Improving the Validity and Generalizability of Adult Autism Research Through Incorporating Family and Cultural Contexts

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Abstract

The relatively nascent empirical knowledge base regarding autism in adulthood provides an opportunity to adopt a contextual approach that conceptualizes autism features, outcomes, and supportive services as interactions between the characteristics of the condition and contextual factors across the life course. Although a contextual approach encompasses many aspects of a person's identity and social ecology, we focus here on the closely interrelated family and cultural contexts, which have been poorly integrated into adult autism research. We argue that designing studies with *a priori* attention to context (e.g., family and culture) will improve the relevance and comprehensiveness of findings, which in turn will improve construct validity and provide a more accurate understanding of autism-related outcomes in adulthood. Similarly, designing and/or selecting measures that have been validated with culturally and linguistically diverse samples will improve the utility of findings and reduce spurious or null effects. More contextually informed methodologies will lead to improved generalizability and practical applications of findings. We offer concrete guidance regarding how to increase the social ecological perspective within adult autism research as it relates to study conceptualization, methodology, and measurement.

Keywords: autism, adulthood, culture, family

Lay Summary

Why did we write this perspective?

People on the autism spectrum are different from each other. They have different families and cultures. Research articles about autism in adulthood do not always talk about what differences in families and culture might mean. We wrote this article to tell researchers why it is important to work with people from different families and cultures.

Why is diversity important in adult autism research?

It is important to include the perspectives of diverse individuals in research. This can help to make sure that research findings apply to all individuals on the autism spectrum and their family members. Researchers should ask research questions that are important to individuals and families from different cultures. Researchers also should make sure that findings apply to adults and families from different cultures.

How can we improve the diversity of adult autism research?

We provide ideas about how to improve autism research. It is important to think about how families experience autism differently. Researchers should ask adults on the autism spectrum and their family members to participate in research. It is also important to make sure that the people who participate in research come from different backgrounds. Researchers should include families who have different races, ethnicities, or cultures.

Researchers should design studies that provide information on how individuals and families experience autism differently. For example, researchers might ask members of the community to help with designing

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research studies. Researchers also might ask participants to talk about their experiences, in addition to asking them to complete questionnaires.

Measures should work well for everyone who participates in research. Researchers should use measures that work for participants who are from a different culture from the researcher or who speak a language that is different from the researcher's primary language. Researchers should consider how each question on the measure applies to diverse individuals and families. Researchers also should make sure that questions are asked in the right ways. For example, questions should be understood similarly by individuals from different cultural groups.

How will these recommendations help individuals and families?

Currently, research tells us about how some adults and families experience autism. In the future, we want to make sure that research tells us about how many more adults and families experience autism. By thinking about families and culture, we will know more about what autism means and what is important for autism research to address. We will know more about how to support individuals and families in ways that match their preferences and values.

Introduction

THE EARLY STAGE of adult autism research¹ provides an opportunity to adopt a contextual approach to improve the validity and generalizability of the research base. Traditionally, autism researchers have assumed an individualistic perspective, particularly when conceptualizing adult outcomes, such as employment and independent living skills. However, biopsychosocial frameworks of understanding individuals in context, such as the World Health Organization's International Classification of Functioning, Disability, and Health,² propose that outcomes represent interactions between the characteristics of the condition and contextual factors, such as family and culture. As the self-advocacy movement, self-determination approaches, and participatory research methods increasingly emphasize an individual focus,^{3,4} a simultaneous consideration of family and culture will provide a more comprehensive view of autism features, outcomes, and supportive services.⁵ We argue that individuals are best understood within their historical and socio-cultural contexts and that this contextual perspective informs our understanding of autism across the life course.⁶ Although a contextual approach encompasses many aspects of a person's identity and social ecology,^{7,8} we concentrate on the closely interrelated family and cultural contexts.⁹ We focus on family and culture in the United States, although many of the ideas are relevant for global cross-cultural autism research.

Family Perspectives on Autism in Adulthood

Family-centered approaches are naturally aligned with understanding individuals in context.¹⁰ Family-centered theory emphasizes families' insights regarding the functioning of individual family members and the family unit, as well as families' roles as advocates and partners in policy-making and service provision.¹¹ Family-centered theory applies across the life course. However, there is a shift to a more individualistic perspective within autism research and services over the transition to adulthood, which is likely influenced by the narrow operationalization of "success" in terms of economic productivity and independence.¹² Whereas federal education legislation mandates the consideration of family perspectives and involvement in special education,¹³ the adult service system promotes an individualistic per-

spective, with a focus on self-advocacy and person-centered planning. This shift to independence reflects the individualistic values common in the United States.

