Making autism research inclusive by attending to intersectionality: A review of the research ethics literature

RUNNING HEAD: Making Autism Research Inclusive

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Abstract:

Growth in autism research necessitates corresponding attention to autism research ethics, including ethical and meaningful inclusion of diverse participants. This paper presents the results of a review of research ethics literature, strengthened by consultation with a task force involving autism professionals, family members, and self-advocates on the spectrum. It reviews research ethics concerns around sex and gender; level of support needs; communication modes; race, ethnicity, geography, and language; socioeconomic status; and age. Exclusion of marginalized subgroups of people with autism is a major ethical concern. Researchers can facilitate inclusion by using inclusive terminology, developing accessible communication strategies, or travelling to meet participants. A person-oriented research ethics framework described in this paper structures the advice offered in the literature to create inclusive and supportive research environments.

Keywords: person-oriented research ethics, intersectionality, demographics, lived experience, stereotypes, inclusion

Increasing prevalence of autism diagnoses in the past several decades have been reported in many international jurisdictions, with an attendant rapidly growing body of research about autism that necessitates corresponding attention to research ethics. At the same time, in North America, autism is often associated with particular stereotypes of whiteness, high socioeconomic status, and masculinity (Cascio, 2015; Daley, Singhal, & Krishnamurthy, 2013; Fein & Rios, 2018; Grinker, 2008; Jack, 2014). In the US, for example, autism is diagnosed four times more often in males and significantly more often in non-Hispanic white children (Baio et al., 2018). Scholars and advocates have expressed concerns about inequities in access to diagnosis by class and race/ethnicity (Begeer, El Bouk, Boussaid, Terwogt, & Koot, 2009; Di Pietro & Illes, 2014; Durkin et al., 2010; Liptak et al., 2008; Mandell, Ittenbach, Levy, & Pinto-Martin, 2007; Mandell et al., 2009; Pierce et al., 2014). They have also expressed concerns about gender disparities (Cridland, Jones, Caputi, & Magee, 2014; Davidson, 2008; Gillis-Buck & Richardson, 2014). These concerns expand upon the ethical obligation of respecting participants as whole persons. They are consistent with recent calls, within research ethics in autism and beyond, to deepen our understanding of the lived world of research participants, including the impact of the intersectionality of autism with other forms of diversity of lived experience (Cascio & Racine, 2018). The term intersectionality refers to the way in which categories such as sex, gender, disability, and ethnicity do not stand alone but rather interact (and intersect) in complex ways that affect individual experience, notably to increase marginalization and discrimination (Crenshaw, 1989; Martino & Schormans, 2018). In this context of autism research ethics, intersectionality means not reducing people with autism to a singular identity, i.e., with autism or disability. It also means attending to the disparities mentioned above, which are particularly highlighted in the black feminist theory roots of intersectionality (Rice et al. 2019) – just as this

theory criticized second-wave feminist movements' exclusion of women of color, it can be applied to criticize autism research, communities, or conversations that exclude participants of color and participants who are otherwise marginalized in ways discussed in more details below.

Intersectionality is important within ethics and research ethics theory. Ethics literature has engaged with intersectionality, albeit only relatively recently so explicitly (e.g, Rice et al. 2019; Rodgers and Kelly 2011). Intersectionality is of longstanding importance in research ethics, especially in terms of vulnerability. Kipnis's (2001) famous taxonomy of vulnerabilities points to how different types of vulnerability intersect with the inherent vulnerability of being a research participant. Recent research has considered how additional vulnerabilities—i.e., greater risk of being harmed by research due to relational asymmetries (Racine and Brachen-Roche 2019 from the broader social world such as racism, ableism, etc.—compound risks of suffering harms and disadvantages. For example, Lahman, Mendoza, Rodriguez, & Schwartz (2011) apply "Culturally Responsive Relational Reflexive Ethics" to studies involving participants who are undocumented. The researchers reject the evaluation of such participants as Other, as always vulnerable, or as lacking capability or competence to participate in research. They focus on the imbalance of privilege between documented U.S. citizen researchers and undocumented research participants, and suggest strategies like using witnessed consent rather than having participants sign their own names to consent forms that might be used to identify them and lead to harm. To fully reckon with vulnerabilities, an orientation to research ethics that includes systematic and personal dimensions of vulnerabilities is therefore desirable.

In this light, addressing intersectional concerns of participants on the autism spectrum[1] aligns with a key guidepost of person-oriented research ethics (Cascio & Racine, 2018), the "acknowledgement of lived world." The person-oriented research ethics approach generally aims to synthesize and apply insights from person-centered care to the context of research ethics, drawing on bioethics concepts such as relational ethics, relational autonomy, evidence-based research ethics, and everyday ethics. It focuses on the ethics of everyday relationships between researchers, research participants, and communities. This approach centers on five guideposts: (1) respect for holistic personhood; (2) individualization; (3) focus on researcher-participant relationships; (4) empowerment in decision-making; and the focus of this paper–(5) acknowledgment of lived world. These interrelated guideposts provide a lens for identifying and reflecting on ethical issues that go beyond the "dramatic" (Zizzo et al. 2016) or "regulatory" (Emanuel and Grady 2007). Acknowledgment of lived world specifically stresses recognizing the factors outside the research context that might have an impact within it. It includes attention to the relationships participants have and to the significant others in their lives, who might also be involved in research directly or indirectly. This guidepost also attends to beliefs, norms, and values–both of the participant and of the researcher. An important part of this acknowledgment is considering demographics outside of autism as well as diversity within autism populations, and how these demographic factors might influence the research process. This consideration complements and reinforces other guideposts, attending to diversity when reflecting on how to show respect for participants, provide individualization, consider rapport and power differences between researchers and participants, and empower participants in decision-making.

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[1] In keeping with APA guidelines, we use person-first language such as "person with autism" or "person on the autism spectrum" in this manuscript. However, we acknowledge that preferences vary and that many people with autism prefer identity-first language such as "autistic person" (Kenny et al. 2016)

Intersectionality is a key concept when it comes to the demographics under this guidepost, and the social categories they constitute (Crenshaw, 1989; Martino & Schormans, 2018).

Intersectionality is particularly important in the case of research with people with disabilities because such participants are often reduced to their label or diagnosis, and other aspects of their identities and experiences are ignored. An intersectional lens accounts for the fact that "disability status is but one part of a person" and considers the ways in which "the lives of people with disabilities are shaped by various social locations and experiences" (Martino & Schormans, 2018, p. 12). In addition to its importance for research ethics, described above, intersectionality has been important in autism studies more broadly. Scholars have taken an intersectionality lens to the disparities in autism diagnoses mentioned above, as well as disparities in access to care (Singh and Bunyak, 2019). A review of qualitative literature on the experiences of racial and ethnic minority families with children with autism found barriers to access rested at the junction of ideological, economic, and political domains–but that this junction was experienced differently in different communities (Latino communities faced language barriers and hostility towards bilingualism; African-American communities faced distinct forms of racial discrimination, etc.) (Singh and Bunyak, 2019). Scholars have also applied intersectional analysis to inform the design of community college supports for students on the spectrum which address the intersectional needs of female, gender nonconforming, and racial minority students with autism (Shmulsky and Gobbo 2019). A self-advocacy project known as "neuroqueer" asserts the fundamentality of intersectionality particularly along axes of disability and queerness (see e.g., Egner, 2019; Yergeau, 2017). Finally, in keeping with the black feminist origins of intersectionality theory, intersectionality is important to autism studies

for issues of racial justice (Jampel, 2018) and representation (Brown, Ashkenazy, and Onaiwu, 2017).

