Implementing Systems-Based Innovations to Improve Access to Early Screening, Diagnosis, and Treatment Services for Children with Autism Spectrum Disorder: an ASD PEDS Network Study

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Abstract

In 2013, the National Institute of Mental Health funded five trials of unique, multi-component, systems-based innovations designed to improve access to early screening, diagnosis, and treatment of autism spectrum disorder (ASD) – collectively known as the ASD Pediatric, Early Detection, Engagement, and Services Network. As part of an ongoing effort to pool data and learn from shared experience, we collected information across all studies about innovation components and implementation strategies. First, each study group completed standardized checklists based on the Template for Intervention Description and Replication (TIDieR) and the Expert Recommendation for Implementing Change (ERIC). Then, we interviewed principal and co-investigators of each study (n=9) to further explore innovation components and assess barriers and facilitators to implementation. Innovation strategies were diverse (five different ASD screeners were used, 40% included Early Intervention trainings, 60% involved new technology). Common implementation strategies included developing stakeholder relationships and provider trainings. Barriers included inefficient systems of care, difficulty engaging families in the innovations, provider attitudes, and organizational culture (e.g. difficulty changing clinic processes). These findings suggest that –

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despite diverse settings and a variety of innovation content – common facilitators and challenges exist in implementing innovations to enhance access to early ASD screening, diagnosis, and treatment.

Keywords

Autism; Early Intervention; Implementation

Introduction

Despite the immediate (Dawson et al., 2010) as well as likely long term (Anderson et al., 2014) benefit of early detection and treatment participation, significant delays exist in access to early screening, diagnosis, and services for young children with autism spectrum disorder (ASD) (Bishop-Fitzpatrick and Kind, 2017). In their most recent report, the CDC noted that the median age of first ASD evaluation in the United States is 40 months, with comprehensive treatment occurring well after that age (Christensen et al., 2016). The process of obtaining appropriate ASD screening, diagnosis, and engaging in treatment involves a number of complex steps, which often includes visits with a primary care provider for screening, visits with a subspecialist for diagnosis, and receipt of an individually-tailored treatment plan (Emerson et al., 2016). Barriers to timely ASD screening, diagnosis, and treatment may result from a variety of factors including the availability of services, patient-provider miscommunication, parental stress, complex payment systems, heterogeneity in early symptom presentation, and culturally biased care (Benevides et al., 2016; Bishop-Fitzpatrick and Kind, 2017; Emerson et al., 2016).

To address these concerns, the National Institute of Mental Health (NIMH) issued a funding opportunity announcement (RFA-MH-14-100) in 2013 to support research that "develops and tests service system interventions that are broadly implementable and that rapidly engage young children with ASD in evidence-based treatment and services early in life" (NIH, 2013). This announcement represents a concerted effort by the NIMH to test and disseminate systems-based innovations that can reduce health care disparities and improve service delivery for young children with ASD. Five research projects were awarded R01-funding to test five different systems innovations, all designed with the same goal of improving access to early screening, diagnosis, and treatment services for children with ASD. These five studies are being conducted in a variety of community and practice settings. We define an "innovation" as a new method or process, with a discrete set of specifically defined elements, developed for the purpose of improving access to ASD services (Proctor et al., 2013). The innovations are diverse and include: early intervention (EI) provider training; patient navigation to link families from primary care to diagnostic and specialty services; primary care pediatrician learning network with affiliated fast-track diagnostic center; systems level intervention for training primary care physicians in screening and EI providers in assessment and treatment; web-based screening and primary care and family education and engagement tool – the Autism Navigator®. Studies are being carried out in Arizona, California, Connecticut, Florida, Georgia, Massachusetts, New York, Pennsylvania, and Washington.

In August 2014, the NIMH brought together the research teams from the five funded projects to form a research network - the ASD Pediatric, Early Detection, Engagement, and Services (PEDS) Network. Via monthly video conference meetings, the network discusses contemporary issues in the field, and shares resources and ideas. The goals of this network include collectively pooling data on common elements as well as leveraging selected measures unique to individual sites over the lifetime of the projects to engage in common scholarship and accelerate advancement in the field of early ASD diagnosis and service receipt. The NIMH recognized that despite differences in study setting and design, when combined, findings from these complementary studies have the potential to transform current ASD service systems by creating an integrated set of strategies for early identification and engagement in treatment that are engineered for rapid adoption and implementation on a broad scale.

