

THESIS

PARENT PERSPECTIVES OF AT-HOME COGNITIVE INTERVENTION FOR  
PRESCHOOLERS WITH DOWN SYNDROME

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## ABSTRACT

### PARENT PERSPECTIVES OF AT-HOME COGNITIVE INTERVENTION FOR PRESCHOOLERS WITH DOWN SYNDROME

Down syndrome (DS) is associated with challenges related to cognitive skills, including executive function (EF). Intervention provided during early childhood can support the development of EF, however there are few cognitive interventions designed for young developmental ages. Parent-mediated interventions (PMIs) are emerging as an effective and scalable intervention approach for clinical populations. PMIs require ongoing parent engagement, and therefore, it is critical for a PMI to meet the needs of its intended users. This study used a community-based participatory research (CBPR) framework to (1) understand the daily routines of families of young children with DS and (2) describe parent perceptions of participating in at-home intervention. Participants were 34 caregivers of children 3 – 6 years old with DS living in Italy or the US. Participants responded to questions related to daily tasks they help their children complete and their perceptions of at-home cognitive intervention. Interviews were transcribed and independently coded (inter-rater agreement = .80). Four themes related to daily routines were identified: *what parents help with*, *how parents help*, *why parents help*, and *how children respond*. Three themes related to parent perceptions of interventions were identified: *advantages of parent-led interventions*, *disadvantages of parent-led interventions*, and *desires for interventions*. Findings suggest that PMIs targeting preschool-aged children with DS should require a short time commitment, blend intervention activities into daily routines, and

include other family members. Findings from this study have important implications for the development of novel interventions aimed at supporting families in this population.

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## INTRODUCTION

Down syndrome (DS) is the most common neurogenetic condition associated with intellectual disability, affecting approximately one in every 700 live births per year in the United States (Mai et al., 2019). DS affects various aspects of development across the lifespan. Several decades of research have indicated that DS predisposes individuals to a specific behavioral phenotype that involves areas of relative developmental strength and challenge (Daunhauer et al., 2014a; Fidler, 2005). It is associated with an elevated risk for distinct developmental outcomes in social-emotional functioning, behavior regulation, self-regulation, motor development, and language acquisition (Esbensen et al., 2021; Fidler, 2005; Silverman, 2007). The phenotypic outcomes associated with DS and the overall levels of developmental delay have important implications for the quality of life for individuals with DS and their families.

Executive function (EF), or the cognitive processes involved in completing goal-directed behavior, has increasingly become a target of interest in intervention for children with DS. Supporting the development of EF early in childhood builds a strong foundation for development across childhood, adolescence, and adulthood. There are many ways to support the development of EF, including the use of computerized therapy programs, clinic-based interventions, school-based programs, and parent-mediated interventions. Parent-mediated interventions (PMI) are delivered at home by parents and are a low-cost and easily scalable intervention option. PMIs are widely used in intervention for children with autism spectrum disorders (ASD; Ingersoll & Berger, 2015; Kasari et al., 2022; Rogers & Dawson, 2010) and they are a promising path forward for children with DS as well. Given the global prevalence of DS (Chen et al., 2022), PMIs for children in this population should be appropriate for use in a range of cultural settings.

Therefore, the current project is part of a cross-national effort to develop an at-home PMI to promote the development of EF in young children with DS. Findings from parent interviews conducted in the current project will inform the structure and aims of the cross-national intervention.



## REVIEW OF THE LITERATURE

### **Executive Function**

In recent years, there has been an increase in attention to the development of executive function in children with DS (Best & Miller, 2010; Daunhauer et al., 2014a). ‘Executive function’ (EF) is a term that refers to a set of cognitive skills that are necessary for completing goal-directed behavior. Among other constructs, EF refers to the cognitive processes involved in working memory, inhibition, planning, and cognitive flexibility (Carlson, 2005). EF begins to develop in infancy and continues to develop through childhood (Carlson, 2005). The emergence of EF in childhood makes it a promising target for early intervention. In infants with DS, precursors to EF (such as visual engagement and attention shifting) predict the later emergence of EF skills (Schworer et al., 2021). Detecting atypical presentation of EF precursors can help to identify areas of cognitive risk early in life. Areas of cognitive risk then inform the targets of cognitive intervention.

In anticipating areas of potential challenge, interventions can support the development of these critical cognitive abilities early in childhood and build a strong foundation for a range of developmental outcomes. In the general population, EF is associated with academic skills, social skills, and daily functioning across the lifespan (Riggs et al., 2006). In individuals with DS, EF is associated with school performance, adaptive behaviors, and daily functioning, such that stronger performance on measures of EF predicts increased school functioning and lower rates of externalizing behavior problems in school-aged children (Daunhauer et al., 2014b; Esbensen et al., 2021). Supporting the development of EF skills in childhood may, therefore, improve aspects of daily functioning for individuals with DS.

### ***Executive Function Intervention***

Interventions targeting EF or its components include computerized adaptive training, noncomputerized training, aerobic exercise, resistance training exercises, yoga, and mindfulness practices (Diamond & Ling, 2020). Training that embeds EF practice in everyday contexts requiring EF is effective for young children and can lead to improvements in cognitive skills and improvements in academic ability (Blair, 2016). Though EF interventions demonstrate mixed results (Morrison & Chein, 2011; Shipstead et al., 2012; Melby-Lervag & Hulme, 2013), research suggests that interventions can enhance EF, particularly for populations at risk for challenges with EF, such as children in clinical populations (Diamond & Lee, 2011).

### ***Executive Function Intervention in Clinical Populations***

Computerized training programs are a well-studied area of EF intervention in clinical populations. For example, Cogmed is a popular training program aimed at improving cognitive skills through adaptive game-like computer activities. In the computerized intervention, participants complete developmentally appropriate visuospatial memory training games (Hessl et al., 2019). Cogmed is targeted toward children and adults with ADHD as well as individuals experiencing attention deficits related to traumatic brain injury, long-term effects of premature birth, and side effects of cancer treatment (Conklin et al., 2017; Lundqvist et al., 2010). The program aims to improve working memory through games that increase and decrease difficulty in response to the participant's choices. Though there is mixed evidence for the effectiveness of Cogmed working memory training, there are well-documented positive effects for children with ADHD (Klingberg et al., 2005), children who have received cancer treatment, and adults recovering from stroke (Sohlberg et al., 2000). Two recent studies have evaluated the use of

Cogmed in children and adolescents with intellectual disability and found positive improvements in cognitive functioning (Bennett et al., 2013; Hessel et al., 2019).

In a controlled trial of EF intervention for individuals with fragile X syndrome (FXS), Hessel and colleagues evaluated the use of Cogmed to improve EF in 100 children and adolescents between 11 and 18 years of age (Hessel et al., 2019). Similar to DS FXS is a neurogenetic condition associated with intellectual disability and deficits in executive function. Hessel et al. (2019) evaluated two versions of Cogmed working memory training in children and adolescents with FXS. One group completed the adaptive Cogmed training, and the other group completed a non-adaptive version. Children and adolescents in both conditions demonstrated improvements in working memory and cognitive flexibility. Importantly, the authors did not report significant differences between participants in the adaptive group and participants in the non-adaptive group, suggesting that engaging in EF training for an hour or two each week can improve cognitive skills even if the level of difficulty remains stable (Hessel et al., 2019).

Cogmed JM is a version of Cogmed Working Memory Training that is designed for preschool-aged children. Similar to the other Cogmed training programs designed for children and adults, Cogmed JM aims to promote attention and working memory skills and to reduce learning difficulties. In 2013, Bennett and colleagues conducted a randomized controlled trial of Cogmed JM in children with DS between 7 and 12 years old. Children in the intervention group completed the training over 13 weeks at school with the assistance of an education specialist. After the training period, children were evaluated using the Cogmed Index of Improvement, working memory lab tasks, and parent report of EF. Children in the intervention condition demonstrated significant improvements on visuospatial short-term memory tasks after the training and these improvements were sustained at 4-month follow up assessments (Bennett et

al., 2013). These findings suggest that computerized adaptive training can be feasibly delivered in school settings and can be effective at promoting EF in children with DS between 7 and 12 years old (Bennett et al., 2013). Though these findings are promising for children and adolescents in clinical populations, computer-based training may not be appropriate for early childhood interventions targeting young developmental ages.

### ***Executive Function Intervention in Preschoolers***

Given that EF predicts school readiness and academic achievement (Daunhauer et al., 2014b; Esbensen et al., 2021), it is important to support EF early in childhood. Intervention in the preschool years could be critical in helping children build a strong foundation for the transition to kindergarten. EF training during the preschool years could set the stage for student success in elementary school and beyond (Blair, 2002). Moreover, some studies suggest that young children benefit more from cognitive training than older children (Diamond & Lee, 2011). There is limited research on promoting EF in preschoolers with DS, however, some studies have reported positive outcomes for typically developing preschoolers participating in intervention programs. For example, the Head Start REDI (Research-Based, Developmentally Informed) program provides preschoolers in the Head Start program with classroom instruction focused on social-emotional skills. Evaluations of this program have suggested that it is effective at improving emotion regulation, social behavior, and learning engagement in young preschool students (Bierman et al., 2008) and effects are maintained at five-year follow-up assessments (Welsh et al., 2020). Furthermore, in the last decade, researchers outside of the US have demonstrated that it is feasible and efficacious to administer school-based EF interventions to typically developing young children (Rothlisberger et al., 2011; Traverso et al., 2015).

In an evaluation of a novel EF intervention for young children, Rothlisberger et al. (2011) demonstrated that school-based programs are efficacious and provide support for the inclusion of evidence-based programs in classroom settings. Rothlisberger et al. (2011) evaluated the efficacy of a group-based EF intervention for prekindergartners and kindergarteners in 22 different school areas across Switzerland and Germany. The researchers assessed 135 children between 5 and 6 years old. The intervention was administered by a trained experimenter twice a week for 6 weeks. Each session was 30 minutes in duration and involved group and individual activities that increased in difficulty at regular intervals. At the end of the intervention period, the researchers reassessed the children on measures of EF and found that compared to children in the waitlist control condition, 5-year-old children in the training group improved on measures of working memory and cognitive flexibility and 6-year-old children improved on measures of inhibition (Rothlisberger et al., 2011). These findings have implications for the development of early childhood intervention programs and provide support for tailoring preschool curricula to include brief EF activities that can build foundational skills to support student adaptation in the primary grades.

In a recent randomized control trial of a school-based EF intervention, Traverso et al. (2015) saw improvements in three key constructs of EF (working memory, cognitive flexibility, and inhibition) for young children with typical development. This finding is notable because previous studies of EF intervention in young children only reported improvements in one (e.g., working memory; Thorell et al., 2009) or two (e.g., working memory and cognitive flexibility; Rothlisberger et al., 2011) dimensions of EF. Traverso et al. (2015) evaluated the efficacy of a novel training program designed to promote EF skills in typically developing preschoolers in Italy. To be appropriate for widespread use, they proposed a cost-effective intervention that

could be easily implemented in educational settings. Their intervention used low-cost, readily available materials, and was implemented in small groups by trained clinicians. The evaluation study included 75 children between 5 and 6 years old attending the same public school in northwestern Italy. All children received baseline and post-intervention assessments. Children in the intervention group participated in 12 30-minute intervention sessions over the course of one month. The intervention was administered during the regular kindergarten school day while the children in the control group completed regular school activities. The intervention activities involved small group play-based activities that progressively required more EF skills.

Compared to children in the control group, children who received the EF training demonstrated improvements in inhibition, working memory, and cognitive flexibility (Traverso et al., 2015). This notable finding adds to the literature base that has seen improvements in working memory and cognitive flexibility (Rothlisberger et al., 2011; Thorell et al., 2009). Though the researchers did not include longer term follow-up assessments of intervention effects, and therefore it is unclear whether these improvements are sustained over time, it is promising that low-cost, play-based, group training can enhance multiple aspects of EF in preschool-aged children.

