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Considerations from the 2017 IMFAR Preconference on Measuring Meaningful Outcomes from School-Age to Adulthood

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The autism spectrum disorder (ASD) research community is increasingly considering the importance of measuring outcomes that are meaningful to individuals with ASD and their families. The 2017 IMFAR preconference aimed to gain the perspectives of how to define and measure "meaningful outcomes" from 280 participants, including people with ASD and their families, service providers, and researchers. Six themes were identified: (a) the definition of "outcome" varies by context and perspective; (b) the need to broaden the scope of what researchers measure; (c) the need for new assessment tools; (d) the need to expand data analytic methods; (e) where to focus (with emphasis on considering different developmental stages and aspects of diversity); and (f) a need for community partnerships to bridge research and daily practice. The challenge that the research community now faces is how to move the evidence base for clinical practice forward while keeping alive the divergence of views and considerations that are relevant for thinking about complex outcomes for the highly heterogeneous group of individuals with ASD. This commentary provides recommendations, with an emphasis on lifespan viewpoints that encompass individual strengths and preferences. *Autism Research* 2018. © 2018 International Society for Autism Research, Wiley Periodicals, Inc.

Lay Summary: The 2017 IMFAR preconference aimed to gain the perspectives of how to define and measure "meaningful outcomes" from a variety of stakeholders. This commentary outlines the six themes identified from keynote and panel presentations and audience-participated discussions. Recommendations are made to emphasize perspectives that look across the lifespan and encompass individual strengths and preferences.

Keywords: lifespan; outcome; stakeholders; strengths

Introduction

Research on "outcomes" for individuals with autism spectrum disorder (ASD) has focused primarily on diagnostic status or some indicator of the person's functioning or impairment. Such outcomes have been measured in a variety of ways, ranging from clinical judgment of whether the child or adult meets ASD diagnostic criteria and scores generated from standard measures of IQ, adaptive function or ASD symptoms to categorical classifications based on clinician/researcher-based decisions about what constitutes a "good" outcome. Considering the variable developmental trajectories among individuals with ASD, the field has increasingly recognized that a one-size-fits-all approach may overlook individual achievements by placing undue focus on outcomes that may or may not be reasonable or desired for some individuals [Taylor, 2017]. Furthermore, accepting a narrow definition of "optimal outcome" may unintentionally restrict our efforts to make significant change across a diverse population of people with ASD, or to consider success in the face of slower progress [Georgiades & Kasari, 2018].

Recognizing the need for a more nuanced view of what may be considered "optimal" and guidelines on how to effectively measure varied achievements, the 2017 IMFAR preconference aimed to gain perspectives on how to define and measure "meaningful outcomes" from individuals with autism and their families, service providers, and researchers. This commentary summarizes the main themes that emerged with respect to measurement of outcomes, followed by discussion and recommendations of how to use this information to move research forward and to inform clinical practice. The conclusion of this full day conference with a wide range of presenters and discussants was the realization that a "successful outcome" varies widely depending on the person considering the

outcome and what they value as meaningful. To move forward in promoting positive outcomes for all people with ASD, researchers must implement both qualitative and quantitative measures that capture a wider, more nuanced range of achievements, including measures of community engagement (e.g., employment, participation in community events).

Method

The IMFAR preconference was held in San Francisco, California, on May 10, 2017 and attended by 280 regional, national, and international attendees from all constituencies. Individuals with ASD and their families, service providers (e.g., regional agency directors, educators, clinicians, paraprofessionals), and researchers were invited. Invitations were sent via email and word-of-mouth to patients and families receiving services at UCSF, local agencies serving individuals with ASD in Northern California and researchers with a known interest in outcomes research in ASD. In addition, information regarding the preconference was published on the IMFAR conference website and distributed via email to members of the International Society for Autism Research. The number of attendees in each stakeholder group was not tracked; affiliations for approximately 160 preregistered individuals indicated 1/2 were associated with nonprofit or community organizations or service agencies (e.g., educators, clinicians, self-advocates), 1/3 were university affiliated (primarily researchers and trainees), and the remaining identified as family members. The other 120 attendees registered on-site and were a mix of all constituencies.

