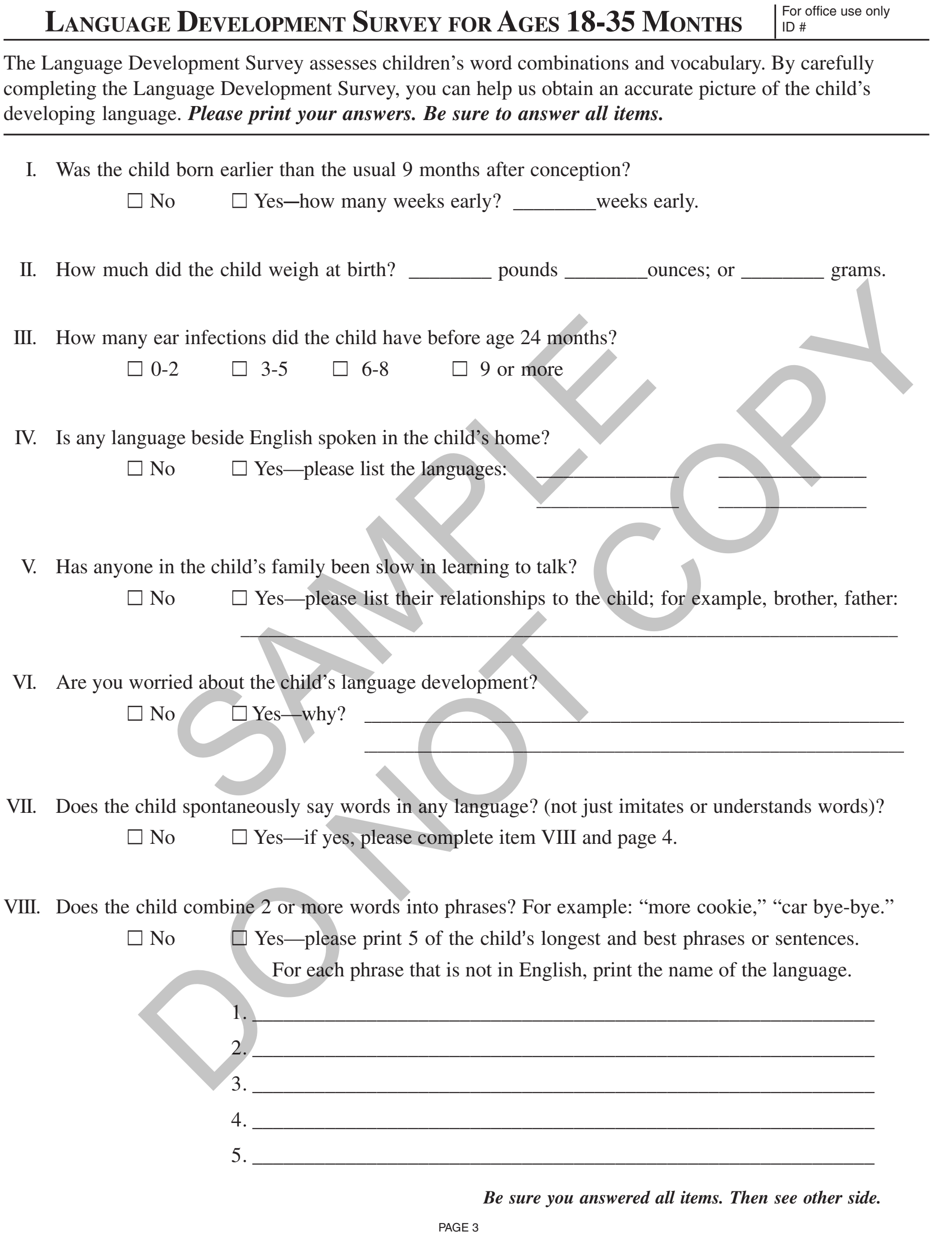
Does the child have any illness or disability (either physical or mental)? ☐ **No** ☐ **Yes—Please describe:**

What concerns you most about the child?

Please describe the best things about the child:

PAGE 2

Language Development Survey for Ages 18-35 Months (page 1



LANGUAGE DEVELOPMENT SURVEY FOR AGES 18-35 MONTHS

For office use only
ID #

The Language Development Survey assesses children's word combinations and vocabulary. By carefully completing the Language Development Survey, you can help us obtain an accurate picture of the child's developing language. ***Please print your answers. Be sure to answer all items.***

I. Was the child born earlier than the usual 9 months after conception?
☐ No ☐ Yes—how many weeks early? ________weeks early.

II. How much did the child weigh at birth? ________ pounds ________ounces; or ________ grams.

III. How many ear infections did the child have before age 24 months?
☐ 0-2 ☐ 3-5 ☐ 6-8 ☐ 9 or more

IV. Is any language beside English spoken in the child's home?
☐ No ☐ Yes—please list the languages: ______________ ______________
______________ ______________

V. Has anyone in the child's family been slow in learning to talk?
☐ No ☐ Yes—please list their relationships to the child; for example, brother, father:
____

VI. Are you worried about the child's language development?
☐ No ☐ Yes—why? ____
____

VII. Does the child spontaneously say words in any language? (not just imitates or understands words)?
☐ No ☐ Yes—if yes, please complete item VIII and page 4.

VIII. Does the child combine 2 or more words into phrases? For example: "more cookie," "car bye-bye."
☐ No ☐ Yes—please print 5 of the child's longest and best phrases or sentences.
For each phrase that is not in English, print the name of the language.

1. ____
2. ____
3. ____
4. ____
5. ____

Be sure you answered all items. Then see other side.

PAGE 3

Language Development Survey for Ages 18-35 Months (page 2)

Please circle each word that the child says SPONTANEOUSLY (not just imitates or understands). If your child says non-English versions of words on the list, circle the English word and write the first letter of the language (e.g., S for Spanish). Please include words even if they are not pronounced clearly or are in "baby talk" (for example: "baba" for bottle).

FOODS
1. apple
2. banana
3. bread
4. butter
5. cake
6. candy
7. cereal
8. cheese
9. coffee
10. cookie
11. crackers
12. drink
13. egg
14. food
15. grapes
16. gum
17. hamburger
18. hotdog
19. ice cream
20. juice
21. meat
22. milk
23. orange
24. pizza
25. pretzel
26. raisins
27. soda
28. soup
29. spaghetti
30. tea
31. toast
32. water

TOYS
33. ball
34. balloon
35. blocks
36. book
37. crayons
38. doll
39. picture
40. present
41. slide
42. swing
43. teddy bear

OUTDOORS
44. flower
45. house
46. moon
47. rain
48. sidewalk
49. sky
50. snow
51. star
52. street
53. sun
54. tree

ANIMALS
55. bear
56. bee
57. bird
58. bug
59. bunny
60. cat
61. chicken
62. cow
63. dog
64. duck
65. elephant
66. fish
67. frog
68. horse
69. monkey
70. pig
71. puppy
72. snake
73. tiger
74. turkey
75. turtle