There is promising research suggesting that (1) EF skills can be promoted through consistent trainings, (2) EF interventions are feasible and effective for individuals with intellectual and developmental disabilities (IDD), and (3) EF interventions are feasible and effective for typically developing children as young as preschool-age. Though there are promising effects of intervention in typically developing preschoolers, there is a gap in the literature on EF intervention for young developmental ages, such as preschool-aged children with cognitive delays. The limited research on EF intervention in young children with IDD is a

gap that should be addressed. There is a need to develop innovative behavioral interventions tailored to the needs of children in this population (Fidler et al., 2021). Compared to neurodevelopmental conditions, such as autism spectrum disorder (ASD), there is a lower incidence of neurogenetic conditions, such as DS, in the general population. Therefore, a common challenge associated with developing targeted syndrome-informed intervention is the cost and feasibility of programs (Fidler et al., 2021). Though school-based interventions are efficacious for children with typical development, they may be more costly and harder to implement on a large scale for children with developmental delays. Conversely, interventions that are delivered at home by parents are low-cost and effective ways to support children at young developmental ages. Through the current project, parents of preschoolers with DS provided insights into their preferences for at-home cognitive intervention. These data begin to address the lack of research on intervention for children in this population, providing opportunities for further work in this area.

### **Parent-Mediated Interventions**

PMI engage parents or caregivers in their child's intervention services. In a PMI, a clinician trains a parent or caregiver to provide therapy or intervention supports to their child at home. Parent training can be provided in one-on-one sessions or group sessions, and interventions may target a range of social, behavioral, motor, or cognitive skills in children. One of the earliest models of PMI was developed in 1969 by Drs. Marsha Shearer and David Shearer for children with disabilities living in rural areas near Portage, Wisconsin. Their proposed model for early childhood education, the Portage Project, was designed for families of children with IDD. In their model, clinicians visited parents in their homes once a week for 12 weeks and trained parents to deliver the intervention. In the week following each training session, parents

implemented the program with their children. The intervention was designed to support the development of milestone skills and behaviors in children with disabilities between birth and 6 years old; and initial studies reported positive effects for participating families (Shearer & Shearer, 1972). In the decades since the Portage Project, more PMIs have been developed for families of children with developmental disabilities, including DS, ADHD, IDD, learning disability, and, most commonly, autism spectrum disorder (ASD).

### ***Parent-Mediated Intervention in ASD***

The extensive literature on PMI in ASD is informative for the development of PMIs for other clinical populations. A lot can be learned from the decades of research in developing, implementing, adapting, and evaluating PMIS for children with ASD. In particular, over the last two decades, there has been a focus on developing and evaluating PMIs in children with ASD. ASD is characterized by delays in social communication and restricted or repetitive behaviors. Recent interventions have aimed to target social communication skills by supporting the development of joint attention, a critical early social communication milestone, during the preschool years. Though there are many interventions and educational curricula designed for this population, Project ImPACT, JASPER, and ESDM are three common examples of evidenced-based, well-evaluated programs. Project ImPACT (Improving Parents as Communication Teachers) focuses on teaching parents of toddlers between 12 – 24 months old to increase their child’s social communication and play skills. In program evaluations, children who completed Project ImPACT showed significant improvements on measures of communication skills (Stadnick et al., 2015).

The Join Attention, Symbolic Play, Engagement and Regulation (JASPER) program is another widely-used and well-researched intervention for young children with ASD that aims to



develop joint attention, play skills, and communication through natural play opportunities (Kasari, 2006, Kasari et al., 2010). The intervention can be delivered by parents, trained clinicians, or educators during semi-structured play sessions at home, school, and clinical centers. In a recent trial, Kasari et al. (2015) compared the efficacy of a parent-mediated version of JASPER to parent-only psychoeducational intervention. Following the intervention period, both groups reported lower levels of parenting stress, but only the parent-mediated version of JASPER was associated with improved child outcomes related to joint engagement and play skills (Kasari et al., 2015). In another study, Kasari and colleagues evaluated the parent-mediated JASPER program in low-resourced communities and found similar results; compared to families who received a parent-only education program, children who received the PMI demonstrated more improvements in joint engagement, joint attention, and symbolic play (Kasari et al., 2014). Though parent-only education is important and can have positive effects (e.g., reducing parent stress), these findings suggest that PMIs that involve young children are more effective at improving child outcomes.

Early Start Denver Model (ESDM) is an intervention for children with ASD that was originally developed to be delivered by clinicians. Since its introduction, it has been adapted to be delivered by parents in home settings. In a randomized controlled trial comparing parent delivery of ESDM (P-ESDM) at home to clinician delivery in community settings, Rogers et al. (2012) did not find significant differences between the two treatment groups. Children who completed the intervention in community settings with clinicians and children who completed the intervention at home with parents both demonstrated improvements in key outcomes, including measures of social communication skills (Rogers et al., 2012). Notably, parents in both groups also improved on measures of parent-child interaction skills (Rogers et al., 2012).

### ***Telehealth Parent-Mediated Intervention in ASD***

Web-based telehealth services are gaining in popularity and are a creative way to reach more families who may not have the time or resources to attend in-person meetings due to financial or geographical constraints (Ingersoll & Berger, 2015). In a telehealth PMI, parents meet with clinicians or coaches via videoconferencing to learn how to deliver the intervention at home. This eliminates the need for families to travel to a clinic or office and reduces barriers to participation. In addition to reducing barriers to participation, telehealth interventions have been demonstrated to be effective at improving developmental outcomes for children with ASD. Recently, Project ImPACT expanded to include a telehealth component, ImPACT Online. Parents participating in ImPACT Online can choose between two versions of the program: self-directed or therapist-assisted. A recent study of the feasibility and acceptability of both versions of ImPACT Online evaluated parent engagement, satisfaction, and parent outcomes, including depressive symptoms (Ingersoll & Berger, 2015). Though engagement was higher for parents in the therapist-assisted group, parents in both the self-directed and therapist-assisted groups reported high levels of engagement and satisfaction at the end of the 12-week program (Ingersoll & Berger, 2015). Similarly, telehealth versions of JASPER and P-ESDM have also demonstrated the feasibility and effectiveness of web-based program delivery (Kasari et al., 2015; Vismara et al., 2016).

### ***Parent-Mediated Intervention in Down Syndrome***

In the last decade, the field of IDD research has seen an increase in the use of PMIs for children with DS. These interventions vary in content, length, and delivery method. Recent PMIs have targeted reading skills, motor skills, and communication and language development for children with DS from birth to 12 years old. PMIs have been implemented as web-based, in-

person, and micro-interventions. Some PMIs designed for typically developing children have been modified to suit the needs of children with DS and have reported positive results. For example, the Headsprout Early Reading (HER) program is a computer-based reading program originally designed for typically developing children in kindergarten through second grade. A recent study by Grindle et al. (2019), found that HER was effective in improving phoneme segmentation and word reading age for children with DS between 8 and 12 years old when the program was implemented at home by parents. Another web-based at-home PMI, Project SKIP, aims at improving motor skills in children with DS between 3 and 7 years old. In an initial pilot of the intervention, children who completed the intervention had improved motor skills compared to a control group (Young et al., 2021).

Moreover, in a recent study, Fidler et al. (2021) assessed the feasibility of a micro-intervention designed to promote the acquisition of a pivotal skill, reaching behavior, in infants with DS. During the brief intervention pilot, parents engaged in face-to-face play with their infants for 5 – 10 minutes a day for 2 – 3 weeks. During the play sessions, the parents used toys provided by the project team. Parent-infant dyads in the control group played as usual. Parent-infant dyads in the treatment group were instructed to use “sticky mittens” (i.e., infant gloves with Velcro) during the play interactions. These mittens were designed to assist with motor skills and promote reaching behaviors in infants. Reaching behaviors are important because they allow infants to obtain and explore objects, and object exploration supports cognitive development (Fidler et al., 2021). Compared to infants with typical development, infants with DS tend to acquire reaching and grasping skills later in development. Findings from this pilot showed positive outcomes for infants in the treatment group. Infants in the treatment condition demonstrated positive changes in reach frequency and swat frequency at follow-up assessments.

These findings demonstrate the feasibility and preliminary efficacy of a low-cost, syndrome-informed, at-home intervention for infants with DS (Fidler et al., 2021).

Unique from HER and Project SKIP, the syndrome-informed micro-intervention conducted by Fidler and colleagues targeted very young developmental ages and was selected because it targets a specific feature of the emerging phenotype in infants with DS. Furthermore, it aimed to promote key developmental milestones and was a just-in-time intervention that built a critical skill (reaching behavior) that is thought to support further developmental cascades and additional skills in early childhood (Fidler et al., 2021). The pilot conducted by Fidler and colleagues was an important step in developing and testing PMIs in very young children with DS. In an effort to expand on this work examining PMIs in young children with DS, the present study recruited parents of preschool-aged children with DS. Preschoolers with DS are in a different developmental stage than infants with DS, and therefore, it is expected that their parents have different goals and priorities for their children. There is an emerging focus on using PMIs in clinical populations, and initial studies suggest that at-home PMIs can be effective at improving targeted skills in young children with DS, and that they are enjoyed by children and feasible for parents to implement. As work on PMIs in clinical populations continues, it is important to consider the perspectives of parents of children in different developmental stages. ***Strengths and***

### ***Challenges of Parent-Mediated Interventions***

PMIs are advantageous for several reasons. PMIs are cost-effective and can be implemented more broadly than clinician-mediated services (Wainer et al., 2017). By involving parents in a child's intervention services, intervention can occur with increased intensity. Parents are able to start intervention early in a child's life and intervention can be provided continuously by parents. Parents can maximize their child's learning by providing therapy at multiple points

throughout the day and at times when their child is most receptive, rather than only during scheduled therapy appointments. Studies suggest that parent participation is associated with successful intervention gains for very young children and, more specifically, parental involvement is associated with positive intervention outcomes for children with disabilities.

PMIs are associated with positive outcomes for parents as well (Jurek et al., 2022; Ingersoll & Berger, 2015; Xinyue & Schertz, 2022). Most research on parental well-being in PMIs has focused on parents of children with ASD. For example, parents who completed the Project ImPACT Online telehealth program for families of children with ASD reported a decrease in depressive symptoms (Ingersoll & Berger, 2015). Similarly, in a recent evaluation of the Joint Attention Mediated Learning (JAML) intervention for children with ASD, Liu and Schertz (2022) reported that compared to parents in a control group, parents who completed the intervention demonstrated significant improvements in their competence in supporting their children's learning. Through active participation in intervention services, parents also gain a better understanding of their child's developmental milestones and developmental trajectory. Increasing a parent's knowledge about their child's growth and development is associated with increased feelings of empowerment and parental self-efficacy and reduced feelings of stress (Jurek et al., 2022).

Though there are many benefits to PMI, there are also challenges associated with at-home interventions. In a recent qualitative meta-synthesis, Jurek et al. (2022) analyzed data from semi-structured interviews and focus groups conducted with 325 parents involved in various PMI targeting social communication skills, disruptive behavior, or both in kindergarten-aged children with ASD. Data came from 23 papers published between 2002 and 2021. Through analysis of the qualitative data, Jurek et al. (2022) identified themes related to parental stress and fatigue

associated with their participation in PMI. Parents described the ‘emotional toll’ of being a critical part of their child’s intervention services (Jurek et al., 2022). Specifically, parents described feeling initially stressed by their child’s diagnosis and further overwhelmed by the amount of information provided in the intervention training sessions (Jurek et al., 2022). Furthermore, the end of participation in the intervention increased feelings of anxiety in parents as they worried about how they would continue supporting their child after the formal intervention and coaching concluded (Jurek et al., 2022). These parent reports suggest that adequate support is a critical component of a PMI. Parents reported that regular contact with a clinician was particularly beneficial for family well-being (Jurek et al., 2022). Multiple sources of support from clinicians, family members, and other parents participating in similar interventions are important for supporting a parent’s emotional well-being during and after participation in a PMI (Jurek et al., 2022).