The limited family-focused perspective on autism in adulthood also may reflect the historical tension between differing perspectives and research agendas of parent- and self-advocates.⁴ This tension includes different views on research agendas that reflect the "autistic community" (autistic adults; self-advocates) and the "autism community" (allies such as family members, health care professionals, and research funders).¹⁴ The autistic self-advocacy and participatory research movements challenge historical trends in which researchers prioritized the perspectives of parents over those of individuals on the autism spectrum.^{4,14} Whereas autistic self-advocates promote the importance of centering autistic perspectives, family-centered research views the autistic person as part of the family system and values the input of adults on the autism spectrum and family members.¹⁰ Importantly, the perspectives of adults and family members align regarding valuing research that directly impacts day-to-day life.¹⁵ This alignment of priorities and an extension to consider culture and diversity are reflected in the Interagency Autism Coordinating Committee's Strategic Plan, which acknowledges a paradigm shift from "autism as disorder" to the diversity of the autism experience, presentation, and context.¹⁶

Autism research has similarly aligned with individualistic approaches. Although relatively small, family-focused research in the context of autism in adulthood has begun to examine topics such as parental and sibling well-being,^{17,18} maternal and sibling relationships with the adult on the autism spectrum,^{19–21} maternal daily experiences,²² parental expectations and attitudes,^{23,24} and maternal caregiving.^{25,26} There also has been recent attention on how family factors predict adult outcomes, such as employment and independent living.^{27,28} Despite this small literature examining individual family members or dyads, a truly family-focused approach has not infiltrated the broader adult autism literature. This is exemplified by the lack of family-level outcomes (e.g., family well-being)²⁹ and systems-level research designs (e.g., considering perspectives of multiple family members).¹⁰ Furthermore, the ability to integrate this literature is hindered by the lack of uniformity in conceptualizing and measuring family-centered constructs. For example, a scoping review of family well-being reported that 56 different quantitative measures of well-being were used within the 86 included studies,²⁹ highlighting the fragmented approach to operationalizing

and measuring family-level constructs. These limitations in considering and measuring families' experiences minimize the comprehensiveness and potential impact of family-based research and reduce the extent to which empirical research can be synthesized and connected to theoretical frameworks.

The adult autism literature also does not reflect the wide variability in the extent and nature of family involvement, which can range from supportive family roles that are similar to those in families without an individual with a disability to guardianship and direct care provision. There is similar diversity in the roles and composition of "family,"³⁰ which may include parents, siblings, extended family members, spouses/partners, biological children, or family-like relationships with nonbiologically related individuals, including those who identify as LGBTQ+. Cultural family values shape families' interactions with autism-related services, including the nature of families' support roles and the extent to which families are involved in decision-making about the future. Furthermore, in the absence of an adequate service system,³¹ families often *are* the "service system" supporting adults on the autism spectrum, either informally or formally.³² Indeed, a systematic review of 25 studies of adult autism outcomes reported that at least 50% of participants did not live independently, and many continued to live with parents.³³

Evidence shows that taking a contextual approach and including family perspectives enriches the validity of adult autism findings. Henninger and Taylor's³⁴ historical perspective on autism-related outcomes in adulthood outlines the shift from defining outcomes in objective terms (i.e., employment, friendship, independent living)³⁵ toward conceptualizing outcomes in terms of the fit between individuals and their environments (e.g., activities corresponding to functional abilities). The resulting shift in findings is exemplified by Billstedt et al.^{36,37} Only 8% of participants were classified as having "fair" outcomes and none were classified as having "good" outcomes based on objective measures of adult independence.³⁶ When the same data were analyzed according to person–environment fit, 62% of adults fell into the "good" or "very good" categories, and 91% of parents/caregivers rated their adult child's well-being as "good" or "very good."³⁷ Clearly, the shift from focusing on objective individual-focused outcomes to assuming a contextual perspective resulted in a dramatically different narrative. We argue that the next stage of adult autism outcomes research should go one step further and also consider cultural influences on "good" outcomes.