The creation of this network of five research projects, all with common goals, yet with different methods, settings, and geographies creates a unique opportunity to formally study implementation of systems-based innovations that can improve service delivery for young children with ASD. This type of blended study design, which embeds an implementation evaluation within an ongoing trial (known as a hybrid effectiveness-implementation study) is gaining recognition as an important method in the field of implementation science (Curran et al., 2012). The goal of this type of study is to assess implementation prior to the completion of an effectiveness trial, in order to speed the progression of intervention testing to wide-spread dissemination (Brown et al., 2017). While a number of patient or provider-level barriers to implementing new innovations for children with ASD have been identified (Dosreis et al., 2006; Drahota et al., 2012; Durkin et al., 2015; Elder et al., 2016; Fenikile et al., 2015; Morelli et al., 2014) to date, no studies have evaluated implementation strategies across diverse innovations or contexts. Understanding implementation across a broad set of innovations and contexts – particularly identifying common challenges and successful strategies – is valuable when planning for large-scale systems change (May et al., 2016). Therefore, we collected data across the five studies about innovation components and implementation strategies (Table 1). Each study group completed standardized checklists based on the Template for Intervention Description and Replication (TIDieR) (Hoffmann et al., 2014) and the Expert Recommendation for Implementing Change (ERIC) (Waltz et al., 2014b). We then interviewed principal and co-investigators of each study (n=9) to further explore intervention components and assess barriers and facilitators to implementation. The goal of this work is to describe the range of strategies used by different investigators and understand common barriers and facilitators to implementation, from the perspective of each investigator. These data can lay the groundwork for future efforts to adopt and spread practices that can reduce delays in care for children with ASD.

Methods

Participants

Participants for this study included the principal investigators (PIs) and co-investigators (Co-Is) of the five ASD PEDS Network R01 studies (n=9). Table 1 outlines details of the studies and participants.

Standardized Checklists

Each PI completed two standardized checklists: 1) the Template for Intervention Description and Replication (TIDieR) (Hoffmann et al., 2014); and 2) the Expert Recommendation for Implementing Change (ERIC) (Waltz et al., 2014a).

TIDieR—TIDieR is a 12-item checklist developed by an international group of experts and stakeholders to improve the completeness of reporting and replicability of interventions (Hoffmann et al., 2014). The checklist requires a brief written description of each of the following 12 items: name of interventions, why (e.g. rationale for interventions), what (materials), what (procedure), who provided, how, where, when and how much, tailoring, modifications, how well (planned), how well (actual).

ERIC—The ERIC checklist was based on findings of the ERIC workgroup, which systematically collected input from a wide range of stakeholders with expertise in implementation science and clinical practice in order to publish a compilation of implementation strategy terms and definitions. The project developed a "menu" of 73 unique implementation strategies (Waltz et al., 2014a). PIs completed the checklist by indicating which of the 73 implementation strategies they were using as part of their study, and then briefly detailing how they were using each strategy. PIs completed both checklist prior to interviews.

Interview Guide

We developed a semi-structured interview protocol, drawing on our previous studies of services for children with ASD (Feinberg et al., 2014; Pierce et al., 2011; Stone et al., 1994; Stronach and Wetherby, 2017; Feinberg et al., 2016; Feinberg et al., 2012; Giserman Kiss et al., 2017) and the Consolidated Framework for Implementation Research (CFIR) (Damschroder et al., 2009). CFIR is composed of five domains which interact to impact implementation. The five domains are: Intervention Characteristics, Outer setting, Inner setting, Characteristics of Individuals, and Process. Within each domain are multiple constructs, which can be probed to identify influences on implementation. CFIR, developed by Damschroder and colleagues, was created as a 'meta-theory' to provide an overarching framework that synthesizes other implementation theories, and has two specific advantages over other frameworks that apply to the current project. First, CFIR offers an overarching typology to promote theory development and verification about what, where, and why something works across multiple contexts. It is useful for formative work, in which specific causal mechanisms for implementation success are not hypothesized a priori. Second, CFIR contains a broad range of contextual dimension (5 domains and 26 discrete constructs) that capture both internal or "inner setting" (e.g. clinic culture, leadership engagement) and external or "outer setting" (e.g. external incentives) influences on implementation. Therefore, it is particularly suitable for studying interventions being implemented in multiple settings and diverse populations.

Our interview guide was designed to explore intervention characteristics as well as outer setting, inner setting, individual, and process factors that influence implementation. Specifically, we covered the following topics: (1) description of the innovation; (2)

description of implementation; (3) exploration of PI and Co-I's implementation experiences; (4) exploration of perceived family experiences with the innovation; and (5) exploration of perceived provider experiences with the innovation. Our semi-structured approach allowed us to address our research questions on barriers and facilitators to implementation, while also allowing participants to expand upon additional issues that arose.