Despite the challenges, well-designed PMI that provide consistent support can have positive outcomes for parents. In the same study by Jurek et al. (2022) in which parents reported feeling overwhelmed, parents also expressed feelings of empowerment and self-efficacy, and positive outcomes for their children. Parents who reported high levels of support from clinicians also reported greater feelings of self-efficacy and lower levels of stress (Zhao et al., 2021). Raising a child with a disability can be stressful, but increased feelings of self-efficacy help to reduce parental stress (Oono et al., 2013; Wainer et al., 2017). Therefore, PMIs can be overwhelming for parents of children with disabilities, but they can also be extremely beneficial when implemented with the appropriate supports. When creating a PMI, developers should consider the specific needs of families in their target population and should make programs flexible enough to adapt to the specific needs of a family (McConnell et al., 2015). PMIs are

emerging as a popular intervention choice for families of children with developmental disabilities (see research on ASD interventions), but there is limited research on at-home interventions designed specifically to support cognitive development in children with DS. Therefore, little is known about the specific needs of families in this target population as it relates to at-home intervention for young children. It is important to consider which intervention qualities make programs feasible and acceptable to families of young children with DS.

An important consideration in developing a PMI is the needs of the families who will be using the intervention. The characteristics of a child, a family, and a program all interact; and this interaction has implications for a child's developmental outcomes and for the success of the intervention program (Robinson et al., 1988). Therefore, program development needs to be responsive to the characteristics of a child and their family. The current project emphasized the importance of program development being responsive to these characteristics in two ways. First, findings from the current study informed the development of a phenotype-informed intervention that is responsive to characteristics of children with DS by leveraging the known strengths and challenges associated with the DS behavioral phenotype. Second, the primary aim of the current study was to analyze qualitative data collected from focus group interviews in order to understand and be responsive to the characteristics of families to whom this intervention is targeted. Including parents of children with DS as active participants in the intervention development process through focus group interviews was informed by a community-based participatory research (CBPR) framework.

### **Community-Based Participatory Research**

CBPR is a research framework that involves members of the community as partners in the research process (Israel et al., 2010). In IDD research, members of the community may

include self-advocates (or individuals with IDD), caregivers, family members, clinicians/practitioners, or service providers. In a CBPR framework, these community members share responsibility with academic researchers and provide insights on topics and the direction of research. Together, academic researchers and community members work to improve the health and well-being of individuals in their community.

Community involvement in research on neurogenetic syndromes has increased in recent decades. For example, researchers and community organizations partner together in community social activities such as awareness days, community walks, and fundraising or volunteer events (Riggs et al., 2020). Neurogenetic syndrome researchers may also be involved with regional IDD groups and share translational research findings with parents or caregivers of individuals with neurogenetic conditions (Riggs et al., 2020). Research conferences focused on IDD research have also often include self-advocates and/or family members in certain aspects of research presentations (Riggs et al., 2020). These efforts shift the focus of IDD research away from conducting research *on* individuals to a focus on conducting research *with* individuals. The present project utilizes three key aspects of a CBPR approach to neurogenetic research by involving participants in the project development, supporting the bi-directional flow of information, and aiming to improve the well-being of the community.

The present project aims to involve parents of young children with DS in the process of developing an intervention supporting their child's cognitive skills. It is vital to include parents as participants in the intervention development process because PMI require parents to be active participants throughout the intervention and therefore, require parent buy-in from the beginning. Feedback from families is critical to the success of an intervention. A CBPR approach relies on the lived experiences of community members and encourages individuals to work collaboratively



to solve problems (Riggs et al., 2020). The use of focus groups in the present project will empower parents to share their unique perspectives and allow parents to share their lived experiences of raising a child with DS. Through this approach, parents can provide valuable insights that we as researchers alone cannot generate. Furthermore, in a CBPR approach to research, data are collected and analyzed with the primary intent to generate findings that will improve the well-being of the community (Riggs et al., 2020). As it applies to the present study, focus group data from parents of children with DS were collected with the intent to apply the findings to the development of an at-home intervention aimed at improving cognitive skills in preschoolers. Guided by aspects of CBPR, we worked with parents in the DS community to understand their preferences toward EF intervention and the feasibility of implementing a novel PMI for preschoolers with DS.

### **Cultural Considerations in Intervention Development**

The present study involved parents from Italy and the US in the process of developing a cross-national PMI for preschoolers with DS. By including families in the intervention development process, it is hoped that parents will have increased participation in and engagement with the intervention activities. In order to support intervention participation, it is also critical to understand the specific needs of the end-users of an intervention before designing and implementing a new program (Riggs et al., 2020). Moreover, it is important for research to include families from different cultural backgrounds to support the development of a culturally responsive intervention from the onset.

Culture has long been an area of study within the field of developmental science. Studying cultural backgrounds is important because individuals develop within the context of their social and cultural environments. Despite the important role culture plays in a child's

development, there is a lack of research on culturally tailored and culturally adapted interventions for families of children with developmental delays (Magaña et al., 2021). Cultural considerations are particularly important for work involving parents as interventionists because understanding the cultural perspectives of families helps program developers understand barriers that may prevent engagement with the intervention (Magaña et al., 2021). In this section, the sociocultural framework posited by Vygotsky is described. Then, literature is reviewed on cultural differences in English-speaking families in the US and Italian-speaking families in Italy. This section concludes with discussion of the implications for intervention development.

### ***Sociocultural Perspective of Child Development***

The present study is rooted in a sociocultural perspective of development. A sociocultural perspective places emphasis on the influence of social, cultural, and environmental factors. Originally posited by Lev Vygotsky in 1927 and 1933, the theory of sociocultural development emphasizes the role of these factors (social, cultural, environmental) in shaping a child's cognitive development (Vygotsky, 1978). A sociocultural perspective stresses the importance of considering the ways in which an individual's social and cultural environment guides cognitive development.

### ***Cultural Differences in Families in Italy and the US***

The present project compares English-speaking parents in the US and Italian-speaking parents in Italy on perceptions of participating in at-home intervention with their preschoolers. Specifically, attitudes regarding descriptions of daily tasks and parent perceptions of their role in helping their child develop independence in tasks of daily living will be analyzed. There are documented differences between families living in the US and families living in Italy. The

following section reviews some of these observed differences and concludes with implications for intervention development.

Historically, Italy and the US are reported as sharing similar Western cultures and similar individualistic orientations (Hofstede, 1991); however, research also suggests the two countries differ in various ways, including parenting practices and perceptions of child development. For example, the International Baby Study and the International Study of Parents, Children, and Schools are multi-year, multi-site, longitudinal ethnographic projects led by Sara Harkness and Charles Super. These projects used qualitative and quantitative methodologies to study cultural influences on parenting beliefs and practices in seven countries, including the United States and Italy. Drawing on data from the International Baby Study, Harkness et al. (2007) examined the association between parental beliefs and patterns of self-regulation in infants. The researchers analyzed data from interviews with 96 mothers across five countries (Italy, Korea, the Netherlands, Spain, and the US). They analyzed transcripts from 1-hour long home interviews with mothers that asked about perceptions of child development and parenting practices. They found significant differences in parent perceptions of their infant's behavior and parent developmental goals for their children across the cultural groups.

Relevant to the current study, Harkness et al. (2007) identified specific distinctions between US mothers and Italian mothers. Through analysis of interviews with American mothers, the authors identified themes related to stimulation of development through a rich environment and sensory input (Harkness et al., 2007). Mothers from the US were more likely to report an emphasis on promoting rapid cognitive development (Harkness et al., 2007). To encourage this rapid cognitive development, mothers were more likely to provide a stimulating environment with sensory and cognitive experiences. Through analysis of interviews with Italian

mothers, the researchers identified themes related to supporting development through emotional closeness (Harkness et al., 2007). Italian mothers were more likely to report focusing on supporting their infants' emotional growth through social interactions and activity. Though this study was published a decade ago, the findings have implications for current and future cross-cultural work. The observed differences in parental perceptions and developmental goals have implications for the aims of parent education and interventions targeted at families in different countries.

In addition to these longitudinal projects, there is an extensive body of literature committed to understanding cross-cultural differences in child development and parenting behaviors for families in the US and families in Italy. Mixed methods studies suggest that parents in the US and parents in Italy differ in their parenting behaviors during the first three months of their first child's life, such that parents in Italy tend to display greater social/affective behavior and to spend more time in synchronous dyadic social exchanges with their infants compared to parents in the US (Hsu & Lavelli, 2005). Analyses of parent-report measures of infant temperament suggested that toddlers in the US score significantly higher than toddlers in Italy on inhibitory control, shyness, frustration, and soothability (Cozzi et al., 2013). Furthermore, analyses of parent-report adaptive behavior found that Italian children scored higher in adaptive communication and motor skills compared to young children in the US (Bornstein et al., 2005). Decades of research describe cross-cultural differences between American and Italian families; however, most cross-cultural studies compare families of typically developing children. The present project will expand this body of literature to include a cross-cultural comparison of families of children with a developmental disability.

### ***Implications for Cross-Cultural Differences in Intervention Development***

As the above review of the literature highlights, cultural background is associated with differences in parenting behavior and parental perspectives of child development. These findings also have practical implications for applied research. In the field of prevention science, literature on cultural differences informs how researchers and interventionists interact with and provide services to families of different cultural backgrounds. As part of a broader research project to develop a cross-national intervention for families, the present study aimed to explore differences in parent perceptions of participating in at-home intervention with their preschoolers and their role in helping their child develop independence in tasks of daily living. Findings from the present study informed the development of an intervention and created opportunities to tailor the program to meet the needs of families in different cultures. Overall, the goal of interviewing parents at the start of the intervention development process was to create a novel program that meets families' needs. Intervention programs that address concerns that are relevant to a community and that consider cultural context may increase community participation, and therefore increase the utility of the program (Castro et al., 2004; Kumpfer et al., 2002).

**Novelty.** Though social, cultural, and environmental factors have a role in development (Vygotsky, 1978) and cultural considerations are important for community participation (Castro et al., 2004; Kumpfer et al., 2002), interventions in the field of prevention science are often developed without considering these factors. It is rare to develop an intervention for multiple languages and countries from the beginning. Interventions tend to be developed for one, often homogenous, population and then adapted for other populations later (Castro et al., 2004). A lot of discussion has focused on cultural adaptations for evidence-based programs, however, there is limited literature regarding the development of cross-national intervention for typically developing children or children with neurogenetic conditions. Though the approach to develop

first and adapt later is common, and evidence-based programs that have been adapted for different cultures are still associated with positive outcomes, the present project takes a novel approach to intervention development by considering the needs and preferences of different groups from the outset.

## CURRENT STUDY

The present study analyzed parent responses to interview questions from focus groups convened in Italy and the US. These two sites were selected for data collection due to an ongoing collaboration among the research teams in which they are developing a novel PMI for young children with DS. The broader project utilizes a CBPR approach to intervention development by including community members, including parents, in the intervention development process. To understand parent attitudes and perceptions, we hosted semi-structured focus group discussions in the US and Italy (Rubin & Rubin, 2016). Data analysis focused on parent responses to questions about their daily routines and about their perceptions of parent-led intervention. The present study had three aims: 1) to describe parent perceptions of daily tasks they help their child complete, 2) to report parent attitudes toward and perceptions of at-home intervention, and 3) to characterize differences in responses from parents in Italy and the US. Findings from this study will inform the development of a cross-national cognitive intervention for young children with DS.

## METHODS

### Participants

Participants were 34 parents of young children with DS. Sixteen parents were English-speaking Americans, and 18 parents were Italian-speaking Italians. Participants were recruited from one site in the US and one site in Italy using flyers shared with regional DS associations and medical centers. Participants reported having previously taking part in research studies at either data collection site and/or were interested in learning more about promoting the development of their child's cognitive skills. To be eligible for participation, participants had to be the primary caregiver of a child with DS between 2 and 6 years old. All materials were administered in the parent's preferred language. Parents were excluded from the study if they did not primarily speak and write in English or Italian.

American parents were 16 females between 29 and 49 years old ( $M = 38.15$ ,  $SD = 5.16$ ). Parental education ranged from completing an associate degree to completing a graduate degree; six American participants (37.5%) had completed a graduate degree. Three participants did not report their education. All American participants identified as White ( $n = 16$ ), and two participants identified as Hispanic/Latino.

