# Providing Interventions for Young Children With Autism Spectrum Disorders:

## What We Still Need to Accomplish

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Over the past 25 years, we have learned a great deal about the diagnosis, treatment, and impact of autism spectrum disorders (ASD) on young children and their families. The authors describe several overarching themes that have emerged in the educational research on young children with ASD. The focus of their article is on education-based research because public education remains the one comprehensive service to which all children with ASD are entitled to free of charge. Four themes (i.e., inclusion, systematic and effective instruction, intensity, and social context) are described in terms of the major findings and impact on policy and practices. The authors conclude with a summary of implications for future research for the next 25 years.

*Keywords:*   autism spectrum disorder; early intervention; inclusion; preschool

It has been almost 25 years since Ivar Lovaas (1987) published his influential article describing the results of the Young Autism Program at University of California, Los Angeles. In that article, he suggested that, as a result of 40 plus hours a week of home-based behavioral intervention, relying primarily on discrete trial training, 9 of the 19 children in his experimental group entered first grade and were indistinguishable from their typically developing peers. Lovaas stated that these children "recovered" (p. 7) from autism spectrum disorders (ASD). Whether one is convinced by the data reported in his article or the many replications, reviews, and meta-analyses that have followed (e.g., Odom, Boyd, Hall, & Hume, 2010; Reichow & Wolery, 2009; Warren et al., 2011), the 1987 article marked a change in how researchers, advocates, families, and practitioners talked about ASD. For many, this article and related research changed ASD from an untreatable disability to one that, with early and intensive intervention, was amenable to specialized treatment.

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We have learned much in the last 25 years about ASD, its diagnosis, treatment, and how this interesting disability is viewed by society. We do know that children with ASD who receive high-quality education and support early *and* throughout their life can be successful. We know that the number of children diagnosed with ASD continues to increase and that the amount of resources (e.g., time, money, and personnel) needed to support adults with ASD, especially those who do not benefit from early intervention (EI), is staggering (Ganz, 2007). Some things have not changed. We still do not know what causes ASD (although we know some things that do not). We still do not know why some children respond to interventions and others with similar profiles do not. Moreover, we still do not know why people selling nonconventional interventions and theories seem to be attracted to ASD more than to other disabilities. We also know that public education, as articulated under the Individuals With Disabilities Education Act (IDEA), continues to be the one comprehensive service to which all children with ASD are entitled and have access to without charge.

The purpose of our article is to propose some overarching themes that have emerged from the last 25 years of research and practice in the area of EI for children with ASD. Our themes come from reviewing the educational literature about early intensive behavioral intervention (EIBI) for children with ASD. We are not as interested in studies and services conducted in clinical settings, but rather, those that are provided by educators in schools and community settings. Therefore, the themes that we identified for discussion are as follows: inclusion, systematic and effective instruction, intensity, and social context.

## Inclusion Issues

Although the last 25 years has witnessed considerable research progress in determining how to maximize the developmental potential of inclusive settings for children with ASD, it is not at all clear that significantly greater numbers of children are included in early childhood settings. Not only is access to inclusive settings a cornerstone of federal legislation but also as we argue below, it is an administrative arrangement necessary for delivery of powerful, effective intervention strategies in the social development domain. What exactly has been learned about young children with ASD and inclusionary practices? Six major findings have emerged, including the following:

1. Children with ASD have been shown to make gains in language, social skills, cognition, engagement in routines, and reductions in ASD symptoms in inclusive settings (McGee, Daly, & Jacobs, 1994; Strain & Bovey, 2011).
2. When children with ASD are in physical proximity to other children with ASD their autistic-like behaviors increase (Strain, 1983).
3. Typical children in these settings have shown only positive outcomes from such inclusive experiences (Strain & Hoyson, 2000).
4. Serious topographies of problem behavior have been addressed successfully in inclusive environments (Horner, Carr, Strain, Todd, & Reed, 2002).
5. It is not true that only "high functioning" children with ASD have benefitted from inclusion (Strain & Bovey, 2011).

6. By far, the most widely replicated strategy (peer-mediated intervention) for addressing the core social behavior deficits in children with ASD relies on the daily presence and formal training of typical children (Strain & Bovey, 2011).