BODY PARTS
76. arm
77. belly button
78. bottom
79. chin
80. ear
81. elbow
82. eye
83. face
84. finger
85. foot
86. hair
87. hand
88. knee
89. leg
90. mouth
91. neck
92. nose
93. teeth
94. thumb
95. toe
96. tummy

VEHICLES
97. bike
98. boat
99. bus
100. car
101. motorcycle
102. plane
103. stroller
104. train
105. trolley
106. truck

ACTIONS
107. bath
108. breakfast
109. bring
110. catch
111. clap
112. close
113. come
114. cough
115. cut
116. dance
117. dinner
118. doodoo/poop
119. down
120. eat
121. feed
122. finish
123. fix
124. get
125. give
126. go
127. have
128. help
129. hit
130. hug
131. jump
132. kick
133. kiss
134. knock
135. look
136. love
137. lunch
138. make
139. nap
140. open
141. outside
142. pattycake
143. peekaboo
144. peepee
145. push
146. read
147. ride
148. run
149. see
150. show
151. shut
152. sing
153. sit
154. sleep
155. stop
156. take
157. throw
158. tickle
159. up
160. walk
161. want
162. wash

HOUSEHOLD
163. bathtub
164. bed
165. blanket
166. bottle
167. bowl
168. chair
169. clock
170. crib
171. cup
172. door
173. floor
174. fork
175. glass
176. knife
177. light
178. mirror
179. pillow
180. plate
181. potty
182. radio
183. room
184. sink
185. soap
186. spoon
187. stairs
188. table
189. telephone
190. towel
191. trash
192. T.V.
193. window

PERSONAL
194. brush
195. comb
196. glasses
197. key
198. money
199. paper
200. pen
201. pencil
202. penny
203. pocketbook
204. tissue
205. tooth brush
206. umbrella
207. watch

PLACES
208. church
209. home
210. hospital
211. library
212. park
213. school
214. store
215. zoo

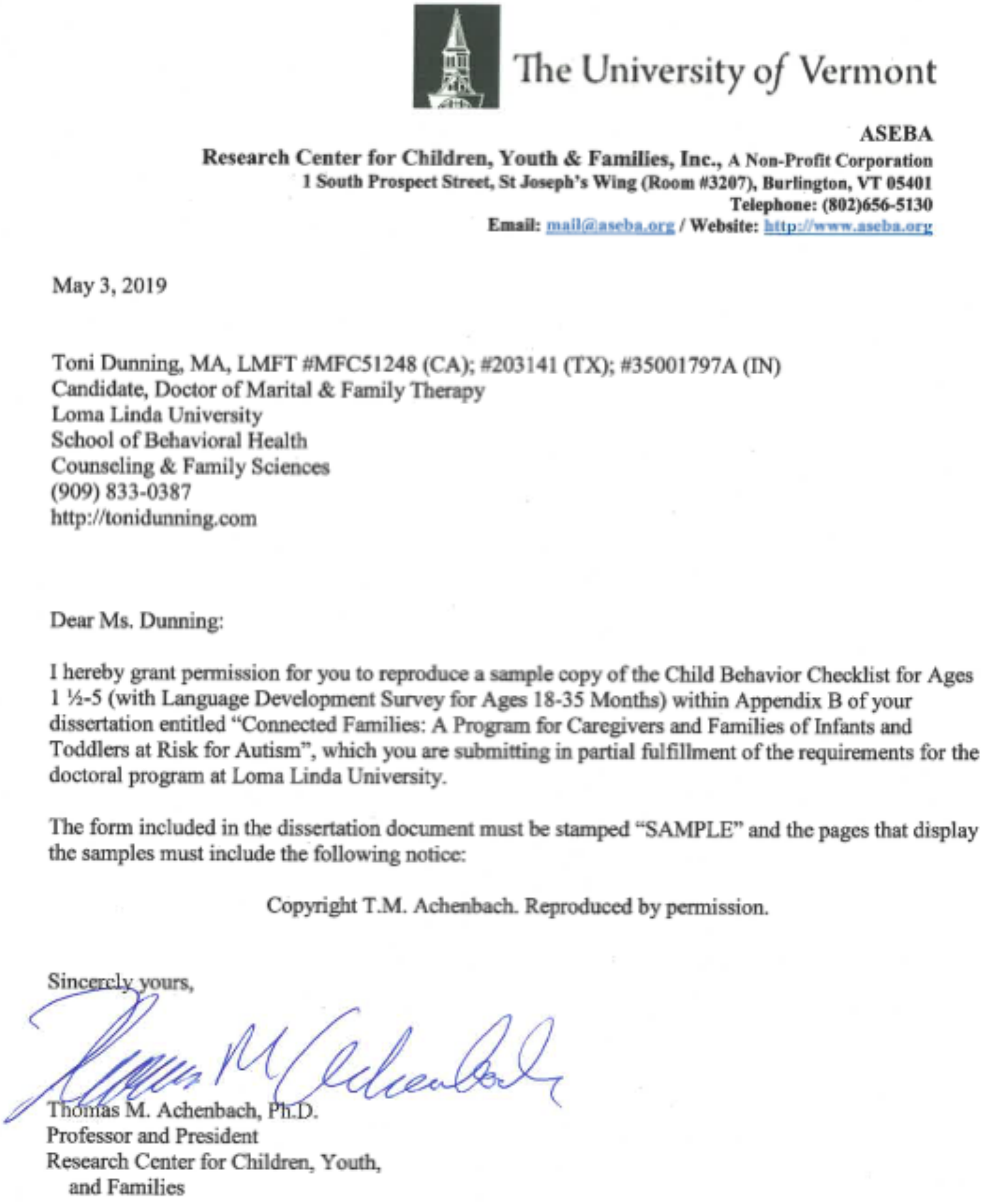
MODIFIERS
216. all gone
217. all right
218. bad
219. big
220. black
221. blue
222. broken
223. clean
224. cold
225. dark
226. dirty
227. dry
228. good
229. happy
230. heavy
231. hot
232. hungry
233. little
234. mine
235. more
236. nice
237. pretty
238. red
239. stinky
240. that
241. this
242. tired
243. wet
244. white
245. yellow
246. yucky

CLOTHES
247. belt
248. boots
249. coat
250. diaper
251. dress
252. gloves
253. hat
254. jacket
255. mittens
256. pajamas
257. pants
258. shirt
259. shoes
260. slippers
261. sneakers
262. socks
263. sweater

OTHER
264. any letter
265. away
266. booboo
267. byebye
268. excuse me
269. here
270. hi, hello
271. in
272. me
273. meow
274. my
275. myself
276. nightnight
277. no
278. off
279. on
280. out
281. please
282. Sesame St.
283. shut up
284. thank you
285. there
286. under
287. welcome
288. what
289. where
290. why
291. woofwoof
292. yes
293. you
294. yumyum
295. any number

PEOPLE
296. aunt
297. baby
298. boy
299. daddy
300. doctor
301. girl
302. grandma
303. grandpa
304. lady
305. man
306. mommy
307. own name
308. pet name
309. uncle
310. name of TV or story character

Other words your child says, including non-English words:
____
____
____
____



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May 3, 2019

Toni Dunning, MA, LMFT #MFC51248 (CA); #203141 (TX); #35001797A (IN)
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Dear Ms. Dunning:

I hereby grant permission for you to reproduce a sample copy of the Child Behavior Checklist for Ages 1 ½-5 (with Language Development Survey for Ages 18-35 Months) within Appendix B of your dissertation entitled "Connected Families: A Program for Caregivers and Families of Infants and Toddlers at Risk for Autism", which you are submitting in partial fulfillment of the requirements for the doctoral program at Loma Linda University.