Interview Procedures

Interviews were conducted in person when possible or by telephone by the first author (SBF), an experienced qualitative investigator, using the interview guide described above. Each participant was sent the guide prior to the interview. Each interview was approximately one hour long and was audio-recorded upon obtaining verbal consent from each respondent. After a short series of closed-ended questions, we asked open-ended questions, eliciting descriptions of each subject's experience with the implementing their innovation. We probed answers to understand how each CFIR construct related to their experience. Our questions focused on understanding both the individual perspective and the contextual impact. This research was deemed exempt by the Institutional Review Board at Boston University School of Medicine.

Data analysis

Checklists—Data generated from the checklists were examined by summarizing items that were either overlapping or non-overlapping across the sites. Totals and averages for each innovation component and implementation strategy were then calculated (Figure 1). The first author (SBF) then reviewed each checklist, along with descriptions of each item included by PIs within each checklist. Responses were used to inform additional probes for semi-structured interviews. For example, if the PIs noted that they used "facilitation" as an implementation strategy within the ERIC checklist, additional probe questions were added to the interviews for that specific PI to further explore their use of facilitation, along with opinions on its overall value regarding implementation.

Interviews—Data generated from interviews were analyzed using the framework approach (Smith and Firth, 2011) - a technique commonly used to analyze qualitative data from studies of health care innovations. The framework approach uses a three-stage method which allows transparency across the entirety of the analysis process. In the first stage, "data management," the first author (SBF) read the transcripts several times and created detailed notes of each respondent's answers to the questions. A set of initial themes was identified, along with supporting quotes. In the second stage, "identifying and testing a thematic framework", the first author presented preliminary codes along with supporting quotes to the entire research team during a day-long face-to-face meeting. During the meeting, the team discussed each code, and refined the list of themes. In the final "explanatory" stage, the first author compiled the refined list of themes and supporting quotes, and sent them electronically to all investigators on the project. Each investigator was once again given the opportunity to comment on themes, or make additional suggestions. Deliberation continued until consensus was reached by all investigators on a final list of themes. Each theme was then mapped onto a CFIR domain by the first author. Finally, this list of themes and

corresponding CFIR domains were emailed to the group. PIs responded with comment, and the list was refined and re-circulated until consensus was reached.

Results

Innovation Characteristics

The five studies represent a diverse set of innovations in a variety of geographic and clinical settings (Table 1). Studies are being conducted in nine different states, six different service systems (primary care, developmental and behavioral pediatrics, early intervention [EI], Women, Infants and Children [WIC], Head Start, and the National Black Church Initiative [NBCI]), and in urban, suburban, and rural settings. The majority (four of five) are focused on traditionally underrepresented populations. Each study employs a different method for screening for ASD (e.g. Modified Checklist for Autism in Toddlers, Revised with Follow-Up [MCHAT-R/F] (Robins et al., 2014); Screening Tool for Autism in Toddlers [STAT] (Stone et al., 2004); Brief Infant Toddler Social Emotional Assessment [BITSEA] (Giserman Kiss et al., 2017) Parents' Observation of Social Interaction [POSI] (Sheldrick and Perrin, 2013); Communication and Symbolic Behavior Scales IT-Checklist [CSBS] (Wetherby et al., 2007); and Early Screening for Autism and Communication Disorders [ESAC] (Wetherby et al., 2009) (see Table 2). Three studies are performing "early" screening (before age 18 months) and two are performing screenings at standard ages (18–24 months). Three of the studies are incorporating new technology into their screening and/or treatment strategy (i.e. tablet-based screening, web-based education), two are using screening instruments without technology enhancements. Innovations target a mix of medical, treatment, and other community providers (e.g. EI, primary care, developmental and behavioral pediatricians, community workers [church leaders, Head Start staff], and families).

Implementation Strategies

Six of the nine implementation strategy domains identified by the ERIC checklist were used by all five studies: using evaluative and iterative strategies, providing interactive assistance, developing stakeholder relationships, training and educating stakeholders, supporting clinicians, and changing infrastructure (Figure 1). The most commonly used implementation strategies were developing of stakeholder relationships (e.g., identifying and preparing champions, using advisory boards and workgroups) and training and educating stakeholders (e.g., providing ongoing consultation, developing educational materials). The least commonly used strategies were: adapting and tailoring to context (e.g., tailoring the implementation strategy to the context) and supporting clinicians (e.g., revising professional roles).