The data are clear. The opportunity to interact successfully, not just be in the same room, with typically developing peers on a regular basis is a necessary component of effective intervention programs for all children with ASD, especially young children. This requirement for social interaction with typically developing children as an ongoing part of intervention is essential for children with ASD from the time of diagnosis, so even toddlers with ASD need opportunities to participate in inclusive programs. Ten years ago Strain, McGee, and Kohler (2001) offered the possibility that a number of inclusion myths were, in all likelihood, responsible for the preponderance of developmentally segregated service options. These myths include:

1. *The Readiness Myth* and its three-pronged emphasis on (a) an initial intervention focus on child compliance in the context of simple motor-imitation tasks, (b) providing children access to more inclusive settings based on their achieving certain behavioral milestones, and (c) always beginning intervention with the most direct, adult-driven instructional methods.
2. *The Tutorial Instruction Myth* and its proposition that children with ASD can only learn via one-to-one instructional arrangements.
3. *The Overstimulation Myth* and its assumption that problem behavior exhibited by children with ASD in inclusive settings is tied directly to the "more stimulating" nature of these settings.
4. *The Behavioral Control Limitation Myth* and its proposition that severe problem behavior can be treated only in restrictive settings.

While we could find no evidence to support any of these myths in 2001 or today and plenty of data in direct contradiction, they persist nonetheless. Why do these myths persist in the face of contradictory evidence and no evidence in their support? We strongly suspect that tradition and funding mechanisms are the main culprits—not particularly good reasons to preserve the status quo.

## Systematic and Effective Instruction Issues

In the past 25 years, there has been a dramatic increase in the number of professional papers, books, blogs, newsletters, and other assorted information disseminated about ASD intervention. A Google search on "autism intervention" produces 11,700,000 hits, and although the quality of much of this information may be dubious, it does influence the discourse on ASD intervention. In a recent article, Odom and his colleagues (2010) looked at research on ASD interventions by identifying 30 comprehensive treatment models (CTMs). These models have published manuals or program descriptions, address multiple developmental domains, are intensive, and have clear theoretical or conceptual frameworks. It is no surprise that the majority of these CTMs were based on applied behavior

analysis (ABA), and even those that did not identify ABA as the theoretical framework of their model relied on behavioral principles to teach essential skills to young children with ASD (e.g., Dawson et al., 2009). This reliance on behavioral strategies to teach children with ASD is reinforced by the recent reports on evidence-based practices developed by the National Professional Development Center (NPDC) on ASD and the National Standards Project (National Autism Center, 2009). There is almost complete overlap between the two lists of practices, and both lists look as if they could have been extracted from the cumulative index of the *Journal of Applied Behavior Analysis* (*JABA*). For example, the NPDC identified 24 evidence-based practices for working with students with ASD. They include reinforcement, prompting, discrete trial training, differential reinforcement, naturalistic interventions, peer-mediated intervention, and extinction. A key point from both of these analyses of the current intervention research is that systematic instruction works to teach students with ASD, across ages and abilities, a diverse range of skills and behaviors.

Although having a list of instructional practices that have an extant evidence base does provide a starting place for educators, it does not ensure that children with ASD have access to systematic and effective instruction. Systematic and effective instruction does not just mean that educators have toolboxes full of the strategies that have been identified as being evidence based by a national panel. It requires that educators know how to identify the instructional needs of their students, develop instructional plans to address those needs, and then match the needs of their students with the instructional strategies that they have at their disposal. The most important step in providing systematic and effective instruction, however, is evaluation. Once the plan is developed and the instruction takes place, data must be collected to ensure that the child is making progress. One could say that we are determining the evidence base of any specific instructional strategy one child at a time. If the current instructional strategy is not yielding the desired outcome, based on the data, then changes to the program must be made. These changes may include more training for the instructor to ensure that the practice is being implemented with fidelity, a different reinforcement system for the child, a change in the intensity of instruction, or a change in the instructional strategy being used. This type of data-based decision making is the key to systematic and effective instruction and should be the cornerstone of every early education program for children with ASD. Like the inclusive programming, the need to receive instruction using effective strategies and ongoing progress monitoring is necessary for students with ASD across the life span, starting at the age of diagnosis and extending far beyond their early childhood years.

