



A public health approach to family supports: Empowering families of children with autism through the ECHO model

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Abstract

Children with autism spectrum disorder (ASD) often receive many direct services designed to improve their clinical outcomes. Indeed, direct service provision is critical to helping those with ASD reach their fullest potential. However, this approach often ignores the contextual factors that are likely to impact the effectiveness of those interventions. Given that a majority of the US health care system is not designed to support families, we argue (1) for taking a public health approach to supporting families and (2) that this will ultimately improve child outcomes. We use the Bioecological Theory of Human Development (Bronfenbrenner & Morris, 1998) as a model of how families, who are often responsible for coordinating care, providing in-home and long-term supports, and coordinating the services a child receives, should receive additional support. We use family well-being to frame the public health problem and review several family support programs. In particular, we use an innovative program, ECHO for Families, as an example of how families can be empowered to support their children, and how this improves family well-being. Additionally, we describe the importance of scaling up family support programs and how the ECHO for Families has been able to meet the unique

needs of a vast frontier state with limited resources. Finally, we argue that conceptualizing family supports as a matter of public health may lead to novel funding mechanisms that could improve well-being of the whole family, as well as improve outcomes for children with ASD.

The prevalence of autism spectrum disorder (ASD) has increased dramatically over the last several decades (Baio, 2012; Baio et al., 2018; Christensen et al., 2016; Maenner et al., 2020; Rice et al., 2010), resulting in significant public health burden. In fact, the projected annual cost of care for those with ASD is expected to reach \$461 billion in the United States alone (Hurley-Hanson, Giannantonio, & Griffiths, 2020). As a result, it is only natural that there has been tremendous interest in creating effective clinical interventions to improve the developmental trajectories of those affected by ASD (e.g., Coren, Ramsbotham, & Gschwandtner, 2018; Reichow, Barton, Boyd, & Hume, 2012; Reichow & Wolery, 2009). While the evidence base for many interventions continues to grow, virtually all clinical approaches to ASD have an individual child-focused approach. That is, most services are offered directly to children who have ASD. Indeed, this direct-service approach is common across a wide range of clinical disciplines including behavioral supports, occupational and physical therapy, speech-language pathology and medicine. Even multi-tiered systems of support offered through educational systems ultimately result in direct service provision (Jimerson, Burns, & VanDerHeyden, 2015).

The direct-service approach makes perfect sense given that the goal of clinical interventions is to improve specific behaviors, functioning, or other clinical presentations of the child. Even the structure of the US healthcare system is set up to focus primarily on individual children and their clinical presentation. For example, clinicians are trained to assess and treat specific clinical problems directly, our reimbursement systems (e.g., Medicaid, private insurance) pay for treatments that will improve the child's functioning when administered directly, and parents are generally eager for their children to receive as many services as possible. While direct services are critical to improving child outcomes, this focus means that other contextual factors that may impact the child and family^a functioning are largely not a target of intervention. Contextual factors could include a wide range of social

^a Note that we use the term "family" in a broad sense. This can include biological, adoptive step or foster parents, extended family, legal guardians and other important individuals that are responsible for the day to day care of a child.

systems, including school systems, healthcare systems, including both payer and practice, family employment and job security, and overall family dynamics.

While not often the target of intervention, contextual factors can have an indirect impact on children with ASD. For example, if a parent of a child with ASD is extremely concerned about the family's financial well-being due to the burden of paying for the child's treatment, this may cause the parent to take on an exceedingly large workload or a second job with the hope of increasing the family's income. Ironically, if the added workload causes the parent to focus less attention on core job-duties this could ultimately hurt the parent's overall job performance. If this leads to disciplinary action or termination, this could then negatively impact the child, even though the child has no direct exposure to those more distal systems (i.e., the parent's work environment). Further, working more might also limit the amount of time the parent has with the child at home, further reducing the amount of support the parent can provide the child to improve behaviors or functioning. Thus, it is crucial to consider how broader social systems might impact a child's development and ultimately their clinical outcomes.

Bronfenbrenner's Bioecological Theory of Human Development (Bronfenbrenner, 1977, 1979; Bronfenbrenner & Morris, 1998) provides a useful framework for conceptualizing how contextual factors impact the outcomes of children with ASD. Although, the theory underwent substantial revision up to Bronfenbrenner's death (Tudge, Mokrova, Hatfield, & Karnik, 2009), all versions of this theory point out that children exist within increasingly complex systems that influence the development of the child (Bronfenbrenner & Morris, 1998). Like layers of an onion, larger, more complex, and broader contextual systems build on the smaller and more intimate systems (see Fig. 1). Importantly, there are constant interactions between and within these contextual systems (Bronfenbrenner & Morris, 1998). The smallest unit of influence of these systems is called the microsystem, followed by the meso, exo and macrosystems. Given that the microsystem is the most proximal system to the child, it is the primary focus of this paper; although, broader systems can have important effects as well.

A large number of social structures are included at the microsystem level, including schools, caregivers, friends, and others that interact with each other and the child. Given the proximity of the microsystem to the child, the social structures within this system are particularly important to child development. That is, the more proximal a system is to a child, the more