Facilitators and Barriers to Implementation

Facilitators—Two themes emerged as facilitators: 1) Stakeholder relationships, and 2) centralized assistance. The primary facilitator to implementation discussed by all investigators was the development of stakeholder relationships prior to implementation. Investigators recognized the value of relationships and reputations that had developed based on prior work. At the same time, all investigators dedicated significant effort to establishing

new relationships as part of their studies, and noted that these relationships were extremely valuable in implementing their work. One investigator said:

"We have a reputation in the community, people know we have been doing this work for a long time, so they are interested in working with us."

Another investigator noted:

"We really got out there, we met with as many people as we could, we let them know that we were from the university and that we had a great resource we could offer them. These relationships made all the difference."

One relationship that was considered particularly valuable was that of a "site champion" who could advocate for their innovation within the clinical setting. An investigator noted:

"In the clinics where we have good site champions, we have greater success. A motivated champion is a huge plus."

The second major facilitator mentioned by investigators was the centralized assistance study teams were able to provide to the clinical sites. Investigators noted the advantage of being able to "trouble-shoot" for clinical sites based on their many years of experience with their innovation. For example, one investigator discussed how their previous experience working within electronic medical record systems allowed them to assist new clinics in implementing their innovation. An investigator said:

"Getting reports into the electronic record can be a big challenge. Since we have done this many times before, we can help people figure out how to use their record system to make this as easy as possible."

Barriers—Four themes emerged in our exploration of barriers to implementation: (1) inefficient systems of care; (2) family engagement; (3) provider attitudes; and (4) organizational culture.

(1) Inefficient Systems of Care: The first barrier that emerged was the challenge of working within complex systems that were often inefficient. All investigators noted inefficiencies in at least one of the systems (educational, health, social service) that they were working to implement their innovation within. They also noted the challenge of cross-system communication and collaboration, and concerns around using their innovation to improve one system, when all the others continued to have issues. For example, an investigator working within the early intervention system noted:

"The system is so slow. In some ways, that helps us, because people really want what we are doing. But, on the other hand, even when we improve screening rates, all the down-stream actors are still really slow, so it can be challenging."

Another investigator noted similar concerns about coordinating between the primary care and educational systems:

"We are really improving screening in primary care, and we get people in [for a diagnosis] really fast. We are doing great with that, but then there aren't enough

treatment providers. They get a diagnosis, but can't always find good treatment. Our system works really well, but the other systems aren't set up for that."

Another investigator said:

"It feels like we plug a hole in the dam and then another one opens downstream."

(2) Family Engagement: Engaging families of very young children in the screening and intervention innovations was another major barrier to implementation. Investigators acknowledged that engaging families was difficult at multiple levels (e.g. organizational, patient) of implementation. For example, many investigators who are working to engage families directly with their innovation reported that some families did not want to be screened for ASD, particularly when they were not already concerned about their child's development. At the same time, investigators working to engage organizations report that some organizations were hesitant to adopt new innovations around screening, as there were concerns they would alienate their patients by "forcing them" to undergo ASD screening. One investigator noted the challenges of disclosing an ASD diagnosis and engaging families in appropriate services:

"These are very difficult conversations to have with families. Families don't want to hear there could be something wrong with their child, so they just refuse any treatment. Even if we have the best services to offer them, they don't want to hear it."

When discussing provider experience with family engagement, one investigator stated:

"Providers are really worried about jeopardizing patient relationships. They know families are very sensitive about this issue that they are not really wanting to hear the word "autism". We actually removed the word "autism" from some of our materials as a response to provider requests."

Another investigator said:

''We've had families get really angry when we bring up screening for autism. One family even threatened to call the police"

A sub-theme that arose related to family engagement was the challenge of working with non-English speaking families. Investigators discussed difficulty finding non-English speaking research or clinical staff, and the associated cost:

"For a long time we didn't have anyone who could do the diagnostic evaluation in Spanish. We looked at contracting out, but it was too expensive. We finally found someone, but the waitlist got so long during the time we didn't have anyone, some people dropped out of the study during that time."

(3) Provider Attitudes: Most (eight of nine) investigators cited provider attitudes as a barrier to implementation. A few investigators stated that providers had major time limitations, and even if they were interested in providing better care to their patients with ASD, they didn't have time to adjust their practice. Other investigators said that providers were accustomed to a lack of diagnostic and treatment services, so were hesitant to enhance

screening practices if they anticipated long wait-times (some said appointments could take over a year to schedule), and/or no access to appropriate treatment services. One investigator noted:

> "Pediatricians really want to help their patients, they are worried, but they have a lot of other things to deal with. Appointments are short, and they can't always bill for this."