Italian participants were 16 females and 2 males between 37 and 54 years old ( $M = 45.22$ ,  $SD = 4.71$ ). Parental education ranged from completing a high school diploma to completing a graduate degree; most Italian participants ( $n = 13$ , 72.2%) had completed a graduate degree. One participant did not report their education. Racial and ethnic identity were not collected for Italian participants. Table 1 displays complete demographic information.

### Measures



The primary measure used for data collection was a script of semi-structured focus group questions developed collaboratively by the research teams for use in this study. The script used in the focus group interviews is included in Appendix A. Questions were developed by research associates and were designed to evoke responses on topics of interest for the two research laboratories involved in the study. As recommended in the literature, questions were designed to be open-ended and were not intended to be leading or double-barreled questions (Rubin & Rubin, 2016). All questions were written to be parent-friendly and to avoid research jargon. Following a semi-structured interview approach, focus group facilitators asked the same, predetermined list of questions during each focus group, however there were also opportunities for facilitators to ask spontaneous follow-up questions when appropriate.

Focus groups are a commonly used, beneficial, and cost-effective method to collect data from a range of participants and are appropriate for exploratory studies (Rubin & Rubin, 2016). During a focus group interview, participants respond to fewer questions than during a one-on-one interview, but they are able to share in-depth answers and agree with, disagree with, or expand on answers from other participants. Focus groups encourage open discussions among participants and allow participants to challenge or support different perspectives (Krueger, 2015). The questions included in the current study are designed to assess parent perceptions of caring for their young children with DS and parent opinions about participating in research for DS. Questions asked during the focus group interviews included broad inquiry about participating in research (“What makes you more / less interested in participating in DS research?”) and educational resources that parents implement at home (“Would you be interested in personally implementing an intervention for your child at home?”).

The body of literature on qualitative methods suggests that focus group interviews are effective data collection tools when groups include about 6 participants and meetings are no longer than 60 minutes (Langford et al., 2002; Morgan, 1997). Additionally, the literature suggests that studies should have at least 3 – 5 focus groups to reach data saturation, at which point no new information is obtained (Morgan, 1997). The present study aligned with these recommendations. There were 34 participants in this study, distributed across two cultural groups (Americans and Italians). Each focus group included 2 – 6 participants and group discussions did not exceed 60 minutes. Facilitators asked five structured questions during each session and asked follow-up questions as necessary (Morgan, 1997).

### **Procedures**

All study procedures were approved by the Colorado State University Institutional Review Board and the University of Padua Institutional Review Board. Informed consent was obtained during scheduling phone calls and participants provided verbal consent again before the start of each focus group interview. Given the sensitive and personal nature of the data collected in this study, precautions were taken to support confidentiality for participants. Each focus group interview was hosted virtually via a video conferencing platform. Parents were not required to use cameras during the video call or to mention any personally identifiable information, including their real names.

### ***Study Design***

The current study used a qualitative approach to understand parent perceptions of daily routines involving their child with DS. Data were collected from parents at one timepoint via focus group interviews. This methodology was suitable for this study because: (1) focus groups are appropriate for addressing exploratory research questions (Casula et al., 2020; Rubin &

Rubin, 2016); and (2) families of individuals with IDD have expressed a preference for the use of focus groups in data collection (Ottmann & Crosbie, 2013). In a comparison of methodological approaches to receiving input from individuals with IDD and their families, Ottmann and Crosbie (2013) found that focus groups were a preferred method of data collection because they provided participants with opportunities to share information and ideas about topics that were important to them. The focus groups in the present study utilized a semi-structured interview format in which trained facilitators followed a specific script but were also able to ask follow-up questions and encourage participants to elaborate on answers. Focus group recordings were transcribed, and transcriptions were coded using a constant comparison analysis approach involving open coding, axial coding, and selective coding (Onwuegbuzie et al., 2009). The data analytic plan is described in more detail later in this paper.

### ***Study Procedure***

Participants were parents of young children with DS living in Italy and parents of young children with DS living in the US. Each focus group included 2 – 6 participants. All focus groups were held virtually via the Microsoft Teams platform and each discussion was facilitated by two trained research associates. Focus group questions were designed to be open-ended and were standardized across both sites. Group moderators were encouraged to ask the questions verbatim, to ask follow-up questions as needed, and to avoid leading questions that could influence participant responses. Parents were encouraged to answer every question and to engage in conversation with the other participants. At the end of the discussion, participants were given the opportunity to provide additional comments about DS research and to mention any topics that had not been previously discussed. After the conclusion of the focus group interview, participants were emailed a demographics questionnaire and a brief satisfaction survey.

Each focus group interview was structured into two parts. During the first part of the interview, facilitators and parents briefly introduced themselves and then the discussion began with facilitators asking parents broad questions about participating in research for DS. In the second part of the interview, the facilitators asked more specific questions about resources parents use with their children. The present study focused only on data collected during the second half of the focus group interviews. Data collected during the first half of the interviews are presented elsewhere. Questions asked during the second part of each interview focused on family routines, the daily tasks with which parents help their children, and parent intervention preferences. A list of the questions asked during the focus group interviews is available in Appendix A.

### **Analysis Plan**

Recordings from the American focus groups were automatically transcribed by the Microsoft Teams platform. Two trained research associates independently listened to the audio recordings and reviewed the automated transcriptions for accuracy. When there were discrepancies between the two transcribers, the first author reviewed the discrepancy and helped the transcribers reach agreement. Transcribers also removed all personally identifiable information from the transcripts. All analyses were conducted in English. The Italian transcripts were translated into English by an Italian bilingual graduate research assistant and then reviewed by an American research associate blind to the research questions. The American research associate reviewing the transcripts checked for spelling and grammar, and reviewed that familiar language, rather than academic jargon, was used by the bilingual research assistant during the translation process. English transcripts from all nine focus groups were analyzed using ATLAS.ti software. The first author developed a codebook to analyze the transcripts. The codebook was

developed through an iterative process involving listening to recordings of focus groups, coding participant responses, identifying themes, and refining codes and categories. After the creation of the initial codebook, the first author collaborated with two independent coders who each coded four transcripts. Differences in interpretation were expected (Braun & Clark, 2013) and discussions led to further refinements of code categories and definitions. Then, the two research assistants independently coded the remaining transcripts. Coder agreement was measured using Krippendorff alpha, and agreement was indicated,  $\alpha = .8$ .

## RESULTS

### Daily Tasks

The first research question aimed to understand parent descriptions of the daily tasks with which they support their children (“What are some examples of daily tasks that you help your child stay focused on to complete? Are you working on developing independence in these tasks?”). A total of 231 quotations from the nine focus group transcripts were identified as relating to parent descriptions of daily tasks they help their child complete. These were coded using 24 codes that fit into four thematic categories: *what parents help with*, *how parents help*, *why parents help*, and *how children respond*. Codes by frequency are displayed in Table 2.

### *What Parents Help With*

Parents in both Italy and the US reported helping their children with tasks of daily living, including completing morning and bedtime routines, getting dressed, bathing, brushing teeth, and washing hands. Participants also described helping children at mealtimes, during daily chores, and while cleaning up toys. Most participants identified at least one task that they helped their child with each day, with some parents identifying up to four daily tasks.

**Daily Chores.** Daily chores were mentioned several times ( $n = 9$ ) in focus group discussions. Daily chores were mentioned seven times in the American focus groups and two times in the Italian focus groups. Participants described their children’s interest in helping with daily household tasks and said that these chores often require adult help and/or supervision. Daily chores included unloading the dishwasher, sorting laundry, or feeding pets. For example, one participant described that her daughter “wants to be the helper and loves to unload the dishwasher.” Another participant mentioned that her son “likes to help unload the dishwasher,

and put his clothes in the hamper, and switch the laundry, and do some of that.” Though children are interested in helping with household chores, they often cannot yet complete these tasks on their own, and therefore, daily chores were described as a regular task with which parents help their children. Child interest in learning new tasks and child desire for independence are described in more detail later in this section as well.

**Getting Dressed.** Putting on clothes and shoes was among the most frequently mentioned daily tasks across the focus group discussions ( $n = 21$ ). Getting dressed was mentioned 14 times in the American discussions and seven times in the Italian discussions. Participants described helping their children to select appropriate clothes, navigate challenging buttons and zippers, and stay motivated to complete the task. One participant mentioned, “He’s better at undressing than dressing. He’s getting better at managing to put the stuff on, but he still needs some help.”

### ***How Parents Help***

Parents reported using a range of strategies to help their children complete daily tasks. Some of the most common strategies included breaking down tasks, setting expectations, using visual supports, motivating their child through the use of music or rewards, and repeating directions. Additionally, participants described strategies to seek out support from professionals in the community in order to help their children.

**Breaking Down Tasks.** Participants frequently mentioned ( $n = 24$ ) that they break down tasks into smaller steps in order to help their children complete daily activities. This was mentioned several times in both American discussions ( $n = 14$ ) and Italian discussions ( $n = 10$ ). Many participants described the process of breaking big tasks into smaller, more manageable tasks and then decreasing parental support over time. One participant said, “We have found that

shortening the steps is more helpful. She can follow one, two step directions.” Another participant agreed, “Everything is broken down into one or two steps.” As previously mentioned, getting dressed was one of the most frequently described tasks with which parents help their children. Participants described a scaffolding approach to helping their children with this task. For example, some parents described supporting their child by laying out clothes and then encouraging their child to put on the clothes by themselves. Other parents described helping their child put a shirt over their neck, but then letting their child put their hands through the sleeves on their own:

We lay out a couple different outfit choices and then he gets to pick the outfit he wants to wear. And then we work on just small things of, like, I’ll get the pants up to his knees, and then he’ll pull them up the rest of the way. Or I’ll get the shirt over his head, but then he’s gotta put his hands and arms through the arm holes.

By encouraging their child to complete part of the process, participants felt that they were building their child’s confidence and reinforcing skills, “[It is important] to structure the activities so that she does the steps that she knows how to do, and then she tries the others, and if she doesn’t succeed, someone intervenes.”

In addition to breaking tasks into smaller steps, participants also described helping their children stay on task during activities. Participants described guiding their children through everyday activities and supervising to make sure the activities are completed. For example, one participant mentioned that her son frequently starts a game or activity and then forgets what he is doing and leaves to do something new, so:

I must try to bring him back to the activity and try to get him to finish it, even if perhaps by scaling down, decreasing the load... Maybe we are doing a puzzle, we still put these



three pieces, we finish this thing then we move on to the next thing. Or we are doing this thing, we put the toy cars in the box before taking another game. And so it is ongoing effort to make him finish the activity he is doing before starting another one. It is not easy; the results are not always what one hopes to have.

**Setting Expectations.** Across focus group discussions, participants discussed the importance of setting expectations for their children before and during tasks ( $n = 17$ ). This strategy was mentioned during American focus groups ( $n = 14$ ) and Italian focus groups ( $n = 3$ ), and it included the use of consistent daily routines and clear explanations of tasks. Parents expressed that following consistent routines made daily tasks easier for both children and parents. When initially asked about how they help their child with daily tasks, one participant said, “the biggest thing is routine.” Another participant said, “I feel like in our home he does fairly well because he just kind of knows the system.”

Parents expressed the importance of helping their children understand tasks and understand what is expected of them because they felt that helping their children understand the demands placed on them set up the children for success. One participant said, “I feel like that understanding of the task is huge.” And another participant shared:

I think it's really more about her knowing what's expected – knowing what the task is, knowing that she can do it, and knowing what's expected...I found that if [Child's Name] doesn't understand what the game is or what you're asking her to do, she kind of fumbles through it. And she's, like, ‘I don't really know what you're asking me to do.’

**Using Visual Supports.** In order to help their children understand task expectations, participants described using visual resources, such as visual schedules. Visual schedules show pictures of each step in a process (e.g., each step in a bedtime routine) so that children can see

the steps that need to be completed and the order in which they need to be completed. Many visual schedules have detachable picture steps so that children can physically remove each piece after they complete the step. Visual resources were the most frequently mentioned strategy ( $n = 17$ ) for participants in the US, but were not mentioned by participants in Italy. In the American focus groups, participants described using visual schedules to help children remember steps in a new or challenging task (e.g., toileting), to know what to do during morning/bedtime routines, and to mark progress toward a developmental goal.