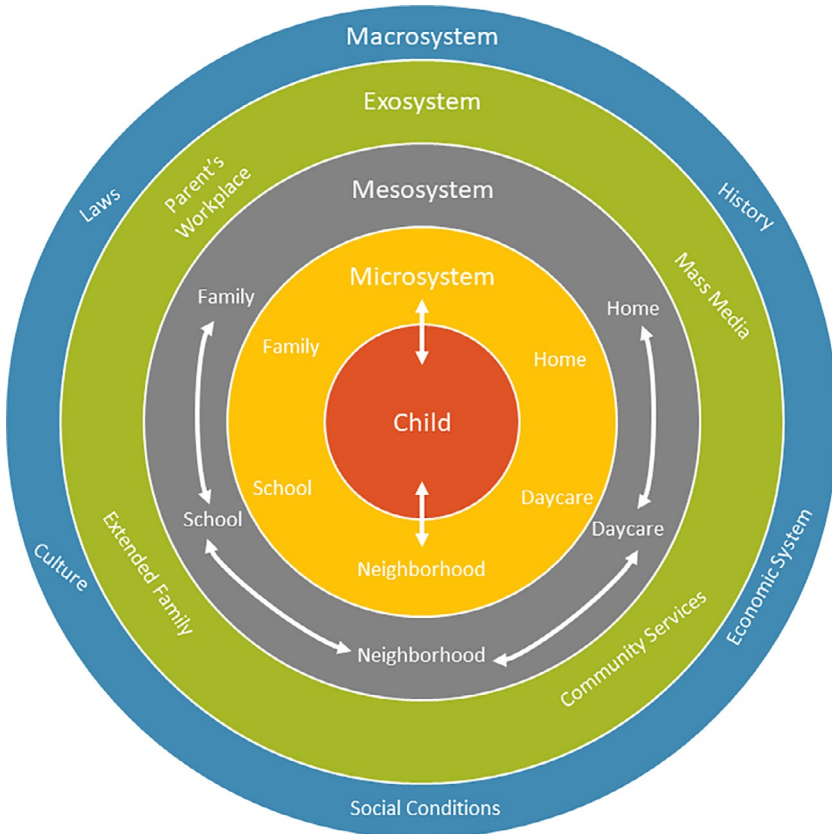


Fig. 1 The Traditional Bioecological Theory of Human Development.

that the processes that derive from those social structures are likely to impact the child's development (Tudge et al., 2009). In most versions of this theory, the family system is on par with other systems in the microsystem. For instance, families are put on equal footing with schools, and other microsystems as depicted in Fig. 1. However, we argue that given the importance of proximal processes (Tudge et al., 2009), the family system should be considered as a critical component of the microsystem, especially for younger children. In particular, the family is the system in which the child spends the most time, and the family often mediates the child's interactions with other microsystems. Therefore, it is the most proximal social structure of all microsystems. For example, parents coordinate the child's schooling, healthcare, and community interactions. They put the child to bed, help brush teeth, cook meals, play with and comfort the child. These are roles

that other structures in the microsystem cannot replace. Therefore, the family system plays a disproportionately large role in the development of children relative to other social structures in the microsystem.

Given this, we suggest that families play a unique role within the microsystem. That is, instead of being equivalent to all other social structures in the microsystems, we argue that family systems should be placed in the most proximal position to the child (see Fig. 2). That is, family systems are often the most proximal of all microsystems to the child and therefore play a mediating role between the child and other microsystem structures. Indeed, families are given a privileged place in many legal systems (e.g., the American legal system usually argues that the best interests of children is to remain with their parents, Elrod & Dale, 2008; “Meyer v Nebraska,”

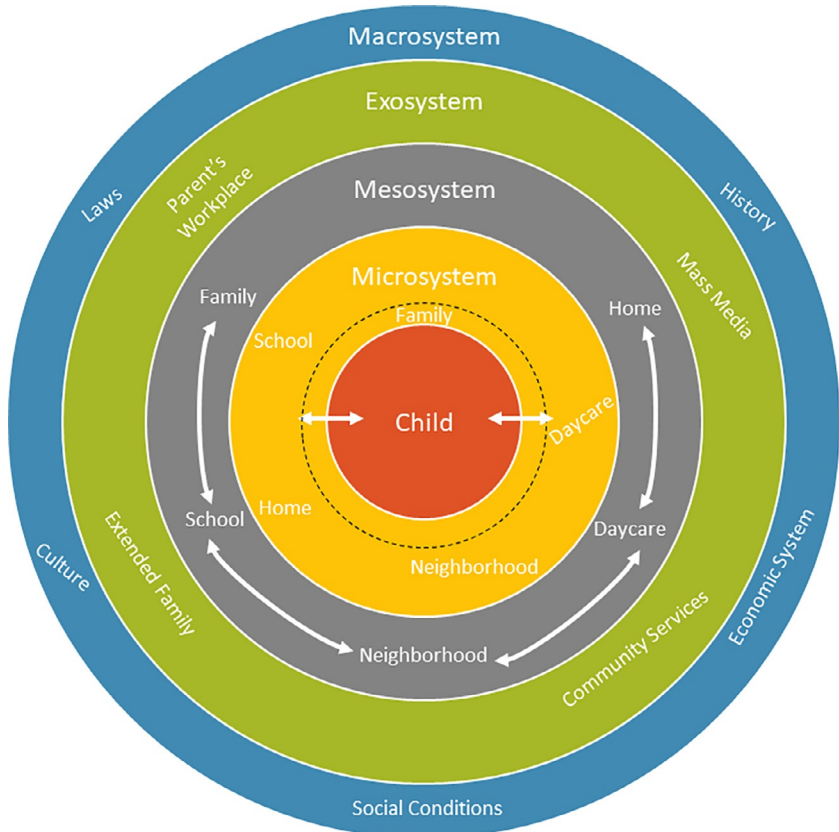


Fig. 2 The Bioecological Theory of Human Development with families situated most proximally to the child.

1923) highlighting the exceptional importance that families play in the lives of children. For example, parents must work with all the other micro-systems, whether healthcare providers, educators, or community groups, to mediate the broader impact of the microsystem on their children. Hence, parents are almost always expected to play an exceptionally proximal role in their children's lives.

