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## Intellectual Disability and Developmental Risk: Promoting Intervention to Improve Child and Family Well-Being

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Initial intervention processes for children with intellectual disabilities (IDs) largely focused on direct efforts to impact core cognitive and academic deficits associated with the diagnosis. Recent research on risk processes in families of children with ID, however, has influenced new developmental system approaches to early intervention. Recent risk and resilience processes are reviewed that connect stress, family process, and the high rates of behavioral problems in children with ID that have substantial influence on child and family outcomes. These models are linked to emerging evidence-based intervention processes that focus on strategic parent skill training and mindfulness interventions that reduce parental stress and create indirect benefits for children's behavioral competencies. A family-focused developmental systems approach (M. J. Guralnick, 2011) is emphasized.

The diagnosis of intellectual disability (ID) creates profound changes in the developmental trajectories for the children, so diagnosed, and multiple challenges for the families that care for those children. ID is characterized by impairments in general mental abilities as well as in adaptive functioning across conceptual, social, and practical domains that occur during the developmental period. ID is a specific type of developmental disability, a larger category that more broadly addresses conditions in which there may be impairments across domains such as physical, language, learning, and behavior. The severity of ID is based on adaptive functioning rather than on IQ alone (American Psychiatric Association, 2013). Historically, expectations for developmental competence in children with ID were limited as the underlying biology of

developmental disorder was deterministic, and developmental limitations were considered largely immutable. However, complex developmental systems now implicate social and contextual influences that operate directly and indirectly to influence child competencies for children at risk of ID (Guralnick, 2011, 2016), suggesting that early intervention can have important developmental benefits. However, intervention approaches must better address key developmental processes, identifying salient challenges that are specific, if not unique, to children with ID and their families. Emerging behavior problems and parent stress are two risks that form a particularly salient nexus for intervention with important implications for child and family well-being over time.

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A lag in sophisticated developmental modeling related to ID (Crnic & Neece, 2015) likely reflects historical expectations that ID resulted in uniformly poor developmental outcomes across domains. This pathological approach has been mostly abandoned for contemporary models that reflect more nuanced perspectives in which developmental processes are not solely determined by some specific biologically disabling condition but are instead influenced by the same complex developmental pathways that reflect the interplay of genes, individual child characteristics, parenting, family, peer, and other contexts that exert their influence over time in all children.

Children with ID and their families represent a unique risk group in a number of important ways, with especially salient concerns to be addressed. Diverging age and ability over time, violated developmental expectations, delayed developmental transitions, and continuing social stigma are among the issues that differentiate these children and their families. Although there is evidence in support of resilient functioning (Fenning & Baker, 2012; Peer & Hillman, 2014) and its connection to developmentally salient interventions (Guralnick, 2016), behavior disorders and more stressed parenting are two frequent consequences of ID. Both, however, have implications for child and parent well-being that are likely to be especially amenable to innovative intervention planning.

For children with ID, the risk for behavior disorders is three to four times that of typically developing children (Emerson et al., 2010), and a growing body of research indicates that the presence of behavioral problems in children with ID may be more predictive of poorer adaptive outcomes than is the presence of the core cognitive deficit that has largely defined the disorder (Baker et al., 2003; Woodman, Mawdsley, & Hauser-Cram, 2015). Consequently, rather than focus on the core cognitive and adaptive deficits of ID, greater attention to related risk and resilience factors that transact with core deficits must be pursued. In particular, the reciprocal connections between child behavior problems and contextual parent stresses associated with the unique challenges of ID are not only more mutable, but they overshadow the core cognitive deficit in implications for child and parent well-being.

### **Salient Risk and Protective Processes**

Although any number of factors might be chosen to represent the most salient risk and protective

processes for children with ID, parent stress and child behavior problems reflect two especially meaningful categories that have profound influences on child development and well-being. Each of these factors can be addressed as individually meaningful influences on developmental outcomes for children with ID; however, a review of emerging literatures suggest that these factors also transact over time in a series of complex mediated and moderated relations that help determine child and family competencies (Crnic & Neece, 2015).