Another investigator said:

> "Primary care doctors are in a very bad position. They want to help their patients, they know something is wrong, but they are used to such long wait-lists for an assessment, they have become skeptical about screening."

(4) Organizational Culture

Investigators noted that the culture of an organization, and its readiness and willingness to adapt new innovations, was also a significant barrier to implementation. Clinic policies and "red tape" were noted as major organizational level barriers. Investigators reported that clinics expressed concern about "what would be asked of them" when considering implementing a new innovation. All investigators dedicated significant time and effort to working with organizations, and all noted that having a "site champion" was critical. One investigator said:

> "Identifying practices is such a process. The practices needed a lot of reminders and outreach after the initial meeting. They seemed interested at first, but it was hard to get them to the table."

Another investigator said:

> "There are so many steps to getting a practice to get involved. It can literally take years."

Setting—Because the goal of this work was to identify both common and unique facilitators and barriers to implementation, we also identified a number of factors that were distinct to specific settings (i.e., emerged as themes in some, but not all studies).

Availability of ASD diagnostic and treatment services was one such theme. Interestingly, this theme was cited as a facilitator by some investigators, and a barrier by others. For example, an investigator working in a setting with few diagnostic centers noted that providers seemed to lack motivation to implement their screening innovation because they knew that it was too challenging for families to obtain a formal diagnosis. The investigator said:

> "There are pediatricians who don't see the point of screening because they know the closest place to get a diagnosis is hours away. That's too far, so many families won't be able to do that. So some pediatricians think there's no point."

Another provider stated that availability of diagnostic services was not a barrier. They did, however discuss how lack of availability of treatment services was actually a facilitator. The investigator said:

"Once we get people to screen, we can get kids a diagnosis very fast. But, since kids don't get much treatment after the diagnosis, we still have a big problem there. Pediatricians are very eager to participate because they know these kids don't get enough treatment, they know it is the best way to get good resources for families."

Discussion

This study is the first to concurrently investigate barriers and facilitators to implementing innovations to enhance early screening, diagnosis, and treatment for young children with ASD across diverse innovations and settings. We found that many implementation strategies were shared across projects (e.g. developing stakeholder relationships, training and educating stakeholders). In our interviews, facilitators to implementation endorsed by all investigators included developing stakeholder relationships, and centralized assistance. Common barriers included: inefficient systems, difficulty engaging families in innovations; provider attitudes; and organizational culture. Taken together, these findings suggest that - among this diverse set of systems innovations - certain strategies and challenges with respect to implementation are universal.

The first barrier that emerged was challenges with inefficient systems of care. Many investigators noted the difficulty of working to improve current systems within the context of so many inefficiencies. Inefficiencies that were noted included dysfunctional medical record systems, long wait-times for patient appointments, and difficulties with "cross-system" communication (e.g. incompatible records systems between EI and primary care). Although multiple research teams described working directly to mitigate these inefficiencies (e.g. wait-times), they reported this as a continued challenge due the additional inefficacies outside of their specific innovation. This finding is not particularly surprising, given the number and diversity (e.g. health care, early intervention, school, social service) of systems that interact to provider services for children with ASD, along with well-described systems issues for healthcare in general (Bindman, 2017). What is notable is that this finding was universal, despite studies being carried out in diverse geographic settings and services systems.

A second common barrier to implementation was family engagement. Of the investigators who are working to directly engage families (n=2), both reported challenges engaging families in early screening, diagnosis, and/or treatment services. The investigators who relied on providers to engage families in the innovations (n=5) reported that providers could be reluctant to approach families about participation due to do concerns that families would not be interested in - or even be upset about - engaging in the screening, diagnosis, and treatment process. These findings echo other studies of barriers to accessing ASD care in vulnerable populations. For example, a diagnosis of ASD is considered stigmatizing in many cultures,(Khanlou et al., 2017; Kinnear et al., 2016; Selman et al., 2017) and studies show that a fear of stigma may create barriers to both obtaining a diagnosis and engagement in services (Blanche et al., 2015; Johnson and Joshi, 2016; Khanlou et al., 2017). At the same time, obtaining an ASD diagnosis and engaging in services can involve intensive levels of parent involvement and training,(Oono et al., 2013) and these requirements may discourage vulnerable families who lack financial resources and support networks, are non-English

speaking, or who have other competing demands which supersede pursing appropriate care. Therefore, although this finding is important, it is not particularly surprising.