The form included in the dissertation document must be stamped "SAMPLE" and the pages that display the samples must include the following notice:

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Sincerely yours,

Thomas M. Achenbach, Ph.D.
Professor and President
Research Center for Children, Youth,
and Families

Devereaux Early Childhood Assessments for Infants/Toddlers (DECA-I/T)

DECA - I

Devereux Early Childhood Assessment for Infants
Record Form
(1 month up to 18 months)

Mary Mackrain, Paul LeBuffe and Gregg Powell

Infant's Name ____________________________ Gender ______________ DOB _______________ Age ________________ (In Months)

Person Completing this Form ______________________ Relationship to Infant ___________________

Date of Rating ___________________ Site/Program __________________________________ Room _____________

This form describes a number of behaviors seen in some infants. Read the statements that follow the phrase: ***During the past 4 weeks, how often did the infant…*** and place a check mark in the box underneath the word that tells how often you saw the behavior. Answer each question carefully. There are no right or wrong answers. Please answer every item. If you wish to change your answer, put an X through it and fill in your new choice as shown to the right.

Never	Rarely	Occasionally	Frequently	Very Frequently
☒	✓	☐	☐	☐

Item #	***During the past 4 weeks, how often did the infant…***	Never	Rarely	Occasionally	Frequently	Very Frequently
1	try to do new things?	☐	☐	☐	☐	☐
2	respond when spoken to?	☐	☐	☐	☐	☐
3	imitate actions of others?	☐	☐	☐	☐	☐
4	enjoy interacting with others?	☐	☐	☐	☐	☐
5	keep trying when unsuccessful?	☐	☐	☐	☐	☐
6	enjoy being cuddled?	☐	☐	☐	☐	☐
7	show interest in what others were doing?	☐	☐	☐	☐	☐
8	show affection for a familiar adult?	☐	☐	☐	☐	☐
9	notice changes in surroundings?	☐	☐	☐	☐	☐
10	seek comfort from familiar adults?	☐	☐	☐	☐	☐
11	adjust her/his energy level to the type of play?	☐	☐	☐	☐	☐
12	act in a good mood?	☐	☐	☐	☐	☐
13	act happy when praised?	☐	☐	☐	☐	☐
14	make eye contact with others?	☐	☐	☐	☐	☐
15	explore surroundings?	☐	☐	☐	☐	☐
16	calm down with help from a familiar adult?	☐	☐	☐	☐	☐
17	express her/his dislikes?	☐	☐	☐	☐	☐
18	smile back at a familiar adult?	☐	☐	☐	☐	☐
19	reach for a familiar adult?	☐	☐	☐	☐	☐
20	respond to her/his name?	☐	☐	☐	☐	☐
21	keep trying to obtain a toy?	☐	☐	☐	☐	☐
22	react to another child's cry?	☐	☐	☐	☐	☐
23	smile at familiar adults?	☐	☐	☐	☐	☐
24	respond positively to adult attention?	☐	☐	☐	☐	☐
25	act happy?	☐	☐	☐	☐	☐
26	act in a way that make others smile or show interest?	☐	☐	☐	☐	☐
27	easily go from one activity to another?	☐	☐	☐	☐	☐
28	seek attention when a familiar adult was with another child?	☐	☐	☐	☐	☐
29	look to a familiar adult when exploring her/his surroundings?	☐	☐	☐	☐	☐
30	enjoy being around other children?	☐	☐	☐	☐	☐
31	show pleasure when interacting with adults?	☐	☐	☐	☐	☐
32	act happy with familiar adults?	☐	☐	☐	☐	☐
33	accept comfort from a familiar adult?	☐	☐	☐	☐	☐

DECA -T

Devereux Early Childhood Assessment for Toddlers
Record Form
(18 months up to 36 months)

Mary Mackrain, Paul LeBuffe and Gregg Powell

Toddler's Name ____________________________ Gender ______________ DOB _______________ Age ________________
(In Months)

Person Completing this Form ______________________ Relationship to Toddler ___________________

Date of Rating ___________________ Site/Program __________________________________ Room _____________

This form describes a number of behaviors seen in some toddlers. Read the statements that follow the phrase: ***During the past 4 weeks, how often did the toddler…*** and place a check mark in the box underneath the word that tells how often you saw the behavior. Answer each question carefully. There are no right or wrong answers. Please answer every item. If you wish to change your answer, put an X through it and fill in your new choice as shown to the right.

Never	Rarely	Occasionally	Frequently	Very Frequently
☒	☑	☐	☐	☐

Item #	***During the past 4 weeks, how often did the toddler…***	Never	Rarely	Occasionally	Frequently	Very Frequently
1	enjoy interacting with others?	☐	☐	☐	☐	☐
2	show affection for a familiar adult?	☐	☐	☐	☐	☐
3	adjust to changes in routine?	☐	☐	☐	☐	☐
4	seek comfort from familiar adults?	☐	☐	☐	☐	☐
5	makes needs known to a familiar adult?	☐	☐	☐	☐	☐
6	act happy with familiar adults?	☐	☐	☐	☐	☐
7	show interest in her/his surroundings?	☐	☐	☐	☐	☐
8	respond when spoken to?	☐	☐	☐	☐	☐
9	show concern for other children?	☐	☐	☐	☐	☐
10	try to comfort others?	☐	☐	☐	☐	☐
11	act happy when praised?	☐	☐	☐	☐	☐
12	participate in group activities?	☐	☐	☐	☐	☐
13	make eye contact with others?	☐	☐	☐	☐	☐
14	enjoy being cuddled?	☐	☐	☐	☐	☐
15	smile back at a familiar adult?	☐	☐	☐	☐	☐
16	ask to do new things?	☐	☐	☐	☐	☐
17	reach for a familiar adult?	☐	☐	☐	☐	☐
18	respond to her/his name?	☐	☐	☐	☐	☐
19	react to another child's cry?	☐	☐	☐	☐	☐
20	smile at familiar adults?	☐	☐	☐	☐	☐
21	easily go from one activity to another?	☐	☐	☐	☐	☐
22	show pleasure when interacting with adults?	☐	☐	☐	☐	☐
23	handle frustration well?	☐	☐	☐	☐	☐
24	makes others aware of her/his needs?	☐	☐	☐	☐	☐
25	accept comfort from a familiar adult?	☐	☐	☐	☐	☐
26	play make-believe?	☐	☐	☐	☐	☐
27	follow simple directions?	☐	☐	☐	☐	☐
28	show preference for a particular playmate?	☐	☐	☐	☐	☐
29	try to clean up after herself/himself?	☐	☐	☐	☐	☐
30	easily follow a daily routine?	☐	☐	☐	☐	☐
31	play with other children?	☐	☐	☐	☐	☐
32	try to do things for herself/himself?	☐	☐	☐	☐	☐
33	calm herself/himself?	☐	☐	☐	☐	☐
34	accept another choice when the first choice was not available?	☐	☐	☐	☐	☐
35	have regular sleeping patterns?	☐	☐	☐	☐	☐
36	express a variety of emotions (e.g. happy, sad, mad)?	☐	☐	☐	☐	☐