### *Behavior Disorders*

The course of behavior disorders in children with ID is not well understood, however, a study of growth trajectories across a 5-year period suggested that children with ID had more behavior problems at each measurement period involved (De Ruiter, Dekker, Verhulst, & Koot, 2007). The increased level of behavior problems is especially salient for families and children with ID given the evidence that behavior problems in children with ID may be more predictive of later child and family functioning than are cognitive abilities (Baker et al., 2003). Other longitudinal research indicates that parental psychological well-being, maternal physical health; parenting stress, maternal sensitivity; and children's social skills and children's school relationships are all adversely impacted by elevated behavior problems in children with ID.

Although the implications of increased behavior problems for child and family functioning are significant, the mechanisms by which these problems emerge are much less well understood. There are suggestions that they may reflect behavioral phenotypes associated with specific forms of ID (Dykens & Hodapp, 2001), but comorbid behavior problems may also be a function of concomitant contextual and developmental risks associated with the presence of ID (Guralnick, 2016; Woodman et al., 2015). In particular, parenting stress and ongoing family and parent processes have been implicated (Pedersen, Crnic, Baker, & Blacher, 2015).

### *Parent and Stress Processes*

From early pathological models, in which families were expected to have negative outcomes across domains, to more contemporary perspectives, in which families demonstrate both strengths and weaknesses and outcomes are more nuanced, families have been a primary focus of attention

when children are diagnosed with ID. Parental physical and psychological well-being, parenting attitudes, parent-child interaction, marital functioning, and social relationships have all been implicated not only as at risk (Crnic, Arbona, Baker, & Blacher, 2009; Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001) but also as potential moderators of risk when family functioning is strong and positive (Blacher, Baker, & Berkovits, 2013). Regardless, stress is one attribute that has consistently been implicated in the creation of risk for parents of children with ID (Peer & Hillman, 2014; Woodman et al., 2015) and may be the catalyst for many of the other risks that these families and children experience.

Parents of children with ID generally report higher levels of stress than do parents of typically developing children (Hauser-Cram, Cannarella, Tillingier, & Woodman, 2013), and stress effects may be developmentally mediated. For parents of children with ID, average levels of stress are higher across all developmental periods from infancy through adolescence (Baker et al., 2003; Lopez, Clifford, Minnes, & Ouellette-Kuntz, 2008), and there is compelling evidence to suggest that parenting stress increases over time (Gerstein, Crnic, Blacher, & Baker, 2009; Hauser-Cram et al., 2001; Neece, Green, & Baker, 2012). Parents of children with ID may experience stress associated with increased caregiving demands and coordination of care (Crnic, Friedrich, & Greenberg, 1983) and the presence of co-occurring behavioral or medical conditions (e.g., Baker et al., 2003). These stressors, coupled with additional financial strain (e.g., Parish, Seltzer, Greenberg, & Floyd, 2004) and feelings of isolation and lack of social support, may place parents of children with ID at risk for psychological distress. Stress processes, however, are mutable and interventions would be especially salient for these parents given the well-established adverse correlates of stressful experience.

Irrespective of developmental risk status, parenting stress has been linked with problematic child adjustment (Deater-Deckard, 2004), although the effect is typically thought to be indirect and mediated by affected parenting behaviors such as inconsistent discipline, less structure and guidance, lower positivity, and unrealistic expectations for children (Crawford & Manassis, 2011). Although the evidence to support such pathways is reasonably well established for families with typically developing children, these same pathways are only now beginning to be explored for children with ID. Indeed, only recently have studies substantiated linkages

over time between parenting stress and elevated behavior problems in children with ID (Neece et al., 2012; Woodman et al., 2015).

The high rate of behavior problems in children with ID appears to reflect an indirect effect that operates to some extent through family stress and its multiple familial correlates, much in the way that Guralnick's (2016) Developmental Systems Model describes. The nature of the relations among these factors is complex, and family functioning can operate in either risk or protective capacities, depending on the attribute in question and its valence. Indeed, risk and resilience processes typically involve complex indirect effects, mediated and moderated over long periods of time that can result in substantial developmental improvement across multiple functional domains (Luthar & Brown, 2007). Emerging intervention models for children with ID and their families have begun to capitalize on these developmental processes.