Despite the critical importance of families in children's development, our healthcare system generally focuses directly on the child rather than any system surrounding the child. Certainly, some disciplines (e.g., social work; education systems) place a greater importance on families and other micro-systems, and parent-training can be a valued enhancement to existing behavioral interventions (Minjarez, Karp, Stahmer, & Brookman-Frazer, 2020; Turner-Brown, Hume, Boyd, & Kainz, 2019). For instance, the Early Start Denver Model (Rogers & Dawson, 2010) trains parents to provide supports for the child that are similar to what the clinician does, but it does not try to directly improve family functioning, family stress levels, work-life balance, or any other microsystems that provide a critical context for the child's overall development. Despite this, families of children with ASD often report that they receive little support that is designed to improve their functioning (Vohra, Madhavan, Sambamoorthi, & St Peter, 2014) and this may lead to lower levels of family functioning overall (e.g., Higgins, Bailey, & Pearce, 2005). Further, because the child's development is embedded within increasingly complex contextual environments that all interact, completely ignoring the child's family system comes with some peril. For example, consider the ambiguity parents of children with ASD must navigate. While the evidence base of effective interventions is growing, there is still relatively weak evidence to support any singular treatment (Reichow et al., 2012, updated in 2016), and each child's individual response to treatment is difficult to predict (Warren et al., 2011). Certainly, clinicians will provide recommendations that are consistent with their discipline (e.g., Stansberry-Brusnahan & Collet-Klingenberg, 2010); however, this is not a standard of care, nor is this recommendation appropriate for all children (Mottron, 2017). Moreover, there is little consensus on what treatments are most effective (Warren et al., 2011; Weitlauf et al., 2014). This means that families of children with ASD must search for the treatment(s) that will work best for their child. As a result, the average number of interventions tried per family is seven to nine (Goin-Kochel, Myers, & Mackintosh, 2007), suggesting that parents are often not satisfied with their child's progress. Moreover, there are often residual symptoms that affect their

functioning even after intervention (Warren et al., 2011). With very little information on which approach is most likely to lead to a specific outcome, parents may never know when their child's development has reached its full potential. Further, this leads to parents trying numerous interventions that may be costly and time consuming. Therefore, with little direct support to the family it is not surprising that parents often report extremely high levels of stress that can ultimately impact their own health and well-being, as well as the well-being of their children with ASD.

Certainly, direct clinical support for the child continues to be critical to ensure that every child develops to his or her full potential, which will subsequently reduce the overall public health burden of ASD (e.g., life-time cost of care, reduced health and well-being). However, ignoring the child's microsystems has the potential to negatively impact family functioning, and thereby hinder the goals of direct clinical interventions as well. Unfortunately, there is little ability for direct clinical services to devote significant resources to anything other than the child. For this reason, we advocate for a comprehensive public health approach to family supports. That is, rather than thinking of family supports as a clinical service, either as an add-on to the child's treatment or in its own right, we should consider supporting families with children with ASD as a matter of public health. This approach advocates for a systems level and iterative approach to program implementation that impacts microsystems that support the child, especially the family. As with all public health approaches, the goal is not to supplant more clinically driven services, but rather to create environments that are conducive to optimal health outcomes. In this case, public health programs promote family well-being through community-based programs which target risk and protective factors to create environments that allow the family to better support their children with ASD. This approach, combined with high-quality clinical care, has the potential to create more empowered and resilient families that are better equipped to support their child's developmental trajectory.



1. The public health approach to supporting families of children with ASD

The discipline of public health is generally concerned with promoting the health and well-being of communities, rather than direct intervention at an individual level (Frieden, 2010). This goal is achieved by reducing population exposures to factors that are known to make diseases or conditions

more likely (risk factors) and increasing the prevalence of factors that are known to protect populations from specific conditions (protective factors; Coie et al., 1993). As these interventions are targeted at communities, public health interventions primarily operate in the micro, meso, and exo system levels to reduce exposure to risk factors and enhance exposure to protective factors. Importantly, because the public health approach focuses on larger systems, it is perfectly acceptable to engage with numerous societal organizations such as education, community living systems, and other non-governmental organizations to improve exposure to risk factors. For example, a program that tries to improve the health of children who have inadequate food security could work through school systems to reduce the cost of school lunches (microsystem). A program targeting the meso-system might include neighborhood food pantries that provide access to food in areas that have few grocery stores. Here we focus primarily on the microsystem given it is most proximal to the child and the family is part of that system.

Most public health programs are developed through some sort of deliberate process that includes a rationale for how the program's activities will reduce the public health burden experienced by a community that is associated with a given condition. While there is variability in the processes used to develop and implement public health programs, generally four iterative steps are used to understand and respond to a given issue (Mercy, Rosenberg, Powell, Broome, & Roper, 1993): (1) the scope of the public health problem must be defined, including understanding key characteristics and consequences, (2) the risk and protective factors associated with the problem must be understood, (3) programs that impact the problem or its risk and protective factors must be developed and evaluated, and (4) these programs must be implemented broadly in a cost-effective way. This is a cyclical process; therefore, ongoing evaluation and monitoring of the programs' effects must be used to further refine understanding of the underlying problem, its causes, and steps that are effective to prevent it.

This general framework has been used successfully to improve public health problems, such as interpersonal violence (Rosenberg & Fenley, 1991), substance use disorder (Substance Abuse and Mental Health Services Administration, 2016), and asthma (Davis & Herman, 2011) to name a few. We will, therefore, use this framework to describe how the public health approach can be used to improve outcomes of families that have a child with ASD. This includes defining the public health problem of reduced family well-being for families of children with ASD, noting some

of the risk and protective factors, and outlining public health programs that can be used to improve this problem. In particular, as an example of how family programs can fit into this framework and positively impact communities, we will describe the ECHO for Families program offered through the Wyoming Institute for Disabilities at the University of Wyoming. This program was developed using this public health framework and is designed to primarily impact families within the microsystem level so they can be more empowered and effective at supporting their children with ASD. Given the flexibility of ECHO for Families and the ease with which it can be scaled up to meet demand from diverse communities and other disabilities, it has the potential to improve the well-being of families who have loved ones with a wide range of disabilities.



2. Raising a child with ASD and family well-being

To adopt a public health approach to family supports for ASD, the public health problem must first be identified. The literature on families of children with ASD provides numerous descriptions of how having a child with ASD can increase parental or family stress (Troy, Connolly, & Novak, 2007), reduce quality of life (Brown, MacAdam-Crisp, Wang, & Iarocci, 2006; Ezzat, Bayoumi, & Samarkandi, 2017) and impact parent mental health (Benson, 2010, 2012; Jellett, Wood, Giallo, & Seymour, 2015). Given that there are a wide range of factors that relate to these outcomes, we use the concept of *well-being* to describe this public health problem. That is, having a child with ASD may negatively impact a family's well-being. Well-being is a broad concept which encompasses an array of social, physical, emotional, and economic components and is of primary concern for families who have children with ASD. For example, a recent scoping review (Tint & Weiss, 2016) revealed that poor family well-being is associated with several problematic outcomes, including decreases in mental and physical health, feelings of social isolation, and financial hardship or burden. Moreover, many risk factors disproportionately impact the well-being of families of children with ASD (Herring et al., 2006; Oelofsen & Richardson, 2006; Tehee, Honan, & Hevey, 2009; Woodman, 2014). Importantly, many factors associated with reduced well-being are contextual factors that are situated in the microsystem. Therefore, it is imperative to consider broader public health approaches that are more able to mitigate these contextual challenges when developing programs focused on helping

families as well as programs that focus on delivering services to the family unit as a whole rather than the child alone.

