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PCORI Project Transforming Research: Understanding Sensory Experiences in ASD,
Stakeholders Working Together (TRUST)



USC Chan Division
of Occupational Science
and Occupational Therapy

Transforming Research: Understanding Experiences ASD, Stakeholders
Working Together - TRUST Conference Overview and Session Summaries
November 4, 2022 - November 5, 2022

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I. TRUST Conference Overview

The TRUST (Transforming Research: Understanding Sensory Experiences in ASD, Stakeholders Working Together, #19922-USC) Project, funded by the PCORI Engagement Awards Program, an initiative of the Patient-Centered Outcomes Research Institute (PCORI) culminated its efforts with a virtual national conference on November 4th and November 5th, 2022 that had 291 registrants including autistic self-advocates, researchers, family members, caregivers, clinicians, students, and other members of the larger community. Many individuals in attendance identified as being a part of multiple stakeholder groups. The purpose of this conference was to highlight the multiple perspectives of different stakeholder groups that have contributed to our understanding of lived experiences throughout all phases of the project and to mobilize this knowledge to the community in order to improve the lives of autistic individuals. Keynote speakers included Katherine (Kate) Boyd from PCORI (Patient-Centered Outcomes Research Institute), Holly Robinson Peete, the mother of an autistic adolescent, Zachary Williams, an autistic researcher, Virginia Spielman, an autistic clinician.

Panel sessions such as the Lessons Learned Panel, Facilitators and Barriers to Research Engagement Panel, and Sensory Processing and Daily Life Panel were all led by various stakeholder group members including autistic self-advocates, caregivers/family members, clinicians, and researchers who participated in the TRUST Project. Summaries of these discussions can be found below.

Throughout the conference, participants engaged in a variety of sessions that addressed the lessons learned from this project and research priorities generated from the project by the stakeholder groups, as well as participated in discussions. The conference also included a virtual art gallery that showcased the various strengths and talents of the autistic community. Submissions included digital art pieces, paintings, drawings, music pieces, and music videos from the autistic community and had over 470 virtual visits.

Registration for the conference was free and open to all participants. Participants were able to access all of the conference content for 30 days after the date of the conference. For the virtual conference platform, we utilized vFairs, a virtual platform that hosted all contents of our conference and provided assistance to all attendees during the duration of the conference via a virtual help desk. Accessibility features of this platform such text size adjustment, video transcriptions and translations, live captioning, color contrast, and screen reader were available to all participants throughout the conference.

II. Keynote – Kate Boyd

Kate Boyd, Senior Program Officer, Engagement Awards, PCORI, provided a keynote where she introduced engagement principles that guide the stakeholder engagement process including reciprocal relationships, co-learning, partnerships, and the importance of transparency, honesty, and trust. She described that the meaningful involvement of participants, caregivers, clinicians,

and other stakeholder members involved is supported throughout the entire research process from the start of planning the study, to conducting the study, and disseminating the study results. Specifically, building relationships for collaboration within these projects with the various stakeholder members was introduced as best practice, which as Kate mentioned, has been much of what the TRUST project has done in terms of building lasting relationships with our autistic self-advocates, clinicians, researchers, and caregivers and family members.

III. Keynote- Zachary J. Williams

Zachary J. Williams is an autistic researcher, an MD/PhD Candidate from Vanderbilt University School of Medicine, and a co-chair of INSAR (International Society for Autism Research) Autistic Researchers Committee. In his keynote session, Zack presented on promoting lived experience in autism research. He discussed participatory research and community collaboration and stressed on the importance of incorporating the feedback of autistic people and stakeholders on research priorities and direct involvement of autistic people in various stages of research process. He discussed various forms of community collaboration, benefits of and barriers to participatory research, and participatory research in autistic-led research projects. Specifically, Zack shared his personal experience of being an autistic researcher and establishing INSAR Autistic Researchers Committee.

IV. Keynote- Virginia Spielmann

Virginia Spielmann, Executive Director, STAR Institute, is an occupational therapist, speaker, and educator in sensory processing and sensory integration. In her keynote session of the conference, Virginia shared her individual experience of growing up with sensory differences, discovering occupational therapy, raising an autistic child, and being diagnosed with autism as an adult. She presented latest resources on the topic of the autistic burnout and made suggestions on additional resources and readings on the topic.

V. Keynote - Holly Robinson Peete

In her keynote session, Holly Robinson Peete spoke about her personal and professional experiences and her family's experience with her son's autism diagnosis. She highlighted the importance of dialoguing with other people and keeping an open conversation with families, clinicians, and anyone else that is part of the autism community. Holly emphasized the importance of considering that each individual's experience is unique and their own. She shared her experiences with RJ's Place, a part of the HollyRod Foundation and a space where wraparound services are provided for parents, siblings and caregiver. RJ's Place focuses on vocational training and job placement

VI. Research Priorities

This session introduced the process in developing the different research priorities of the various stakeholder groups within the TRUST project which consisted of rating and ranking top priorities

through each stakeholder group meeting and merged group meetings. Guiding principles for the priorities (i.e. population characteristics, key aspects of lived experiences, and methodological approaches) were discussed as ways to be incorporated in future research endeavors. Selected commonalities among the research priorities included sensory processing issues across the lifespan and services, interventions, and strategies for the autistic community, sociocultural influences, environmental adaptations and modifications, and the relationships of sensory processing differences to other aspects of performance and life.