### Emerging Intervention Processes

Current interventions for the social and emotional consequences of ID reflect an emerging recognition of the importance of developmental systems (Guralnick, 2011) as well as an emphasis on key family mechanisms that link chronic conditions to important functional competencies. Indeed, Guralnick (2011) has emphasized that intervention programs must carefully identify those family interactions and resources that may be especially stressed or perturbed by the presence of a child with ID, as these elements often result in additive risk for behavior disorders. Among the interventions that have been applied and tested with various levels of methodological rigor, two primary evidence-based approaches have emerged for prevention and intervention of co-occurring emotional and behavioral disorders in children with ID. The first approach directly targets specific parenting behaviors that are associated with more positive developmental and behavioral outcomes, whereas the second addresses parental stress and its multifaceted influence on child and family well-being. The potential synergy between these approaches is of particular interest.

#### *Parent Training Strategies*

A robust literature suggests that supporting developmentally sensitive parenting skills reduces the risk of later problem behavior for children with

ID while simultaneously supporting family well-being and parent mental health (Floyd, Harter, Costigan, & MacLean, 2004; McIntyre, 2008a, 2008b). Thus, drawing on a long tradition of parent management training with well-documented efficacy in reducing disruptive behavior (Eyberg, Nelson, & Boggs, 2008), behavioral parent training has been established as a particularly effective intervention for children with ID and their families.

The efficacy of parent training for reducing disruptive behavior in young children, irrespective of developmental risk, is well documented (see Kaminski, Valle, Filene, & Boyle, 2008), and a range of behavioral parent training models have been empirically validated with respect to reducing challenging behavior in children and adolescents with ID (see McIntyre, 2013 for a review). For example, McIntyre adapted Webster-Stratton's Incredible Years Parent Training (IYPT) for use with parents of preschool children with mixed etiology developmental delays (IYPT-DD; McIntyre, 2008a). Using discussion, video modeling, role playing, and didactics, challenging behavior is reduced through altering negative and coercive parent-child interactions (Webster-Stratton, 2001). Adaptations to the IYPT protocol included the addition of a section about the blessings and challenges of raising a child with ID, a section about advocacy and community resources, and a section about descriptive functional behavioral assessments and implementation of interventions based on functional behavioral assessments (see McIntyre, 2008a). The intervention involved 12 weekly group sessions (8–12 parents/group), 2.5-hr sessions covering the topics of developmentally appropriate play and positive behavior management, with a focus on enhancing positive parent-child interactions and reducing negative parent-child interactions. These adaptations proved to be feasible and efficacious for reducing negative parent-child interactions and child behavior problems as well as increasing parents' positive feelings toward their child with ID following intervention (McIntyre, 2008a). Furthermore, these adaptations focused on child and family resources and parent-child interactions, which are the cornerstone of the Guralnick's (2011) developmental systems framework.

In a follow-up randomized controlled trial evaluating the efficacy of IYPT-DD on reducing negative parent-child interactions and problem behavior, significant Group (IYPT-DD vs. usual-care control)  $\times$  Time (pre-/posttreatment) interactions emerged to demonstrate larger reductions in both negative parent-child interactions (Cohen's

$d = 1.53$ ) and child behavior problems (Cohen's  $d = 0.70$ ) for the intervention families over time (McIntyre, 2008b, 2013). On the whole, these results support the focus on parenting processes as a critical mechanism for preventing or improving specific problem behaviors in young children with developmental delay and provide evidence that supports the adaptation of IYPT for children with developmental disabilities.

The salience of parenting process interventions for children with ID is not specific to IYPT. Indeed, convergent evidence exists from like programs as well that have been modified for use with families of children with ID. For example, Triple P has been modified for use with parents of children with ID (Stepping Stones Triple P; Plant & Sanders, 2007) and Parent-Child Interaction Therapy has been applied to parents of children with ID (Bagner & Eyberg, 2007). Other similar behavioral parent training programs have been designed and developed specifically for families of children with ID or autism spectrum disorder, such as Signposts for Better Behavior (Hudson et al., 2003) and the RUPP Parent Training program (Aman et al., 2009). Each of these intervention programs has produced meaningful reductions in child problem behavior.