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Date:	Wednesday, May 15, 2019 at 6:34:43 AM Pacific Daylight Time
From:	Susan Damico <sdamico@devereux.org>
To:	Dunning, Toni (LLU) <tdunning@llu.edu>
Attachments:	image001.jpg, image002.png, image003.png, image004.png, image005.png, Infant RF English.pdf, Toddler RF English.pdf

Toni,
Thank you for your inquiry. I am attaching the front pages of the Devereux Early Childhood Assessment for Infants and Toddlers. I can grant permission for you to use these in this format in your appendix of the dissertation. These pdf documents clearly show the copyright information and so we are comfortable with this format.

If you decide to use the tools, we can license you the rights to build the tools into a system of your own, or you can purchase use of our own electronic system. I would be happy to discuss the process for these options when you are ready to have such discussions.

Best of luck, Susan

Susan Damico| Director
Devereux Center for Resilient Children | 444 Devereux Drive, Villanova, PA 19085
(w) 610-542-3108 (f) 877-983-3322

From: Dunning, Toni (LLU) <tdunning@llu.edu>
Sent: Tuesday, May 14, 2019 5:28 PM
To: Susan Damico <sdamico@devereux.org>
Subject: Permission to reproduce DECA I/T in Dissertation Appendix
Importance: High

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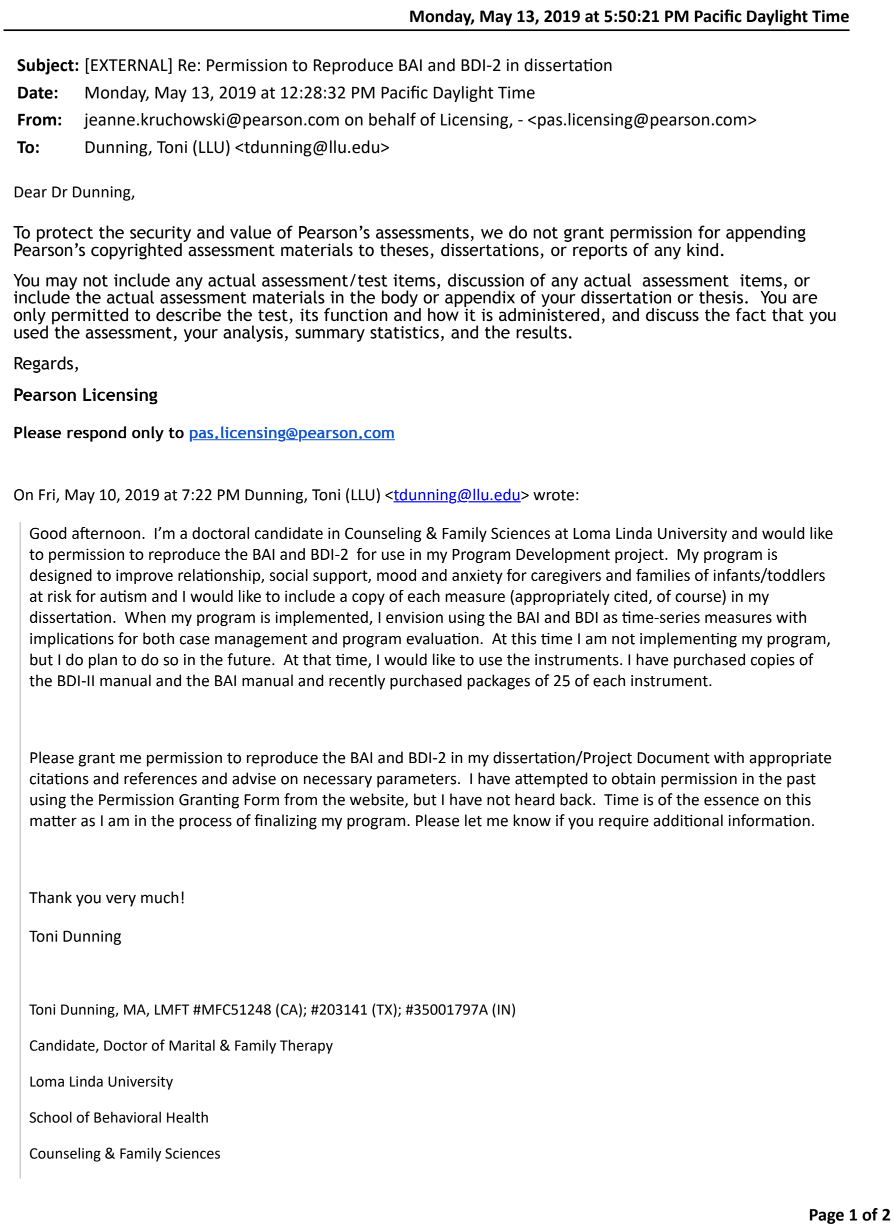
Good afternoon. My name is Toni Dunning and I am a doctoral candidate at Loma Linda University in San Bernardino County. My doctoral project is a program development for caregivers and families of infants/toddlers at risk for Autism. My program is designed as a nonduplicative supplement to Early Start programming with three components: positive behavior support/caregiver training; caregiver group; and family therapy. Therefore, in support of infant/toddler development, my doctoral project (dissertation) discusses caregiver and family needs and theoretical base for the program, a program manual, and a framework for program evaluation. I am planning to use both the CBCL with LDS and the DECA-I and DECA-T to identify the child's needs and would like permission to reproduce both Devereux instruments in the Appendix of the dissertation. If you could please let me know whether this is possible as well as any parameters you have for their use, that would be most appreciated. Also, if and when we do implement the



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To: Dunning, Toni (LLU) <tdunning@llu.edu>

Dear Dr Dunning,

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You may not include any actual assessment/test items, discussion of any actual assessment items, or include the actual assessment materials in the body or appendix of your dissertation or thesis. You are only permitted to describe the test, its function and how it is administered, and discuss the fact that you used the assessment, your analysis, summary statistics, and the results.

