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Interventions for Parents of People with Intellectual Disabilities

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Abstract Parents of children with intellectual disabilities (ID) consistently report higher levels of parenting stress than parents of typically developing children, which has psychological and physical consequences for both the parent and child. Further, high levels of parenting stress are often associated with poor outcomes in behavioral interventions for children with ID. Thus, parental stress and mental health concerns in general are critical targets for intervention. Nevertheless, there are few evidence-based treatments aimed at reducing stress in parents of children with ID. Parent-led support groups are the most common type of intervention for these parents; however, little empirical evidence is available to support the efficacy of these interventions. Other evidence-based interventions include mindfulness, cognitive-behavior therapy, respite, and behavioral parent training interventions. We argue for a combined intervention model that addresses both parental stress and child behavior problems directly in order to optimize outcomes for children with ID and their families.

Keywords Intellectual disabilities · Developmental disorders · Parenting stress · Children with ID · Review

Introduction

Parents of children with intellectual disabilities (ID) typically report higher levels of parenting stress compared to parents of

typically developing children with approximately one third of parents reporting clinical levels of stress suggesting a need for treatment [1–3]. These elevated levels of stress have both psychological as well as physical consequences as parents of children with ID have been found to have disruptions in their stress response system, as reflected in low cortisol, which can lead to decreased immunity and increased vulnerability to stress-related diseases [4, 5].

High levels of parenting stress are very concerning given the associated negative outcomes for both parents *and* their children. Our own research and others indicate that highly stressed parents, compared to relatively less stressed parents, are significantly more vulnerable to parental depression, marital conflict, poorer physical health, and less effective parenting [6–9]. Their children are at increased risk for child behavior problems, lower social competence, and later psychopathology [1, 10–13]. Thus, parental stress and mental health concerns more broadly are critical foci for intervention for improving both parent and child outcomes. Despite the scope of the problem and the host of associated negative outcomes, relatively few evidence-based treatments exist for reducing stress among parents of children with ID. Further, treatments targeting behavior and social-emotional problems and in children with ID have rarely addressed the influence of parental stress on child outcomes [14]. This article will review interventions targeting stress and other mental health problems among parents of people with ID as well as interventions aimed at reducing child behavior problems that are delivered via parent training.

Interventions Targeting Stress and Mental Health Concerns

Parent-Led Support Groups Parent-led support groups are the most commonly used type of intervention for parents of

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children with ID [15]. These groups are normally initiated by other parents of children with ID or community agencies and include a less-structured, open discussion-based format where parents are invited to share their experiences raising a child with ID with the group. Each week usually has a discussion topic (e.g., stress and coping strategies, parenting skills, navigating the developmental service agencies) and there is a parent or two who facilitate the discussion. Although descriptions of various models have been published (e.g., 16), strong evaluation data have rarely been reported and the impact of these interventions on parental stress has not been assessed [17].

Cognitive-Behavior Therapy Interventions Cognitive behavior therapy (CBT) is a widely used therapeutic modality in which negative patterns of one's thinking about the self and the world are challenged in order to change negative behavior patterns and improve mood. CBT has consistently been shown to be effective in treating a wide range of mental health issues (e.g., depression, eating disorders, phobias), on a large spectrum of severity [18, 19]. A few studies have looked at the efficacy of these CBT treatments in targeting mental health problems among parents of children with ID. Unfortunately, many of the available studies use CBT techniques as a part of their intervention but include other intervention components as well, so the degree to which CBT techniques are effective for parents of children with ID is not clear. Further, often the details of the CBT interventions used are not specified or manualized, making replication difficult. Finally, the majority of these studies do not use an active treatment control and, therefore, we cannot determine the impact of non-specific treatment effects like the support of a group or contact with a mental health professional.

Mindfulness-Based Strategies Mindfulness interventions represent a logical approach for parents of children with ID who experience high levels of stress. Although the research base supporting mindfulness interventions for these families is growing quickly, the methodological rigor of the research varies considerably. With the exception of a large-scale trial conducted by Dykens and colleagues, these studies generally have a small sample size, lack an active control group, do not include follow-up data, and do not measure treatment integrity [20]. Further, studies tend to examine different mindfulness interventions to make adaptations to standard mindfulness interventions (e.g., mindfulness-based stress reduction, mindful parenting, mindfulness-based cognitive therapy); however, they often fail to provide sufficient details of the interventions provided and adaptations made. Therefore, it is difficult to combine findings across studies and replication is challenging. Nevertheless, initial results support the efficacy of mindfulness interventions in reducing stress among diverse samples of parents of children with ID from early childhood to emerging adulthood [20–22]. Findings from these investigations

suggest that mindfulness interventions produce 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. Mindfulness-based stress reduction (MBSR) is the most widely studied mindfulness intervention, and most mindfulness interventions use some adaptation of MBSR. MBSR is manualized and includes eight weekly 2.5-h group sessions, a day-long meditation retreat during week 6, and 45 min of daily home practice guided by instructional audio CDs [23].

Formal mindfulness exercises aim to increase the capacity for mindfulness (present-moment awareness with a compassionate, non-judgmental 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). Thus, although all parents in the mindfulness intervention may share the experience of having a child with ID, individual parents can apply the techniques to whatever source of stress is most salient to them in the moment.