A focus on school-age to adulthood was chosen to allow exploration of how meaningful outcomes may vary or change depending on age and/or developmental stage. Four speakers, chosen by the conference co-chairs (VHB, RLH) for their expertise in measuring outcomes in intervention studies and/or descriptive clinical research were invited to provide keynotes: Connie Kasari (school-age/adolescent); Leonard Abbeduto (adolescent/young adult); Laura Grofer Klinger (adults); and Tony Charman (lifespan/longitudinal). In addition, there were two breakout sessions (school age/adolescent and transition age/adult years) that began with 3–4 discussant presentations followed by audience discussion. Discussants were chosen by conference co-chairs to provide a variety of perspectives (i.e., person with ASD, parent, service provider, or researcher). Keynote and panel presenters addressed questions regarding more technical aspects (e.g., data analytic methods) after their presentations as needed. A discussion leader facilitated audience comments to ensure that a range of perspectives (including people with ASD and family members) were shared and that discussion was not dominated by the most assertive participants. Two note takers per breakout session simultaneously recorded both summarized points and direct quotes, and then organized notes by broader points that emerged. Following the preconference, the preconference co-chairs derived a list of discussion themes based upon breakout session notes and keynote summaries submitted by the speakers. Together (and with consensus from co-authors), they identified the six most prominent themes and generated recommendations to guide future outcomes research.

Results

Theme 1: The Definition of Outcome Varies by Context and Perspective

Across keynotes, panels, and discussions, the most prominent recurring theme was the perspective that what is considered a meaningful outcome varies depending upon the purpose for which an outcome is being defined, who is asked, and what outcome measures are being used. Discussions centered around two primary contexts: outcomes measured to reflect the success of an intervention in an efficacy or effectiveness study and outcomes describing achievements by an individual or group.

In efficacy and effectiveness research, the declaration of a primary outcome is critical, as treatments—whether psychological or pharmacological—have a primary target that they aim to change. Primary outcomes are often assessed using proximal measures that are specific and aim to be largely objective and quantitative (e.g., symptom counts, severity). Where they are more subjective (e.g. affect, interest, engagement), they are objectively defined constructs that are still carefully quantified. Standardization of outcome measures is often a high priority in treatment research, as it allows for pooling of data to assess outcomes across studies (e.g., meta-analyses). Proximal measures are advantageous, as they are by definition close to the targets that the intervention is attempting to change. They may, however, be constrained in how much they reflect the intervention's impact more broadly, such as on daily life. On the other hand, distal measures might be unwise to choose as primary outcomes as they assume that change in the treatment target will have broader implications and impact and may not be expected to change in the short-term timeframe typically measured in intervention studies. Few longitudinal intervention studies have been conducted that provide both measures of narrowly defined short term outcomes as well as broadly defined long term outcomes that might be the most meaningful to people with autism and their families.

In more descriptive research and in clinical practice, there is a tendency to try to follow suit in the

measurement of outcomes by defining specific "optimal" achievements, such as independent living, lack of symptoms, obtaining full time employment, or having a certain number of friends. This approach is focused on community-based, distal outcomes. However, a cautionary note to using this approach is the importance of recognizing the diversity of strengths and challenges encompassed by people on the autism spectrum for whom expectation of such outcomes may or may not be appropriate or desired. Henninger and Taylor [2014] highlighted that the outcome domains rated by families as most important matched conventional categories of normative adult achievements (e.g., living arrangements, employment). However, families placed more emphasis on the person–environment fit, rather than an "ideal level" that might be based more on societal norms or as broadly defined as in the neurotypical population. For example, for many adults with ASD, part-time work or volunteering in a productive occupation may be an "optimal outcome" as opposed to a 40-hr work week. As such, many positive outcomes may be missed by measures designed to capture predefined or normative achievements.

Theme 2: Need to Broaden the Scope of What Researchers Measure

A second theme highlighted was the variability in perspectives of what types of outcomes and level of achievement would be considered positive or significant as well as the order of priority when considering how to define meaningful or optimal to each constituency. Across stakeholders, providers, and researchers, there was acknowledgement that many individual factors can affect a person or group's preferences and priorities. There was also recognition that partnerships are essential to learn what is valued from different constituents, such as the person with ASD, their parents, and other family members and providers.