Regards,

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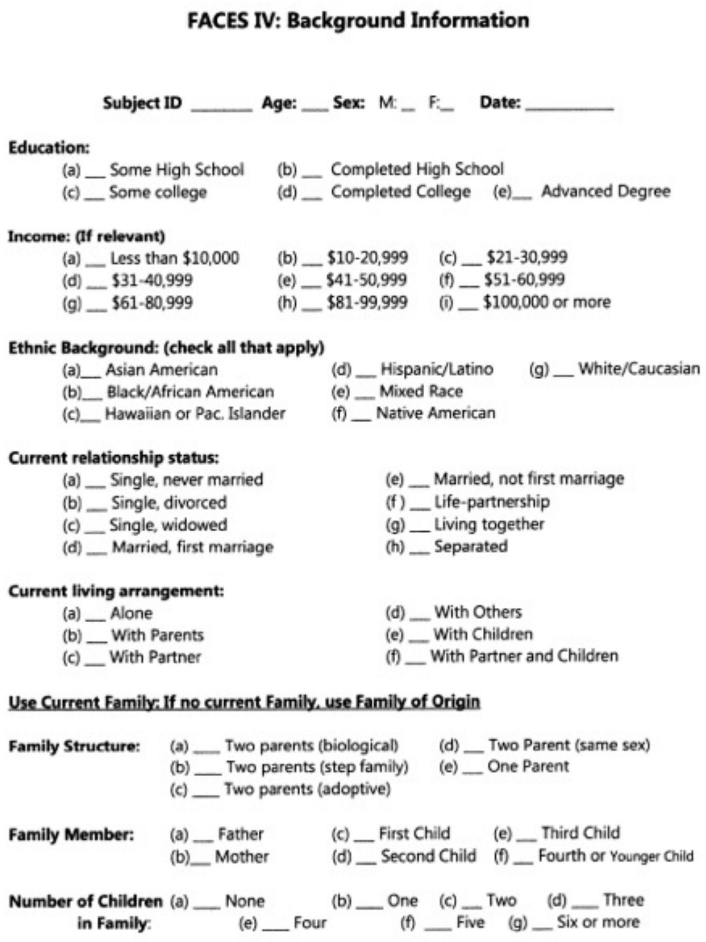
On Fri, May 10, 2019 at 7:22 PM Dunning, Toni (LLU) <tdunning@llu.edu> wrote:

> Good afternoon. I'm a doctoral candidate in Counseling & Family Sciences at Loma Linda University and would like to permission to reproduce the BAI and BDI-2 for use in my Program Development project. My program is designed to improve relationship, social support, mood and anxiety for caregivers and families of infants/toddlers at risk for autism and I would like to include a copy of each measure (appropriately cited, of course) in my dissertation. When my program is implemented, I envision using the BAI and BDI as time-series measures with implications for both case management and program evaluation. At this time I am not implementing my program, but I do plan to do so in the future. At that time, I would like to use the instruments. I have purchased copies of the BDI-II manual and the BAI manual and recently purchased packages of 25 of each instrument.
>
> Please grant me permission to reproduce the BAI and BDI-2 in my dissertation/Project Document with appropriate citations and references and advise on necessary parameters. I have attempted to obtain permission in the past using the Permission Granting Form from the website, but I have not heard back. Time is of the essence on this matter as I am in the process of finalizing my program. Please let me know if you require additional information.
>
> Thank you very much!
>
> Toni Dunning
>
> Toni Dunning, MA, LMFT #MFC51248 (CA); #203141 (TX); #35001797A (IN)
>
> Candidate, Doctor of Marital & Family Therapy
>
> Loma Linda University
>
> School of Behavioral Health
>
> Counseling & Family Sciences

Page 1 of 2

Measures to Evaluate Family Interaction Needs and Change

FACES IV (page 1)



FACES IV: Background Information

Subject ID _______ **Age:** ___ **Sex:** M: __ F:__ **Date:** __________

Education:
(a) __ Some High School (b) __ Completed High School
(c) __ Some college (d) __ Completed College (e)__ Advanced Degree

Income: (If relevant)
(a) __ Less than $10,000 (b) __ $10-20,999 (c) __ $21-30,999
(d) __ $31-40,999 (e) __ $41-50,999 (f) __ $51-60,999
(g) __ $61-80,999 (h) __ $81-99,999 (i) __ $100,000 or more

Ethnic Background: (check all that apply)
(a)__ Asian American (d) __ Hispanic/Latino (g) __ White/Caucasian
(b)__ Black/African American (e) __ Mixed Race
(c)__ Hawaiian or Pac. Islander (f) __ Native American

Current relationship status:
(a) __ Single, never married (e) __ Married, not first marriage
(b) __ Single, divorced (f) __ Life-partnership
(c) __ Single, widowed (g) __ Living together
(d) __ Married, first marriage (h) __ Separated

Current living arrangement:
(a) __ Alone (d) __ With Others
(b) __ With Parents (e) __ With Children
(c) __ With Partner (f) __ With Partner and Children

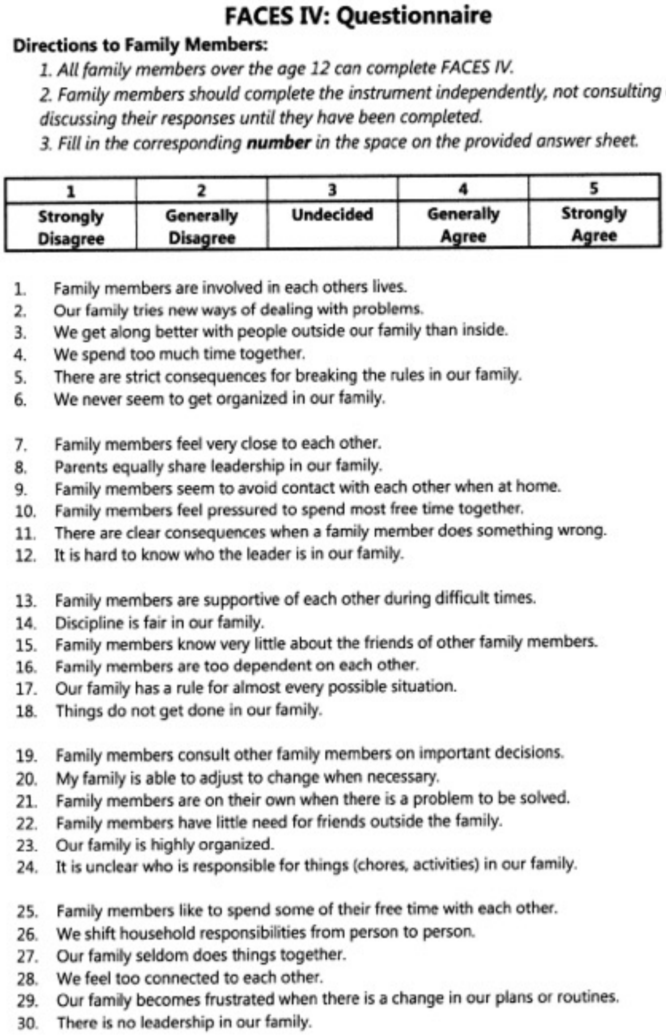
Use Current Family: If no current Family, use Family of Origin

Family Structure: (a) ___ Two parents (biological) (d) __ Two Parent (same sex)
(b) ___ Two parents (step family) (e) __ One Parent
(c) ___ Two parents (adoptive)

Family Member: (a) __ Father (c) __ First Child (e) __ Third Child
(b)__ Mother (d) __ Second Child (f) __ Fourth or Younger Child

Number of Children in Family: (a) ___ None (b) ___ One (c) __ Two (d) ___ Three
(e) ___ Four (f) ___ Five (g) __ Six or more

FACES IV (page 2)



FACES IV: Questionnaire

Directions to Family Members:

1. All family members over the age 12 can complete FACES IV.

2. Family members should complete the instrument independently, not consulting or discussing their responses until they have been completed.