A specific family engagement challenge that was described by all investigators was working with non-English speaking families. Investigators noted that finding research or clinical staff who were bilingual could be difficult, and that even when they could find appropriate staff, the additional cost was unsustainable. A number of investigators said that wait times were longer for non-English speaking families because there were fewer staff who could provide services in their language. At the same time, only one study included families who were not primarily English or Spanish speaking. The challenges associated with providing care in someone's native language likely compounds barriers that already exist for culturally diverse, vulnerable families. Multiple studies show that differences in cultural attitudes and approaches towards child development can impact how minority families respond to the challenges of having a child with ASD (Harshini and Preeti, 2017; Zuckerman et al., 2014a; Zuckerman et al., 2014b; Elder et al., 2016). For example, Zuckerman and colleagues found that, among Latina mothers of children with ASD, there was limited knowledge about ASD, and often differing views between mothers and providers about the child's development and the importance of treatment services (Zuckerman et al., 2014a). Sage and Jegatheesan (Sage and Jegatheesan, 2010) report similar findings in their study of South Asian families, in which they found a gap between service providers' and families' views of the child's home environment, and observed that these differing perspectives resulted in families withdrawing from services. A limitation of these prior studies is that they focus on a single ethnicity, a single step in the screening, diagnosis, and treatment process, and/or are performed in limited geographic areas. Our data complement these previous studies by assessing experiences across many innovations, service systems, and geographies. Moreover, our data are being collected simultaneously as innovations are being tested, while prior studies obtained retrospective data, after families had already engaged in ASD services. Despite differences in study methods between the current study and prior work, findings are generally consistent, and suggest that cultural, language, and income barriers to care for young children with ASD may be universal regardless of where, how, or what type of services families are engaged in.

Another important finding of this study is the challenge investigators reported in working with providers and clinics in adopting new systems to improve early ASD screening, diagnosis, and treatment. Although there is a significant body of literature describing barriers to adoption of new innovations within clinical practice (Chan et al., 2017; Baatiema et al., 2017; Vlaeyen et al., 2017; Colquhoun et al., 2017; Liang et al., 2017), few of these studies address ASD services, which are unique in that they require interface with multiple services systems (e.g. medical, educational, social). The extant literature focuses on challenges to implementing treatment interventions (e.g. Applied Behavioral Analysis) for school-aged children with ASD in community settings. For example, Stahmer and colleagues found that many community treatment providers lacked knowledge of evidence-based practices (EBPs) for children with ASD, and were often providing non-evidence-based care (Huang et al., 2010) . In their paper on implementation of innovations, Dingfelder and Mandell apply the "Diffusion of Innovation" theory as a means to understanding how, why, and how rapidly new practices are adopted by individuals providing care to children

with ASD (Dingfelder and Mandell, 2011). Using literature from ASD intervention and dissemination science, they discuss why effective interventions are seldom adopted, with a focus on how the adopter's (e.g. primary care physician, EI provider) perceptions of the innovation affects implementation. They focus on three attributes as seen by the adopter: relative advantage (i.e. is the innovation seen as better than current practice), compatibility (i.e. is the innovation compatible with existing practice and systems), and complexity (i.e. how many components, and how difficult it is to carry out the innovatino). In our study, two factors emerged that were similar to those identified by Dingfelder and Mandell: relative advantage and compatibility. For example, all investigators endorsed the value of having a "champion" who was passionate about ASD and motivated to improve practice (i.e., relative advantage). Investigators also discussed the need to work within the systems that existed in their study sites, and the difficulty of getting providers to change systems of their current practice (i.e., compatibility). Notably, all five innovations are complex (as a result of the funding announcement which called for multi component, systems interventions), yet complexity did not emerge as a barrier to implementation in the current study. Although we do not have a definitive explanation for this finding, it is possible that, because these innovations are being implemented within the context of large, NIMH-funded studies, the resources available to each study team may support implementation and ease the burden of implementing multi-component innovations (e.g., study coordinators, research assistants). It will be important to further investigate potential barriers and facilitators to each component, and to combine components, in future implementation studies.

The final theme identified was the role of organizational culture in implementation. Organizational culture is defined as, "'the pattern of shared basic assumption -- invented, discovered or developed by a given group as it learns to cope with its problems of external adaptation and internal integration -- that has worked well enough to be considered valid and therefore to be taught to new members as the correct way to perceive, think and feel in relationship to those problems" (Schein, 1992; Schein, 1985). All investigators dedicated significant time and effort to identifying and working with organizations to engage them in their respective studies, and all cited challenges in recruiting organizations as a major issue. For example, one investigator noted that there was great variety in level of interest in improving services for children with ASD, as well as differences in willingness to make changes to practice. It was noted that if the leadership of an organization was very motivated to help children with ASD, engaging the organization was much easier. Multiple investigators reported that sites would often demonstrate initial interest, but fail to follow through. When organizations were perceived as unmotivated, most investigators reported that they "think twice" about trying to work with them. These findings are significant in planning for future studies of implementation of ASD screening, diagnosis, and treatment innovations. Studies of organizational culture, climate, and/or other factors that may motivate organizations to improve services for children with ASD are certainly warranted.