## Intensity Issues

Due to the dramatic growth in the prevalence of young children with ASD and the evidence of the benefits of EI, there is a growing demand for evidence-based preschool services for young children with ASD. In 2001, the National Research Council (NRC) conducted a comprehensive review of educational treatments (e.g., specific interventions and comprehensive programs) for young children with ASD (below 8 years) and made the following recommendations for treatment: (a) begin as soon as ASD is suspected, (b) provide systematic, intentional instruction addressing individual strengths and needs, (c) include

parent training, (d) use a low student–teacher ratio, (e) administer ongoing program evaluation and assessment to make data-based decisions, and (f) provide intensive instruction for at least 25 hr per week. In 2007, the American Academy of Pediatrics (AAP) issued a clinical report recommending that young children (below 6 years) with ASD receive at least 25 hr of educational services per week in settings with low student–teacher ratios and opportunities for one-on-one instruction (Myers & Johnson, 2007). Although, most of the evidence-based educational treatments for young children with ASD are behaviorally based, neither report specified the types or approaches to treatment.

These reports were based on comprehensive programs for young children with ASD. Several of these programs focused on the intensity of EI and equated intensity with the number of hours of services provided per week. For example, Lovaas (1987) and Smith et al. (2006) reported larger gains in IQ for children receiving upward of 40 hr per week of behaviorally based intervention (i.e., EIBI) than for children receiving fewer hours of service per week. Results of other studies have suggested that the recommended 40 hr per week of intervention might not be necessary. However, many have methodological limitations and none have conclusively demonstrated a main effect for the number of hours per week. In fact, contemporary research suggests that intensity involves more than the number of hours. Nonetheless, the AAP and NRC reports had important implications for ASD services for young children, and left many pediatricians, parents, and educational districts scrambling to provide the 25 plus treatment hours; hours of services for many have become the Holy Grail of ASD intervention. Importantly, the extent to which children with ASD receive *high-quality* services using evidence-based practices, regardless of the number of hours, remains relatively unknown. We know that as the number of children with ASD increases, public schools and EI systems are attempting to meet the needs of the children in their programs. Furthermore, recent research indicates that many families of young children with ASD experience difficulties accessing the recommended quality and intensity of services (Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007).

The scientific evidence would suggest that there is nothing magical about 25, 30, or even 40 hr of intervention. If one is interested in maximizing the probability of good outcomes, the following variables must be part of the "intensity" equation:

1. *EI:* Research conclusively indicates that intervention should begin as soon as ASD is *suspected* (e.g., Dawson et al., 2009; Dawson & Osterling, 1997; Howlin, Magiati, Charman, & MacLean, 2009; Rogers & Vismara, 2008).
2. *High fidelity by skilled staff:* Interventions implemented with high fidelity by trained staff are related to better outcomes (e.g., Reichow & Wolery, 2009; Strain & Bovey, 2011).
3. *Multiple and varied embedded learning opportunities:* Multiple, contextually relevant opportunities to acquire and practice new skills should be provided using child-focused, intentional instructional practices (e.g., Schwartz, Sandall, McBride, & Boulware, 2004; Wolery, 2005). Student–teacher ratios should be low to allow staff to provide multiple and varied opportunities to respond each day. The NRC (2001) recommended no more than two children with ASD per adult in each classroom.
4. *Comprehensive curricula:* Curricula should include three components. First, goals should be developed individually and focused on core or pivotal skills that are socially important and functional (NRC, 2001). Second, instructional strategies should be evidence based and include programming for maintenance and generalization (Dawson & Osterling, 1997).

Third, assessment should be ongoing and comprehensive; data-based decision-making practices should be used to revise and update goals and interventions.

5. *Functional approach to problem behavior:* Children with developmental delays, including ASD, are more likely to display challenging behaviors. Thus, programs should have systems in place for preventing and alleviating challenging behaviors. All programming should be positive and include three components: preventive strategies, systematic instruction to teach socially appropriate replacement behaviors, and appropriate responses to the challenging behaviors. Evidence-based practices should be used to gather information (i.e., functional behavior assessments) about the function(s) of the challenging behavior, which should drive the behavior plan (e.g., functional communication training, contingent reinforcement of alternative behaviors; NRC, 2001).

6. *Typical peers:* Children with ASD should be included with their typically developing peers to the maximum extent possible. There is considerable research to support placement of children with ASD in high-quality inclusive classrooms (e.g., Strain & Bovey, 2011; Strain, Hoyson, & Jamieson, 1985).