**Motivating Children.** Lastly, participants mentioned the use of motivational strategies to encourage children to complete tasks ( $n = 16$ ). These strategies included providing rewards, speaking in an enthusiastic parent voice, and using music. These strategies were mentioned several times in American discussions ( $n = 5$ ) and Italian discussions ( $n = 11$ ). Some participants described a preference for using positive reinforcement (e.g., rewards) to encourage their children to complete non-preferred tasks, such as brushing teeth. Other participants described using songs to help their children stay engaged during non-preferred tasks of daily living, “He likes to sing a lot, so I use songs to keep him on track.” Another participant mentioned that she makes up songs to sing to her child to help him remember the steps in their morning routine:

He does everything absolutely by himself. This helps him a lot, he asks me to sing...When I don't sing – I don't always feel like singing – I notice the difference. I see that we have to tell him many times...I have to repeat many times and I see that he is more distracted. Instead, if I start singing, he does everything, he anticipates what I am going to say, so you can see that he is really focused on what he has to do...He does it with more enjoyment, with more fun.

Italian participants also described using an enthusiastic ‘parent voice’ to motivate their children to complete daily tasks, particularly non-preferred tasks such as putting on shoes and coats to go to school. Participants felt that an enthusiastic attitude helped motivate their child and gained their child’s interest:

The other method we always use, and I think this is something everyone does, is to play up the situations, so, first I tell him what we are going to do in an excited way, and then he is full of expectation, and his attention is high, and his level of participation is high too because he is excited to do what I have announced.

### ***Why Parents Help***

Discussions regarding parent motivation for helping their children during daily tasks occurred organically during broader discussions of daily routines (e.g., “What are some examples of daily tasks that you help your child stay focused on to complete? Are you working on developing independence in these tasks?”). Participants described three main reasons for providing assistance to their children during daily tasks: physical limitations, time limitations, and a desire to prepare their children for the transition to school.

**Physical Limitations.** Participants frequently described ( $n = 15$ ) helping their children to complete routine daily tasks because their children lack the physical strength, size, or motor abilities needed to complete tasks without assistance. Physical limitations were mentioned in conversations with parents in Italy ( $n = 4$ ) and the US ( $n = 11$ ). For example, parents noted that their children often struggle to open food packages, zip up jackets, button pants, and tie shoes. Participants also mentioned that they help children carry things for safety reasons (e.g., sharp knives or heavy containers of dog food) when their children help with household chores. In these cases, parents described their children as *knowing how to do the task* but requiring parental

assistance due to their age, size, or motor skills. Participants expressed some frustration that their children understand how to do tasks and want to have independence in doing tasks but are not fully capable yet. A salient example of understanding a task but lacking the physical ability was toileting. During one focus group discussion, two participants discussed the ways in which their children's potty-training efforts were disrupted by the adult-size toilets and sinks in their home bathrooms:

We've tried to accommodate on various things, but there's limitations in her abilities, you know. Even simple things, like she has the ability to go to the bathroom on her own and she does so at school, but we don't have a nice little toilet and a nice low sink. And so we've accommodated as much as we can, but that routine gets a little bit messed up.

The other participant agreed, "We run into the same issue where our toilets are very tall and he can't get on them by himself." In these examples, parents expressed that their children have more autonomy at school and are able to complete a daily task (using the toilet) on their own, but they require assistance from an adult when attempting the same task at home.

**Time Limitations.** Participants also mentioned ( $n = 6$ ) that time is an important factor that contributed to their desire to help their children with daily routines rather than encourage their children's independence. Though children understand how to do certain tasks and though parents wanted to teach independence in daily tasks, participants mentioned that it was often quicker for an adult to provide assistance to the child. Participants mentioned that time is a particularly important factor during morning routines when families are trying to leave the house on time:

The problem is that I am always in a hurry, so we try to work on autonomy but it is difficult because the day is always too short, I have three of them to manage and so he

would obviously need more time, I often do it first rather than making him do it and this is my mistake. But I find it hard to make more time... we already wake up very early every morning!

Similarly, participants described independence as a ‘blessing and a curse’:

Back to what someone else said, it's like, you know, them becoming independent is a blessing and a curse at the same time because you're like, “Yay, you can do it by yourself! But come on, we don't have time.”

**Prepare for Transition to School.** Despite the physical limitations and the time limitations, participants also mentioned ( $n = 6$ ) a desire to foster their children’s independence in tasks in order to ease the transition to school. This was mentioned in American discussions ( $n = 5$ ) and Italian discussions ( $n = 1$ ). Parents expressed general concern about preparing their children for school. As parents of children with IDD, they were particularly worried about their children meeting expectations at school, “[She will be] transitioning to kindergarten [next year] and I'm already worried about her going in a little bit behind where everybody else is.” In order to reduce concerns about their children being ‘behind’, participants expressed a desire to help children, “be as independent as possible.” In one discussion, a mom whose son recently transitioned to kindergarten shared her experience with the group:

I definitely think it was a big jump from preschool to kindergarten in what they were expected to do – how long they were expected to sit and what they were actually expected to do walking into kindergarten. It was like, “holy cow!”

By helping to encourage independence in some small daily tasks at home, parents hoped that they could help their children build up to the skills needed to engage in classroom settings when they start school.

### *How Children Approach Tasks*

Lastly, in conversations regarding parental assistance with daily tasks, participants also described how their children approach tasks. Participants described three ways children responded to parental help. Children were described as having knowledge of how to complete tasks, a desire for independence, and a context-dependent preference for parental assistance.

**Desire for Independence.** Though participants described many tasks they help their children complete each day, they also described a strong desire for independence seen in children in this age group. Participants frequently noted that their children know how to complete tasks ( $n = 22$ ) and have a desire for completing tasks independently ( $n = 15$ ). One parent described the desire for independence as helpful for her child because it encouraged her to learn a new skill: walking up and down stairs on her own. Through mastering this new task, her child gained confidence and became more interested in completing other tasks independently. Another participant described her child's desire for independence as positive "[because] she doesn't want others to do it for her." One participant described the pride her child feels when she completes tasks independently, "She is happier when she sees that she does things by herself." Another parent described their child's interest in completing tasks alone as "bittersweet" because it indicates she is growing up.

**Context-Dependent Preference for Assistance.** Despite the desire for independence described by many participants, it was also mentioned ( $n = 6$ ) that children's abilities can seem "context-dependent" such that children may demonstrate greater independence in certain situations but prefer parental assistance in other situations. For example, participants described their children as showing more independence at school because they imitate other students and/or have more child-friendly materials, such as the child-sized toilets previously mentioned.

However, at home, some children prefer help from their parent or a trusted adult and ask for assistance in completing tasks they know how to do. One participant said, “She just chooses not to...She asks me to help her almost every day.” Similarly, another participant described her son as being potty trained (“He completely knows how to.”) but preferring to have parental support (“He [says], ‘I want you to help me.’”). Another participant emphasized the importance of their child’s relationship with the adult who is offering help:

There are always differences [in how much help he wants]. For example, it depends on the person he is with at that moment. Because when he is with his mother or grandmother he wants to be helped more, but with other adults, much less. So there are other things that come into play, such as the level of relationship with the other person.

### **Perceptions of Parent-Led Intervention**

The second research question in this study aimed to understand parent perceptions of parent-led interventions for children with DS (e.g., “Would you be interested in personally implementing an intervention for your child at home? What are the pros/cons?”). A total of 224 quotations from the nine focus group transcripts were identified as relating to parent perceptions of parent-led intervention and were coded as one of 25 codes that fit into four code categories. Code categories included *advantages of parent-led interventions*, *disadvantages of parent-led interventions*, and *desires for interventions*. Codes by frequency are displayed in Table 3.

#### ***Advantages of Parent-Led Intervention***

Participants expressed many positive benefits for parent-led interventions. Across all nine focus group discussions, participants expressed positive attitudes toward parent-led intervention because it would allow parents (1) to participate in the intervention at home where their children

are comfortable, (2) to engage in the intervention more frequently, and (3) to learn new strategies to work with their children.

**Participate at Home.** Participants mentioned ( $n = 5$ ) that one advantage of parent-led intervention is that their children are more comfortable in their home environment. This was mentioned in American focus groups ( $n = 3$ ) and Italian focus groups ( $n = 2$ ). Participants described it as an advantage for children to work on new skills at home so they, “don’t have to get used to a new space. [That would be] a really positive experience for her.” Another parent expressed positive feedback about previous participation in projects involving home visits, “that was interesting to me because then you’re on his turf, and I think you see things differently when he’s in *his* environment.” In another discussion, one participant shared:

Sometimes kids do better in their home environment. Sometimes it's the opposite. I feel like [Child’s Name] does pretty well in our home environment. We have our basement all set up, so it's got all his stuff. He has stuff for table time...He can kind of do his own thing. So, I think that could be a pro for him, is that he would be more comfortable in his own space and be able to work through it.

**Engage More Frequently.** In addition to parents expressing a preference for programs that could be delivered at home because their child is more comfortable at home, they also expressed a preference for parent-led intervention because the activities could be used more frequently and at more favorable times. This was mentioned several times throughout discussions in American focus groups ( $n = 1$ ) and Italian focus groups ( $n = 6$ ). Delivering interventions at home not only reduces the burden on parents to travel to another site in order for their children to receive services, but it also allows children to practice the intervention more often. Participants expressed that they may be able to deliver the intervention activities at a



higher frequency than clinicians because they inherently have more time with their children than a clinician who provides care to a child once a week. Reflecting on a previous experience in at-home intervention, one participant said, “Here's what I liked about it: the fact that we're the ones doing these things, the fact that we're the ones acquiring these skills, it allows us to do it much more often than a therapist could.” Similarly, another participant commented on the advantages of the increased dosage of a parent-led intervention:

There are many pros [of at-home intervention], because clearly, the child spends a great amount of time with the parents every day. Therefore, it is clear that the family can do much more than a clinician, in the sense that they can dedicate much more time. The clinician works there for an hour a week, the parent sees the child every day and could take advantage of the thousands of opportunities that arise during the day.

Furthermore, when parents are responsible for delivering program activities, they can choose to engage in the activities with their children at more favorable times (i.e., when their child is in a good mood and receptive to learning). When asked for their opinion on at-home interventions, one participant succinctly stated, “I think in order for something to work, it has to be done at-home.”

**Learn New Strategies.** Lastly, participants frequently expressed ( $n = 8$ ) positive interest in at-home interventions because it provides parents the opportunity to learn more about how to work with their children and how to support their children’s development. At-home interventions providing benefits to parents and children was mentioned in American discussions ( $n = 5$ ) and Italian discussions ( $n = 3$ ). Overall, participants expressed that including parents in interventions “is something that helps us as well as the child.” One participant described parent-led interventions in this way:

[The pros of at-home intervention are] infinite because the parent receives guidance, receives help to understand their child better, to do their best, and moreover, it is an activity that is part of everyday life and therefore causes less discomfort to the child, and you can give him more chances to repeat it over time.

Additionally, parents expressed an interest in being more involved in their children's intervention services in order to observe their children's growth. Parents were interested in understanding the milestones their children reached during private therapies and felt that doing interventions at home would allow them to directly see developmental gains. One parent described, "I really like watching her learn. I love to see that development. It's been really hard on me being an educator, sending her to school and I don't get to see her interactions." Furthermore, participants mentioned that a benefit of at-home intervention is that it would allow parents to learn more skills to help them play with and interact with their children, "It is nice because it is a good way to connect and see where they are struggling and excelling and gauging where they are." Overall, participants expressed favorable attitudes about at-home intervention because it has benefits to the family beyond those seen in the target child; it also has positive implications for the broader family system.

### ***Disadvantages of Intervention***

Though participants mentioned many benefits of PMI, they also described disadvantages of this approach. There were three key themes from conversations about drawbacks to PMI: *stress and time, parent is not a clinician, and parents just want to be a parent.*

**Stress and Time.** Overall, time was one of the most frequently mentioned disadvantages of parent-led intervention ( $n = 19$ ). Concerns related to stress and time were mentioned several times in American discussions ( $n = 11$ ) and Italian discussions ( $n = 8$ ). Broadly, participants

mentioned time as a barrier to participating in parent-led intervention. One participant mentioned their involvement in other services, “I’m already spending six hours a week doing therapy on top of her school. Plus, we have dogs and work and houses and cars...” Similarly, another participant described their current everyday commitments as, “crushing us a little bit.” Even when participants expressed a strong interest in participating in a parent-led intervention, they felt that, “when I think about actually fitting into our routine, it’s a whole different level of commitment I can’t actually pull off.”