Parent behavior likely mediates the effect of behavioral parent training interventions on child behavior problems such that the more the behavioral parent training intervention reduces negative parent-child interactions, increases positive parent-child interactions, and increases parental competence and self-efficacy, the more the child's behavior problems will improve and the less stressed parents are likely to be. However, parenting stress likely serves to moderate the impact of the behavioral parent training intervention on parenting behavior and competence such that the more stressed the parent, the less they learn and are able to implement from the behavioral parent training intervention and the less their parent-child interactions improve. Indeed, chronic stress can affect cognition, learning, and memory (Lupien, McEwen, Gunnar, & Heim, 2009) as well as emotional health (e.g., Schneiderman, Ironson, & Siegel, 2005). Specific to the intervention context, parenting stress was found to reduce the effectiveness of both teacher and parent-delivered intervention programs for preschool-aged children with autism spectrum disorder (Osborne, McHugh, Saunders, & Reed, 2008). Thus, stress is likely to create difficulty with emotion regulation and behavioral response in challenging situations, resulting in less learning which in turn can have direct implications for the delivery of

behavioral parent training interventions. Notably, parent training approaches have not typically focused on critical indirect influences such as the potential for reductions in parental stress (McIntyre, 2013), which likely attenuates the efficacy of interventions (e.g., Osborne et al., 2008).

### *Mindfulness-Based Strategies*

Given that high levels of parenting stress have been associated with less beneficial outcomes for children in early intervention programs (Strauss et al., 2012) and fewer gains in parenting skills in behavioral parenting training interventions (e.g., Baker, Landen, & Kashima, 1991), mindfulness interventions represent a logical approach for parents of children with ID who experience high levels of stress that in turn produce adverse developmental consequences. Several mindfulness interventions (e.g., mindfulness-based stress reduction, MBSR) have undergone extensive research showing their effectiveness in reducing general stress, anxiety, and depression, and promoting overall well-being (Grossman, Niemann, Schmidt, & Walach, 2004). The evidence indicating mindfulness interventions reduce stress for a broad range of individuals provides some confidence that mindfulness interventions will also be highly effective with parents of children with ID (Grossman et al., 2004). The research base supporting mindfulness interventions for families of children with ID is beginning to grow quickly, but the methodological rigor of the research varies considerably. With the exception of a large-scale trial conducted by Dykens, Fisher, Taylor, Lambert, and Miodrag (2014), studies generally have small sample sizes, lack active control groups, do not include follow-up data, and do not measure treatment integrity. Furthermore, studies tend to examine different mindfulness interventions and often fail to provide sufficient details of the interventions provided. Therefore, it is difficult to aggregate findings across studies, and replication is impossible. Despite these shortcomings, early findings support the efficacy of mindfulness interventions in reducing stress among diverse samples of parents of children with ID (Bazzano et al., 2013; Dykens et al., 2014; Neece, 2014), producing medium to large effect sizes in reducing parental depression, anxiety, and distress as well as improving self-compassion, psychological well-being, and life satisfaction.

Mindfulness interventions vary widely with regard to duration, intensity, format, setting, and content. However, MBSR is the most widely studied mindfulness intervention, and most mindfulness

interventions use some adaptation of MBSR. MBSR is manualized (Kabat-Zinn, 1990) and includes 8 weekly, 2.5-hr group sessions, a day-long meditation retreat during Week 6, and 45 min of daily home practice guided by instructional audio CDs. Formal mindfulness exercises aim to increase the capacity for mindfulness (present moment awareness with a compassionate, nonjudgmental stance) and include a body scan, mindful yoga, and sitting meditation. The practices do not focus on a particular source of stress (e.g., issues associated with having a child with ID). So although all parents in the mindfulness interventions may share the experience of having a child with ID, individual parents can apply the techniques to whatever source of stress is most salient in the moment. Such interventions may be particularly beneficial to parents of children with ID who experience a wide range of stressors across several contexts that may negatively influence family patterns of interactions and subsequent child outcomes (Guralnick, 2016).