3. Fill in the corresponding ***number*** *in the space on the provided answer sheet.*

1	2	3	4	5
Strongly Disagree	**Generally Disagree**	**Undecided**	**Generally Agree**	**Strongly Agree**

1. Family members are involved in each others lives.
2. Our family tries new ways of dealing with problems.
3. We get along better with people outside our family than inside.
4. We spend too much time together.
5. There are strict consequences for breaking the rules in our family.
6. We never seem to get organized in our family.

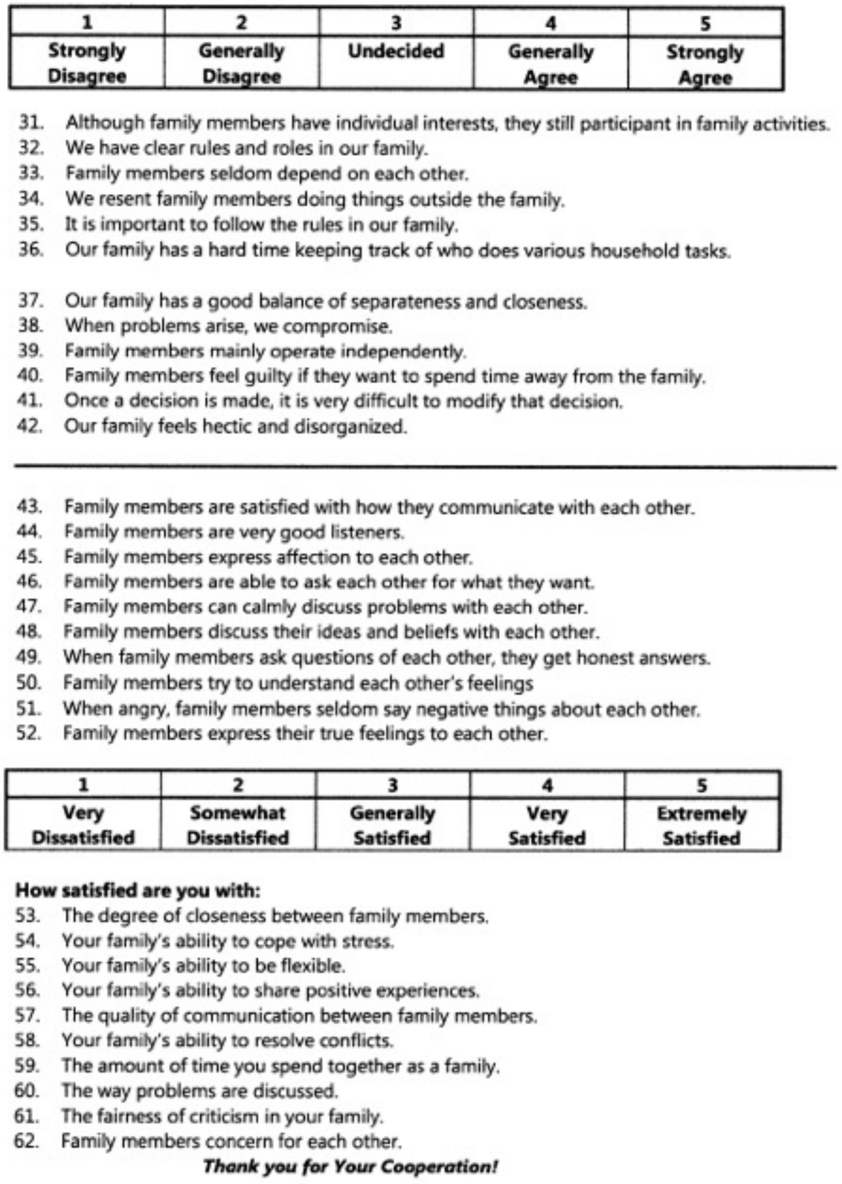
7. Family members feel very close to each other.
8. Parents equally share leadership in our family.
9. Family members seem to avoid contact with each other when at home.
10. Family members feel pressured to spend most free time together.
11. There are clear consequences when a family member does something wrong.
12. It is hard to know who the leader is in our family.

13. Family members are supportive of each other during difficult times.
14. Discipline is fair in our family.
15. Family members know very little about the friends of other family members.
16. Family members are too dependent on each other.
17. Our family has a rule for almost every possible situation.
18. Things do not get done in our family.

19. Family members consult other family members on important decisions.
20. My family is able to adjust to change when necessary.
21. Family members are on their own when there is a problem to be solved.
22. Family members have little need for friends outside the family.
23. Our family is highly organized.
24. It is unclear who is responsible for things (chores, activities) in our family.

25. Family members like to spend some of their free time with each other.
26. We shift household responsibilities from person to person.
27. Our family seldom does things together.
28. We feel too connected to each other.
29. Our family becomes frustrated when there is a change in our plans or routines.
30. There is no leadership in our family.

FACES IV (page 3)



1	2	3	4	5
Strongly Disagree	**Generally Disagree**	**Undecided**	**Generally Agree**	**Strongly Agree**

31. Although family members have individual interests, they still participant in family activities.
32. We have clear rules and roles in our family.
33. Family members seldom depend on each other.
34. We resent family members doing things outside the family.
35. It is important to follow the rules in our family.
36. Our family has a hard time keeping track of who does various household tasks.

37. Our family has a good balance of separateness and closeness.
38. When problems arise, we compromise.
39. Family members mainly operate independently.
40. Family members feel guilty if they want to spend time away from the family.
41. Once a decision is made, it is very difficult to modify that decision.
42. Our family feels hectic and disorganized.

---

43. Family members are satisfied with how they communicate with each other.
44. Family members are very good listeners.
45. Family members express affection to each other.
46. Family members are able to ask each other for what they want.
47. Family members can calmly discuss problems with each other.
48. Family members discuss their ideas and beliefs with each other.
49. When family members ask questions of each other, they get honest answers.
50. Family members try to understand each other's feelings
51. When angry, family members seldom say negative things about each other.
52. Family members express their true feelings to each other.

1	2	3	4	5
Very Dissatisfied	**Somewhat Dissatisfied**	**Generally Satisfied**	**Very Satisfied**	**Extremely Satisfied**

How satisfied are you with:

53. The degree of closeness between family members.
54. Your family's ability to cope with stress.
55. Your family's ability to be flexible.
56. Your family's ability to share positive experiences.
57. The quality of communication between family members.
58. Your family's ability to resolve conflicts.
59. The amount of time you spend together as a family.
60. The way problems are discussed.
61. The fairness of criticism in your family.
62. Family members concern for each other.

Thank you for Your Cooperation!