Cultural Perspectives on Autism in Adulthood

Family-focused and culturally sensitive perspectives are integrally linked, although autism researchers have often considered them separately.³⁶ A cultural perspective has begun to be incorporated into studies of autism in childhood^{38–40} and transition to adulthood,^{41,42} where distrust in the health care system in African American communities and disability-related stigma in Latino communities may delay or prevent engagement with services. However, a cultural perspective remains almost completely absent from adult autism research. Race/ethnicity-based disparities in autism outcomes persist over the transition to adulthood and likely set up trajectories of service disengagement throughout adulthood.⁴³ However, studies of autism in adulthood seldom even

report on sociodemographic characteristics of participants, let alone consider sociodemographic or cultural factors in conceptual frameworks or analyses.³¹

Racial/ethnic minority families experience bias, prejudice, and discrimination within health care systems.⁴⁴ Moreover, cultural preferences influence families' access, engagement, and satisfaction with autism-related services. These interrelated sociocultural factors likely influence autism outcomes over time, including family outcomes. For example, among mothers co-residing with their adolescent or adult children on the autism spectrum, Latina mothers reported lower distress and higher well-being than non-Latina White mothers. This difference was mediated by Latina mothers' higher satisfaction with co-residence; Latina mothers were less likely to discuss negative aspects of co-residence than non-Latina White mothers.⁴⁵ Despite heterogeneity across Latinos (e.g., nationality, race, socioeconomic status, faith), they often have shared experiences (e.g., history of immigration, Spanish language) and values.⁴⁶

In a conceptual article, La Roche et al.⁴⁷ highlight that culture is inextricably linked to our understanding of autism, reflecting Bornstein's⁴⁸ definition of culture as "a set of distinctive patterns of behaviors that are shared by a group of people and that serve to regulate their daily living." Culture influences how people interpret behavior and evaluate the extent to which it is typical. As there is no definitive biological or genetic test to confirm autism spectrum disorder, diagnostic decisions are based on self-reported autism features and/or behavioral observations and interpretations by clinicians, parents, or teachers. These interpretations and judgments are influenced by the rater's worldview and beliefs about what constitutes typical behavior within their culture.⁴⁷ Thus, behaviors used to diagnose autism spectrum disorder or document autism features cannot be understood outside their cultural context. This cultural lens is relevant into adulthood. For example, the objective rating system of adult outcomes developed by Howlin et al.³⁵ is based on aspects of independence (i.e., employment, living situation) that may have less relevance for more collectivist cultures that value interdependence. This potential mismatch raises questions about whether measures are biased against certain cultural groups, and in turn, whether group differences (e.g., based on race, ethnicity, or culture) reflect true differences or measurement error. Most autism assessment measures have been developed and validated with relatively nondiverse samples and generally have not followed best practices for linguistic or cross-cultural validation,⁴⁹ and are likely less valid when used cross-culturally.⁴⁷

The concept of cultural validation is exemplified by Magaña and Smith.⁴⁶ In response to lower rates of autism diagnosis and symptoms in U.S.-based Latinos, they examined the validity of the Autism Diagnostic Interview–Revised (ADI-R), a gold standard diagnostic tool, in Latinos. Although a Spanish translation of the ADI-R exists, neither the English nor Spanish versions included Latinos in the development or adaptation process, leaving unanswered questions about the cultural equivalence and relevance of the measure. When comparing lifetime ADI-R scores for adolescents and adults on the autism spectrum who identified as Latino or non-Latino White, Magaña and Smith⁴⁶ found that Latinos had fewer restrictive and repetitive behaviors, including item-level differences in circumscribed interests, unusual preoccupations, and compulsions or rituals, which underlay differences in classification of autism/nonautism. Subsequent research indicated that the

sensitivity of the ADI-R with majority Spanish-speaking parents of Latino children and adolescents on the autism spectrum is better using *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)* (vs. *Diagnostic and Statistical Manual of Mental Disorders, Fourth edition–Text Revision [DSM-IV-TR]*) diagnostic criteria⁵⁰; DSM-5 criteria have not yet been evaluated in adults.

In sum, we argue that incorporating family and cultural perspectives into adult autism research will improve the validity and generalizability of findings via more comprehensive conceptualizations, research designs, and measurement approaches. From a clinical perspective, family-focused and culturally sensitive approaches lead to better outcomes, including quality, safety, access, acceptability, and satisfaction and may reduce disparities in service utilization.⁴⁴ Although research on autism in childhood has increasingly considered family and culture, these considerations are mostly absent from the adult autism literature, despite calls to incorporate context into adult autism research.⁵¹ The current article builds on these general calls to consider family and cultural perspectives by offering more concrete guidance regarding *how* to increase the social ecological perspective within adult autism research. We outline recommendations related to conceptualization, methodology, and measurement (Fig. 1).