In addition to concerns about the time commitment associated with parent-led interventions, some participants also described feeling overwhelmed by the idea of not succeeding in the program, “I [don’t want to] miss a day and then be stressed out about it.” More broadly, participants described experiencing stress related to not spending enough time with their children (“I always feel guilty because I don’t dedicate much time to her”), spending too much time specifically with their child with IDD (“[Her sister] has always struggled with her receiving extra attention”), and potential guilt about not executing a parent-led program perfectly (“I don’t want to fail at something”).

**Parent is Not a Clinician.** Another frequently mentioned disadvantage of parent-led intervention is that parents are not clinicians. Participants noted that they do not have experience in providing intensive therapy to their children. Most parents are not also trained clinicians, and therefore, participants felt they may lack the skills and training needed to be effective interventionists for their children. One participant expressed, “I don’t feel like a clinician, I don’t feel fit, I don’t feel accepted as an instructor for my son.”

Furthermore, participants expressed that, compared to parents, clinicians may be better at pushing children to engage in interventions activities and, therefore, clinicians may be able to

help children gain more benefits from a program. As previously mentioned, some parents said that their children preferred the home environment and worked well “on [their] own turf.” However, other participants felt that their children respond better to other adults. These participants expressed that clinicians know how to help children reach their goals because they have more experience working with children with disabilities. One participant noted that their child works better outside the house because, “he goes there to do activities, not to do what he wants. At home [where he can do what he wants], it is much more difficult.” Similarly, one participant felt that her daughter is more willing to be pushed by a therapist and humorously shared:

I found that [Child’s Name] works better with therapists and teachers compared to me. She's much more against doing it with me. She’s like, ‘You're my mom and I'm not doing this,’ ...But then a therapist comes in and I'm like, ‘Oh my gosh, you can write your whole alphabet and I didn't even know it! You didn’t even show me that!’ [Laughs]

**‘I Just Wanna be Your Mom’.** Another interesting finding was that some participants expressed that a disadvantage of parent-led intervention is that it forces parents to be clinicians rather than parents. Parents of young children with IDD face large amounts of pressure to enroll their children in the right therapies, meet with the right professionals, and practice the right skills. One participant described it as feeling like, “the fact that you have to be always on the ball...the fact that you can never stop.” Participants expressed that they want to be able to spend time with their children without also focusing on building new skills:

I think for us, there are a lot of areas we're working on at once - we have gross motor, fine motor, executive functioning, everything. There's a lot and sometimes it's like, "I just wanna be your mom. I don't wanna be your therapist. I just wanna be your mom." And so

I think that's one of the cons [of parent-led intervention] and sometimes it's nice to be like this other person is your physical therapist. They will help you.

Furthermore, participants expressed that sometimes they just want to be a parent without having to ensure everything they do with their child is in pursuit of a developmental goal. For example:

You are always trying to teach them something and I don't think it should always be like that, because there should be moments of pure play, of pure fun, of reading for the pleasure of reading a book, without worrying about teaching... even if reading a book is teaching... but without emphasizing it.

Overall, this theme was mentioned three times in the discussions with American parents and one time in the discussions with Italian parents, but it elicited strong feelings of agreement among the participants:

And I couldn't agree more with what was just said that. We sometimes just wanna be their mom, you know? And it's just, it can be kind of tricky where it's like we're constantly feeling like: we gotta go here, we gotta do this, and we gotta make sure we're teaching this. And we're constantly doing all these things. So, just being able to be a mom is great as well... So we don't feel like we literally need to put the other hat on, "Okay, now I'm going to sit down with you and I'm going to be the occupational therapist for the next 20 minutes." And just being able to live our little lives.

### ***Desires for Parent-Led Interventions***

In discussions about participating in parent-led intervention at home with their young children, participants organically described their wants and needs for new programs aimed at supporting development in young children with DS. Broadly, parents expressed an interest in programs that align with their existing goals for their child, have clear directions, and can

involve multiple family members. More specifically, parents expressed an interest in programs that are tailored to meet their child's individualized goals, fit into their daily routine, and can be flexibly adapted as needed.

**Align with Parent Goals.** Parents expressed the importance of the intervention matching their goals for their children without being a burden on the family or the child. One participant described helpful interventions as those that are, “short, simple, and really functional.” Similarly, another participant wanted to see clear benefits for her child and her family:

I just never want anything to feel tedious for [Child's Name], you know? Obviously we're including him in [treatments] because we think it'll be beneficial...And we just want it to be fun and where he's benefiting from it, and we are too.

Other participants expressed an interest in building on their child's existing strengths and abilities, “Yeah, I agree. [Intervention activities] that kind of fit into what we're doing and already working on and can just expand on those activities would be great.”

**Clear and Structured.** Another theme that was identified across transcripts was the desire for clear directions for parents. Participants expressed that clear instructions would reduce stress and increase interest in delivering the at-home intervention. Though parents expressed a preference for intervention activities that could blend into their life, they also expressed interest in clear directions and implementation guidelines. Some parents noted that clear guidelines would reduce the stress of the intervention and alleviate the feeling of, *am I doing this right?*

One participant expressed that, “it is not always the case that something is taught, and then you know how to do it.” There is a need for clear directions from the outset, helpful materials, and ongoing support from an expert/professional. Participants reported positive feelings about having the opportunity to bounce ideas off of another person and to hear feedback

directly related to them and their child. When asked if she would be interested in using an intervention at home with her child, one mother replied, “If it was very clear of how to do it and what to look for while doing those interventions and maybe tips and tricks also for implementing it, then yes.”

Moreover, participants expressed a need for regular support from an intervention team. Parent preferences for support varied across individuals, but generally included a preference for regular touch points weekly, bi-weekly, or monthly and additional contact as needed. When asked how often they would prefer to be contacted *by a professional*, one participant responded:

The opposite would be important: the availability of the research team to be contacted by the parent in case of problems. For example... if an activity is given to me [and] I attempt it with my child but he reacts poorly, and he doesn't like it, things like that... It would be important for me as a mother to have the possibility to interact with the team.

**Include Family Members.** Many participants expressed that an advantage of at-home intervention is that it can allow the whole family to take part in the activities without interrupting family time. Therefore, participants frequently mentioned ( $n = 5$ ) a desire for an at-home intervention to be able to include siblings and/or other caregivers. Parents expressed that their other children sometimes wanted to take part in intervention activities with their child with DS as well. During one focus group discussion, a participant expressed her desire for siblings to be included in an intervention program for her daughter. This prompted agreement from another participant:

Totally! I mean, his older brother would love nothing more than to be participating [in the intervention]. I think sometimes, even though I reassure them that this is work for [Child's Name], he feels a little left out, you know?...’Cause it looks like play, you know?

[He says], “I wanna play! How can I help play?” So that – yes, I never even thought about that, but that would be super, super huge.

And another mother mentioned that she would prefer to use an intervention that allowed her husband to join in the activities too because she felt this would help him engage with their daughter:

When [Child’s Dad] is home, he really likes to be involved. He doesn't get a chance to cause he works like an hour away too. But it is nice when multiple adults can interact when it's available but not needed [because] we don't always have that... So it just depends. But it is nice if we can incorporate it.

Italian participants, too, expressed concern for siblings with typical development feeling “left out” of their sibling’s intervention if it takes place at home:

For me, there is something that came to my mind now while we were talking, something that worries me in general when it comes to raising [Child Name], it doesn't concern [Child Name], but it concerns her sisters. In the sense that I always have a bit of a concern about spending too much time with her and leaving them aside a bit. Not so much the older sister as the twin sister, who has always struggled with [Child Name] receiving extra attention. So maybe the fact that this takes place in the house...there's a consideration that comes to mind now that worries me that the twin sister may “suffer” from this extra attention that will be given to [Child Name].

Though siblings may recognize that the intervention is challenging for the child with DS or that their sibling needs extra support, parents expressed that, “It's not necessarily the content, or the time we dedicate to [Child Name], but it's how [the child’s siblings] perceive what we do.”



**Individualized.** Participants described the importance of individualized and tailored intervention for their children. In order for a program to be effective, participants expressed that it needs to be adapted to fit the needs of each specific child who engages with it, “because again every kid is just different, you know. There are some similarities with kids with Down syndrome, but they're still very different from each other.” Other participants agreed, “For anything to work, it has to be individualized...It needs to be tailored individually...for it to be really impactful it's gotta be focused on her.”

**Fit into Routine.** When asked about different types of parent-led interventions, participants frequently expressed an interest in interventions that involved the activities with which they already help their children. Given that parents previously described helping their children with many daily tasks and feeling short on time, parents reported a preference for parent-led interventions that could be embedded into their existing routines:

For me, [I prefer an intervention] that fits into other daily activities, because if you find a way to make the daily activity beneficial twice...[I'd prefer] if you can insert something that we have to teach into something that we already do during the day, so we are not competing to do one more thing.

Moreover, parents wanted interventions that fit into their lives and can be completed in a variety of environments:

[I would want to know] where could we do it? Could we do it before bed? Could we do it on the floor? Could we do it on the bed? Could we do it in a bathtub? You know, kind of like, how could you weave it into your life?

Furthermore, parents expressed a preference for interventions that are “quick and easy” and can be adapted to meet their needs:

It can be tricky sometimes...so just doing things with [Child's Name] that he already does and maybe just adding steps or whatever the case may be is a lot easier than really trying to sit down with him and spend a longer period of time working on something [new].

Overall, participants were interested in interventions that fit into their lives. One parent expressed that, “the reality of participating [in an intervention] is time and functionality, or how well it meshes with what we're already doing.”

## DISCUSSION

EF is associated with positive developmental outcomes for children with DS, and early childhood is a key period during which intervention can support the development of these cognitive skills; however, there are few EF interventions available for children with young developmental ages. One effective and scalable intervention approach for clinical populations is PMI, which leverages parents as interventionists. PMIs require ongoing parent engagement, and therefore, it is critical for a PMI to meet the needs of its intended users. Little is documented about the specific needs of young children with DS and their families today. To address this gap, the present study aimed to understand daily routines of families of young children with DS and parent perceptions of participating in at-home intervention. Across nine focus group discussions in Italy and the US, 34 participants responded to questions related to these research topics. Participant responses were transcribed, coded, and analyzed. Four themes related to daily routines were identified (*what parents help with, how parents help, why parents help, and how children respond*). Three themes related to parent perceptions of interventions were identified (*advantages of parent-led interventions, disadvantages of parent-led interventions, and desires for interventions*). Through qualitative analysis of parent responses, three key recommendations for the development of a novel PMI were identified: require a short time commitment, blend intervention activities into daily routines, and include family members. Findings from this study have implications for the development of interventions aimed at supporting families in this population.

### **Require a Short Time Commitment**

Across focus groups and across discussion topics, time constraints were a recurring theme described by participants. For example, many participants mentioned that their children expressed a strong desire to complete tasks independently (including helping with household chores and getting dressed), however, parents often chose to help their children complete these tasks because tasks were completed quicker when parents helped. Additionally, parents expressed interest in participating in a PMI but also noted that the strongest disadvantage to a parent-led intervention would be the time commitment. Many parents perceived time constraints as a potential barrier to participation in a parent-led intervention. As one parent succinctly stated, “The days are just too short.”

This recurring theme suggests that the amount of time required for participation is an important factor to parents when they are selecting an intervention for their children. This has implications for clinicians recommending interventions to families and for researchers modifying or developing interventions for families in this population. In order to meet the needs of parents with young children, program developers should create programs that are easy to administer and should design activities that can be completed in a short amount of time.