In this paper, we focus on the intersectionality of autism with other social categories, specifically sex and gender; level of support needs; preferred communication modes; race, ethnicity, geography, and language; socioeconomic status; and age. We draw on a critical-interpretive review of the literature (McDougall, 2015) on autism research ethics combined with deliberative co-reflection on these issues with autism stakeholders. We argue that taking intersectionality into account is a useful strategy for researchers to pursue the acknowledgment of the lived world, as proposed in the model of person-oriented research ethics (Cascio & Racine, 2018; Barned et al. 2019). Reflecting on these issues can help researchers plan and conduct studies involving participants on the autism spectrum ethically and meaningfully. Although the specific issues at stake differ when considering different aspects of intersectionality, the common themes are that research that does not consider intersectional needs excludes diverse experiences of autism and reproduces autism stereotypes. These findings demonstrate the importance of this strategy for pursuing justice within research.

Methods

The review of ethical aspects of intersectionality presented in this paper derives from a combination of literature review and task force deliberation aimed at understanding autism research ethics issues broadly. The literature review process, discussed in more detail below, used a systematic-interpretive method in keeping with best practices in bioethics (McDougall, 2015). Results of this literature review were shared with a task force of 17 individuals concerned with autism research, including the three authors of this paper, other researchers, self-advocates on the spectrum, parents of people with autism, professionals who work with people with autism,

and advocacy and service organization representatives associated with Autism Canada, Autism

Ontario, Autism Speaks Canada, the Canada/Israel Autism Research Initiative, the Fédération

Québécoise de l'autisme, H.A.L.E. Autism, SaskFEAT, and the Worktopia Project. This task

force composition reflects people who might be conducting studies, participating in studies, or

giving permission for researchers to approach children, students, or service users with autism

about participating. More information about the task force can be found at our website

(https://www.autismresearchethics.net/task-force), which we also use to connect with broader

autism communities, share updates, and solicit feedback on the project. This feedback led to

further refinement and brainstorming.

To identify literature relevant to autism and research ethics, ProQuest Philosopher's

Index, Web of Science, and Ovid Medline were searched (in fall 2016) for keywords related to

autism spectrum conditions and research ethics, broadly defined. We used a broad range of

autism-related keywords. Given that we did not have a date limit on our search, we also included

keywords and MeSH terms that were used in the former DSM-IV and ICD-10. We also searched

for Rett Syndrome in recognition of its similarity with autism spectrum conditions. Although

there are important clinical and neurobiological differences between Rett Syndrome and autism

(Percy, 2011), we recognize that several academic and popular sources considered Rett

Syndrome to have been part of the autism spectrum (Autism Support Network, 2016; Chien, Lin,

Chou, & Chou, 2011; Cukier et al., 2012; Deweerdt, 2011; Konstantareas, 1998; WebMD, 2018)

and therefore informative for understanding everyday ethical issues. We similarly searched for

Fragile X Syndrome, due to the wealth of genetic research on autism focused on Fragile X

specifically, but excluded articles about Fragile X that were not associated with autism (e.g.,

Fragile X-associated tremor/ataxia syndrome). In this paper, we specify if an article is specifically concerned with Fragile X syndrome or Rett syndrome.

Search terms for ProQuest were autis* OR asperger* OR "Fragile X" OR Rett; ethics-related search terms were not used because this database already focused on philosophy (including ethics), and the 224 articles identified were manageable analyze; this allows us to cast a wide net. Search terms for Web of Science were TS=(autis* OR asperger* OR "Fragile X" OR Rett) AND TS=(research ethics OR bioethic* OR neuroethic* OR consent* OR assent* OR dissent* OR confidential* OR privacy OR disseminat* OR decision-making OR vulnerab* OR autonom* OR rapport). This search identified 1976 articles. Search terms for Ovid Medline expanded on these search terms through the use of MeSH terms that are not available in Web of Science. Altogether, Medline search terms were (exp Child Development Disorders, Pervasive/ OR exp Fragile X Syndrome/ OR exp Rett Syndrome/ OR autis*.mp. OR asperger*.mp. OR fragile x.mp. OR rett.mp.) AND (exp Confidentiality/ OR exp Informed Consent/ OR exp Ethics/ OR exp Research Design/ OR research ethics.mp. OR bioethic*.mp. OR neuroethic*.mp. OR consent*.mp. OR assent*.mp. OR dissent*.mp. OR confidential*.mp. OR priva*.mp. OR disseminat*.mp. OR decision-making.mp. OR vulnerab*.mp. OR autonom*.mp. OR rapport.mp.). This search identified 2574 articles. After removing duplicates, we screened 222 articles from ProQuest, 1186 from Web of Science, and 2426 from Medline, for a total of 3834 articles. For screening purposes, titles and abstracts were reviewed to determine which articles might contain information on research ethics and participants on the autism spectrum. Exclusion criteria were applied to exclude articles that were not about humans, were only abstracts with no full paper (conference abstracts), were in a language other than those read by the researchers (English, French, and Italian), or were not about people on the spectrum. Articles about parent

perspectives were included only if they were about parent perspectives on the participation of people with autism in research; studies with parent participants that were about parent experiences or perspectives on other topics were excluded. Remaining articles were then reviewed in full to determine if they addressed autism research ethics. Common reasons to exclude articles at full review were that they did not discuss ethics at all, or only included minimal information on ethics (e.g., they had no information beyond noting that an ethics committee approved the project or that participants gave consent). Both articles explicitly about ethics and those that contained "hidden" ethics data (Dubois, 2008) were included. Dubois defines "hidden" ethics information as the useful empirical data (and we might add – normative, philosophical justifications) that are discussed in an article that "is not published in a journal that [research ethics committee] members might regularly read," "does not include any keywords or subject headings that pertain to research ethics," and/or "when the authors of the study themselves either do not recognize or do not explicitly discuss the ethical significance of their findings" (Dubois, 2008, p. 3).

This process excluded 3455 articles, leaving 379 articles included. Content related to the person-oriented research ethics guidelines was extracted from these 379 articles. This information was organized in spreadsheets with columns for each guidepost. Articles often addressed more than one guidepost. Across all included articles, 235 addressed respect for holistic personhood, 112 individualization, 79 researcher-participant relationships, 77 empowerment in decision-making, and 184 acknowledgement of lived world. The extracted information was then read in a more holistic fashion to identify themes. Themes were listed in an outline format with specific articles or excerpts referenced as supporting evidence. This generated a large volume of content which was then condensed and reorganized iteratively until

an outline of interrelated ideas, issues, and suggestions under each guidepost was created. This paper presents a subset of the extracted data regarding the guidepost 'Acknowledgment of Lived World' which focus on intersectional concerns, from 39 identified articles summarized in Table 1. Table 1 describes the article (bibliographic information, whether the ethics content was explicit or hidden, and the general article type), classifies it into the categories described below (sex and gender; level of support needs; communication modes; race, ethnicity, geography, and language; socioeconomic status; and age), and identifies the part of the research process to which its ethics content refers. As such, it provides multiple avenues of entry for researchers seeking inspiration in the literature, whether they begin by considering a specific intersectional concern (e.g., gender) or a specific part of the research process to make more inclusive (e.g., recruitment).

[Table 1 near here]

Given the nature of this paper and the critical-interpretive review method adopted (McDougall, 2015), the following section is organized to combine results and commentary. It first provides a review of the literature on a given aspect of intersectionality and then comments on its relevance for the acknowledgment of the lived world of research participants. The rotation between review and comment section (on single topics) is intended to make the paper easier to read.

Review and comments

The literature identified key demographic factors associated with intersectionality and autism: sex and gender; level of support needs; communication modes; race, ethnicity, geography, and language; and socioeconomic status. Ethical considerations regarding each of these factors are presented in turn, followed by the implications of each for research ethics and ethical research.