Research Recommendations

Conceptual

- Craft research questions with family and culture in mind by considering how the researcher's world view, cultural lens, values, or implicit biases influence the

questions asked, outcomes assessed, and interpretations of research findings, particularly when evaluating outcomes as inherently good or bad.^{12,52}

- From the earliest stages of research design, elicit input from community members (especially those whose identities, cultural backgrounds, and/or family structures differ from the researcher's) on research questions and protocols to provide a broader perspective, offer culturally informed insights, and reveal potential biases and gaps in research conceptualization or design. This may include forming a community advisory board, conducting pilot studies with specific cultural groups, and/or hiring research staff from the autistic community.^{4,53}
- Conceptualize outcomes at the family level and attend to cultural differences regarding family membership. Aligned with broader efforts to increase inclusivity,⁵⁴ family membership is best determined by asking participants who is in their family (e.g., biologically or legally related individuals or family-like relationships with nonbiologically related individuals).
- Conceptualize family research as reflecting the family unit. Most existing "family" research centers on maternal caregiving.²⁹ Research that examines family relationships generally focuses on mother–child relationships, which do not reflect the multidimensional and systemic nature of families. In particular, family studies should include siblings, who often assume an increasing support role over the life course.⁵⁵
- Consider how intersectionality among participants' identities^{56,57} may affect processes or outcomes being studied. Some aspects of identities may be related to

FIG. 1. Recommendations for considering family and cultural context in adult autism research.

autism, disability, culture, nationality, race, ethnicity, gender, sexual orientation, and education. Ensure that research allows *participants* to identify how they experience, define, and emphasize aspects of identity, and design research that considers multiple aspects of identity simultaneously.⁵²

- Ground adult autism research in theoretical frameworks that explicitly include socioecological factors.^{2,7} Use updated research findings to revise theories developed to explain autism that were based on research limited by participant selection, poor access to research, and forming conclusions based on nonrepresentative samples.

Methodological

- Because family-focused constructs reflect systems-level processes, measure outcomes that reflect the family as a whole or the specific dyadic or system-level constructs being studied. If collecting family data from individual family members, describe findings as individuals' *perceptions* of family-level processes, not objective measures of the system.¹⁰
- Collect data from multiple family members to gain a more comprehensive understanding of family-level constructs, autism-related functioning, and service use. Anticipate that outcomes may differ by reporter (e.g., autistic adult versus parent)¹⁵ and formulate *a priori* strategies for acknowledging different perspectives and considering both/all perspectives when examining associations among self- and parent/family-reported variables.⁵⁸
- Family systems theories emphasize adaptation over time, and these life course changes are relevant to studying autism across adulthood.⁶ Implement longitudinal approaches to inform change processes, including examining bidirectional associations between family-level and individual autism-related outcomes over time and identifying points at which family-based policies or interventions may be most relevant.^{29,59}
- Because autism outcomes are inextricably tied to culture, incorporate sociocultural variables into analytic frameworks.^{47,59} Use approaches that consider multiple variables across different cultures.⁶⁰ Either enroll samples that are diverse across culture, race, ethnicity, and SES, or focus on minority-only samples that reflect autism disparities.⁴⁶ Report on sociodemographic sample characteristics, be explicit about to whom findings apply, and identify limitations of nondiverse samples (i.e., lower validity and generalizability of findings).
- Implement community-based, active recruitment strategies to increase sample diversity and reduce reliance on university- or clinic-based data collection, which often result in biased samples not representative across race, ethnicity, family structure, or SES.⁶¹
- Because individuals' functioning is best understood within context,² implement person-centered approaches that account for individual differences, such as cluster or latent class analyses. In contrast to variable-centered designs that examine how given *variables* relate to each other, person-centered designs use more holistic approaches to understand how variables (including autism-related and contextual factors) combine and operate within *individuals*.⁶² Incorporate

qualitative and/or mixed-methods designs to explore cultural nuances and intersectionality, as these designs are well suited to studying complex, nuanced family and cultural aspects of autism.⁵² Qualitative methods can be used alone or as a precursor to quantitative approaches that confirm and specify the nature of qualitative findings.²⁹