7. *Family input:* Family input and involvement are critical factors in the success of a young child with ASD. Family involvement ranges from in-home parent training (e.g., Lovaas, 1987; Schwartz et al., 2004; Strain & Bovey, 2008), family consultation in the home (e.g., McGee et al., 1994), parent support groups, and invitations to team meetings to discuss their child's progress.

In summary, "intensity" *is* multidimensional, individually determined, and based on empirically supported practices. The sole focus on hours is and has been shortsighted.

This issue of hours as the definition of intensity is especially problematic for children with ASD below the age of 3. Many children with disabilities below the age of 3 receive the majority of their publically funded EI services at home using a parent-coaching model. According to the federally funded National Early Intervention Longitudinal Study, children receive an average of 1.5 hr a week of Part C services. Furthermore, EI services often take a more general approach and often do not focus on identified core deficits in autism (Kasari, Freeman, & Paparella, 2001). Although what constitutes an appropriately intensive program for toddlers with ASD is still a question that needs more research, most professionals and families can agree that 1.5 hr a week of services is inadequate. The challenge to the research community, however, is to not attempt to answer the question of intensity for toddlers with ASD and their families with a prescription of hours but rather, with a process for judging support needs and whether those needs are addressed.

## Social Context Issues

As delineated in the previous sections, the research on interventions for young children has evolved such that a set of evidence-based practices for children with ASD exists. Most of this research is focused on *how to teach* specific behaviors (e.g., what works, for whom, under what conditions)? However, the behaviors that should be taught are often ignored or assumed (e.g., "Does the child have to know all her colors?" "Is it essential that he stops flapping his hands when he is excited?" "Does he have to know his complete address?" "Does she have to categorize community helpers or identify farm animals?"). In other

words, researchers were less likely to ask, "Should we teach this behavior?" Or, more importantly, "What skills may be associated with children's success and happiness at school, home, and in the community?" (NRC, 2001).

Over the past 25 years, there has been a noteworthy shift in the outcomes of intervention research. Although the majority of randomized group studies, especially those in which the intervention takes place at home or in a clinic, continue to use changes in cognitive development as a primary indicator of success, more researchers and some funding agencies are realizing the importance of broadening the scope of outcomes that are examined. Researchers have proposed that there are pivotal or core skills related to ASD symptomatology (e.g., intentional communication, social skills), more efficient learning of other meaningful outcomes (e.g., response—reinforcement contingency, attending to relevant stimuli), and improved long-term independent functioning (e.g., Dawson & Osterling, 1997; Koegel & Koegel, 2006; Smith et al., 2006). Likewise, there has been an increased focus on generalization and maintenance of skills to natural environments (i.e., under naturally occurring antecedents and consequences with teachers, parents, and peers). Specifically, research has evolved to consider and even emphasize the child's *social context* and long-term outcomes when developing intervention goals and identifying interventions. The social context refers to the daily routines, activities, settings, people, and materials that are part of the child's day. Interventions are increasingly focused on behaviors that immediately improve the child's independent functioning in natural settings (e.g., toilet training, verbal requesting) or behaviors that are essential for learning other important skills and long-term outcomes (e.g., imitation, joint attention). In fact, considering whether the outcome is meaningful and worth teaching for the individual child and family is considered an ethically sound practice.

The emphasis 25 years ago on ASD interventions for young children focused on using a remedial approach (e.g., learning to recite one's phone number, rather than learning to use a phone) or a developmentally inappropriate one (i.e., related to the child's chronological age rather than developmental age or scores from standardized assessments developed and normed with typically developing children). In their review of the research published between 1987 and 1994 on comprehensive programs for children with ASD, Wolery and Garfinkle (2002) found that most programs reported the following types of outcome measures: IQ/cognitive status, developmental progress or achievement, reduction in ASD symptomatology or changes in the ASD diagnosis, and postintervention placement. They noted that few studies reported outcomes related to attention, engagement, imitation, or play, which are essential for learning other meaningful skills. More recently, Wolery, Barton, and Hine (2005) reported a similar phenomenon in their review of ASD intervention articles from *JABA* published between 1968 and 2003. They found more studies examined outcomes related to cognitive or discrimination skills in the early volumes of *JABA* and an increase in outcomes related to social skills, engagement, or attention in recent volumes of *JABA*. They noted an overall lack of articles measuring generalization to natural settings, or outcomes related to imitation, play, adaptive behaviors, or independence.