Sex and Gender: Review

A growing number of sources note that girls and women are understudied and underrepresented in autism research, which also excludes them from the indirect benefits of research such as services (Krahn & Fenton, 2012; Shefcyk, 2015). Shefcyk (2015) further calls for the inclusion of girls and women on the spectrum throughout the research process, to provide input on how to address the perspectives and needs of such participants. Although sex and gender were occasionally considered in other ways (e.g., sex of the child does seem to influence parent attitudes towards genetic research in small but significant ways; Johannessen et al., 2016), most concerns about sex and gender were about inclusion and exclusion.

Sex and Gender: Comment

This literature focuses on the key theme of exclusion resulting from lack of attention to intersectional needs, which may perpetuate stereotypical representations of autism as only affecting men and limit understanding of how others experience autism.

Exclusion based on sex is an issue of justice in terms of the distribution of risks and benefits in research as well as the right to science. In clinical research, researchers may exclude in order to keep a homogenous sample and increase clarity of results. The trade-off is limited generalizability. This important issue extends beyond autism. For example, clinical research which excludes female participants may then generate results which are not applicable to women, with dangerous health consequences (e.g., unknown efficacy in or risks to fertile women by drugs that were developed without such participants; lack of attention to women's health issues) (Charo, 1993). Non-clinical research may also exclude female participants, perhaps unintentionally through issues like recruitment material design, discussed in more detail below. The social consequence is the perpetuation of the stereotype that people with autism are men.

Lack of representation can be seen as an issue of justice. It also means fewer resources for women and girls with a diagnosis or who suspect they may be diagnosable, who are looking to the literature to understand their experiences. Recently the field has begun to document a 'camouflaging' phenomenon, particularly in women with autism, who mask social difficulties by hiding socially unacceptable behavior or acting out socially valued behaviors, essentially pretending to be neurotypical (Lai et al., 2017). This body of research includes the development of a self-report scale (Hull et al., 2018) and examinations of how camouflaging is associated with particular reasons, social contexts, or demographics as well as anxiety and stress (Cage & Troxell-Whitman, 2019). For these reasons, there is a call for more research that explicitly includes people with autism of diverse genders.

Moreover, the above concerns focus primarily on inequities of sex and gender conceived of in a binary way. However, this binary conception itself generates under-addressed ethical issues because of the harm and discomfort it can cause to people with non-binary gender identities. Such harm includes non-recognition of the identity of such individuals, which both demonstrates a lack of respect for persons and an injustice in terms of lack of representation. Many people, including many people with autism, identify with genders outside the man-woman binary, including genderqueer, genderfluid, and agender (Cage & Troxell-Whitman, 2019; George & Stokes, 2017). Attention to these gendered experiences of autism is important to many people with autism in both published literature (Yergeau, 2017) and in the authors' experiences with research participants. One source identified through this literature review did acknowledge potentially high rates of gender non-conformity among people with autism who were assigned female at birth, but this possibility was not identified as an ethical issue (Bargiela, Steward, & Mandy, 2016). However, there are research ethics concerns emerging from these neurodiverse

experiences of gender (or gendered experiences of autism). Not only can it be disrespectful to not recognize non-binary gender identities, it can also lead to actual exclusion from research and therefore raise concerns of justice with respect to the right to science described in the previous paragraphs. Recruitment materials that use binary gender terminology may also be off-putting for potential participants who do not recognize themselves in the materials and therefore may be disinterested in participating. It could also lead to misgendering in reports by researchers who assign binary sex categories to participants who take part anyway (and sometimes label these sex categories as gender).

Level of Support Needs: Review

Another intersecting factor that plays an important role in variation among people on the autism spectrum is level of support needs. We use this phrase to refer to the amount of assistance a person with autism needs in various aspects of life, and include a number of indicators researchers often use, such as measured IQ, severity, degree of adaptive behavior, and specific diagnosis (particularly from studies pre-2013, which used DSM-IV categories such as autistic disorder, pervasive developmental disorder–not otherwise specified, and Asperger's syndrome). For instance, children's level of behavioral difficulties and IQ can impact parents' satisfaction with research (Tierney et al., 2007) or influence parents' willingness to participate in research (Glasson & Wray, 2004). Other have documented how specific diagnosis can impact parents' opinions on research (Johannessen et al., 2016). We chose to use the language of 'support needs' over the commonly used language of 'high vs. low-functioning autism,' due to compelling arguments against functioning language made by self-advocates and critical autism studies scholars that such labels are stigmatizing and imprecise (Orsini & Davidson, 2013; Silberman, 2015).

As with sex, the studies that addressed levels of support need generally focused on the ethics of including or excluding different groups, aiming to tackle the question: Is it better to include a narrow or broad range of participants, based on levels of support needs? Scahill and Lord (2004, p. 23) aptly summarize the tension from a statistical standpoint in treatment-oriented research, noting, "The scientific debate usually turns on the issue of heterogeneity versus homogeneity of the sample. From a practice perspective, highly restrictive entry criteria ensure a homogenous sample, but may make it more difficult to identify and recruit subjects and limit the generalizability of findings." While some have argued for including a broad range of participants in order to maximize the potential for productive research findings (Lajonchere & Consortium, 2010), including wide variation may raise difficulty in interpreting results, limiting the ability of knowledge users to make treatment decisions or otherwise to effectively understand a subgroup of the spectrum. Using participants with more similar support needs increases such clarity, but raises difficulty of external validity. It may be unclear how findings are applicable to people with different levels of need.

The issue of representation across the spectrum of levels of support needs emerged in the literature not only with respect to research design, but also in the context of stakeholder involvement in the research process and in research agenda setting. Elsabbagh and colleagues (2014) note that "individuals diagnosed with autism and representing this stakeholder group may lead independent lives and have the capacity to express their own views, but the impact of autism on others is more severe, therefore precluding their participation in traditional engagement frameworks" such that "not all stakeholders will be adequately represented and engaged." The lack of engagement with stakeholders with higher levels of support needs is therefore ethically relevant in terms of fair representation of all stakeholders' needs and perspectives in research and

research priority-setting and, as a consequence, of eventual access to services based on research and policy representing the interests of people on the spectrum.

Level of Support Needs: Comment

As with sex and gender, there are trade-offs statistically between clarity and generalizability with respect to level of support needs. Nonetheless, these findings address a similar theme: some research and research collaborations may not include the experiences of people with autism and higher levels of support needs. People with intellectual disability are especially excluded from non-beneficial research and/or research that asks them to share their own perspectives (Martino & Schormans, 2018). While there are important reasons for this exclusion, there are also arguments that people with ID want to be involved in research and should be empowered to do so (McDonald, 2012; Tilly, Money, & Group, 2015; Williams, Ponting, & Ford, 2015). People with ID and autism are similarly able to participate and many are interested in doing so (Beresford, Tozer, Rabiee, & Sloper, 2004; Loyd, 2013, 2015; Preece & Jordan, 2010; Ruef & Turnbull, 2002; Tozer, Atkin, & Wenham, 2014). The research ethics issues may be distinct. For example, some suggestions for working with people with ID include using eye contact as a sign of engagement (Cameron & Murphy, 2007), which may not be the same for people with autism.