The risk and protective factors associated with family well-being are quite diverse. One particularly problematic impact on family well-being results from financial hardship (Herring et al., 2006; Oelofsen & Richardson, 2006; Tehee et al., 2009; Woodman, 2014). Financial hardship is a known predictor of parental stress for families of children with disabilities (Minnes, Perry, & Weiss, 2015) and unfortunately, families of these children are more likely to face financial hardships due to the unique caregiving needs of their children. For instance, there are significant differences in income levels between families with children who are delayed and families with non-delayed children (Baker, Blacher, Crnic, & Edelbrock, 2002). Reduced family income could be due to one parent having to stay at home to care for their child with ASD (Blanche, Diaz, Barretto, & Cermak, 2015; Brobst, Clopton, & Hendrick, 2009; Horlin, Falkmer, Parsons, Albrecht, & Falkmer, 2014) or because of the added financial burden associated with paying for interventions and services for their child. Indeed, the lifetime cost of caring for individuals with ASD is enormous, ranging from 1.4 to 3.6 million dollars per individual (Buescher, Cidav, Knapp, & Mandell, 2014; Cakir, Frye, & Walker, 2020). Although this figure includes public funding, there is a significant cost to families as well (Buescher et al., 2014; Horlin et al., 2014; Knapp, Romeo, & Beecham, 2009). While income and care costs vary widely, this means that families of children with ASD will be at risk for decreased well-being as a result of financial issues. Further, while many public health programs do address indirect aspects of financial difficulty such as vocational rehabilitation and job training for the child with ASD, the issues directly pertaining to financial hardship that would improve family well-being (e.g., direct support related to reduced family income) may not be effectively addressed, resulting in a lack of effective change for the family unit.

Social stigma is also a major risk factor for the well-being of families with children with ASD. While parents often report that receiving an ASD diagnosis for their child is a positive incident because it allows them to resolve parenting concerns, the ASD diagnosis can also lead to feelings of separation from the rest of their community. Reports of losing friendships following their child's diagnosis or being disconnected from others who do not have a child with ASD is unfortunately common (e.g., Farrugia, 2009; Kinnear, Link, Ballan, & Fischbach, 2016). This may be due, in part, to a lack of acceptance or understanding of ASD in the surrounding community which

frequently seems to result in social stigma (Farrugia, 2009). Ultimately, this contributes to feelings of social isolation and exclusion for families of children with ASD (Kinnear et al., 2016) and reduced social engagement in typical social opportunities because of their caregiving responsibilities or misunderstandings regarding the appropriateness of their child's behavior (Marsack & Perry, 2018; Myers, Mackintosh, & Goin-Kochel, 2009). This stigma and social isolation similarly extends to typically developing siblings of children with ASD (Myers et al., 2009), who can also experience reduced well-being (Chan & Goh, 2014; Dauz Williams et al., 2010).

Beyond social isolation and stigma, a family's inability to access services that are most appropriate for their child can be extremely challenging. First, service systems are so complex that many families struggle to access ASD-specific services without the assistance of care coordinators (Vohra et al., 2014). Indeed, families must interact with a wide range of service systems, including healthcare providers (e.g., medicine, allied health, dental and mental health), payors (e.g., insurance and Medicaid), educational systems (Part B and C, special education, IEPs and 504 plans), vocational support programs, and legal systems (e.g., guardianship, advocacy). Challenges to accessing supports is further compounded with limited income and insurance coverage (Pearson & Meadan, 2018). Additionally, the lack of clear information about the most effective services for their child can harm overall family well-being as individualizing care to meet their child's specific needs is incredibly difficult for most families of children with ASD (Anderson, Lupfer, & Shattuck, 2018). To further complicate this issue, there may be geographic barriers to accessing care. For instance, families in rural states often have to travel much further to receive frontline services such as applied behavior analysis and speech-language pathology relative to their non-rural counterparts (Mello, Goldman, Urbano, & Hodapp, 2016; Pearson & Meadan, 2018). Additionally, given that response to treatment is difficult to predict in children with ASD (Warren et al., 2011) and that most families try upward of seven different types of interventions to improve outcomes (Goin-Kochel et al., 2007), scarcity of information about which services would be most effective (Warren et al., 2011; Weitlauf et al., 2014) could exacerbate any negative impacts of accessing services on family well-being.

It is also important to note that along with all of these contextual impacts on family well-being, child behavioral problems continue to be an important risk factor for decreased family well-being. For example, child executive functioning difficulties and social impairments are contributors to parental stress (Tsermentseli & Kouklari, 2019), and a larger number of behavioral

problems and more pervasive behavioral problems are strongly associated with higher levels of parental stress (Burke & Hodapp, 2014; Firth & Dryer, 2013; Herring et al., 2006; Plant & Sanders, 2007; Robinson & Neece, 2015; Woodman, 2014). Moreover, the type of disability present in a child can be indicative of how much stress is faced by parents. Specifically, there seems to be higher levels of parental stress for families of children with ASD relative to other intellectual and developmental disabilities (IDD; Burke & Hodapp, 2014; Hayes & Watson, 2013; Kirby, White, & Baranek, 2015). The unique caregiving aspects associated with the behavioral problems in children with ASD can also impact well-being in that higher difficulty of caregiving is associated with higher levels of parental stress (Plant & Sanders, 2007). Therefore, clinical intervention continues to be a critical part of improving the well-being of families. Although, this process is most effective when families are involved (Salazar, 2020) and parents may have goals for their children that may not be effectively addressed by certain clinical interventions (Singh, Moody, Ricles, & Smith, 2018). Thus, it is important for clinicians and parents to have a robust and meaningful partnership as the child's needs are addressed.

