**Symposium Title:** Embracing Stakeholders as Partners in Disability Research: Methods, Findings, and Frameworks

**Chair:** Katherine Walton¹

**Discussant:** Christine Brown²

**Overview:** Community stakeholders, particularly individuals with disabilities, have historically been largely ignored or overlooked by IDD researchers. In large part due to the efforts of an increasingly vocal community of advocates with disabilities, a larger number of research studies have begun incorporating stakeholder perspectives at all stages of the research process. Involving stakeholders in the research process has the potential to improve the quality and relevance of research and increase the likelihood of implementation of research findings in community settings. Moreover, increasing representation of stakeholders in research, particularly stakeholders with IDD, is increasingly recognized as an ethical mandate, echoing the “nothing about us without us” rallying cry of stakeholder groups. The presentations in this symposium will highlight projects that have incorporated stakeholder perspectives in various ways and at various stages of the research process, and will focus both on the unique value contributed by stakeholders, as well as on best practices and lessons learned regarding incorporating stakeholders with IDD and their families as research partners. The first presentation will discuss findings from a series of focus groups with parents and teachers of young children with ASD, and how these findings will contribute to the development of a new measure of social communication for young children with ASD. The second presentation will discuss the creation and implementation of a Learning Collaborative model, including a Disability Experiences Expert Panel made up of self-advocates with IDD, in research on health and mental health in people with IDD. The third presentation will focus on the creation of a stakeholder-driven early ASD intervention research agenda and framework for stakeholder consultation to research teams. The final presentation will describe information gathered in collaboration with program administrators, service coordinators, providers, and caregivers regarding their perspectives on the use of telehealth within Colorado’s Part C Early Intervention program and how these findings are being used to address system needs.

**Paper 1 of 4**

**Paper Title:** Use of Stakeholder Focus Groups to Develop Content and Structure of a New Measure of Social Communication for Young Children with Autism Spectrum Disorder

**Authors:** Katherine Walton¹, Alayna Borowy¹, Christopher Taylor³

**Introduction:** Children with autism spectrum disorder (ASD) show pervasive, often severe deficits in social communication that are a major target of early intervention programs. Sensitively and efficiently tracking both long- and short-term change in early social communication skills is essential in both research and community settings. However, current measures of social communication in ASD suffer from limited sensitivity to change, incomplete content coverage, and high burden of administration (Anagnostou et al., 2015). As part of a larger effort to develop a new parent- and teacher-report measure of social communication in young children with ASD, this study aimed to identify key social communication domains, skills, and behaviors considered most important to parents, teachers, and experts.

**Methods:** Twenty-one parents, nine teachers, and fourteen expert clinicians participated in a total of seven focus groups regarding their perceptions of social communication challenges and needs in young children (ages 2-6) with ASD. Thematic analysis was used to analyze focus group transcripts and extract themes and subthemes from the groups.
Results: Participants identified challenges with expressive language, receptive language, and social skills. In addition, they noted important differences in social behaviors across contexts and partners, and described ways in which communication challenges and emotion regulation problems compounded and interacted with one another. Respondents also identified strategies for supporting and building social communication skills. Sub-themes included content regarding differences in interactions with adults vs. peers, key deficits in use of expressive communication in flexible and functional ways, and difficulties with understanding and responding to others’ emotions.

Discussion: Parents, teachers, and experts identified a number of key concerns with social communication in young children with ASD. Some identified areas of concern (e.g., interaction between communication and emotion regulation deficits; differences in communication capacities and strategies across settings) are not well represented on existing measures of social communication intended for use in this population. As development and validation of this new measure of social communication continues, focus group content will be integrated during the item development process, including addition of items in areas tapping key areas of divergence between focus group themes and current measure content. This strategy is consistent with best practices in development of patient-reported outcome measures (Food and Drug Administration, 2009) and will likely result in a measure with increased relevance and sensitivity to changes in key areas of social communication related concerns for parents and teachers.