First, there is a need to recognize that targeted outcomes defined by providers or researchers may not always align with priorities of individuals with ASD or their families. Although a researcher's goal may be to develop an intervention to improve social reciprocity and increase social contacts, it may come at a cost to the individual who does not enjoy frequent social interaction. Assumptions of desired end-points based on normative values (e.g., more interaction is better) may not promote positive well-being for everyone—researchers must also assess the significance of a particular outcome to individuals with ASD and whether they find the intervention acceptable. McConachie et al. [2015] found that, while professionals mostly considered core ASD symptoms as key

outcomes to measure, parents of young children were concerned about their child's happiness, well-being, and relationships both inside and outside the family. These examples also serve to remind researchers and clinicians of the need to include parents, teachers and other significant figures in their lives who may have different perspectives of what interferes in daily life or could improve well-being. In both research and service contexts, the differing outcome priorities across stakeholders have implications for defining positive achievements (and subsequent measures of what constitute success). For example, having an occupation or functional role in society was noted as one of the most important themes reported by caregivers when asked to describe a successful transition to adulthood [Henninger & Taylor, 2014]. However, caregiver respondents placed emphasis on feeling productive or contributing to the community, rather than paid or full-time employment.

Outcome frameworks, such as every child matters (ECM; Department for Education and Skills, 2003 may provide a useful starting point when considering what domains to measure. Because, for individuals with ASD, achievements within these frameworks must also be evaluated in the context of their age and abilities with a recognition that progress or goals may vary from expectations based on normative development [Sloper, Beresford, & Rabiee, 2009; Henninger & Taylor, 2014]. Moreover, different stakeholders may have different views or experiences in any given domain; thus, obtaining multiple perspectives may be important in defining meaningful measures and outcomes. For example, many studies gather information from parents or teachers; however, parents are not with their children at all times (e.g., at school) and teachers may not be aware of peer relationships outside the classroom during unstructured times (e.g., recess). Even when children with ASD self-report a reciprocated friendship, they may not engage with their friend on the playground, appearing to be as isolated as other children who do not report friends in the class (Kasari, Locke, Gulsrud, & Rotheram-Fuller, 2011, 2012; Locke, Shih, Kretzmann, & Kasari, 2016), highlighting how social function and reciprocity may vary by context assessed.

It is noteworthy that "loss of diagnosis" was not a highly prioritized outcome (see Georgiades & Kasari, 2018). There was more emphasis on subjective well-being and reduction of common co-occurring conditions than a desire to not have ASD. This is an important consideration, as many published outcome studies focus on factors that predict loss of diagnosis as a so-called optimal outcome. Whereas happiness, well-being, and quality of life (QoL) issues are subjective and can be difficult to assess, there is an emerging literature exploring these factors in ASD. In particular,

several QoL measures developed for use with other populations (e.g., chronic health conditions) have been implemented in ASD studies [e.g., van Heijst & Geurts, 2014; Shipman et al., 2011]. Outcomes such as physical and mental health may lend themselves to more objective study. Evidence for poor healthcare outcomes including poor physical and mental health [Croen et al., 2015], declines in learning and memory with aging [Powell, Klinger, & Klinger, 2017], and increased mortality rates [Mandell, 2018] suggests that a broader focus on healthcare outcomes is essential in identifying targets for intervention. Further, self-determination, quality of life, and happiness and health are key constructs studied in the general aging and social psychology literature and should be attainable for everyone, regardless of age, language or cognitive ability level, personal beliefs, etc.

Although studies of children and young adults often focus on understanding deficits to inform intervention, greater attention to factors that predict health and well-being across the lifespan should be seen as similarly informative and necessary to measuring outcome. Characterizing a child or adult's outcomes requires a nuanced view that goes beyond presumed "optimal" levels of the outcome of interest. Triangulating information using multiple methods (e.g., observational, questionnaire) and reporters (e.g., self, peers, teachers, caregivers) from a range of contexts (e.g., playground, classroom, home) will provide the most robust picture of the outcome or achievement being assessed, as well as insights into areas for future intervention.

Theme 3: Need for New Assessment Tools

Discussions also underscored a need to develop new measures of more individualized and meaningful achievements. For example, a member of our discussion noted that he liked to contribute to society by donating blood regularly. Many agreed that this was a contribution that would be valued by many people but that may not have been captured on a traditional survey. Perhaps a more qualitative approach would capture these experiences.