Contributions and Limitations

This study contributes to the field in several ways. First, to our knowledge, it is the only study that assesses implementation of innovations directed at young children with ASD across diverse clinical settings and innovation strategies. Second, it is focused on innovations

designed to alleviate disparities in access to early screening and intervention, which is of particular concern to the ASD population as significant disparities exist in the timing of diagnosis and treatment for these children, and earlier access to services leads to meaningful improvement in outcomes. Finally, it integrates an implementation evaluation with multiple ongoing trials, effectively creating a hybrid type I implementation evaluation (Curran et al., 2012). The value of this type of hybrid design is that it can produce data to prepare for dissemination of an innovation *prior* to the completion of an effectiveness trial, therefore allowing for more rapid dissemination if proven effective. The value of this type of study design is reinforced by the final theme that emerged - the "greyness" between innovation and implementation. The difficulty in differentiating innovation from implementation is well recognized as an important challenge in the field of implementation science. Studying implementation in a hybrid design can help study teams to consider these differences prior to the completion of a study, and plan for future implementation and dissemination.

There are also limitations to this work. Our sample included only nine interviews; however, all PI's and Co-I's were interviewed, and therefore the sample was as comprehensive as possible for this project. Second, we relied on a single group of informants (investigator interviews). Triangulating data from our interviews with other sources (such as medical record review or direct observation), would be valuable, but was not feasible based on the resources available for this study.

Conclusions

This is the first study to explore facilitators and barriers to implementing systems-based interventions to improve access to early screening, diagnosis, and treatment services for children with ASD, from the perspective of investigators of five large, multi-site trials. Common successful strategies included developing relationships with site partners prior to starting the innovation, identifying a specific individual at each site to ensure intervention protocols are followed (i.e. a site champion), and centralizing assistance (e.g. central site at an academic center for supervision and technical assistance). We also found a number of common barriers, including inefficient systems, engaging families in the process of early screening, diagnosis, and treatment, and enlisting providers to participate in innovations. We anticipate that describing the strategies, successes, and challenges of these five large, multi-site studies can assist future investigators, policymakers, and advocates working to implement, adopt, and spread new innovations to enhance screening, diagnosis, and treatment for young children with ASD. Recommendations include: 1) further exploration – through either qualitative or quantitative methods – of families' and providers' motivations and needs regarding the early screening, diagnosis, and treatment for ASD; and 2) better understanding of how providers and organizations make decisions regarding implementing early screening within their clinical practice. Given the challenges to family engagement, we suggest that future work might also focus on the development of both patient-facing implementation strategies (e.g. direct-to-consumer marketing), and organizational-level implementation strategies, including identifying site champions at clinical locations, and screening potential partner organizations for their motivation and ability to effect change. In addition, lessons from the mental health literature on family engagement in services (e.g., improving the parent-provider alliance, provider experience and expertise) may provide

useful strategies for improved implementation (Brookman-Frazee et al., 2010; Chacko et al., 2012; Tetley et al., 2011).