The last decade is marked by an increased focus on meaningful goals and outcomes that promote participation in natural settings or efficient learning of other important skills. Interventions are focused on functional, participation-based outcomes for young children with ASD in natural environments. Research indicates that participation in daily activities and routines provides natural and purposeful opportunities for learning and development

for young children with ASD. Moreover, there is an increased focus on the maintenance and generalization of skills to natural settings and environments with the naturally occurring stimuli. Contemporary outcomes are characterized by the following:

1. Functional behaviors (e.g., increasing the communication skills using Voice Output Communication Aids [VOCA] within daily routines),
2. Participation-based skills with instructional opportunities embedded into daily routines and activities (e.g., teaching children to imitate a peer during naturally occurring art activities or circle time),
3. Developmentally appropriate skills (e.g., teaching developmentally appropriate play skills),
4. Social skills with typical peers or siblings (e.g., teaching peers to initiate and respond to children with ASD within natural setting),
5. Family input (e.g., getting input from families on procedures, goals, and outcomes of intervention), and
6. Generalization and maintenance (e.g., generalization and maintenance of play behaviors over time without prompts).

## What Should We Try to Do for The Next 25 Years?

In the past 25 years, the field of EI/early childhood special education (ECSE) has made tremendous strides in working with very young children with ASD and their families. We have seen that many of the children with whom we have worked leave ECSE programs and make successful transitions into general education, and some of us have even seen these children move on to college and adult independence. We have also seen some children, who receive the same type of intervention, continue to have intense support needs throughout their school years and into adulthood. More importantly, EI/ECSE programs are seeing more and more children with ASD. Where 25 years ago it would have been notable if a program serving children birth to 3 years old had any children with ASD, now many EI programs are serving many children with ASD from 18 to 36 months. Although we should be proud of what we have accomplished in the past, there are still many challenges facing the next generation of providers, researchers, and advocates. They include dissemination, adoption, and sustainability of innovation; increased attention to outcomes influenced by quality of life; family support; and research to address children who have been nonresponders.

## Dissemination, Adoption, and Sustainability of Innovation.

Every student with ASD should be able to access a high-quality, effective, inclusive intervention at his or her neighborhood school. These programs must include the necessary instruction and support so that children, including toddlers, with ASD have the opportunities and the skills to interact with their typically developing peers on a daily basis and develop meaningful and lasting social relationships. Until we accomplish that goal, we will not be providing the promise of IDEA. Currently, we have a number of comprehensive

treatment approaches, such as LEAP (Learning Experiences and Alternative Programs for Preschoolers and their Parents; Strain & Bovey, 2011) and Project DATA (Developmentally Appropriate Treatment for Autism; Schwartz et al., 2004) that can be implemented in public schools. Although we can always learn more about different models or approaches to intervention, it is essential that the field devote resources and attention to research on how to implement strategies that are designed for young children with ASD to be educated in public schools alongside their typically developing peers. Before we can implement these programs, we need to ensure that the infrastructure to support them exists. This infrastructure must include adequate funding, training, and support to ensure that whatever program is implemented is done so with fidelity and that the supports are put in place so that programs can be sustained. In addition, we must redesign the personnel preparation system to ensure that all educators and allied health professionals (e.g., speech language pathologists, occupational therapists) receive training to prepare them to work with children with ASD and related disorders. Part of this new curriculum must include experiences with the type of systematic instruction, progress monitoring, and data-based decision making that is necessary to teach children with ASD and related disorders, and the knowledge about and supervised practice working with professionals from other disciplines.