Fortunately, there are also a number of protective factors that safeguard families of children with ASD against decreases in well-being. Self-compassion (Robinson, Hastings, Weiss, Pagavathsing, & Lunsky, 2018), hardiness (Weiss, 2002), sense of competency (Weiss, Tint, Paquette-Smith, & Lunsky, 2016) and maternal positivity (Jess, Totsika, & Hastings, 2018) are all associated with well-being in that greater levels of these factors are correlated with lower levels of parental stress. While some personal characteristics, such as these, can prove difficult to change on their own, parental empowerment that is developed through parental support is also a strong predictor of family well-being (Guralnick, Hammond, Neville, & Connor, 2008; Minnes et al., 2015; Plant & Sanders, 2007; Woodman, 2014). Moreover, this protective factor is more easily modified than are personality characteristics. That is, parental support can be introduced at any time in order to increase a family's sense of empowerment, thus protecting against stress and improving well-being. Most frequently, this form of support is provided through an expansion of community resources, a network of knowledge, and access to other parents who have had a similar experience, which reduces feelings of social and/or geographical isolation (Guralnick et al., 2008; Plant & Sanders, 2007; Woodman, 2014). Parental support has been shown to predict successful levels of adaptation (Weiss, 2002), increase parental resilience (Peer & Hillman, 2014), and can even predict parental stress in a child's elementary school years (Guralnick et al., 2008).

While there are numerous risk and protective factors that impact family well-being, it is important to remember that there are complex relationships between the involved social structures that may not easily be altered. For example, many clinical interventions—while providing expert care to the child with ASD and focusing on risk factors such as behavioral problems—often do not sufficiently address familial concerns that contribute to well-being as only a small number of these contributors can be addressed by clinical interventions or trainings. For example, Applied Behavior Analysis (ABA), child toilet trainings, and behavioral interventions can address some child behavioral problems while psychosocial therapy can improve parents' mental health. However, support that is only offered within clinical systems is likely to conform to the limits and structures of the healthcare system and will, therefore, focus predominantly on a limited subset of the factors that impact parent stress and well-being.

Further, there are likely to be residual symptoms that cannot be eliminated by direct clinical services (e.g., stimming) and thus should be addressed within the family setting, or microsystem to alleviate parental stress and improve family well-being. Considering the malleability of parental support and its contributions to well-being as established by previous literature, this is an important opportunity for family support programs to help families of children with ASD to improve outcomes. Given that the current approach to clinically supporting children does not usually have concomitant effects on the parents or family, we argue that there should be a shift in how family supports are structured.



3. Public health programs for families of children with ASD

With the scope of the public health problem identified, the next step is to examine strategies and develop public health programs that address that need. Given the diversity of factors contributing to family well-being, it is critical that programs are able to respond to the range of needs a family may face. Direct clinical intervention will continue to address child behavioral characteristics through our existing healthcare systems. However, many of the risk and protective factors are part of microlevel systems that cannot be easily impacted through a clinical approach. As such, many family support programs have been developed to provide parents with tools to help their child and family succeed. For example, inclusion programs (Baker-Ericzén, Brookman-Fraze, & Stahmer, 2005), parent education, intervention, training, and support groups (Al-Khalaf, Dempsey, & Dally, 2014; Iida

et al., 2018; Kuravackel et al., 2018; McConkey & Samadi, 2013; Niinomi et al., 2016; Turner-Brown et al., 2019), respite care (Chou, Tzou, Pu, Kröger, & Lee, 2008), home-based support services (Heller, Miller, & Hsieh, 1999), and center-based trainings (Roberts et al., 2011) are forms of programs that have been developed for families of children with ASD or other related IDD.

Programs of this nature appear to be highly acceptable and have encouraging outcomes data on well-being. These existing programs seem to improve family functioning (Moody et al., 2019), reduce parental stress (Al-Khalaf et al., 2014; Baker-Ericzén et al., 2005; Heller et al., 1999; Niinomi et al., 2016; Turner-Brown et al., 2019), increase parental satisfaction with community functioning and service needs (Heller et al., 1999), improve parents' mental well-being (Iida et al., 2018; McConkey & Samadi, 2013; Roberts et al., 2011; Turner-Brown et al., 2019), enhance parental feelings of social support (Kuravackel et al., 2018), and increase self-reported quality of life (Niinomi et al., 2016; Roberts et al., 2011). There is even evidence that impacting family functioning can lead to decreases in children's problematic behaviors (e.g., Iida et al., 2018; Kuravackel et al., 2018), further suggesting that improving microsystem factors can improve child functioning. Indeed, this emphasizes the interaction between contextual factors and the child's development and provides additional confirmation that supporting families is critical to the outcomes of the whole family unit.

While there are numerous family support programs available, those that are most likely to have lasting and meaningful impact on families, and their children, are those that enhance family-empowerment (Ashcraft et al., 2019; Factor et al., 2019). Family-empowerment refers to the degree to which parents feel in control of the decisions and choices related to the health of their child (Ashcraft et al., 2019). More importantly, family-empowerment is associated with several outcomes that enhance parents' ability to support their children, including increasing involvement in daily care, symptom management, enhanced advocacy and decision making (Ashcraft et al., 2019). Not only does family-empowerment have significant impacts on children, but programs that enhance empowerment are generally highly regarded by parents, and therefore more likely to encourage sustained participation. Additionally, programs that are able to incorporate numerous aspects of the child's microsystem—for example, their medical provider, their educators, and their parents—may be more effective in creating a strong sense of family empowerment. One novel and innovative parent-support program

that is designed to enhance parent-empowerment, called ECHO for Families, leverages a larger capacity building model called Project ECHO™.