Several reviews have highlighted the dearth of developmentally appropriate measures to assess outcomes in young children [McConachie et al., 2015], minimally verbal school age children [Kasari et al., 2013], and adults [Brugha, Doos, Tempier, Einfeld, & Howlin, 2015] with ASD. Our discussions emphasized a particular need for valid assessments of subjective experiences, such as social well-being, quality of life, and fulfillment of support needs. Some measures already exist and have been used in ASD research [e.g., the Pediatric Quality of Life Scale; Varni et al., 2003]. However, there is a need for measures designed to capture unique aspects of QoL in individuals with ASD [Markowitz et al., 2016]. Newly designed measures should strive to capture individual satisfaction in

subjective areas (rather than a pre-described level), as well as allow for flexible administration and response types to support self-reporting from individuals with varying levels of expressive abilities. In addition, implementation of observational measures with carefully defined coding schemes may yield more ecologically valid objective outcomes [e.g., intentional communication in the classroom; Pasco, Gordon, Howlin, & Charman, 2008], than standardized tests, which are subject to floor effects and limited generalizability.

For example, Abbeduto and colleagues [Berry-Kravis et al., 2013] have been exploring the use of expressive language sampling (ELS) as an outcome measure for ASD and other neurodevelopmental disorders. ELS involves collecting and analyzing brief samples of spoken language in fairly naturalistic situations in which there is sufficient control of the materials, format of the interaction, and partner behavior to ensure consistency of administration across participants and occasions of measurement. They have developed conversational and narrative ELS procedures that yield measures of various aspects of language ability (e.g., vocabulary, syntax, and fluency). These measures display strong psychometric properties, with minimal practice effects, strong test–retest reliability, and evidence of construct validity for individuals with fragile X syndrome or Down syndrome. ELS also captures phenotypic differences among disorders and shows a long period of development in typically developing individuals, making it useful across a large range of ages and abilities. Further validation in ASD is needed, as is work on automation of the analytic procedures to make ELS feasible in large-scale treatment studies.

Use of technology is also being incorporated into outcome studies, allowing for remote collection of data (e.g., telemedicine, web-based platforms) and more efficient coding of behaviors (e.g., language and behavioral coding software; Language Environment Analysis (LENA) system). Qualitative constructs such as community integration can be quantified at a basic level using technology that can track locations and time spent in different community settings (e.g., global positioning system). This advance is important for measurement in real-world settings and the participation of a broader demographic (i.e., rural areas, people without transportation/resources). Other recent innovations include using neurophysiological measures of brain response (e.g., MRI, EEG) and other biomarkers increasingly being used to measure change in treatment trials [e.g., Jones, Dawson, Kelly, Estes, & Webb, 2017]. Despite their promise to help us understand the *mechanisms* that might underlie interventions and how these relate to the behavioral outcomes, there remains much work to be done for biomarkers to be linked to the outcomes preferred by stakeholders. Irrespective of the type of measure being discussed, there was

an emphasis on the need for measures to be developmentally appropriate (i.e., for children and adults, including those with cognitive or language impairment) and sensitive to change to allow tracking of achievements across the lifespan.

Although there is a clear need for measures that capture a range of positive achievements, there is also a critical need to develop measures that provide a more nuanced description of individual needs and can demonstrate the significant role that community supports may play in a person's daily functioning. Existing measures of ASD symptoms, often developed primarily for use with children, may not capture the full range of challenges in adults [Bal, Kim, Fok, & Lord, 2018] and assessments of intellectual functioning may highlight areas of strength for adults with average or higher IQs. Results from either measure can be misinterpreted as evidence that the adult needs fewer supports. This can lead to many adults with ASD being denied services and experiencing significant unmet service needs [Dudley, Klinger, Meyer, Powell, & Klinger, 2018], which limits their long-term prospects for achieving their potential. Development of measures that are designed to contrast achievements and needs with and without supports will help to advance understanding of the range of possible outcomes and ways to maximize individual potential.

Theme 4: Need to Expand Data Analytic Methods

In addition to the need for new assessment tools, researchers emphasized the utility of considering different statistical methods to advance our understanding of outcomes and achievements. For example, in her keynote, Kasari noted the use of classification and regression trees (CART), a statistical learning technique that can be used to create data-driven subgroups. This method has been implemented to guide researchers' decisions about individualization and adaptation of interventions. Using this method, Shih, Patterson, and Kasari [2016] found that a 14% improvement in peer engagement at the 4-week midpoint of an intervention predicts the child's intervention outcome. Such information can be used to build adaptive treatment models to improve outcomes for children responding slowly to an intervention. Adaptive intervention methods are also emerging in autism research, and can help to personalize interventions. Here, an individual's response to intervention can trigger a systematic change in the intervention to further accelerate progress in a slow or fast responding individual. These research designs include SMART trials [Sequential Multiple Assignment Randomized Trial; e.g., Kasari et al., 2014] that utilize dynamic treatment regimens that allow trials to go beyond assessing whether an intervention achieves a given outcome and instead informs for which

individual with ASD an intervention can promote the targeted outcome.