Regarding maintenance of these therapeutic effects, the majority of participants report continued practice following the MBSR intervention [24]; however, most follow-up data are short-term (3 or 6 months), especially for non-clinical populations. Dykens and colleagues used an abbreviated version of MBSR with parents of children and adults with ID and included booster sessions to enhance maintenance effects [20]. 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 intensity 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 across studies. Carmody and Baer 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 be effective [25].

Respite Interventions Having a child with special needs can be exhausting. Thus, a common intervention for these

parents is respite care [26]. Respite care was designed to give parents who have a child with ID temporary child-care and support and is considered to be a critical component of formal support interventions [27]. Research has shown that parental stress decreases as a result of receiving respite care [26, 27]. Consistent with developmental theoretical models hypothesizing that parenting behavior is a key mediator of the link between parental stress and child behavior problems, studies also indicate that reductions in parental stress following respite care also reduce the risk of dysfunctional parenting [27]. In addition to reductions in parenting stress, research has also revealed that respite care may provide the child with ID with more experiences outside the home, prevent breakdown of family emotional processes, decrease the likelihood of placing the child with ID in residential care, and enhance family relations, social activities, and emotional well-being [27, 28].

Child-Focused Interventions Delivered Via Parents

Research has repeatedly confirmed that child behavior problems are the most consistent predictor of parental stress and that these two variables have a very close and strong association with one another [1, 10, 29]. Thus, interventions have often assumed that in order to reduce parental stress, one must target child behavior problems and, therefore, a number of interventions delivered to parents of children with ID are actually aimed at using the parent to improve behavior problems in the child with ID.

Behavioral Parent Training Interventions There is a large body of literature demonstrating that promoting developmentally sensitive positive parenting skills reduces the risk of later problem behavior for children with ID, while simultaneously supporting family well-being and parent mental health [30–32]. Thus, drawing on a long tradition of parent management training with well-documented efficacy in reducing disruptive behavior for typically developing youth, behavioral parent training has been established as an effective intervention targeting behavior problems in children with ID [33].

A range of behavioral parent training models have been empirically validated with respect to reducing challenging behavior in children and adolescents with ID [14, 34]. 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) [31]. Group leaders use discussion, video modeling, role-playing, and didactics to cover topics in five specific areas including play, praise, rewards, limit setting, and handling challenging behavior. Challenging behavior is reduced through altering negative and coercive parent–child interactions [35]. Adaptations to the IYPT protocol for children with developmental delays included the addition of a section about

the blessings and challenges of raising a child with disabilities, a section about advocacy and community resources, and a section about descriptive functional behavioral assessments (FBA) and implementation of interventions based on FBAs [31]. The intervention involves 12 weekly group sessions (8–12 parents/group), 2.5-h 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 [31].

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) by time (pre/post-treatment) 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 [32]. On the whole, these results support the focus on parenting processes as a critical mechanism for improving and preventing specific behavior problems in young children with developmental delays and provide evidence that supports the adaptation of IYPT for these children.

The relevance of parenting interventions for children with ID is not specific to IYPT. Indeed, similar findings have been observed for other behavioral parent training interventions 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) and Parent Child Interaction Therapy has been applied to parents of children with ID [36, 37]. Other similar behavioral parent training programs have been designed and developed specifically for families of children with ID or ASD, such as Signposts for Better Behavior and the RUPP Parent Training program [38, 39]. Each of these intervention programs have produced meaningful reductions in child problem behavior underscoring the importance of targeting parenting behavior in order to reduce child problem behavior.

Despite the effectiveness of behavioral parent training programs for reducing behavior problems in children with ID, we still know relatively little about moderators and mediators of treatment outcomes, maintenance and sustainability of intervention effects, or how to address barriers to intervention participation such as parent mental health concerns. Parent training approaches have historically not focused on critical moderators of treatment outcome that have been identified, such as parental stress which is associated with poorer child outcomes in behavioral parent training interventions. Given the strong relationship between child behavior problems and parenting stress, these studies often assume that reductions in child behavior

problems following parent training will also lead to reductions in parental stress. However, among the few studies that have measured parent mental health outcomes in these child-focused interventions, some find that behavioral parent training approaches do not consistently result in reductions of parenting stress [40]. Thus, a combined intervention that targets both child behavior problems and parenting stress may prove to be optimally effective for improving both child and parent outcomes.

Future Directions

Conclusion

Parents of children with ID consistently report high levels of stress and mental health concerns as well as an increased need for services [10, 41, 42]. Unfortunately, few evidence-based interventions for reducing parental stress among parents of children with ID currently exist and there is minimal research evidence available concerning family-based interventions for treating child behavior problems. A recent meta-analysis found only 19 studies representing 11 different family-based treatments targeting behavior problems among children with IDD, all of which were parent-training programs targeting parenting behavior rather than parenting stress [14]. This is concerning given that parenting stress has been associated with poor outcomes for interventions focused on children with ID. More specifically, high parental stress predicts less beneficial outcomes for children in early intervention programs and fewer gains in parenting skills in behavioral parenting training interventions [42–47]. Thus, a combined intervention model that addresses both parental stress and child behavior problems may be most effective for parents of children with ID. Given that elevated parental stress has been associated with decreased efficacy of behavioral interventions for children, addressing parental stress should substantially improve the impact of innovative behavioral parent training approaches [45].

We know from scientific studies and professional experience that “families matter,” especially for children with ID. Parents’ mental health and well-being has a significant impact on children’s development and, therefore, in any attempt to intervene and help children, we must also consider and intervene with families.

Compliance with Ethical Standards

Conflict of Interest Cameron L. Neece and Evan J. Lima declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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