The ECHO Model was originally created to address the lack of access to specialized care for patients with hepatitis C across the state of New Mexico (Arora et al., 2007, 2011, 2014; Arora, Thornton, Jenkusky, Parish, & Scaletti, 2007). Employing a hub-and-spoke design, hepatitis C specialists at the hub would provide training to other healthcare providers at spoke sites. Employing video-conferencing technology, participants and experts would meet from all around the state to learn from and teach others through didactic presentations, case-based learning, and mentoring through the formation of a community of practice. Specialists at the hub-site would present a didactic training on a topic of interest while participants interact through questions and discussions. Participants at spoke sites would have the opportunity to present a case regarding a current problem of practice or challenge. The specialists at the hub as well as other participants at spoke sites would then provide recommendations and suggestions for addressing the concerns of the practitioner.

In this way, participants receive personalized support to help them provide the specialized care their patients need without requiring patients to travel long distances or wait for months to see specialists. During ECHO sessions, hub and spoke participants engage in two-way sharing of knowledge and experience as well as mentoring and a social support network developed through this community of practice (Arora et al., 2011, 2014; Arora, Geppert, et al., 2007; Arora, Thornton, et al., 2007). The ECHO Model has since been adopted by many organizations and institutions and has been used to address other health disparities such as mental health (Fisher et al., 2017; Mehrotra et al., 2018; Sockalingam et al., 2017), education (Root-Elledge et al., 2018), and a wide array of medical concerns (e.g., pain management, Ball, Wilson, Ober, & Mchaourab, 2018; geriatrics, Bennett et al., 2018; cancer, Lopez et al., 2017). Most recently, the Wyoming Institute for Disabilities has adapted the ECHO model to create ECHO for Families. This network provides families of children with ASD with additional support to improve empowerment via the same four elements as all ECHO networks: (1) short information sessions delivered by experts on topics of need in the community, (2) presentations from the community about issues they are currently facing, (3) delivery through teleconferencing technology so that participants can join regardless of their location, and (4) ongoing evaluation to ensure that the content of the network continues to meet the needs of participants.

ECHO for Families is an exciting innovation in family supports for several reasons. First, it is a parent-empowerment based model. The whole program is designed to provide parents with resources that they can use to make decisions on their own terms. This is accomplished by providing high-quality information as well as providing them with connections to other parents who share their experience. This allows for the creation of meaningful community among participants and allows each participant to advocate for their child as they see fit. Further, because they are provided a venue to talk about the challenges they are currently experiencing, parents are able to develop actionable strategies to address those challenges. Further, because the content of each ECHO for Families session is set by the participants, the program is able to adapt to the changing needs of the community. This is all accomplished without direct clinical intervention, and instead focuses on risk and protective factors associated with microsystem structures. Therefore, this model employs a public health framework to support families of children with ASD. ECHO for Families will be described in more detail below.



4. The problem of scaling up family support programs and the unique approach of ECHO for families

The final step in the public health approach is to scale up the program so that it can reduce the public health burden more broadly and therefore impact the population as a whole. Critically, scaling up allows for the benefits of this approach to be impact public health. Yet, this step in the public health process is arguably the most challenging for family support programs. Many of the barriers to the scaling-up process require systems-level changes, or even shifts in societal thinking about the role of family supports. However, while challenging, these are not insurmountable challenges and we argue that creating a more favorable landscape for the implementation of family support programs is the most important factor in improving family well-being for those who have children with ASD. For instance, the public health approach to public health may lead to accessing novel funding streams, such as through state, local or federal public health agencies, implementation grants or similar mechanisms.

That said, it is important to understand the barriers to scaling up family support programs. For instance, by nature of the diversity of risk and protective factors that impact family well-being, most programs are not able to impact all risk and protective factors. As a result, there are a wide range

of family programs that are designed to focus on a subset of factors associated with family well-being. This approach can be extremely beneficial to parents experiencing a particular risk factor at a specific time. For instance, a family that needs respite care immediately may derive enormous benefit from a program that can provide this service. However, family needs may change, and other risk and protective factors may not be addressed by a given program. As a result, the family may still experience decreases in overall well-being despite positive impacts on a subset of risk or protective factors. This also means that the family may need to have access to a diverse family programs so they can access different services as their needs change. However, this puts the family back in the position of needing to coordinate a variety of services, similar to what they face with their child's clinical care.

Second, the funding mechanisms used to sustain family support programs are often challenging. For example, these programs are frequently funded through charitable contributions or grants and may not have a reliable revenue stream. As a result, many family support organizations may struggle financially, which may make it difficult for these organizations to remain solvent, let alone scale up their programs. This ultimately results in many family support programs struggling to help all families in need of their services (Heller et al., 1999; Hudson, Cameron, & Matthews, 2008). Of course, financing of healthcare services is a complex and critical issue right now. However, in the absence of reliable revenue streams such as reimbursement through insurance or Medicaid, many families may not have the financial resources to pay for the real cost of some family services (e.g., Hudson et al., 2008).

Additionally, the format of many existing family support programs can present issues for scaling up programs to meet the needs of rural or low-resource families. For instance, many programs are based on in-person trainings, and interventions may rely on a family's ability to attend all sessions. However, resource limitations such as problems with finding a caretaker, an inability to travel long distances, and rural isolation (Kuravackel et al., 2018; Turner-Brown et al., 2019) can impair the potential effectiveness of these programs and make it impossible to scale these models up to the whole community. Further, as with clinical treatments, the idiosyncratic nature of ASD can also present a barrier to success, as there is often a lack of fit between standardized programs and the specific needs of some children and families (Roberts et al., 2011). Thus, many families need to explore numerous programs to determine an appropriate fit for their child, but this may be difficult to accomplish if access to programs or resources is limited.

Finally, even when implemented within clinical programs, problems arise in relation to sustained funding, conflict between clinical structures, and the appropriate place of family advocacy or support within those structures.

Although scaling up programs may be difficult, it is possible. However, to be successful, programs must develop innovative delivery models that allow for greater impact, and they must be built on strong partnerships with the community and funders to ensure that the impact can be sustained. One example of this is the University of Wyoming (UW) ECHO for Families of children with ASD. This network was developed in 2018, in collaboration with families from around the state of Wyoming to ensure that it would meet their current needs. Accordingly, the network's identity was crafted with direction from families as they identified what they wanted to achieve through participation in an ECHO network. Additional input was gathered from state agencies, community organizations and autism experts to ensure that the content would be relevant for state systems and was consistent with current best practices. ECHO for Families is guided by a family-determination perspective that is built on the belief that families are in the best position to identify what they need and can determine what strategies or resources to use to improve their well-being. The formation of the network, the session training, topic planning, and the case presentation feedback and suggestions are all guided by this belief.