Charman described advances in statistical techniques that address common issues in research. For example, Green et al. [2017] used a novel statistical method that analyzed the "area between curves" of effect sizes for treatment and control groups. This allowed the analysis to include different developmentally appropriate measures of the same underlying construct administered at multiple pre- and post-treatment timepoints, thereby increasing precision of treatment effect estimates [see also Pickles et al., 2016]. This approach addressed the change in outcome measures as the children grew older during the trial, a common issue in developmental intervention research.

Increased attention to novel analytical approaches will become important as researchers strive to advance our understanding of individualized achievements and factors that influence personally meaningful outcomes.

Theme 5: Where to Focus

Discussions about which domains of achievements and outcomes to measure, and whether researchers have suitable tools, dovetailed with a general discussion of the domains to be studied at different developmental stages.

The first consensus was that the notion of an outcome suggests finality and fails to reflect the dynamic nature of development. Thus, it is perhaps misleading to interpret deficits or achievements measured at a single time point as an outcome. For example, Taylor, Henninger, and Mailick [2015] reported that two-thirds of their adult sample had participated in competitive employment or postsecondary education, yet less than one-quarter were consistently engaged in these activities during the study. A different conclusion regarding employment outcomes may have been reached had participants only been assessed once. Intervention research should include multiple follow-up points and longitudinal studies are needed to assess meaningful outcomes across time and developmental periods.

Additional research is needed to determine whether achievements that are considered significant in one developmental period have implications for later meaningful achievements. For example, there is often an emphasis on development of peer-relationships for school-age children, but it is unknown whether such relationships are sustained, contribute to psychological well-being, or promote development of satisfactory adult relationships. Longitudinal studies that identify predictors of later outcome provide information regarding where interventions may be needed earlier in development and provide information about the types of meaningful outcome measures that need to be developed. For example, there is growing evidence that daily living skills may plateau

and/or decline across adolescence and adulthood [Meyer, Powell, Butera, Klinger, & Klinger, 2018] and that these skills are important to later employment. Thus an earlier focus on interventions that target daily living skills and measures to evaluate daily living skills across development and across intellectual ability level are needed.

Finally, there was a call to recognize diversity in the ASD community and to explore the extent to which different cultural, linguistic, religious and other aspects of diversity may affect outcomes—both desired (e.g. cultures that value community cohesion vs. individual achievement), expected and achieved. There was a general feeling that much child research has focused on those with higher IQ, whereas adult research has focused on people with lower IQ. The lack of diversity (including, but not limited to racial, religious, cultural, socio-economic) in ASD research has left gaps and impeded our ability to inform families and professionals about best practices to support progress for individuals with ASD.

Theme 6: Need for Community Partnerships to Bridge Research and Daily Practice

Finally, although not specifically related to measurement of outcomes or achievements, per se, discussions highlighted the need for increased partnership between researchers, individuals with ASD and their families, and service providers. Such partnerships serve many roles, including: (a) informing research directions and the development and implementation of research studies; (b) enhancing community understanding and translation of research findings to everyday practices in the home, clinic, and educational setting; (c) increasing sustained training opportunities for providers to implement such practices to improve quality of care and education; (d) informing development of lifespan supports and services; and (e) informing policy that would improve access to services and supports (particularly large-scale needs, such as housing and competent healthcare). Models for developing such partnerships have been developed (e.g., http://www.shapingautismresearch.co.uk/) and should continue to evolve as these partnerships grow [Fletcher-Watson et al., 2018].

Discussion

Among the attendees, there was general agreement that the essence of measuring outcomes in research often extends beyond quantifying a single end-point to trying to capture meaningful change across development. Although the question, "how does research inform clinical practice?" is frequently asked, discussions highlighted a need to consider "how *should* research be informing clinical practices?" There was also consensus that what

matters most is whether or not the people whose outcomes and achievements are being measured are satisfied, productive, well and happy in their daily lives. It is essential to know if researchers are missing key areas that people with ASD, their families and advocates desire to improve because they are overly-focused on what professionals deem important or meaningful.