## Increased Attention to Outcomes Influenced by Quality of Life

We need to ensure that the programs we provide to young children teach skills and behaviors that are related to better functioning at home, school, and community, rather than those that are easy and convenient to teach. In 2007, Ted Carr suggested that quality of life should be the outcome variable for positive behavior support plans. We would like to borrow his idea and suggest that the construct of improved quality of life for children and family be the outcome variable to evaluate the success of programs for children with ASD. One of the criticisms of the research on CTM for young children with ASD is that there is not an outcome variable that is common to all studies. Many studies report significant changes in cognitive ability (e.g., Dawson et al., 2009; Lovaas, 1987). Although this is an impressive and important outcome measure, it is not directly related to the core deficit areas of ASD or to children's ability to participate in inclusive schooling (Estes, Rivera, Bryan, Cali, & Dawson, 2011) or family life. We challenge researchers in the next 25 years to develop a strategy to assess children's ability to participate in family life, engage in community activities, and be successful in school. Although this is not a traditional type of outcome for research studies, it might be the type of outcome that is most appropriate for assessing the effectiveness of outcomes for young children with ASD. This type of quality-of-life outcome would be culturally responsive and family centered. This type of outcome measure could also bridge the measurement problem that many researchers face as they attempt to follow toddlers with ASD through preschool and into elementary school. A quality-of-life measure could potentially be a continuous, dynamic measure that would be responsive to change from the beginning of a child's intervention history throughout his or her lifetime. Using a quality-of-life-inspired outcome measure also would require researchers and practitioners to work with families to assess priorities before beginning intervention and then to evaluate the success of an intervention based on a child's ability to participate in valued family and community activities, rituals, and routines rather than on a standardized test score.

## Support for Families

Research suggests that family members of children with ASD experience more stress than parents of typically developing children and even more stress than parents of children with other disabilities (e.g., Bristol, Gallagher, & Schopler, 1988). Parents of children with ASD often have to be teachers, advocates, researchers, and caregivers. Furthermore, the family might include parents, siblings, grandparents, and other family members, and supports should be provided to all involved. We need to develop effective programs to provide families with formal and informal supports to enhance their capacity to teach, and make decisions about and advocate for their family members with ASD. Formal supports might be provided through the child's program within the public school system by teachers, advocates, pediatricians, and other members of the child's Individualized Education Program (IEP) team. Informal supports might by provided through parent support groups, neighbors, and community groups. These supports often are readily incorporated in Individual Family Service Plans (IFSPs); however, they are often not included in IEPs. Structures and systems to intentionally embed these supports need to be developed. For example, states such as Oregon use IFSPs with children with special needs from birth to age 5. This allows for a more intentional system of support for families of children with ASD and provides one example of how we might systematically support families of children with ASDs.

## Research About the Nonresponders

All of the authors of this article are keenly and painfully aware of the lingering issue of the "nonresponders" to otherwise evidence-based practices. The only answers have been tried, and they have failed. The nonresponders are not just the older-at-entry group, they are not simply the offspring of families living in poverty, and they are not the children who got less of something. To address and hopefully eliminate the intervention challenge of nonresponders requires, in overview, a two-pronged research agenda:

1. First, it is noteworthy to point out that the vast majority of discrete, evidence-based tactics were developed 10, 20, 30, even 40 years ago. We desperately need innovation to expand the range of intervention options. In the social sciences, we are traditionally incremental and conservative. Safe science gets funded; being on the cutting edge often means not making the cut! We would offer the view that nonresponders and their families cannot wait for incremental developments in the field.
2. Second, we need to specifically fund research on nonresponders. We believe it is likely that the more fruitful research will be multidisciplinary because we have eliminated many of the obvious "behavioral" variables that could account for variation in response to intervention. The search for predictive variables will be expensive, and it will require many study participants and multiple measures collected over time.

## Conclusion

The past 25 years have been an extraordinary time to be a researcher in the area of ASD. We have seen this disability category move from being relatively rare to a prevalence of

approximately 1 in 110. We have seen the prognosis for young children with ASD switch from grim to hopeful. We still, however, have a lot of work to do. As we continue to learn how to identify children with ASD earlier, we need to ensure that there are EI programs in place to meet the enormous needs of these children and families (Schwartz & Sandall, 2010). We need to ensure that public policy and public funding ensures that all children with ASD have access to services, so that children who are economically disadvantaged and have ASD are not put at double jeopardy. Finally, we have more to learn about how to support these young children with ASD as they become older children and eventually adults with ASD. Although we are confident that we have effective and replicable programs for preschoolers with ASD, we cannot say the same for school-aged children and adults. Even students who respond very well to EI are likely to require some ongoing support throughout their lifetime. Understanding what these supports are, how we can provide them, and whether we can somehow better address their needs in early childhood will surely keep us engaged for the next 25 years.

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