VII. Stakeholder Perspectives Panel: Sensory Processing and Daily Life

Session Summary

During this session, panelists including autistic self-advocates, clinicians, caregivers and family members, and researchers discussed how various sensory processing experiences have impacted their lives, in addition to general strategies that have helped them better participate in everyday life. Many of these strategies were noted to not be immense changes, but basic shifts in attitudes towards sensory processing. Awareness and acceptance of differences, in the panelists' views, would allow easier access to the environment and open up new avenues. Further, they added that accommodating simple changes within the environment would be beneficial not only to individuals with sensory processing needs but society as a whole.

VIII. Lessons Learned Panel

Session Summary

This session of the conference discussed the lessons learned from the TRUST project from the perspectives of the different stakeholder groups, including caregivers and family members, autistic self-advocates, clinicians, and researchers. A key takeaway identified by the stakeholder panelists was that participation in the project provided the opportunity to "identify the gaps in language and communication" and regarded this aspect as a diverse learning experience. The collaboration within the project enabled the panelists to gain an understanding of other stakeholders' perspectives to reinforce ideas of equity, diversity, and inclusion. The need to incorporate feedback from other groups while designing research in order to make studies as accessible as possible was mentioned as another important lesson learned. Opportunities to interact with members of different stakeholder groups highlighted the importance of understanding the lived experience of cultural differences encountered by individuals with sensory processing needs. Including stakeholders at all research levels and building true engagement is a gradual process that can take place by continuous input and feedback to discuss strategies to increase participation in research.

IX. Stakeholder Perspectives Panel: Facilitators and Barriers to Research Engagement

Session Summary

This session of the conference discussed the facilitators and barriers to research engagement, and what can be done to ameliorate barriers to research engagement in the future. Some examples of facilitators include emphasizing collaboration and not just passive participation and inclusion of various stakeholders from the beginning of the process. Some barriers to research engagement include difficulties in communication (varying types, miscommunication), inadequacies in recruitment and participation, and insufficient data interpretation. In order to decrease barriers to engagement, research must acknowledge the importance of communication, including the communication of results at the end of the study, make research easy and accessible, and provide free publications after the research is published to all stakeholders. Additionally, incentives should be considered more than just monetary gifting, but rather a sign of respect to the time and efforts of participants.

X. Language and Discourse - inclusivity, communication, accommodations

Session Summary

This session on Language and Discourse, also titled “Language Matters,” explored the ways in which the terms and identifications we use can serve to stigmatize or to empower individuals and communities. In conversation, autistic self-advocate Raul Munoz and researcher Mary Lawlor discussed how the historical use of hierarchical and deficits-driven models, such as functional labels, have shaped much of research on and clinical treatment of autism. The session further discussed the importance of engaging across stakeholder groups to share lived experience and highlight the heterogeneity of the autism community in order to identify language that promotes the agency and strengths of autistic individuals in research, clinical practice, and beyond.

XI. Partnering up/Narrative Workshop

Session Summary

During the Narrative Workshop and Partnering Up session of the TRUST conference, discussion occurred around the importance of partnering up with different stakeholder groups, the idea of narrative, and how narrative strategies can be used to build partnership. Examples from the TRUST project were presented and highlighted the importance of multiple perspectives as a way to understand and value different expertise and rethink consensus. Asking questions such as “How do we come to know enough about each other?” can allow us to build more effective partnerships and reach greater outcomes. The idea of narrative was discussed as a form of expression that allows people to find their voice and enact change. The TRUST project utilized storytelling as a strategy to build relationships among stakeholder group members. For example, as part of the introductions in the first stakeholder group meeting, participants were asked to introduce themselves by sharing how they came to be involved in the autism community. This focus on lived experience enabled stakeholder groups members to frame their contributions in a way that they felt was most important. Participants also shared the value they found in utilizing narrative in their own research endeavors and how it has helped them connect with their research participants.

XII. Intersectionality

Session Summary

Intersectionality is a definition presented by Dr. Kimberle W. Crenshaw that refers to the study of overlapping and intersecting social identities and related oppression, domination, or discrimination (Crenshaw, 2017). It is a unique experience for people at the intersection of multiple marginalized identities and the ways in which aspects of identity and social categories can shape experiences, opportunities, and participation (Angell, 2022). During the Intersectionality Panel session, presenters also shared about childhood experiences, education, work, community life, and self-advocacy. Facilitators and barriers to participation at home, educational institutions, and work were discussed. Panelists also offered their suggestions on the ways to promote access to information about autism and sensory processing.

XIII. General Session: Knowledge Mobilization, Community Partners, & Engagement Tools

Session Summary

During this session, Dr. Grace Baranek discussed ways to utilize and mobilize the knowledge and experiences gained through the TRUST project to larger parts of the community and collaborative ways in which use of engagement tools can be expanded to represent the needs of the project's different stakeholder groups. Dr. Erna Blanche discussed application of knowledge mobilization or ways in which community partners' experiences with the TRUST project might influence their engagements with the autistic community. Community partners included researchers, clinicians, 5-Eleven hoops, and Autism Speaks. SPAN, a community network consisting of researchers and clinicians, a product of the TRUST project was presented. Furthermore, engagement tools including Autistic Adults and other Stakeholders Engage Together (AASET) were discussed by Dr. Stephen Shore and Dr. Teal Benevides.