Different domains of development—and the instruments commonly used to measure them—have been derived from largely independent conceptual frameworks that overlap with widely varying models (and even philosophical approaches) to understanding a condition such as ASD. In some ways they relate to whether one conceptualizes ASD from a medical model perspective of a condition or disorder that needs "fixing" or a social model of disability whereby the challenges faced by individuals with ASD require societal and structural changes to better support and accommodate individuals with these characteristics to maximize adaption, functioning and well-being [Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013]. The International Classification of Functioning, Disability and Health (ICF) Core Sets for ASD provides a framework for considering the latter [Mahdi et al., 2018; Bölte et al., 2018].

These tensions are somewhat easier to resolve in clinical practice than in the more research-driven world of clinical trials. Clinical care is about seeing the "whole person" in the context of key environments and thinking about the client's well-being, development and community engagement. In clinical trials, however, the stringencies of robust design and methodology force researchers to make decisions about prioritization and ranking of outcomes to test a primary outcome measure necessary to receive regulatory agency approval. Initiatives such as the Core Outcome Measures in Effectiveness Trials [COMET; Prinsen et al., 2014] focus on bringing researchers together to establish a consensus on "core outcome sets" to be reported in clinical trials and might be a model to be followed in an effort to arrive at shared meaningful outcomes in that specific context. The challenge that the whole community now face is how to move the evidence base for clinical practice forward while keeping alive the divergence of views and considerations that are relevant for thinking about research describing the complex changes across development for the heterogeneous group of individuals with ASD.

Considering the six major themes that emerged, the authors provide the following recommendations:

1. Researchers must be aware of who is defining the outcomes and acknowledge that the meaning of the identified outcome may vary by constituent group. Differing views should be seen as a source of information to guide future research and the development of new interventions.

2. Perspectives of the person with ASD, family members, service providers, and researchers should be considered. Researchers must be cognizant of the limitations of a given instrument and, where possible, consider utilizing multiple methods that capture different aspects of an outcome that reflects both subjective and objective achievements. The social validity also needs to be considered, such as whether the intervention is acceptable, meaningful, feasible, does not take too much time and does not inadvertently cause harm to the individual.

3. Greater emphasis should be placed on constructs of self-determination and quality of life, including mental and physical health. Satisfaction and well-being should be a priority that is attainable for everyone.

4. New measures need to be developed in partnership with stakeholders to ensure that they capture meaningful constructs and can be flexibly administered to accommodate different subgroups (e.g., those with cognitive or language impairments, people in rural areas or different countries).

5. New methodologies and statistical approaches are needed to address the complex range of outcomes achieved by people with ASD.

6. Increased collaborations are needed to promote longitudinal studies of ASD that can investigate stability and change observed across developmental contexts. These studies should track a range of proximal and distal measures to facilitate identification of predictors of later outcomes and guide the development of more informative measures.

7. It is imperative that research increase understanding of how different aspects of diversity (e.g., racial, cultural, linguistic, religious) may affect what is meaningful to people with ASD and their families.

8. Partnerships must be built between researchers and the community both to inform what research is done and to ensure translation of research findings to daily practices. Outcome measures should translate into meaningful support plans for community agencies (schools, vocational rehabilitation) and community practitioners.

Strengths and Limitations

The 2017 IMFAR preconference was intended to bring together a range of stakeholders in the autism community, including people with ASD and their families, service providers and researchers, to inform the field's definition of "meaningful outcome" and generate ideas about how to effectively measure such achievements in research. While a strength of this approach was to have a variety of stakeholders, there may have been bias with respect to the viewpoints represented at the preconference and, thus, in this commentary. Although a large number of people were invited (e.g., all INSAR members), stakeholders who were not able to come to San Francisco for the conference are likely underrepresented (e.g., international stakeholders). In addition, all participants in the discussion were verbal; there were not attendees using augmentative and alternative communication devices and those who preferred to contribute their thoughts in another way may not have shared their perspectives. Future meetings may consider a remote viewing option (e.g., teleconference) that would allow stakeholders to participate from off-site using different modalities.

Conclusion

In ASD research, outcome studies have focused primarily on "optimal" or "poor" outcomes. The field needs to move forward in understanding what are meaningful achievements for people with ASD of all ability levels and place greater emphasis on how to support positive well-being for everyone, regardless of age, ability, culture, or geography.

Acknowledgments

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