Although data on the maintenance of effect are limited, the majority of participants report continued practice following MBSR (Carlson, Speca, Faris, & Patel, 2007). Most follow-up data are short term (3 or 6 months), especially for nonclinical populations. Dykens et al. (2014) used an abbreviated version of MBSR with parents of children and adults with ID, and included booster sessions to enhance maintenance effects. However, it is not clear whether these sessions provide an additional therapeutic benefit beyond the standard intervention.

Although MBSR is cost effective in many ways (e.g., delivered in a large group vs. individual sessions), it is also an intensive intervention that requires a significant time investment for both participants and teachers. Unfortunately, research is unclear about how intensive a mindfulness intervention must be to result in significant reductions in stress regardless of the severity of risk in the population. Several investigations have reported benefits with relatively low intensive interventions; however, these studies differ in the outcomes examined, the measures used to assess outcomes, and often lack sufficient detail about the content of the intervention which makes it difficult to aggregate results. Carmody and Baer (2009) examined the association between MBSR intervention contact hours and effect sizes for psychological effects across 30 studies, one of which involved parents of children with disabilities and found no relation between the intervention intensity and outcome effect sizes, suggesting brief versions of MBSR may merit further study.

*Intervention Blueprint*

Unfortunately, there are few large-scale studies that are powered to examine key mechanisms of change, moderators of outcomes, and sustainability of intervention effects for children with ID and their families. Furthermore, behavioral parent training approaches do not consistently result in reductions of parenting stress (Singer, Ethridge, & Aldana, 2007), and mindfulness interventions for parents of children with ID do not always lead to reductions in child behavior problems (Dykens et al., 2014) despite the fact that such relations have been reasonably well established. Parents of children with ID have varying levels of parental stress (Glidden & Schoolcraft, 2003), and we contend that those parents with especially high stress will find it difficult to make long-term parenting behavior change that results in sustainable changes in child behavior problems in the absence of parental stress reduction. Consistent with Guralnick's (2016) model, family resources, specifically the mental health, coping styles, and perceived competence and confidence of parents, must improve in order for family patterns of interaction to improve, thereby optimizing child outcomes. Thus, once parents are less stressed following the mindfulness intervention, they can better learn positive parenting and appropriate behavior management parenting skills to address the child's challenging behavior. Therefore, we argue for an integrated model of intervention that directly targets parenting stress within the context of building parenting skills that promote more positive parent-child interactions. Given that elevated parental stress has been associated with decreased efficacy of behavioral interventions for children with disabilities (e.g., Osborne et al., 2008), addressing parental stress should substantially improve the impact of innovative behavioral parent training approaches. However, this remains an empirical question. A central argument to our intervention blueprint is that parents of children with ID experience both quantitatively more and qualitatively different stressors making the parent-child interactions more challenging at times. Other intervention directions consider contextual risk factors and resources (e.g., Guralnick, 2016), and reductions in parenting stress can serve not only as change agents that improve the quality of parent-child interaction (Crnic & Ross, in press) but also allow parent and family resources to facilitate more positive parent-child relationships under conditions of developmental risk (Crnic & Neece, 2015; Guralnick, 2016).

An important next step in our intervention work will be to investigate the additive or synergistic effects of MBSR on the uptake of behavioral parent training in families with young children with ID. We hypothesize that the preschool period may be the ideal developmental stage to target for this intervention as the preschool period is a critical window for intervention when children achieve the most gains (Itzchak & Zachor, 2011). Simultaneously, parenting stress peaks during the preschool period when child behavior problems begin to emerge (Gerstein et al., 2009; Neece et al., 2012). Thus, we propose that delivering this intervention during the preschool period will have the maximum influence on the pathway from parent stress to child behavior problems in children with ID. Within this approach, mindfulness interventions based on MBSR can be synergistic in combination with behavioral parent training, providing a more integrated and comprehensive approach to developmental change.