Communication Modes: Review

The way a person with autism communicates–particularly whether or not they communicate with verbal speech–forms another important form of diversity that needs to be considered. Similar to people with intellectual disability, people who communicate non-verbally have also often been excluded from research (Beresford et al., 2004; Loyd, 2013, 2015; Preece & Jordan, 2010). Communication styles as an ethical concern was particularly raised by Nicolaidis

and colleagues (Nicolaidis et al., 2011), writing about participatory research that included individuals with autism not only as research participants but as members of the research team actively involved in planning studies. The authors write about the power of the internet to "equalize communication for autistic adults [sic; identity-first language is preferred by the co-authors and collaborators with autism on this project] who may experience challenges interpreting body language, who cannot process auditory language in real time, or who require longer response times in conversations" (p. 147). While the internet can facilitate inclusion of some people on the spectrum, the authors raise the ongoing concern, "how do we include autistic [sic] individuals who do not have Internet access or who cannot communicate well in writing?" (p. 149). This remains an ongoing tension and one that is reflected in literature calling for attention to the representativeness of community partners in research including by gender (Shefcyk, 2015) and level of support needs, (Elsabbagh et al., 2014); as well as cautioning against tokenism (Pellicano, Dinsmore, & Charman, 2014).

Communication Modes: Comment

The autism research community increasingly recognizes that ensuring meaningful representation of people with autism in research design and implementation is beneficial, and that the voices of people with autism should be heeded. At the same time, there is concern that the only voice heard is of those that are able to communicate verbally (Elsabbagh et al., 2014). Although it may difficult for verbal researchers to communicate with nonverbal participants, it is possible and has been done using written forms of communication (Nicolaidis et al., 2011), and also the "five finger" system that uses gesture to vote on key issues (Nicolaidis et al., 2011). Other systems include, Talking Mats (Cameron & Murphy, 2007), alternative and augmentative

communication (Fuentes & Martin-Arribas, 2007; Trehin, 2003), and observation of non-verbal communication (Parsons, Reid, Bentley, Inman, & Lattimore, 2012).

<center>*Race, Ethnicity, Geography, & Language: Review*</center>

In this section we have chosen to group a number of categories which themselves represent intersections that are difficult to disentangle: race, ethnicity, geography, and language. While we might group these social categories together as "culture," the term itself has been highly contested by experts (Boggs et al., 2004), and its operationalization in clinical and social research has been heavily criticized for only using proxy variables and for ignoring structural factors like poverty and discrimination (Kao, Hsu, & Clark, 2004; Singer, 2012; Viruell-Fuentes, Miranda, & Abdulrahim, 2012; Vogeley & Roepstorff, 2009). In this section we therefore seek to be more precise, drawing on the language used in the literature that reflects a series of interrelated concerns.

Daley and colleagues (2013) provide rare in-depth coverage of issues in cross-cultural autism research. They write about a range of ethical issues relevant especially to clinical and epidemiological research, including stigma associated with the language of genetics and implications of heredity; the ethics of screening and diagnosis in low- or no-service availability contexts; as well as the ethics of recruitment and possibility of meaningful consent in such settings. With respect to demographics and intersectionality, they specifically discuss the importance of cross-culturally validated screening tools for epidemiological studies, which goes beyond simple linguistic translation, and includes attention to the cultural relevance of checklist items as well as examining the underlying assumptions of these tools regarding parental knowledge of child development. They specifically discuss problems with translations of the M-CHAT tool, and raise questions about observational tools as well (e.g., ADOS).

Cross-cultural issues related to challenges of international collaboration have also been raised. International multi-site studies involve differences in ethics review as well as legal and regulatory issues affecting databases (Johnson et al., 2010; Leonard et al., 2013). Low and middle income countries may lack the skilled professionals necessary for certain components of research and research ethics administration (Daley et al., 2013; Hens, Peeters, & Dierickx, 2016). Similarly, autism practice guidelines themselves may have limited utility in these contexts (Elsabbagh et al., 2014). While these sources talk about the challenges of multinational and cross-cultural research, other scholars have noted that the lack of international and cross-cultural research in itself is a limitation to the generalizability of findings (Bailey et al., 2014).

While attention to cross-cultural research has been limited, much more attention has been dedicated to research in multicultural, multilingual, or immigrant communities (Dietrich et al., 2005; Glasson & Wray, 2004; Pasiali, LaGasse, & Penn, 2014; Warnell et al., 2015; Zamora, Williams, Higareda, Wheeler, & Levitt, 2016). Themes include translation and cultural adaptation of validated instruments (Dietrich et al., 2005), language barriers to recruitment and participation (Glasson & Wray, 2004; Pasiali et al., 2014; Warnell et al., 2015), and the need for researchers with language and cultural competence skills (Dietrich et al., 2005). Computer-assisted tests to reduce examiner effects that may be linked to cultural differences may also be useful, but such tests may not be appropriate for participants with little familiarity with computers (Dietrich et al., 2005). Particularly in the US, much of this attention is Latinx communities[2]. Dietrich and colleagues (2005) overview options for translated and/or "culture-

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[2] The term "Latinx" has been put forth by intersectional activist communities (particularly Spanish speakers in the United States) as a gender-neutral or non-gendered alternative to "latino" or "latina," and an alternative to formulations such as "latin@."

fair" tests, but also raise concerns that it is sometimes difficult to determine significance using these tests. Zamora et al. (2016) focus on recruitment strategies tailored for Latinx communities.

Researchers have also raised concerns about certain populations being underserved and under-researched. Geographically, this includes both rural and inner city residents (Glasson & Wray, 2004; Lord et al., 2005). Geographically diverse rural settings may necessitate doing the research in participants' homes or schools, in multiple sites "to accommodate families and prevent loss to follow-up" (Dietrich et al., 2005). Other under-researched groups include Native American and African American people in the United States (Johnson et al., 2009), and indigenous peoples living in Canada (Di Pietro & Illes, 2014; Johnson et al., 2009). A history of research and political abuses against these minority populations can contribute to lack of research or lack of interest in participating (Di Pietro & Illes, 2014; Johnson et al., 2009). Information about participant ethnicities is difficulty to find, as Pierce and colleagues (2014) demonstrate in a comprehensive review of ethnicity reporting (or lack thereof) in autism research. While one study examined the role of ethnicity as a potential moderator of satisfaction with research (Tierney et al., 2007), most discussion of ethical concerns regarded the ways in which researchers should be mindful of race, ethnicity, geography, and language, and how these factors may influence the research experience or exclusion from it.

Race, Ethnicity, Geography, & Language: Comment

Findings from this literature provide another angle on the theme that certain experiences of autism are under-represented. As with sex, stereotypes play a role here. Just as the stereotype of people with autism is that they are male, it is also that they are white. Participants' experiences of racialization and other forms of minoritization can create situations of "double vulnerability" or "double minority" status. Racial and other minorities have been harmed by

research in the past and researchers need to attend to mistrust of research that may have resulted

when engaging potential research participants or communities. While some of these harms may

be linked to the history of research involving people with developmental disabilities (e.g., the

Willowbrook Hepatitis study), others are tied to intersectional histories linked to race, ethnicity,

geography, and language (e.g., the Tuskegee Syphilis study).

Task Force members shared similar concerns to the literature when discussing the

guidepost of acknowledgement of lived world. Task Force members advocated using or creating

"culture-free" tests and integrating "cultural awareness" into tools like ADOS, similar to the

literature described above. Some Task Force members had experience working with First

Nations in Canada, and advocated for the engagement of established networks and the leadership

of First Nations communities using a partnership model.

Socioeconomic Status: Review

Another important factor, sometimes overlapping with the above, is socioeconomic status

(SES). As has been argued for most axes of inclusion, excluding people with low SES from

research can lead to harm by ignoring their risk and burden (Dietrich et al., 2005). People with

low SES may be excluded in recruitment due to various barriers, and therefore be

underrepresented (Warnell et al., 2015). Even for relevant results, "stakeholders in different

communities are likely to confront very different challenges in making use of research advances

in autism, if they need to simultaneously focus on issues of survival and physical health"

(Elsabbagh et al., 2014).

There are ethical implications to research design based on SES. Methods where the

researcher travels, such as focus groups in community settings, could help mitigate recruitment

biases based on access. Online research is a popular, low-effort way to recruit participants.