PREPARE ENRICH®

Toni Dunning
May 3rd, 2019

Permission to Use FACES IV Package

We are pleased to give you permission to use the **FACES IV Package** in your research project, teaching or clinical work with couples or families. In order to use FACES IV, you must use the entire FACES IV Package which contains 62 items.

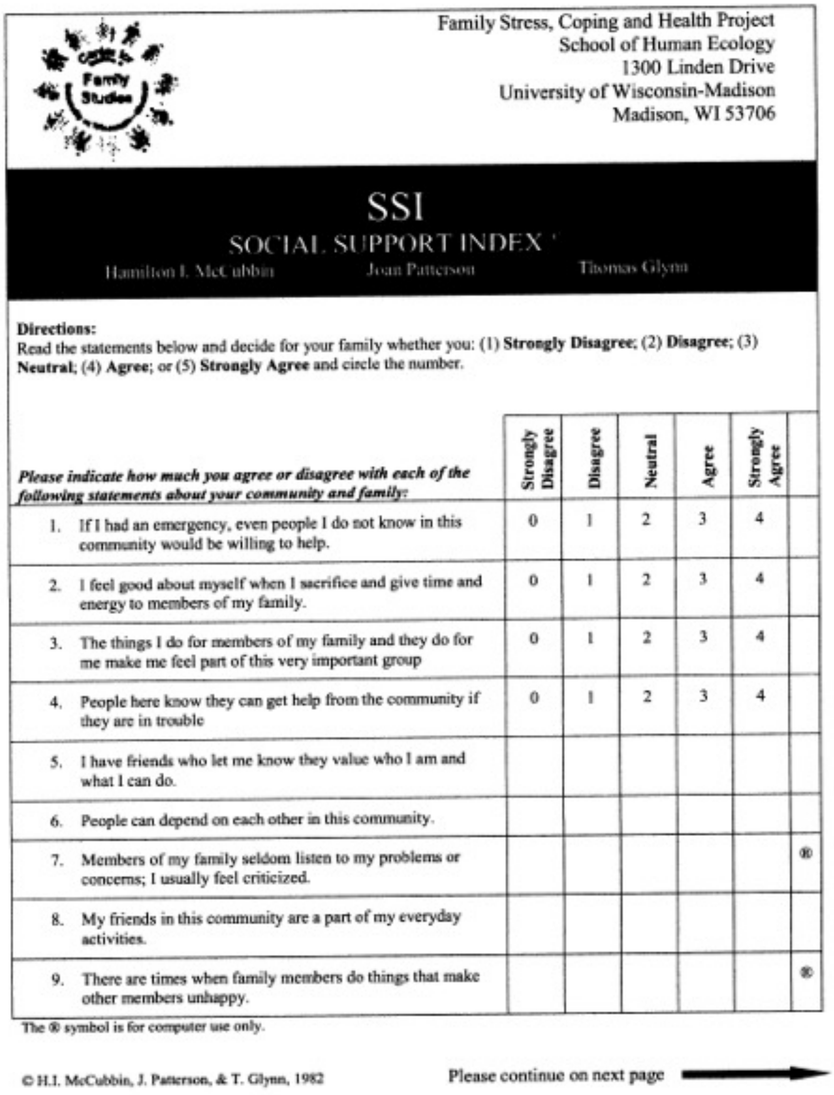
You may either duplicate the materials directly or have them retyped for use in a new format. If they are retyped, acknowledgement should be given regarding the name of the instrument, the developers' names, and PREPARE/ENRICH, LLC.

In exchange for providing this permission, we would appreciate a copy of any papers, theses or reports that you complete using the **FACES IV Package.** This will help us to stay abreast of the most recent developments and research regarding this scale. Also, we are requesting that you provide us with a *set of your data* so that we can build a large and diverse norm base. We will acknowledge your contribution to the master database. We will not use your data for individual studies on your topic or any topic. We would appreciate it if you used the format we have provided in an Excel spreadsheet (Microsoft). We thank you for your cooperation in this effort.

In closing, we hope you find the **FACES IV Package** of value in your work with families.

PREPARE/ENRICH, LLC 800.331.1661 www.prepare-enrich.com 651.635.0511 2660 Arthur St, Roseville, MN 55113

Social Support Index (page 1)



Family Stress, Coping and Health Project
School of Human Ecology
1300 Linden Drive
University of Wisconsin-Madison
Madison, WI 53706

SSI

SOCIAL SUPPORT INDEX

Hamilton I. McCubbin Joan Patterson Thomas Glynn

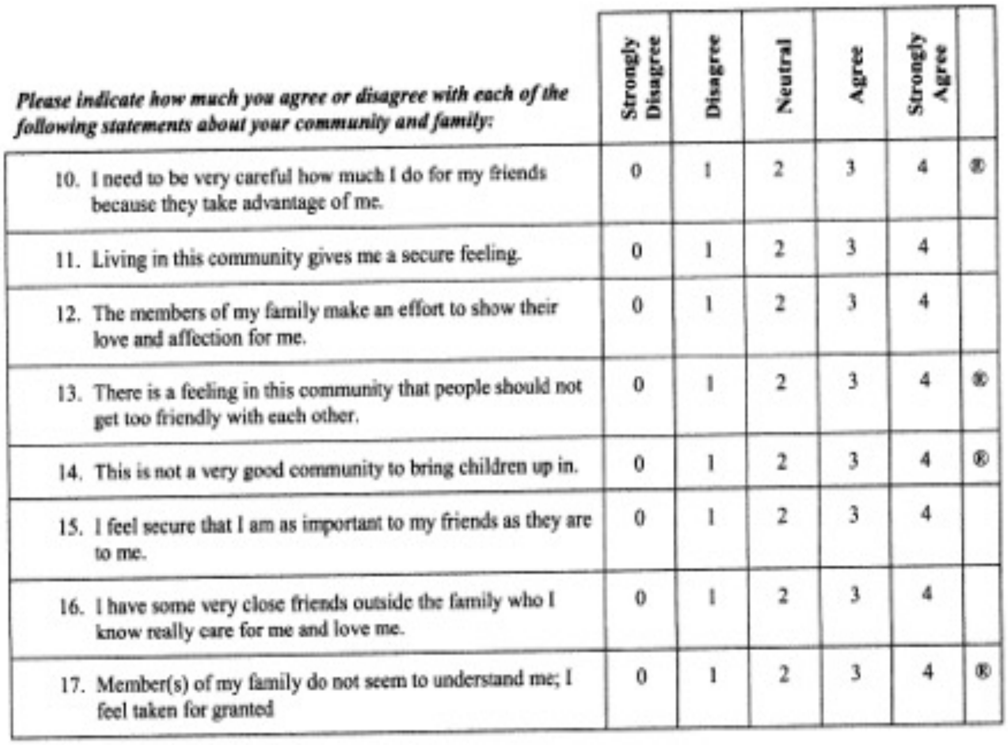
Directions:
Read the statements below and decide for your family whether you: (1) **Strongly Disagree**; (2) **Disagree**; (3) **Neutral**; (4) **Agree**; or (5) **Strongly Agree** and circle the number.