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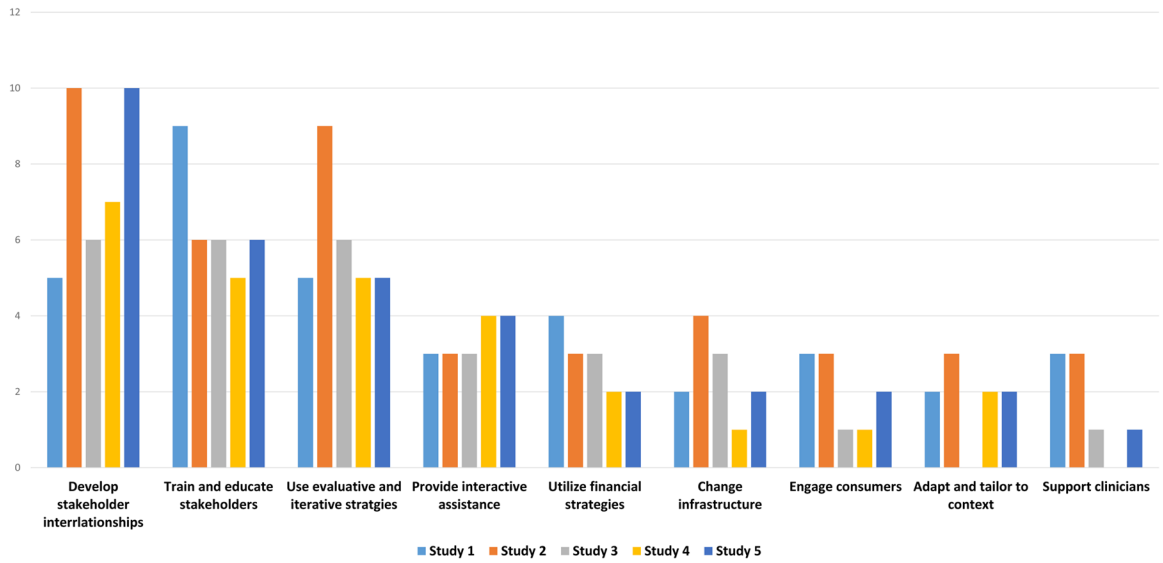
Figure 1.
Number of implementation strategies used in each of the nine ERIC domains for each of the five ASD Peds Network studies.
ERIC: Expert Recommendations for Implementing Change

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Table 1

Overview of Five ASD PEDS Network R01-funded Studies

PI	Study Name	Intervention Description	Screening Tool(s) Used	Age at Screen	Target Population	States	Region	Setting
Carter	Multi-stage screening for ASD in EI settings	Training EI providers to screen and refer for ASD diagnosis	Brief Infant Toddler Social Emotional Assessment (BITSEA) (Giserman Kiss et al., 2017)and Parents' Observation of Social Interaction (POSI)(Sheldrick and Perrin, 2013)	14 to 33 months	EI providers	Massachusetts	Urban	Early intervention
Feinberg	Project Early	Family Navigation to improve access to diagnostic and treatment	Modified Checklist for Autism in Toddlers, Revised with Follow-Up (MCHAT-R/F)(Robins et al., 2014)	18 and 24 months	Primary/specialty providers and families	Massachusetts, Connecticut, Pennsylvania	Urban	Primary and specialty care
Pierce	Get Set Early Model	Creation of a pediatrician learning network and referral center	Communication and Symbolic Behavior Scales Infant Toddler-Checklist (CSBS ITC)	12, 18, and 24 months	Primary care pediatricians	California, Arizona	Urban/Sub-Urban	Primary and specialty care
Stone	Screen-Refer-Treat (SRT) Model	Training primary care physicians in screening and Early Intervention providers in assessment and treatment	Modified Checklist for Autism in Toddlers, Revised with Follow-Up (MCHAT-R/F)(Robins et al., 2014) and Screening Tool for Autism in Toddlers (STAT)(Stone et al., 2004)	18 – 30 months	Primary care physicians and EI providers	Washington	Rural and Urban	Primary care and Early Intervention
Wetherby	Mobilizing community systems to engage families in early ASD detection and services	Online provider training, screening, and provider/family navigator engagement tool	Early Screening for Autism and Communication Disorders (ESAC) (Wetherby et al., 2009)	12, 18, and 24 months	Primary Care and Community organizations and families	Florida, Georgia, New York, Pennsylvania	Urban and Rural	Primary care, federally-funded agencies, National Black Church Initiative (NBCI)

Table 2

Innovation Strategies Used Across Study Designs

Strategy	Number of Studies
Provider Training	
• Primary Care Provider Trainings	5
• Early Intervention Training	2
Type of Screening Instrument	
• Modified Checklist for Autism in Toddlers (MCHAT-R/F) (Robins et al., 2014)	2
• Screening Tool for Autism in Toddlers (STAT) (Stone et al., 2004)	2
• Brief Infant Toddler Social Emotional Assessment (BITSEA) (Giserman Kiss et al., 2017)/ Parents' Observation of Social Interaction (POSI)(Smith et al., 2013)	1
• Communication and Symbolic Behavior Scales Infant-Toddler Checklist (CSBS ITC)(Wetherby et al., 2002b; Wetherby et al., 2008)	1
• Early Screening for Autism and Communication Disorders (ESAC)(Wetherby et al., 2009)	1
"Early" Screening (<18 months)	3
New technology utilization for screening, diagnosis, or treatment	3
Type of Provider Targeted by Innovation	
• Primary Care	4
• Specialty Care	3
• Early Intervention	2
• Community Service Providers	1
• Families	2