However, not everyone has an internet connection (Bocchi et al., 2012; see also Daley et al., 2013; Nicolaidis et al., 2011) or familiarity with computers (Dietrich et al., 2005). As with the other social categories, SES has been investigated as a measure in parent satisfaction (Tierney et al., 2007). However, the focus is on what barriers to recruitment are posed by socioeconomic challenges, and what biases in research arise from socioeconomic homogeneity of participant populations.

Socioeconomic Status: Comment

Again these findings address the theme that lack of attention to intersectional needs leads to exclusion, in this situation often unintentional. Socioeconomic barriers may make it difficult for people to participate in research including travel time, costs, and differences between researcher and participant resources like internet. Task Force members noted several ways in which SES affects the research process, most notably by virtue of the fact that it impacts who tends to be able to participate. The lack of a vehicle or the ability to take time off work can make getting to research studies difficult, and results may be skewed due to these biases. There also may be lower buy-in from potential participants who are more focused on addressing day to day needs. Researchers can work to overcome these barriers by being the more mobile party, going to where participants are.

Age: Review

Finally, age arises as an important demographic category that affects research ethics. Autism is often, although not always, diagnosed in childhood, making childhood research ethics overall quite important in autism research. Childhood research ethics is too comprehensive a field to review here (for more detail see for example Nuffield Council on Bioethics, 2015), but it addresses key issues in how to ethically and meaningfully include children in the research

process, represent children's perspectives in research, and empower children to make decisions about participating in a study. The studies identified in this literature review do include both child and adult participants. Although many people associate autism primarily with children, children are often excluded from many important types of research. Children are often enrolled in many studies, especially genetic studies, by their parents (Lappe, 2014; Singh, 2015; Tabor et al., 2011), but they are often excluded from research on first-person perspectives (Beresford et al., 2004; Loyd, 2013; Preece & Jordan, 2010) and pharmacological research (Persico et al., 2015; Scahill et al., 2001), both of which have important implications for the lives of children on the spectrum.

      Literature explicitly about age issues in autism research ethics largely focuses on the role of significant others' in children's lives, especially around consent. Many sources stress the importance of ensuring children can assent or dissent even if they are not formally consenting (Cridland, Jones, Caputi, & Magee, 2015; Francois, Powell, & Dautenhahn, 2009; Goldstein et al., 1989; Loyd, 2013; Preece & Jordan, 2010; Racine, Bell, & Shevell, 2013; Stein & King, 2016). Others, usually parents but sometimes teachers or service staff, are often asked to provide the formal consent. This raises the question of who has the right to give proxy consent (Carlson, 2013; Hens et al., 2016; Perry, 2012). Notably, Perry (2012) argues that parents may not be the best people to provide proxy consent due to the prominent disagreements between parents and adult self-advocates within autism movements about the dissonance between a narrative focused on reducing autism symptoms or "curing" autism and one that advocates for support and acceptance. Perry instead suggests considering the role of the narratives of adults with autism in planning and executing autism research involving children, including in designing consent and assent information. This issue is also relevant when considering the common study format in

which researchers ask for information from parents of people with autism (including adults), without involving people with autism themselves as participants. In one study on Fragile X, researchers report considering with the research ethics committee whether it would be permissible to ask parents to report on their adult children in this way without their consent (Bailey et al., 2014).[3]

Age: Comment

While age can be considered another demographic factor relevant to research ethics, a full discussion is beyond the scope of this paper. In brief, as with sex and ethnicity there are age-based stereotypes around autism, namely that the stereotypical person with autism is a child. Therefore, adults with autism are often excluded from consideration in conversations about autism. At the same time, most research on first-person perspectives of autism is conducted with adults. Children are often excluded from the opportunity to present their perspectives, and children who are framed as doubly-vulnerable by virtue of both age and diagnosis are even more excluded (Priestley, 1998). Age is often raised in ethics about consent, particularly relationships with parents and others providing consent on the behalf of children.

Conclusion

People with autism are diverse and this diversity springs from many different sources. Accordingly, intersectionality is an important concept that draws attention to the exclusion of marginalized subgroups of people with autism (e.g., by sex, gender, language, ethnicity, level of support needs, SES, age, and so on) as a major ethical concern. Autism intersects with other demographic characteristics of participants leading to sometimes unique needs and

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[3] They decided it was permissible for males (all presumed "decisionally impaired") and that it was permissible for females only when they had legal guardians (not for females without legal guardians).

considerations that researchers should address, such as using inclusive terminology, developing accessible communication strategies, or travelling to meet participants with access barriers. Thinking about addressing these needs within a person-oriented research ethics frameworks gives researchers the tools to create inclusive and supportive research environments and to acknowledge the lived world of research participants.

Research and practice that aims to support people with autism benefits from attention to intersectionality that strives for greater inclusion. Quantitative research results are more generalizable when inclusive, as researchers can be more confident that the results apply to a wider range of people. Research, often qualitative, that specifically addresses the unique needs and experiences of marginalized subgroups can also broaden understanding of autism by unpacking stereotypes and their impact in everyday life. Participatory research is also strengthened by attention to the diversity of stakeholders on the spectrum and how to best support engagement in the participatory research process. Practice, especially evidence-based practice, often draws on research and can therefore also be strengthened by studies that consider intersectionality and research designs that address intersectional needs. Attention to intersectionality in research ethics promotes justice by combatting exclusion and marginalization.

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Conflict of Interest

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Ethical Approval

The literature review and task force process did not involve human participants or animals. The interactive portion of the project website, soliciting feedback from the community, was approved by the Research Ethics Boards of the Institut de recherches cliniques de Montréal (reference number 2018-926) and York University (e2018-081).

Informed Consent

No individual participants were included in this study.

Authors' Contributions

ER and JW conceived of the study. MAC designed and supervised the literature review, oversaw website development, coordinated the task force workshop, communicated with community members providing feedback, and supervised the task force report drafting process. ER and JW advised on the literature review design, resolved uncertainties and disagreements about the literature and task force writing process, and participated in drafting the task force report. All authors co-led the task force workshop. ER supervised French translations of materials. All authors participated in the drafting of the manuscript. All authors read and approved the final manuscript.

References

Autism Support Network. (2016). What is Rett syndrome? | Autism Support Network.

http://www.autismsupportnetwork.com/news/what-rett-syndrome. Accessed 18 April

2019.

Bailey, D. B., Raspa, M., Wheeler, A., Edwards, A., Bishop, E., Bann, C., . . . Appelbaum, P. S.

(2014). Parent ratings of ability to consent for clinical trials in Fragile X syndrome.

Journal of Empirical Research on Human Research Ethics, 9(3), 18-28.

doi:10.1177/1556264614540591

Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., . . . White, T.

(2018). Prevalence of autism spectrum disorder among children aged 8 years—Autism

and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014.

MMWR Surveillance Summaries, 67(6), 1.

Bargiela, S., Steward, R., & Mandy, W. (2016). The experiences of late-diagnosed women with

autism spectrum conditions: An investigation of the female autism phenotype. Journal of

Autism & Developmental Disorders, 25, 25.

Barned, C., Lajoie, C., & Racine, E. (2019). Addressing the practical implications of

intersectionality in clinical medicine: Ethical, Embodied and Institutional Dimensions.

The American Journal of Bioethics, 19(2), 27–29.

Begeer, S., El Bouk, S., Boussaid, W., Terwogt, M. M., & Koot, H. M. (2009). Underdiagnosis

and referral bias of autism in ethnic minorities. Journal of Autism and Developmental

Disorders, 39(1), 142.

Beresford, B., Tozer, R., Rabiee, P., & Sloper, P. (2004). Developing an approach to involving children with autistic spectrum disorders in a social care research project. British Journal of Learning Disabilities, 32(4), 180-185.