### **Embed in Daily Routines**

Relatedly, participants expressed an interest in intervention activities that can be embedded into the activities in which they already engage with their children. Given the aforementioned time constraints experienced by participants, an intervention that is embedded into existing family activities and routines has the potential to increase both interest in an intervention and ability to engage in an intervention. Parental interest to engage is critical to the success of a PMI. A PMI that embeds intervention activities into tasks of daily living has the potential to positively impact child development without placing an additional burden on parents.

As mentioned by many participants, families with young children are commonly involved in many activities. Their daily routines include traveling to school or extracurricular activities, working on school assignments, and completing household tasks. Additionally, parents described many areas in which they help their children each day, including morning and bedtime routines, bath time, mealtime, and while getting dressed. Therefore, parents often spend many hours each day with their children, but they may not necessarily have a lot of free time with their children. The abundance of time together (though not necessarily the abundance of free time together) suggests that interventions that are embedded into daily routines or into daily playtime could be a potentially good fit for families of young children with DS.

### **Include Family Members**

Similar to the desire for interventions to be blended into daily routines, parents also expressed interest in interventions that are flexible and adaptable to dynamic family schedules. Specifically, participants expressed interest in a parent-led intervention that includes other family members, including siblings, non-primary caregivers, and grandparents. The topic of siblings came up in multiple discussions and parents expressed concerns related their children with typical development. Parents said that they do not want their children with typical development to feel excluded when their children with DS engage in specialized interventions. Participants expressed concern that their children with typical development may feel excluded if a parent spends more time with their sibling with DS or if the activities look fun and engaging. Interventions are ‘work’ for children with DS and are designed to support the development of important milestones, however the games and activities may appear fun and engaging to young siblings with typical development, and these siblings may want to join in.

Some of these concerns arose during the height of the COVID-19 pandemic when most schooling and therapy services had to be completed remotely. During the focus group discussions, parents described that their children with typical development enjoyed trying to complete remote therapy activities with their child with DS and the children were disappointed if they were excluded from certain activities. Seeing their children's desire to be included in their sibling's intervention activities contributed to parent interest in an at-home intervention that has the option to include other family members.

## **Implications**

### ***CBPR Approach***

The present study used a CBPR approach to involve members of the community in the research process. This study served as an example of utilizing CBPR methodology with a clinical population, an approach that is still uncommon in research on neurogenetic conditions (Riggs et al., 2021). Parents of children with DS shared their lived experiences and described their perceptions of the advantages and disadvantages of parent-mediated cognitive intervention. The rich descriptions provided by parents should inform the structure, timeline, and content of novel interventions aimed to support families in this population. Findings from this study have important implications for intervention development and adaptation because interventions should be designed with the user in mind. Including participants in the intervention development process aims to increase participant responsiveness to and engagement with the intervention. This is important because interventions are only effective if they are used by the intended population. Findings from this study will contribute to the development of a novel cross-national PMI to promote EF in children with DS.

### ***Cross-Nationality Similarities and Differences***

Broadly speaking, cultural identity is associated with the values a parent places on their child's developmental outcomes (Rubin & Chung, 2006). This study was among the first to include a cross-national sample of parents of children with IDD. Though many similarities were seen between the American parents and the Italian parents, an intervention designed to promote positive developmental outcomes for families from diverse cultural backgrounds must consider whether cultural adaptations are required to make the program relevant for the intended populations. Results from the current study demonstrated many similarities across the two cross-national samples. Participants in Italy and the US both described similar tasks of daily living with which they help their children. Across the two samples, parents described the need to support their children in common daily activities such as brushing teeth and getting dressed. Participants at the two sites also expressed similar motivations for helping their children, including their child's physical limitations and time limitations. Though parents in both Italy and the US sought out creative ways to help their children stay on task and complete routines with enjoyment, there were differences in how parents described helping their children. Participants in Italy mentioned the use of songs and music, while parents in the US mentioned the use of visual aids and visual schedules. The differences in strategies may need to be considered when developing materials for cross-national interventions.

Furthermore, parents in Italy and the US both described many similar advantages of participating in a PMI, and participants in Italy and the US frequently stated that time and stress would be disadvantages to a PMI. However, some differences were identified in parent perceptions of the disadvantages of participating in a PMI. Quantitative analyses were not conducted with these data, however some themes were mentioned multiple times by one group and only one time or not at all by the other group. For example, parents in the US frequently

mentioned concerns related to the many services in which they participate and expressed a desire to ‘just be a parent’ rather than be involved in more intervention activities. Parents in Italy only briefly mentioned these same feelings one time, but they frequently mentioned concerns related to not having the skills needed to deliver intervention services to their child. Italian participants expressed concerns related to the training and guidance they would hope to receive before and during a PMI. Similarly, participants in Italy frequently mentioned concerns related to their child’s behavior. Specifically, some participants in Italy mentioned that their child responds better to intervention from therapists. These differences may indicate a need for more tailored intervention options that provide a scalable amount of support that responds to family needs. Future directions for this work could involve more quantitative analyses to understand differences between parents in Italy and parents in the US as it relates to the strategies they use to motivate their children and their concerns about participating in intervention services with their children.

### **Strengths and Limitations**

This study described parent responses to questions about daily routines and perceptions of at-home intervention, and it has multiple strengths. For example, the study strategically included parents from two countries in order to provide more comprehensive data to inform the development of a cross-national intervention. To reduce participant dropouts, focus groups were offered at several times throughout the week and were limited to one hour in length; this time limit allowed for rich conversation but did not interfere with participants’ daily lives. To reduce social desirability bias, most questions were asked in an open-ended format and participants were encouraged to speak freely throughout the conversation.



Though this study has multiple strengths, there are several limitations to consider, including lack of generalizability and lack of quantitative measures to supplement the qualitative data. The findings from this qualitative study will be informative when considering the needs of families with similar characteristics to the families studied, however qualitative data cannot typically be generalized beyond the study sample (Onwuegbuzie & Leech, 2007). Though the samples were drawn from the communities in which the research occurred, there was a lack of diversity across participants. Participants were predominantly white, female, and highly educated. Compared to parents with lower levels of education or lower socioeconomic backgrounds, the parents sampled in this study may have access to more resources and may be better equipped to participate in a parent-led intervention. Therefore, the opinions expressed by participants in this study may differ from the opinions of parents with fewer resources. Future work should aim to increase representation across ethnicities, education levels, and socioeconomic statuses.

Similarly, cultural homogeneity within a country cannot be assumed. The few cultural differences identified in this study serve as a starting point for developing cultural adaptations throughout the intervention development process, but researchers can expect intracultural variations in parent perceptions and those may be as large as the identified intercultural variations (Senese et al., 2011). Another limitation of this study is the lack of quantitative methods. Administering a standardized questionnaire to assess parent opinions on their child's independence in tasks of daily living would have provided quantitative data that could have been triangulated with the qualitative data to allow for a deeper understanding of the research questions.

## **Future Directions**

Future directions for this work should aim to (1) conduct focus group interviews with participants from more diverse demographic backgrounds and (2) conduct member checks with participants to check for accuracy and increase the validity of the described findings. Conducting focus group interviews with participants from more diverse backgrounds is an important next step. Most immediately, focus group interviews should be conducted with Spanish-speaking families in the US. Spanish is the second most commonly spoken language in the US; however, the present study only collected data from English-speaking parents in the US. Efforts are already underway by our research team to include this significant, but historically underrepresented, group in research. Additionally, next steps for this work should include member checking with the families who participated in the focus group interviews described in the present study. Findings from the present study directly contributed to the development of a novel PMI for children with DS. In the next phase of research, participants will be invited to review the preliminary version of the novel PMI. After their review, parents will participate in another interview during which they can share their opinions on the novel PMI and describe how it did or did not meet the needs they previously described. *Conclusion*

The central aim of this study was to characterize parent descriptions of daily routines for their young children with DS and to describe their perceptions toward at-home intervention in a cross-national sample. This study was innovative in its inclusion of a cross-national sample of families of children with IDD and in its use of a CBPR approach with members of this population. This study built on previous work that has demonstrated cultural differences between parents in the US and parents in Italy and expanded the literature to include families of children with IDD.

Cross-cultural comparisons that examine variations in parent beliefs can be used to inform cross-national work. As the field of developmental science continues to emphasize the importance of developing evidence-based interventions, it is important to understand the role that contextual factors, such as cultural identity, will play in the creation and implementation of interventions used across the globe. Cultural considerations that support the feasibility of administration and contribute to program effectiveness cannot be ignored during the intervention development process. Historically, interventions are developed to meet the needs of one specific cultural group and then later adapted for additional cultural groups. In a novel approach to intervention development, findings from this study will support two cross-national research teams as they work in parallel to develop a PMI that meets the needs of families in Italy and the US.

**Table 1***Participant demographics*

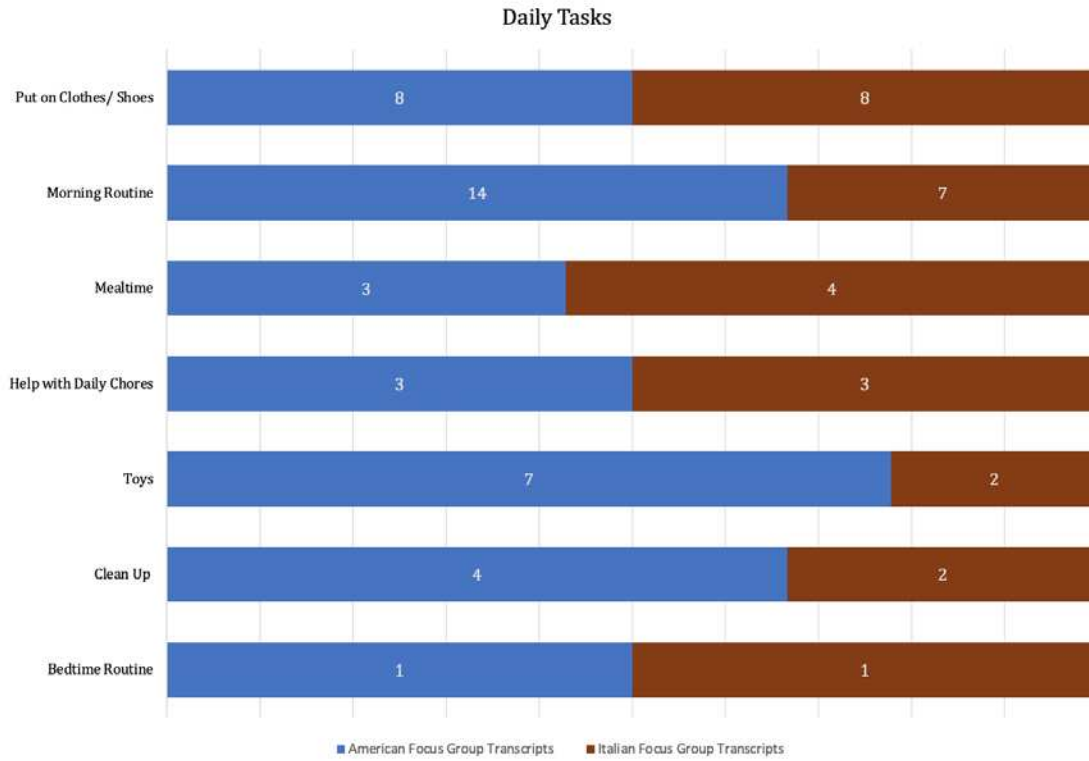
	Italy	US
N	18	16
Age M(SD)	45.22(4.71)	38.15(5.16)
Education <i>n</i> (%)		
Graduate Degree	13 (72.2%)	6 (46.2%)
Some Graduate School	0	1 (7.7%)
Bachelor's Degree	1 (5.6%)	4 (30.8%)
Associate Degree	0	2 (15.4%)
High School Diploma	2 (22.2%)	0
Sex <i>n</i> (%)		
Female	16 (88.9%)	16 (100%)
Race <i>n</i> (%)		
White	Not reported	16 (100%)
Ethnicity <i>n</i> (%)		
Hispanic/Latino	Not reported	2 (15.4%)