Parents will first receive a potent 6-week stress reduction intervention that primes receipt and uptake of the 10-week behavioral skills training that would follow. Both the mindfulness and parent training interventions we are proposing are shorter than the standard interventions delivered (8 and 12 sessions, respectively), as there is growing evidence that these interventions can be less involved (Jensen & Lowry, 2012) even when delivered to parents of children with ID (Dykens et al., 2014). Research suggests that parents of children with developmental disabilities who practice MBSR strategies show improved satisfaction with parenting and satisfaction with the relationships with their children (Singh et al., 2007). Furthermore, for parents who practice mindfulness, meditation gradually becomes a part of their everyday lives (Singh et al., 2010). It is the adoption of a "mindful way of life" that may be important for initial uptake and sustainability of behavior changes made in parent-child interactions and reductions in parenting stress. We draw on past intervention work (McIntyre, 2008b, 2013; Neece, 2014) in the design of a 16-week intervention to reduce challenging behavior in preschool children with ID. We anticipate both decreased child behavior problems (mediated by changes in parent-child interactions) and lower parenting stress (mediated through changes in parental emotional dysregulation). These changes will position parents to be more responsive, sensitive, and accepting, which may in turn lead to improvements in child social and behavioral functioning over time.

We recognize the complexities of implementing the proposed intervention in real-world community settings. The majority of existing research on behavioral parent training and mindfulness interventions with parents of children with ID has used relatively homogeneous samples of English-speaking, educated parents. Thus, the efficacy of the proposed intervention for diverse and low-income families of children with ID may be of question. Therefore, it is critical that initial studies evaluating the feasibility and efficacy of the proposed intervention blueprint include diverse samples in order to maximize generalizability.

Sustainability of effects and sustainability of programs are topics of particular importance to the field of implementation science (e.g., McIntosh, Filter, Bennett, Ryan, & Sugai, 2010). Sustainability has been virtually ignored in the intervention literature of children with ID. In terms of sustainability of effects, few studies report long-term follow-up assessments of interventions designed to reduce challenging behavior in children with ID (McIntyre, 2013), calling into question durability of intervention effects. Clearly, research that involves assessing long-term outcomes is an important step in addressing this gap; however, increasing initial family engagement with intervention may be a critical initial step. Furthermore, emphasizing stress reduction may be key to engaging with families. Indeed, Kazdin and Whitley (2003) report that parenting stress predicts attendance in behavioral therapy sessions, treatment dropout, and child progress. Our proposed intervention capitalizes on caregivers' motivation to reduce their parenting stress, which in turn may result in improved engagement with the behavioral parent training component of the intervention. Long-term follow-ups are important to determine maintenance of intervention effects, but we suggest that initial engagement may be an especially powerful predictor of treatment outcomes.

### Summary and Future Directions

For more than a decade, Guralnick (2011, 2016) has promoted a developmental systems approach for integrating core individual, family, and contextual elements that can frame successful approaches to early intervention for children with developmental risk. The core working hypothesis of the developmental systems approach as applied to early intervention for all vulnerable children is that its effectiveness depends on the program's ability to

establish or restore as optimal a level of family patterns of interaction as is possible. Emerging research suggests the important role of parenting and family processes for the behavior and social competence of children with ID, especially in relation to behavior disorders that have major implications for long-term child and family well-being (Crnic & Neece, 2015; Woodman et al., 2015).

The integration of behavioral parent training and mindfulness-based interventions for parents of children with ID is an important area for future investigation. There is a small but growing literature that supports the potential synergy of mindfulness components to behavioral interventions to best capitalize on family processes as mechanisms of change (e.g., Singh et al., 2014). Future investigation will determine whether integrating a parental stress reduction module maximizes the efficacy of parent training and behavior interventions that target challenging behavior among children with ID. Given that elevated parental stress has been associated with both increased behavior problems in children with ID and decreased efficacy of behavioral interventions for children (Strauss et al., 2012), addressing parental stress should substantially improve the impact of interventions for these children and families.

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