Bocchi, L., Orlandi, S., Manfredi, C., Puopolo, M., Guzzetta, A., Vicari, S., & Scattoni, M. L. (2012). Early diagnosis of autism spectrum disorders - Design of the data acquisition and management system. In A. Jobbagy (Ed.), 5th European Conference of the International Federation for Medical and Biological Engineering, Pts 1 and 2 (Vol. 37, pp. 187-190).

Boggs, J., Brumann, C., Herzfeld, M., Hirsch, E., Reyna, S., SewellJr, W., . . . Boggs, J. (2004). The culture concept as theory, in context. Current Anthropology, 45(2), 187-209.

Brown, L. X. Z., Ashkenazy, E., & Giwa-Onaiwu, M. (2017). All the Weight of Our Dreams: On Living Racialized Autism. Lincoln, NE: DragonBee Press.

Cage, E., & Troxell-Whitman, Z. (2019). Understanding the reasons, contexts and costs of camouflaging for autistic adults. Journal of Autism and Developmental Disorders. doi:10.1007/s10803-018-03878-x

Cameron, L., & Murphy, J. (2007). Obtaining consent to participate in research: the issues involved in including people with a range of learning and communication disabilities. British Journal of Learning Disabilities, 35(2), 113-120.

Carlson, L. (2013). Research ethics and intellectual disability: broadening the debates. Yale Journal of Biology & Medicine, 86(3), 303-314.

Cascio, M. A. (2015). Cross-cultural autism studies, neurodiversity, and conceptualizations of autism. Culture, Medicine and Psychiatry, 39(2), 207-212.

Cascio, M. A., & Racine, E. (2018). Person-oriented research ethics: Integrating relational and everyday ethics in research. Accountability in Research, 25(3), 170-197.

Charo, R. (1993). Protecting us to death: Women, pregnancy, and clinical research trials. St. Louis University Law Journal, 38, 135-188.

Chien, I. C., Lin, C. H., Chou, Y. J., & Chou, P. (2011). Prevalence and incidence of autism spectrum disorders among national health insurance enrollees in Taiwan from 1996 to 2005. Journal of Child Neurology, 26(7), 830-834.

Crenshaw, K. (1989). Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. University of Chicago Legal Forum, 139-167.

Cridland, E. K., Jones, S. C., Caputi, P., & Magee, C. A. (2014). Being a girl in a boys' world: Investigating the experiences of girls with autism spectrum disorders during adolescence. Journal of Autism and Developmental Disorders, 44(6), 1261-1274. doi:10.1007/s10803-013-1985-6

Cridland, E. K., Jones, S. C., Caputi, P., & Magee, C. A. (2015). Qualitative research with families living with autism spectrum disorder: Recommendations for conducting semistructured interviews. Journal of Intellectual & Developmental Disability, 40(1), 78-91. doi:10.3109/13668250.2014.964191

Cukier, H. N., Lee, J. M., Ma, D., Young, J. I., Mayo, V., Butler, B. L., . . . Gilbert, J. R. (2012). The expanding role of MBD genes in autism: Identification of a MECP2 duplication and novel alterations in MBD5, MBD6, and SETDB1. Autism Research : Official Journal of the International Society for Autism Research, 5(6), 385-397.

Daley, T. C., Singhal, N., & Krishnamurthy, V. (2013). Ethical considerations in conducting research on autism spectrum disorders in low and middle income vountries. Journal of

Autism and Developmental Disorders, 43(9), 2002-2014. doi:10.1007/s10803-012-1750-2

Davidson, J. (2008). "More labels than a jam jar": The gendered dynamics of diagnosis for girls and women with autism. In P. Moss & K. Tegthsoonian (Eds.), Contesting Illness: Processes and Practices (pp. 239-258). Toronto: University of Toronto Press.

Deweerdt, S. (2011). Reclassification of Rett syndrome diagnosis stirs concerns. Spectrum News. https://www.spectrumnews.org/news/reclassification-of-rett-syndrome-diagnosis-stirs-concerns/, accessed 18 April 2019.

Di Pietro, N. C., & Illes, J. (2014). Disparities in Canadian indigenous health research on neurodevelopmental disorders. Journal of Developmental & Behavioral Pediatrics, 35(1), 74-81.

Dietrich, K. N., Eskenazi, B., Schantz, S., Yolton, K., Rauh, V. A., Johnson, C. B., . . . Berman, R. F. (2005). Principles and practices of neurodevelopmental assessment in children: Lessons learned from the Centers for Children's Environmental Health and Disease Prevention Research. Environmental Health Perspectives, 113(10), 1437-1446. doi:10.1289/ehp.7672

Dubois, J. M. (2008). Hidden data for research ethicists: An introduction to the concept and a series of papers. Journal of Empirical Research on Human Research Ethics, 3(3), 3-5.

Durkin, M. S., Maenner, M. J., Meaney, F. J., Levy, S. E., DiGuiseppi, C., Nicholas, J. S., . . . Schieve, L. A. (2010). Socioeconomic inequality in the prevalence of autism spectrum disorder: Evidence from a US cross-sectional study. PLoS ONE, 5(7): e11551. doi:10.1371/journal.pone.0011551

Elsabbagh, M., Yusuf, A., Prasanna, S., Shikako-Thomas, K., Ruff, C. A., & Fehlings, M. G. (2014). Community engagement and knowledge translation: Progress and challenge in autism research. Autism, 18(7), 771-781.

Fein, E., & Rios, C. (2018). Autism in Translation: An Intercultural Conversation on Autism Spectrum Conditions: Palgrave Macmillan.

Francois, D., Powell, S., & Dautenhahn, K. (2009). A long-term study of children with autism playing with a robotic pet: Taking inspirations from non-directive play therapy to encourage children's proactivity and initiative-taking. Interaction Studies, 10(3), 324-373. doi:10.1075/is.10.3.04fra

Fuentes, J., & Martin-Arribas, M. C. (2007). Bioethical issues in neuropsychiatric genetic disorders. Child and Adolescent Psychiatric Clinics of North America, 16(3), 649-661. doi:10.1016/j.chc.2007.02.003

George, R. & Stokes, M.A. (2017). Gender identity and sexual orientation in autism spectrum disorder. Autism, 22(8), 970-982.

Gillis-Buck, E. M., & Richardson, S. S. (2014). Autism as a biomedical platform for sex differences research. BioSocieties, 9(3), 262-283.

Glasson, E. J., & Wray, J. (2004). Obtaining consent affects the value of the Western Australian autism register. Medical Journal of Australia, 181(9), 514-515.

Goldstein, R., Joja, O., Psatta, D. M., Petrescu, M., Paraschiv, I., & Popa, M. (1989). Vasotocin improves intelligence and attention in mentally retarded children. Physiology & Behavior, 46(6), 967-970.

Grinker, R. R. (2008). Unstrange Minds: Remapping the World of Autism: Basic Books.

Hens, K., Peeters, H., & Dierickx, K. (2016). The ethics of complexity. Genetics and autism, a literature review. American Journal of Medical Genetics Part B-Neuropsychiatric Genetics, 171(3), 305-316. doi:10.1002/ajmg.b.32432

Hull, L., Mandy, W., Lai, M.-C., Baron-Cohen, S., Allison, C., Smith, P., & Petrides, K. V. (2018). Development and validation of the Camouflaging Autistic Traits Questionnaire (CAT-Q). Journal of Autism and Developmental Disorders, 49(3), 819-833. doi:10.1007/s10803-018-3792-6

Jack, J. (2014). Autism and gender: From refrigerator mothers to computer geeks. Urbana, Illinois : University of Illinois Press.

Jampel, C. (2018). Intersections of disability justice, racial justice and environmental justice. Environmental Sociology, 4(1), 122-135.