References/Citations:


Paper Title: The Disability Experiences Expert Panel: Empowering Self-Advocates to Engage in Participatory Action Research

Authors: Andrew Buck¹, Christine Brown², Jill Hollway⁴, Katherine Walton¹, Luc Lecavalier³, L. Eugene Arnold¹, Chelsea Cobranchi¹, Alexa Murray¹, Dan Davies⁴, Susan Havercamp¹

Introduction: The Rehabilitation Research and Training Center (RRTC) project at the Ohio State University Nisonger Center aims to make health measures more accessible for self-report by adults with IDD, learn more about the rate of co-occurring mental health conditions among adults with IDD, and develop best practice guidelines for health professionals who support adults with IDD. Since the goal of this project is to conduct research that improves the long term health-related care, function, and quality of life outcomes for adults with IDD, individuals with IDD were recruited and trained to inform the RRTC research process as members of the Disability Experiences Expert Panel (DEEP). The Disability Experiences Expert Panel (DEEP) is a group of individuals with intellectual and developmental disabilities (IDD), who are engaged in participatory action research (Baum, 2016) as consultants alongside investigators from The Ohio State University (OSU) Nisonger Center.

Methods: Twelve adults with IDD were recruited through existing networks and social media posts. Two Nisonger Center staff co-chair the DEEP, which meets at the Nisonger Center and communicates through emails. DEEP members were trained in the topics of research and self-advocacy, which culminated in a Person Centered Plan that included assessment of learning style, communication strategies, self-advocacy skills inventory, supported decision making checklist, and a health goal. During the first phase of the project, the DEEP group reviewed health assessments, modified research consent forms, and assisted to develop a pain rating scale to improve accessibility for individuals with IDD. The investigator team used this feedback, and well as feedback

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from a team of experts, to create a pilot version of health and quality of life self-report measures with adaptations for individuals with IDD. Cognitive interviews were conducted with adults with IDD (n=8) and their caregivers to gain additional qualitative feedback on these measures and make further modifications.

**Results:** Following this iterative input process of measure design and qualitative data collection, the two measures (initially containing a total of 54 items in traditional written self-report formats) were shortened to contain a total of 31 items. Item stems and response choices were shortened and augmented with visuals, and were integrated into an easy-to-use, app-based response interface specifically designed for collecting self-report responses from individuals with IDD (Davies et al., 2017).

**Discussion:** Use of a participatory action framework, in coordination with investigator and expert input and cognitive interviewing, resulted in a substantially simplified and easily usable interface for collection of self-report health data from individuals with IDD. The next phase of this project will focus on pilot testing the newly developed health and quality of life measures with a larger group of adults with IDD (n=50) to examine internal consistency, ease and rate of responding, and test-retest stability (n=25). This will result in measures that are prepared for larger-scale data collection (n=400) in coordination with a national prevalence study examining health and mental health in adults with IDD.

**References/Citations:**

**Paper 3 of 4**

**Paper Title:** Rethinking Stakeholder Roles in ASC Early Interventions: Moving from Participants to Engaged Collaborators

**Authors:** Allison Wainer5, Katherine Walton1, Alayna Borowy1, Rachel Gordon5, Project STEER Stakeholders

**Introduction:** Children with Autism Spectrum Conditions (ASC) experience a variety of challenges, including problems with social communication, cognition, and adaptive skills. Multiple types of early interventions (EI) are available; yet, data about how to select, prioritize, and individualize different intervention approaches for a particular child is absent. Further, there is a clear mismatch between the range of outcomes studied in research, and the outcomes/values described by stakeholders like adults with ASC, caregivers and clinicians. This may reflect the fact that stakeholders have rarely been engaged in discussions about which outcomes and measurement approaches should be used in EI research. As such, the goal of this effort, called Project STEER (Stakeholders Engaging in Early Intervention Research) is to develop a sustainable model that puts stakeholders at the center of ASC EI research.