ECHO for Families sessions utilize the same format as the original medical model for ECHO: a didactic presentation followed by a case presentation, delivered over video conferencing (e.g., Zoom™) with ongoing program evaluation. The only changes made in this adaptation of the ECHO model (1) were modifying the language used to remove clinical terminology in order to become more family-friendly and (2) adding procedures to ensure the confidentiality and safety of participants. For example, "didactic presentations" became "training topics" and "case presentations" became "family narratives." Additionally, participants are repeatedly informed that this is not a clinical service, and measures were taken to allow family members to present cases. However, all other features of the ECHO sessions remain the same: the cultivation of a community, two-way exchange of knowledge and ideas, and personalized support through mentoring and a social support network.

The goal for each ECHO session is to address a concern identified by families and provide actionable, high-quality health information so that families can utilize their learning immediately. Training topics have included behavioral strategies, transition planning, self-advocacy, workplace

readiness skills, social skills, and roles and responsibilities at IEP meetings, among others. Family narratives have varied widely and have touched on a number of situations and challenges. Morning routines, behavior struggles, parent-teacher coordination, family-agency coordination, advocating for needs, and many others have been topics of family narratives. Importantly, family narratives are always about a concern that a parent is currently facing, regardless of the day's training topic, and the whole network is given an opportunity to provide suggestions based on their own unique experiences. While content experts are available to provide guidance on best practices, this model is based on collaborations among parents, rather than professional recommendations.

As such, the success of ECHO for Families depends on strong family-professional partnerships that use the belief in family-determination as a guidepost. While this ECHO network is focused on supporting families of children with ASD, it is often the case that individuals from different professions who work with these families are also in attendance. For example, behavioral specialists, case managers, social workers, special education teachers, and many others have attended ECHO for Families sessions, either as training presenters, content experts, or simply as participants interested in working with families in this community of practice. Importantly, the quality of family-school partnerships is incredibly impactful on parental well-being (Burke & Hodapp, 2014) given that the school transition period (i.e., transitioning an adult child out of school) is highly correlated with greater levels of stress (McKenzie, Ouellette-Kuntz, Blinkhorn, & Démoré, 2017). Thus, by including a wide variety of specialists in ECHO sessions, obstacles relating to a child's school environment or transition period can be sufficiently addressed with direct support from relevant professionals.

While the ethos of ECHO for Families is important, the ECHO model has been key to scaling up the program to reach the whole state, and region. In particular, the ECHO model is based on teleconferencing technology. This allows for substantial cost and time savings to parents. For instance, Wyoming, the primary implementation site for ECHO for Families, is a large, sparsely populated state and, with the exception of Cheyenne and Casper, most communities are considered rural or frontier (Wyoming Department of Health, 2020). With the use of videoconferencing technology as the primary mode of conducting ECHO sessions, the ECHO Model is uniquely situated to reach far more communities around the state of Wyoming than would be possible with programs that meet in-person. Families do not need to travel in order

to attend sessions and can join from wherever they may be, which minimizes the indirect costs to families to participate (e.g., childcare, commute time, travel expenditures). This is particularly important during the winter months in which there are frequent storms and road closures. The negative effects of social and geographical isolation are also mitigated through the cultivation of this community of practice.

Further, ECHO for families is an extremely cost-effective strategy which makes it attractive to funders who are primarily interested in maximizing the impact of each dollar used by the program. For instance, after initial costs for staffing and equipment, there are few additional costs required to expand ECHO programs. In terms of the equipment needed, hubs are encouraged to outfit a videoconferencing space where the hub team can facilitate ECHO sessions with video and audio, though this is not required. Hub team members can meet from their personal devices, many of which may already be equipped with video cameras and microphones. After initial setup, there are few costs for expanding an ECHO network and facilitating additional ECHO sessions or even creating additional ECHO networks focused on addressing other health disparities. Though, as ECHO programs expand and begin facilitating several networks, additional staff may be needed. As for equipping participants, depending on the videoconferencing platform chosen by the program coordinators, all that is usually required is an internet connection. According to the Pew Research Center, 90% of adults in 2019 have access to an internet-capable device, and this number is expected to continue to grow (Pew Research Center, 2019). Programs may choose to allocate funds for video cameras and microphones to be sent to participants in need. Other programs may elect to make other arrangements that are either free or low-cost such as arranging for local libraries or community college campuses to provide computer access during the scheduled ECHO sessions.

While the ability to reach a large number of families in a cost-efficient manner makes this model attractive, it must still be appealing and useful to the families that use the program. Program evaluation data suggests that parents and family members find ECHO for Families valuable and worthwhile. For example, participants from the 2018–2019 ECHO for Families network reported increases in knowledge and skills to use new strategies (see Table 1) as well as increased motivation for and implementation of new autism strategies (see Table 2). More importantly, families reported feelings of self-efficacy and a connection to other families (see Table 3). Qualitative interviews with participants of the ECHO for Families network

Table 1 Participant self-rating of knowledge and skills from the 2018–2019 ECHO for families network.

Knowledge/skill	Mean post-level	Mean retrospective pre-level	Mean difference	SD	t	n	P value
Structuring directions	3.96	3.08	0.89	1.03	4.37	26	<0.001
Setting up effective and appropriate consequences	3.85	3.19	0.65	1.09	3.05	26	0.005
Giving positive feedback to children	4.38	3.92	0.46	0.86	2.74	26	0.01
Teaching rules, routines, and expectations	4.04	3.62	0.42	1.03	2.10	26	0.05
Strengthen relationships/ connecting to child to prevent behavior	3.88	3.50	0.39	1.17	1.68	26	0.11
Transition planning	3.35	3.00	0.35	1.02	1.74	26	0.10
Self-advocacy and student-led IEP meetings	3.35	3.04	0.31	0.79	1.99	26	0.06
Workplace readiness skills	3.15	2.77	0.39	0.70	2.81	26	0.01

Table 2 Participant increases in knowledge, skills, motivation, and use of new strategies from the 2018–2019 ECHO for families network.