Johannessen, J., Naerland, T., Bloss, C., Rietschel, M., Strohmaier, J., Gjevik, E., . . . Andreassen, O. A. (2016). Parents' attitudes toward genetic research in autism spectrum disorder. Psychiatric Genetics, 26(2), 74-80. doi:10.1097/ypg.0000000000000121

Johnson, S. B., Whitney, G., McAuliffe, M., Wang, H., McCreedy, E., Rozenblit, L., & Evans, C. C. (2010). Using global unique identifiers to link autism collections. Journal of the American Medical Informatics Association, 17(6), 689-695.

Johnson, V. A., Edwards, K. A., Sherman, S. L., Stephens, L. D., Williams, W., Adair, A., & Deer-Smith, M. H. (2009). Decisions to participate in Fragile X and other genomics-related research: Native American and African American voices. Journal of Cultural Diversity, 16(3), 127-135.

Kao, H.-F. S., Hsu, M.-T., & Clark, L. (2004). Conceptualizing and critiquing culture in health research. Journal of Transcultural Nursing, 15(4), 269-277.

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which

terms should be used to describe autism? Perspectives from the UK autism community.

Autism, 20(4), 442-462.

Kipnis, K. 2001. Vulnerability in research subjects: A bioethical taxonomy. *In*: National

Bioethics Advisory Commission (NBAC), Ethical and Policy Issues in Research

Involving Human Participants. Volume II: Commissioned Papers. (Pp. G1-G13)

Rockville, MD: NBAC.

Konstantareas, M. M. (1998). Allegations of sexual abuse by nonverbal autistic people via

facilitated communication: Testing of validity. Child Abuse & Neglect, 22(10), 1027-

1041. doi:10.1016/s0145-2134(98)00082-9

Krahn, T. M., & Fenton, A. (2012). The extreme male brain theory of autism and the potential

adverse effects for boys and girls with autism. Journal of Bioethical Inquiry, 9(1), 93-

103.

Lahman, M. K. E., Mendoza, B. M., Rodriguez, K. L., & Schwartz, J. L. (2011) Undocumented

research participants: Ethics and protection in a time of fear. Hispanic Journal of

Behavioral Sciences, 33(3), 304-322.

Lai, M.-C., Lombardo, M. V., Ruigrok, A. N., Chakrabarti, B., Auyeung, B., Szatmari, P., . . .

Consortium, M. A. (2017). Quantifying and exploring camouflaging in men and women

with autism. Autism, 21(6), 690-702.

Lajonchere, C. M., & Consortium, A. (2010). Changing the landscape of autism research: The

autism genetic resource exchange. Neuron, 68(2), 187-191.

Lappe, M. D. (2014). Taking care: Anticipation, extraction and the politics of temporality in

autism science. BioSocieties, 9(3), 304-328. doi:10.1057/biosoc.2014.14

Leonard, H., Glasson, E., Bebbington, A., Hammond, G., Croft, D., Pikora, T., . . . Bourke, J. (2013). Application of population-based linked data to the study of intellectual disability and autism. In R. C. Urbano (Ed.), Using Secondary Datasets to Understand Persons with Developmental Disabilities and Their Families (Vol. 45, pp. 281-327).

Liptak, G. S., Benzoni, L. B., Mruzek, D. W., Nolan, K. W., Thingvoll, M. A., Wade, C. M., & Fryer, G. E. (2008). Disparities in diagnosis and access to health services for children with autism: Data from the National Survey of Children's Health. Journal of Developmental & Behavioral Pediatrics, 29(3), 152-160.

Lord, C., Wagner, A., Rogers, S., Szatmari, P., Aman, M., Charman, T., . . . Yoder, P. (2005). Challenges in evaluating psychosocial interventions for Autistic Spectrum Disorders. Journal of Autism and Developmental Disorders, 35(6), 695-708; discussion 709-611.

Loyd, D. (2013). Obtaining consent from young people with autism to participate in research. British Journal of Learning Disabilities, 41(2), 133-140. doi:10.1111/j.1468-3156.2012.00734.x

Loyd, D. (2015). Gaining views from pupils with autism about their participation in drama classes. British Journal of Learning Disabilities, 43(1), 8-15. doi:10.1111/bld.12078

Mandell, D. S., Ittenbach, R. F., Levy, S. E., & Pinto-Martin, J. A. (2007). Disparities in diagnoses received prior to a diagnosis of autism spectrum disorder. Journal of Autism and Developmental Disorders, 37(9), 1795-1802.

Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGuiseppi, C., Durkin, M. S., . . . Pinto-Martin, J. A. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. American Journal of Public Health, 99(3), 493-498.

Martino, A. S., & Schormans, A. F. (2018). When good intentions backfire: University research ethics review and the intimate lives of people labeled with intellectual disabilities. Forum Qualitative Sozialforschung/Forum: Qualitative Social Research, 19(3), 1-18. doi:10.17169/fqs-19.3.3090

McDonald, K. E. (2012). "We want respect": Adults with intellectual and developmental disabilities address respect in research. American Journal on Intellectual and Developmental Disabilities, 117(4), 263-274.

McDougall, R. (2015). Reviewing literature in bioethics research: Increasing rigour in non-systematic reviews. Bioethics, 29(7), 523-528.

Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Ashkenazy, E., Boisclair, C., . . . Baggs, A. (2011). Collaboration strategies in nontraditional community-based participatory research partnerships: lessons from an academic-community partnership with autistic self-advocates. Progress in Community Health Partnerships, 5(2), 143-150.

Nuffield Council on Bioethics (2015). Children and Clinical Research: Ethical Issues. London: Nuffield Council on Bioethics.

Orsini, M., & Davidson, J. (2013). Critical autism studies: Notes on an emerging field. In J. Davidson & M. Orsini (Eds.), Worlds of Autism (pp. 1-28). Minneapolis: University of Minnesota Press.

Parsons, M. B., Reid, D. H., Bentley, E., Inman, A., & Lattimore, L. P. (2012). Identifying indices of happiness and unhappiness among adults with autism: Potential targets for behavioral assessment and intervention. Behavior Analysis in Practice, 5(1), 15-25.

Pasiali, V., LaGasse, A. B., & Penn, S. L. (2014). The Effect of Musical Attention Control Training (MACT) on Attention Skills of Adolescents with Neurodevelopmental Delays: A Pilot Study. Journal of Music Therapy, 51(4), 333-354. doi:10.1093/jmt/thu030

Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. Autism, 18(7), 756-770.

Percy, A. K. (2011). Rett syndrome: Exploring the autism link. Archives of Neurology, 68(8), 985-989.

Perry, A. (2012). Autism beyond pediatrics: Why bioethicists ought to rethink consent in light of chronicity and genetic identity. Bioethics, 26(5), 236-241. doi:10.1111/j.1467-8519.2011.01952.x

Persico, A. M., Arango, C., Buitelaar, J. K., Correll, C. U., Glennon, J. C., Hoekstra, P. J., . . . Adolescent, C. (2015). Unmet needs in paediatric psychopharmacology: Present scenario and future perspectives. European Neuropsychopharmacology, 25(10), 1513-1531. doi:10.1016/j.euroneuro.2015.06.009

Pierce, N. P., O'Reilly, M. F., Sorrells, A. M., Fragale, C. L., White, P. J., Aguilar, J. M., & Cole, H. A. (2014). Ethnicity reporting practices for empirical research in three autism-related journals. Journal of Autism and Developmental Disorders, 44(7), 1507-1519.

Preece, D., & Jordan, R. (2010). Obtaining the views of children and young people with autism spectrum disorders about their experience of daily life and social care support. British Journal of Learning Disabilities, 38(1), 10-20. doi:10.1111/j.1468-3156.2009.00548.x

Priestley, M. (1998). Childhood disability and disabled childhoods: Agendas for research. Childhood, 5(2), 207-223.