Please indicate how much you agree or disagree with each of the following statements about your community and family:	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	
1. If I had an emergency, even people I do not know in this community would be willing to help.	0	1	2	3	4	
2. I feel good about myself when I sacrifice and give time and energy to members of my family.	0	1	2	3	4	
3. The things I do for members of my family and they do for me make me feel part of this very important group	0	1	2	3	4	
4. People here know they can get help from the community if they are in trouble	0	1	2	3	4	
5. I have friends who let me know they value who I am and what I can do.						
6. People can depend on each other in this community.						
7. Members of my family seldom listen to my problems or concerns; I usually feel criticized.						®
8. My friends in this community are a part of my everyday activities.						
9. There are times when family members do things that make other members unhappy.						®

The ® symbol is for computer use only.

Please continue on next page →

Social Support Index (page 2)



Please indicate how much you agree or disagree with each of the following statements about your community and family:	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	
10. I need to be very careful how much I do for my friends because they take advantage of me.	0	1	2	3	4	®
11. Living in this community gives me a secure feeling.	0	1	2	3	4	
12. The members of my family make an effort to show their love and affection for me.	0	1	2	3	4	
13. There is a feeling in this community that people should not get too friendly with each other.	0	1	2	3	4	®
14. This is not a very good community to bring children up in.	0	1	2	3	4	®
15. I feel secure that I am as important to my friends as they are to me.	0	1	2	3	4	
16. I have some very close friends outside the family who I know really care for me and love me.	0	1	2	3	4	
17. Member(s) of my family do not seem to understand me; I feel taken for granted	0	1	2	3	4	®

Subject: [EXTERNAL] RE: SSI
Date: Monday, May 13, 2019 at 10:26:26 AM Pacific Daylight Time
From: Jason Sievers <jasievers@gmail.com>
To: Dunning, Toni (LLU) <tdunning@llu.edu>
Attachments: SSI Description - English.pdf, image010.jpg

Dear Toni –

Thank you for your interest in the SSI measure. Attached you will find the measure with all of its information. In addition, if you translate the measure into a language other than English, please send us a copy.

Respectfully,

Laurie "Lali" McCubbin, PhD
Jason A. Sievers, PhD
Hamilton I. McCubbin, PhD

Resilience, Adaptation and Well-Being Project
Email: mccubbinresilience@gmail.com
Website: www.mccubbinresilience.org

From: Dunning, Toni (LLU) <tdunning@llu.edu>
Sent: Friday, May 10, 2019 8:02 PM
To: mccubbinresilience@gmail.com
Subject: SSI
Importance: High

Good afternoon. I'm a doctoral candidate in Counseling & Family Sciences at Loma Linda University and would like to obtain a copy of the Social Support Index for use in my Program Development project. My program is designed to increase social support for caregivers and families of infants/toddlers at risk for autism and I would like to include the measure (appropriately cited, of course) in my dissertation. When my program is implemented, I envision using the SSI as a pre- and post-measurement of family social support with implications for both case management and program evaluation. I have attempted to locate the instrument at https://www.mccubbinresilience.org/measures.html to no avail. I find a description, but would like to have access to an instrument that I can show in the dissertation. At this time I am not implementing my program, but I do plan to do so in the future. At that time, I would like to use the instrument itself.

Could you please let me know where I can find the SSI, the cost and parameters for placing a copy in my Project Document/dissertation, and prospective costs for program use? Time is of the essence on this matter as I am in the process of finalizing my program.

GROUP SESSION RATING SCALE (GSRS)

Group Session Rating Scale (GSRS)

Name _______________________Age (Yrs):____
ID# ______________ Gender_______________
Session # ____ Date: _______________________

Please rate today's group by placing a mark on the line nearest to the description that best fits your experience.

Relationship

I did not feel understood, respected, and/or accepted by the leader and/or the group.	I--I	I felt understood, respected, and accepted by the leader and the group.

Goals and Topics

We did *not* work on or talk about what I wanted to work on and talk about.	I--I	We worked on and talked about what I wanted to work on and talk about.

Approach or Method

The leader and/or the group's approach is a not a good fit for me.	I--I	The leader and group's approach is a good fit for me.

Overall

There was something missing in group today—I did not feel like a part of the group.	I--I	Overall, today's group was right for me—I felt like a part of the group.

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OUTCOME RATING SCALE (ORS)

Outcome Rating Scale (ORS)

Name ________________________Age (Yrs):____ Gender_____________
Session # ____ Date: ________________________
Who is filling out this form? Please check one: Self_______ Other_______
If other, what is your relationship to this person? ____________________________

Looking back over the last week, including today, help us understand how you have been feeling by rating how well you have been doing in the following areas of your life, where marks to the left represent low levels and marks to the right indicate high levels. *If you are filling out this form for another person, please fill out according to how you think he or she is doing.*

Individually
(Personal well-being)

I--I

Interpersonally
(Family, close relationships)

I--I

Socially
(Work, school, friendships)

I--I

Overall
(General sense of well-being)

I--I

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SESSION RATING SCALE (SRS)

Session Rating Scale (SRS V.3.0)

Name ________________________Age (Yrs):____
ID# _________________________ Gender:_______
Session # ____ Date: ________________________

Please rate today's session by placing a mark on the line nearest to the description that best fits your experience.

Relationship

I did not feel heard, understood, and respected.	I--I	I felt heard, understood, and respected.

Goals and Topics

We did *not* work on or talk about what I wanted to work on and talk about.	I--I	We worked on and talked about what I wanted to work on and talk about.

Approach or Method

The therapist's approach is not a good fit for me.	I--I	The therapist's approach is a good fit for me.

Overall

There was something missing in the session today.	I--I	Overall, today's session was right for me.

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Subject: [EXTERNAL] RE: Permission to reproduce SRS, GSRS, and ORS in Dissertation
Date: Wednesday, May 15, 2019 at 4:44:22 AM Pacific Daylight Time
From: Scott D. Miller, Ph.D. <scottdmiller@talkingcure.com>
To: Dunning, Toni (LLU) <tdunning@llu.edu>
Attachments: image002.png

Hi Toni…

Congrats on completing your dissertation!

Yes, you may reproduce the scales.

Here's what I ask:

1. Use the watermark feature in WORD to write "Examination Copy" across the face of the measures; and
2. Put the following link in the footer at the bottom of the tool:

"To request a free license, go to https://scott-d-miller-ph-d.myshopify.com/collections/performance-metrics/products/performance-metrics-licenses-for-the-ors-and-srs"

Let me know if there's any other way can be of help.

Scott D. Miller, Ph.D
Director, International Center for Clinical Excellence

P.S.: Join colleagues from around the world for the ICCE Summer Intensives. For more information or to register click on the images below:

From: Dunning, Toni (LLU) <tdunning@llu.edu>
Sent: Tuesday, May 14, 2019 3:25 PM
To: info@scottdmiller.com
Subject: Permission to reproduce SRS, GSRS, and ORS in Dissertation

Good afternoon, Dr. Miller.