**Table 2***Frequencies for codes related to daily tasks*

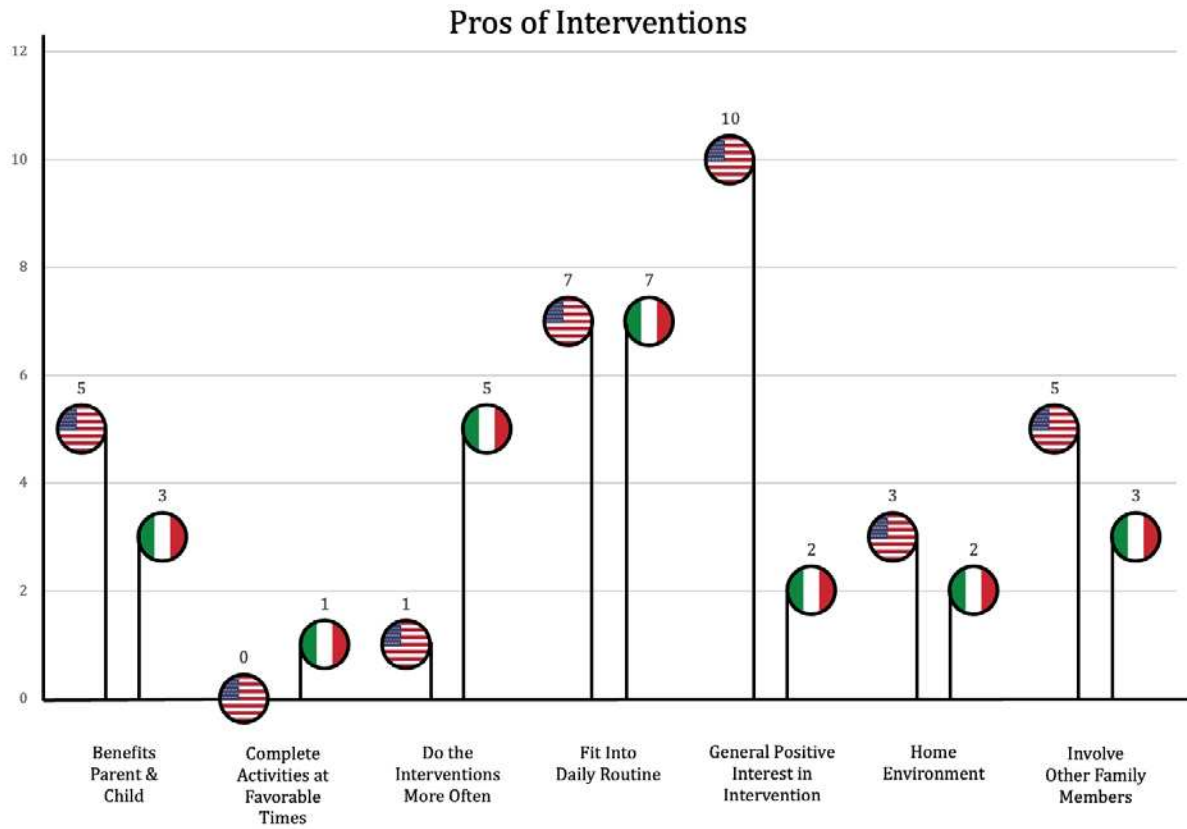
	<b>American Focus Groups</b>	<b>Italian Focus Groups</b>	
	Frequency	Frequency	Totals
<b>Child approach to tasks</b>			
desire for independence	5	10	15
knows how to	14	8	22
prefers help from an adult	3	3	6
<b>Daily tasks</b>			
bedtime routine	1	1	2
clean up toys	4	2	6
help with daily chores	7	2	9
mealtime	3	3	6
morning routine	3	4	7
put on clothes/shoes	14	7	21
wash hands/bathe/brush teeth	8	8	16
<b>How parents help</b>			
break down tasks	4	0	4
provide rewards	3	1	4
provide scaffolding	10	10	20
provide structure	15	3	18
remain calm, be patient	1	4	5
repetition	7	2	9
support from professionals	4	4	4
use 'parent voice'	0	3	3
use songs/music	2	7	9
use visuals	17	0	17
<b>Why parents help</b>			
prepare for kindergarten	5	1	6
safety	0	1	1
task requires advanced motor skills	11	4	15
time - quicker for parents	2	4	6
<b>Totals</b>	<b>139</b>	<b>92</b>	<b>231</b>

**Table 3***Frequencies for codes related to parent-led interventions*

<b>Code</b>	<b>American Frequency</b>	<b>Italian Frequency</b>	<b>Totals</b>
<b>Cons of At-Home Intervention</b>			
just be their mom	3	1	4
parent is not a clinician	1	6	7
responds differently with parents	3	9	12
stress	2	1	3
time	11	8	19
<b>Desires for Intervention</b>			
brief intervention activities	5	9	14
flexible / adaptable	3	3	6
fun and functional	9	2	11
include siblings	3	2	5
tailored to each child	5	2	7
longer intervention activities	6	10	16
<b>Pros of At-Home Intervention</b>			
benefits both parent and child	5	3	8
complete activities at favorable times	0	1	1
do intervention more often	1	5	6
fit into daily routine	7	7	14
general positive interest	10	2	12
comfortable in home environment	3	2	5
involve other family members	5	3	8
<b>Preferred Type of Intervention</b>			
activity-based	3	11	14
education-based	5	4	9
mixed	7	4	11
play-based	7	7	14



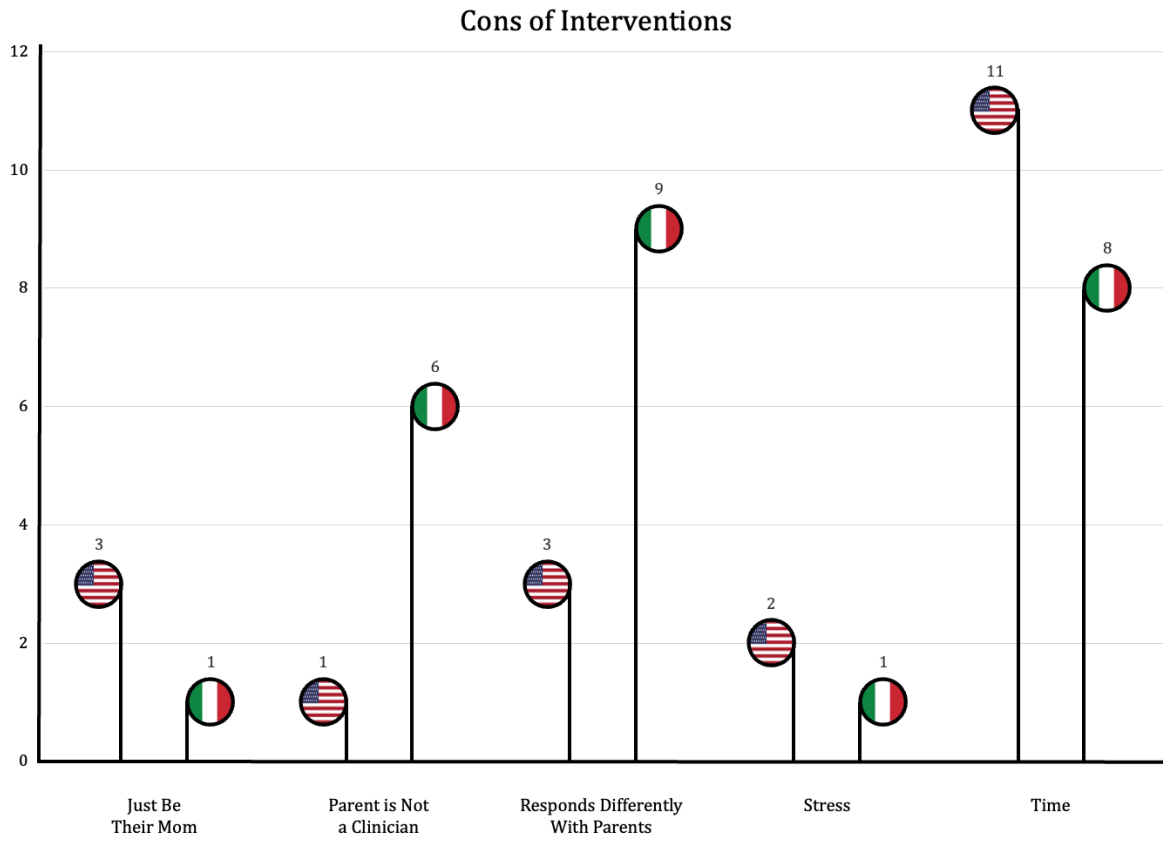
**Figure 1**  
*Daily Tasks*



**Figure 2**

*Advantages of Parent-led Intervention*





**Figure 3**

*Disadvantages of Parent-led Intervention*

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## APPENDIX A: FOCUS GROUP SCRIPT

We will begin the session by introducing the structure of the focus group, the importance of this being a safe space, and that anyone is welcome to skip a question. We will also note that we may call on people who have not provided an answer to any of the questions. The questions begin with an icebreaker about why each parent has chosen to participate.

### **Introduction/Ice Breaker:**

\*Hello everyone. Thank you all very much for joining us today, and for participating in our focus group. [Introduce ourselves.] We would like to start by asking you to introduce yourself (first name only) and tell us why you decided to participate in this focus group.

\*\*Great, thank you everyone. Next, I'd like to tell you all about our research and what we're going to be talking about today. We're interested in your thoughts and opinions about your involvement as a parent in interventions at home for your child with Down syndrome. While I do have a list of questions here to ask you, please feel free to speak freely and bring up whatever you think is important. Also, please feel free to engage with one another. We encourage you to do so.

\*\*\*Please ask any questions you might have throughout our conversation today. The discussion should **last about an hour**. Do you have any questions before we begin?

\*\*\*\*As a reminder, we would like to record our conversation. We are going to begin the recording now.

### **Discussion Questions:**

We would like to start by asking you some questions about participating in research for/about Down syndrome in general.

1. What makes you interested in participating in research?
  - a. Follow-up question: Do certain words or topics make you more interested in participating in research projects, such as executive function or socio-emotional learning?
2. What makes you less interested in participating in research?
  - a. Prompts:
    - i. Barriers related to time, childcare, distance to travel, research doesn't seem interesting/important, etc.
3. Would it interest you to participate in programs that are designed to support you as the caregiver of a child with Down syndrome?
  - a. Prompts:
    - i. Stress management, coping strategies, problem solving, parenting skills, mindfulness, education about child development/skill-building
  - b. Follow-up question: Are there specific skills or benefits that would make you more likely to opt into a parent-focused program? What interests you about that skill?
  - c. Follow-up question: Have you previously participated or considered participating in any parent-focused programs or classes designed for parents of children with DS or developmental disabilities?
    - i. If yes, what made you interested in that program/class? How did the program/class benefit you as an individual? How did it benefit your family?

- d. Follow-up question: If you were to participate in a program designed to support parents of children with DS, how much time might you want to devote to learning and practicing new skills?

\*\*\*\*\*Now we would like to ask you some questions about interventions that caregivers implement with their child at home. As our team begins to develop new interventions, we would like our work to be informed by your preferences and opinions. One new intervention that we are developing focuses on executive function, or the thinking and problem-solving skills that we use to achieve our goals and complete everyday tasks. This new intervention would help young children learn how to stay focused on tasks, remember their next steps, and complete a task from beginning to end.

4. What are some examples of daily tasks that you help your child stay focused on to complete, like getting dressed, or cleaning up toys?
  - a. Follow-up question: Are you working on developing independence in these tasks?
5. Would you be interested in personally implementing an intervention for your child at home?
  - a. Follow-up Question: What are the pros/cons?
  - b. (Poll) Which of the following types of intervention would you be most interested in implementing at home?
    - i. Educational (e.g. teaching your child a new skill)
    - ii. Activity-based (e.g. art project)
    - iii. Play-based



- b. Follow-up question: If you were participating in a research project where you were implementing an intervention from home, how much contact would you want from the research team?
    - i. Prompts: daily, weekly, as needed
    - ii. Follow-up: What methods of communication would you prefer with the research team?
      - 1. Prompts: email, phone, virtually present some of the time or all the time during the intervention
6. The purpose of our focus group today has been to understand what you as parents would be interested in or concerned about regarding participating in research related to your child with Down syndrome. Is there anything else you would like to tell us today?