**Methods:** In its initial year, Project STEER has used a Participatory Action Research approach to develop a research agenda that reflects strategies, measurement, and outcomes relevant to ASC EI stakeholder goals and priorities. Our participatory action approach uses collaborative reflection and systematic data collection to mobilize specific actions (Baum, MacDougall, & Smith, 2006); this approach has been particularly well suited for the current project aims given that a lack of collaboration, focus and clearly defined next steps have hampered prior attempts to create a meaningful research agenda in this area. Project STEER stakeholders include adults with ASC, parents of children with ASC, and community-based clinicians/policy makers in Columbus, Ohio and Chicago, Illinois. Across Columbus and Chicago, Project STEER has successfully engaged a total of 34 stakeholders (10 autistic adults, 10 parents of children with ASD, 10 clinicians/policy makers, 4 researchers) in facilitated group meetings to
collectively define problems with current approaches to identifying and measuring EI outcomes and jointly identify recommendations that put stakeholder-driven perspectives at the center of the EI research agenda

**Results:** Project STEER facilitated discussions elucidated several areas that are considered high-priority research topics by stakeholder groups. Themes identified by the groups focus on better support for families, more coordinated and cohesive service delivery systems, increased emphasis on quality of life for the child and family, and consideration of intervention approaches and treatment targets that account for the heterogeneity of ASC. In addition, stakeholders identified a need for more effective and accessible dissemination of research findings, particularly those outlining best practices and evidence-based interventions for young children with and at-risk for ASCs.

**Discussion** Project STEER represents a critical step forward in realigning the research questions and approaches considered and used by researchers with the goals and priorities of stakeholders. The first phase of the project has allowed for identification of topics that stakeholders believe should be at the center of scientific endeavors. Using this information, we will next use Delphi methodology to further refine this collaborative research agenda with a group of stakeholders across the United States. The finalized Project STEER agenda will be disseminated broadly across lay, scientific and policy-focused outlets.

**References/Citations:**

**Paper Title:** Report on the Use of Telehealth in Early Intervention in Colorado: Engaging Key Stakeholders to Understand the Strengths and Challenges with this Service Delivery Method

**Authors:** Katherine Pickard\(^6\), Beth Cole\(^7\), Arlene Stedler-Brown\(^8\)

**Introduction:** Increased access to the internet makes the use of telehealth a more viable and cost-effective service-delivery option for early intervention (EI) services (Little et al., 2018). Moreover, telehealth may be one way to overcome barriers faced by families living in rural and frontier communities who are less likely to receive consistent EI services. Despite telehealth presenting as a promising service delivery method, its use as a service delivery model for EI is relatively new and only a handful of studies to date have examined its use within the context of a statewide program (Behl et al., 2017; Meaden & Daczewitz, 2015). The focus of this presentation is to outline a partnership across families, providers, administrators, and researchers with the goal to better understand factors that influence the utilization of telehealth in Colorado’s Part C Early Intervention program. Specific questions addressed in this presentation include: 1) What are the perceived benefits and challenges of using telehealth?; and 2) What might improve the feasibility and acceptability of telehealth as a service delivery option?

**Methods:** Anonymous surveys were initially used to understand perceptions of telehealth, actual experiences with telehealth, and perceived benefits and challenges using this service delivery method. Responses to the surveys were submitted by 112 providers, 39 service coordinators, 8 program administrators, and two families. Participants responded from diverse areas of Colorado, including both rural and urban areas. Follow-up focus groups were conducted with program administrators and families to gather more nuanced information regarding the benefits and challenges identified in initial survey responses. Surveys and focus group interviews were de-identified and reviewed by the three investigators to condense the data into analyzable

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themes with concrete definitions. Each investigator independently coded the data. Consensus coding was used to establish reliability when there was disagreement on specific themes.

**Results:** Overall, participants indicated a number of benefits associated with using telehealth, including its promotion of flexibility, access to providers, and better family engagement. In addition to added flexibility, survey participants emphasized that using telehealth also supports a family coaching model that facilitates parent empowerment and engagement. Despite promoting family coaching practices, some of what was learned through this partnership is that not all providers have training in family coaching models and/or have limited experience coaching families, let alone over telehealth. Other primary barriers identified by participants included access to high speed internet and perceptions that telehealth is less effective and less personal than in-person services.

**Discussion:** This report is one of the first to examine provider, administrator, and family perceptions regarding the use of telehealth services within a statewide EI program. The partnership results lend themselves to a discussion of next steps in the implementation of telehealth in Colorado’s Part C program.

**References/Citations:**