As a result of your participation, to what extent...	% Who said...					
	"Did not participate enough"	"Hardly at all"	"A little bit"	"Some"	"Quite a bit"	"A lot"
Has your knowledge about autism increased?	7.7%	11.5%	23.1%	30.8%	15.4%	11.5%
Have your skills related to autism increased?	15.4%	11.5%	15.4%	38.5%	7.7%	11.5%
Has your motivation related to autism increased?	11.5%	7.7%	11.5%	42.3%	11.5%	15.4%
Have you implemented any autism strategies at home?	11.5%	11.5%	15.4%	38.5%	11.5%	11.5%

Table 3 Participant ratings of self-efficacy and connectedness from the 2018–2019 ECHO for families network.

Statement	% Strongly disagree	% Disagree	% Agree	% Strongly agree	% Not applicable
“I am planning to try something I’ve learned today.”	0%	3%	33%	58%	6%
“I believe I can successfully apply what I’ve learned today.”	0%	1%	36%	58%	5%
“Attending today’s session has helped me feel connected to other families.”	0%	4%	40%	47%	9%
“I feel like I have expanded my network by participating in today’s session.”	0%	6%	40%	46%	8%

further support the program’s impact on family well-being. Notably, anecdotal reports from parent participating in ECHO suggests that it reduces stress, improves community connections, increases social support, and result in higher self-efficacy for families. Even for parents with lower levels of self-reported familial stress and higher degrees of knowledge relating to ASD prior to participation in ECHO, the increases in confidence gained through participation, mainly because of the opportunity to expand their personal and professional networks, enabled families to feel more confident in their decision-making. As stated by one participant, ECHO “provides an ‘extra layer’ of knowledge to help inform decision-making.” Additionally, in considering the differences between clinical interventions and ECHO for Families, while participants did acknowledge the importance of clinical interventions, they also noted that parent education is often lacking, whereas ECHO focuses on parent education. Further, ECHO allows for real-life skill building, and can even “trigger ideas or intentions related to clinical treatment or outcomes,” as detailed by one participant. In other words, clinical interventions are like the “medicine” while ECHO is the “therapy,” and the combination of the two results in better outcomes relative to clinical outcomes alone.

Overall, from evaluation and interview results, it appears that ECHO for Families is able to provide social support to families, which may lead to increased confidence in decision-making, knowledge of trainings and interventions, and reduced levels of stress. Thus, ECHO for Families addresses challenges with family well-being and provides appropriate supports to reduce the impact of risk factors and stressors related to having a child with ASD. Simply put, as a public health approach to family supports that is based on family empowerment, ECHO for Families offers a non-clinical alternative to parents that delivers actionable information which is relevant to the family's current needs. Further, this allows for families to make choices based on their own desires while assuming family outcomes are the result of complex interaction of knowledge, emotional and social support, access to resources, and sense of competence.

Also, it is important to note, the ECHO Model is easily adaptable and can be used to address a number of other family concerns. For example, the ECHO for Families network has addressed in-home behavioral supports, IEPs versus 504 plans, transitions to the workforce, sibling and spousal issues, navigating healthcare systems, and even emotional difficulties. WIND has scaled up the ECHO for Families program to help support families of children with other special healthcare needs. For example, families of children with ADHD, depression, and intellectual and development disabilities can also attend the ECHO for Families sessions for support. Given the prevalence of IDD in children, approximately 1 in 6 (e.g., [Boyle et al., 2011](#)), and the issues with residing in geographically or socially isolated areas, ECHO for Families provides an exciting opportunity for parents of children with other conditions who have similarly experienced impediments to family well-being.



5. Conclusion

Children with ASD will continue to need direct clinical intervention to improve developmental outcomes, specifically behavioral problems, especially when considering how the US healthcare system refers and reimburses clinicians based on direct-support services. However, there is little evidence for best practice in clinical interventions, with many families of children with ASD left to experiment with different interventions until they find the right fit for their child. Clearly, more research is needed to develop individualized, evidence-based clinical interventions for children with ASD. Yet, this cannot come at the expense of family well-being.

Due to the lack of a clear standard of care based on strong research, parents may struggle to determine when their child has reached full growth potential. However, the Bioecological Theory of Human Development (Bronfenbrenner, 1977, 1979; Bronfenbrenner & Morris, 1998) and public health frameworks (Mercy et al., 1993) provide support for enhancing contextual factors in a child's microsystem in order to improve overall family well-being. In fact, enhancing family well-being, especially through empowering the family to be an effective caregiver in a way that makes sense for their unique family circumstances will ultimately benefit the child. Parental support programs that are built on an empowerment approach will reduce the public health burden as well as the lifetime cost of care for those with ASD. But more importantly, it will improve the lives of families of children with ASD, including the outcomes of the children themselves.

Therefore, we argue for the adoption of a public health approach to family supports. By doing so, this will create healthcare, educational and community systems that will be more effective at delivering care to the child with ASD, supporting development, and ensuring that the family will be able to effectively mediate the child's ongoing development and care. Further, this approach allows existing interventions to be more impactful (e.g., Iida et al., 2018; Kuravackel et al., 2018; Salazar, 2020), especially as they are scaled up. ECHO for Families is one example of how public health programs can effectively and efficiently support families. ECHO for Families also has the added benefit of being flexible enough to work within rural or urban settings, and the ability to focus on a variety of changing family needs while still empowering parents to develop skills to support their children. However, regardless of the program, by reconceptualizing family supports as a matter of public health, we will create environments that promote the health and well-being of the families, while empowering the family to create change within their microsystem that leads to better outcomes for their children. This is the goal for all children with ASD; however, no single intervention can accomplish this on its own. Families will continue to be central to reaching this objective. By empowering families to be effective partners with the clinical community we can better achieve our common goals and create the social structures that will lead to the best outcomes for all those touched by ASD.

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