Measurement

- Include family-focused measures that are aligned with the research question(s) and contribute to understanding and interpreting outcomes (e.g., quality-of-life measures that include family support and relationships) and/or that contextualize findings (e.g., family climate, cohesion).
- Administer measures to multiple family members to ensure that each person's perspective on a construct (e.g., family relationships) is represented.¹⁵ Utilize statistical methods that allow for nonindependent data to be analyzed.
- Clarify the conceptual overlap and differences in family well-being and relationship measures to allow for better comparisons across studies.²⁹
- Select measures that were developed and normed with culturally diverse populations or that have undergone comprehensive cross-cultural adaptation and validation.⁴⁹
- When translating and adapting measures, use multiple native translators, check the translation quality, and ensure that linguistic and cultural equivalence is achieved.⁴⁹ This includes ensuring semantic equivalence (i.e., similar meaning within words and sentence structures), prioritizing meaning over literal translations of idioms or colloquialisms, and ensuring that concepts being measured and corresponding items are present in that culture.⁴⁹
- When designing new measures, avoid using idioms, metaphors, or other culturally bound phrases (e.g., "reading between the lines").^{63,64}
- Pretest new or adapted measures. Conduct cognitive interviews with diverse members of the adult autism community to ensure that participants are interpreting items as intended.⁶⁵ Continue to iteratively update the measure and conduct cognitive interviews until a final clear version is attained.
- Conduct psychometric analyses to evaluate the reliability and validity of new and/or adapted measures and establish norms for racial, ethnic, or cultural groups.⁴⁹

Example

We have incorporated family and cultural considerations into our adult autism research. For example, we are developing Siblings FORWARD (Focusing On Relationships, Well-being, And Responsibility ahead), a community-based telehealth program to engage nonautistic adult siblings to participate in planning for the future with their sibling on the autism spectrum. We conceptualized this research using socioecological frameworks^{7,8} and formed a community advisory board to guide our research. Given cultural differences in family roles, we included a focus on ensuring relevance and acceptability for Latino families.

Methodologically, we are implementing active recruitment approaches, particularly for Latino families. Bilingual Latina researchers reach families primarily through face-to-face communication at community events and are available to screen and interview families at locations and times convenient for participants. During the program development and pilot phases, we included in-depth qualitative interviews with Latino and non-Latino adults on the autism spectrum, siblings, parents, and service providers and specifically examined cultural influences on program perceptions. Thus, program development and refinement were closely informed by the needs and preferences of the communities of interest. During the pilot phase, we gave preference to quantitative outcome measures that have been validated cross-culturally.

To date, findings highlight broad enthusiasm for the program across siblings, autistic adults, and providers.⁶⁶ There is similarity in the identified barriers to autism-related future planning across Latino and non-Latino communities (e.g., limited service resources to address individual- and family-level needs) that we aim to address with Siblings FORWARD, and the program's goals and content are well received across cultures. However, cross-cultural differences have emerged. For example, Latino families and service providers prefer that the program be offered before the transition to adulthood to prevent disconnection from services that is more common in minority youth transitioning to adulthood, and Latino families requested more focus on autism education and stigma.

Conclusion

The relatively nascent empirical knowledge base regarding autism in adulthood provides an opportunity to improve methodological rigor and generalizability when building the foundation of this literature. Designing studies with *a priori* attention to context will improve the relevance and comprehensiveness of findings, in turn improving construct validity and providing a more accurate understanding of autism-related outcomes. Similarly, designing and/or selecting measures that have been validated with culturally and linguistically diverse samples will improve the utility of findings and reduce spurious or null effects. More contextually informed methodologies will lead to improved generalizability and practical applications of findings.

Although this article focused on conceptualization, methods, and measurement, the importance of contextual considerations and community input and engagement extend to interpretation, application, and dissemination of research findings. For example, it will be important to appropriately apply culturally specific findings (i.e., using findings derived from a cultural group to inform work with that particular group) and broad recommendations for culturally responsive practice and policy, rather than advocating universal approaches to research or practice.⁶⁷ Also, it will be useful to synthesize research that includes diverse perspectives to refine the validity and generalizability of conceptual models relevant to autism in adulthood. These research recommendations should proceed alongside broader efforts to systematically and structurally attend to the characteristics and perspectives of scientific leaders in the field; more diverse investigators with expertise in culturally and contextually responsive research will further enhance the depth and va-

lidity of this research. Although this article focuses on family and cultural diversity, future work may espouse a broader approach that considers additional aspects of identity and context (e.g., policy, cohort experience).

Authorship Confirmation Statement

Dr. Long, Ms. Gordillo, and Dr. Orsmond contributed to article conceptualization and writing. All co-authors have reviewed and approved the current version of the article before submission. This article has been submitted solely to *Autism in Adulthood*. It has not been submitted or published, in whole or in part, within any other outlet.

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