Racine, E., Bell, E., & Shevell, M. (2013). Ethics in neurodevelopmental disability. In J. Bernal
       & R. Beresford (Eds.), Handbook of Clinical Neurology Vol 118 (3rd series).

Racine, E., Bracken-Roche, D. (2019). Enriching the concept of vulnerability in research ethics:
       An integrative and functional account. Bioethics, 33(1), 19-34.

Rice, C., Harrison, E., and Friedman, M. 2019. Doing justice to intersectionality research.
       Cultural Studies-Critical Methodologies, 19(6), 409-420.

Rodgers, J. & Kelly, U.A. 2011. Feminist intersectionality: Bringing social justice to health
       disparities research. Nursing Ethics, 18(3), 397-407.

Ruef, M. B., & Turnbull, A. P. (2002). The perspectives of individuals with cognitive disabilities
       and/or autism on their lives and their problem behavior. Research and Practice for
       Persons with Severe Disabilities, 27(2), 125-140. doi:10.2511/rpsd.27.2.125

Scahill, L., & Lord, C. (2004). Subject selection and characterization in clinical trials in children
       with autism. CNS Spectrums, 9(1), 22-32.

Scahill, L., McCracken, J., McDougle, C. J., Aman, M., Arnold, L. E., Tierney, E., . . . Vitiello,
       B. (2001). Methodological issues in designing a multisite trial of risperidone in children
       and adolescents with autism. Journal of Child and Adolescent Psychopharmacology,
       11(4), 377-388. doi:10.1089/104454601317261555

Shefcyk, A. (2015). Count us in: Addressing gender disparities in autism research. Autism,
       19(2), 131-132.

Silberman, S. (2015). NeuroTribes: The Legacy of Autism and the Future of Neurodiversity.
       New York: Avery.

Singer, M. K. (2012). Applying the concept of culture to reduce health disparities through health
       behavior research. Preventive Medicine, 55(5), 356-361.

Singh, J. S. (2015). Narratives of participation in autism genetics research. Science, Technology & Human Values, 40(2), 227-249.

Shmulsky, S. and K. Gobbo. (2019). Autism support in a community college setting: Ideas from intersectionality. Community College Journal of Research and Practice, 43(9), 648-652.

Stein, M. A., & King, B. H. (2016). Unequal individual risk and potential benefit balanced by benefits to the population at large in autism clinical trials? The American Journal of Bioethics, 16(4), 72-74.

Tabor, H. K., Brazg, T., Crouch, J., Namey, E. E., Fullerton, S. M., Beskow, L. M., & Wilfond, B. S. (2011). Parent perspectives on pediatric genetic research and implications for genotype-driven research recruitment. Journal of Empirical Research on Human Research Ethics, 6(4), 41-52. doi:10.1525/jer.2011.6.4.41

Tierney, E., Aman, M., Stout, D., Pappas, K., Arnold, L. E., Vitiello, B., . . . Shah, B. (2007). Parent satisfaction in a multi-site acute trial of risperidone in children with autism: A social validity study. Psychopharmacology, 191(1), 149-157.

Tilly, L., Money, F., & Group, M. E. M. R. (2015). Being researchers for the first time: Reflections on the development of an inclusive research group. British Journal of Learning Disabilities, 43(2), 121-127.

Tozer, R., Atkin, K., & Wenham, A. (2014). 'My brother likes meeting new people, but don't ask him any direct questions': Involving adults with autism plus learning disability in a qualitative research project. British Journal of Learning Disabilities, 42(4), 292-300. doi:doi:10.1111/bld.12073

Trehin, P. (2003). Ethics of research on intellectual disabilities and autism: Point of view of a parent. In by M. Elia, V. Romano and P. Curatolo, (Eds.) Consensus in Child Neurology (pp. 17-23). Toronto, ON: BC Decker, 2003

Viruell-Fuentes, E. A., Miranda, P. Y., & Abdulrahim, S. (2012). More than culture: Structural racism, intersectionality theory, and immigrant health. Social Science & Medicine, 75(12), 2099-2106.

Vogeley, K., & Roepstorff, A. (2009). Contextualising culture and social cognition. Trends in Cognitive Sciences, 13(12), 511-516.

Warnell, F., George, B., McConachie, H., Johnson, M., Hardy, R., & Parr, J. R. (2015). Designing and recruiting to UK autism spectrum disorder research databases: Do they include representative children with valid ASD diagnoses? BMJ Open, 5(9), e008625.

WebMD. (2018). Rett Syndrome Symptoms, Causes, and Treatments. https://www.webmd.com/brain/autism/rett-syndrome#1, accessed 18 April 2019.

Williams, V., Ponting, L., & Ford, K. (2015). A platform for change?: Inclusive research about "choice and control'. British Journal of Learning Disabilities, 43(2), 106-113. doi:10.1111/bld.12123

Yergeau, M. (2017). Authoring Autism: On Rhetoric and Neurological Queerness: Duke University Press.

Zamora, I., Williams, M. E., Higareda, M., Wheeler, B. Y., & Levitt, P. (2016). Brief Report: Recruitment and retention of minority children for autism research. Journal of Autism and Developmental Disorders, 46(2), 698-703.

Zizzo, N., Bell, E., & Racine, E. (2016). What is everyday ethics? A review and a proposal for an integrative concept. The Journal of Clinical Ethics, 27(2):117-28.

Article *Hidden or Explicit?* *Article Type*	Demographic Categories						Content Relevant to Demographics & Intersectionality	Part of the Research Process					
	S/G	**LVL**	**COM**	**R/E/G/L**	**SES**	**AGE**		**RD**	**REC**	**CON**	**DC**	**DM**	**DISS**
Bailey et al 2014 *Explicit* *Empirical Ethics*				x		x	• Consulted research ethics committee about asking parents to report on their adult children without children's consent. • Noted lack of international and cross-cultural research as a limitation to the generalizability of findings.		x	x			
Bocchi et al. 2012 *Explicit* *Conceptual Paper*					x		• Noted that high speed internet access in participants' homes cannot be taken for granted.				x	x	
Carlson 2013 *Explicit* *Conceptual Paper*						x	• Discussed who might be appropriate surrogate decision-makers in light of potential motivational differences.				x		
Cridland et al. 2015 *Explicit* *Conceptual Paper*						x	• In-depth discussion of methodological and ethical issues in interview studies involving people with autism and families • Stressed importance of child assent and confidentiality of child's data from parents.				x	x	
Daley et al. 2013 *Explicit* *Conceptual Paper*				x	x		• Discussed ethical issues in cross-cultural autism research in low and middle income countries.	x	x		x		x
Di Pietro & Illes 2014 *Explicit* *Conceptual Paper*				x			• Identified and criticized lack of autism research among Native American Peoples and Canadian Aboriginal Peoples.	x	x				

						Notes						
Dietrich et al 2005 *Explicit Conceptual Paper*				x	x	• Lessons learned from large-scale research in developmental assessment. • Identified and criticized lack of research including people with low socioeconomic status, and addressed issues related to socioeconomic status as well as ethnicity and geography. • Reviews translated and/or "culture-fair" tests, use of alternative research approaches to accommodate geography.	x	x		x		
Elsabbagh et al. 2014 *Explicit Clinical/ Intervention Study*		x	x	x	x	• Discussed community engagement in autism research. • Identified lack of representation of people with higher levels of support needs or lack of verbal communication. • Identified limited utility of certain practice guidelines in low- and middle- income countries. • Identified challenges posed by more immediate concerns of survival and physical health for some stakeholders.	x					x
Francois, Powell, & Dautenhahn 2009 *Hidden Clinical/ Intervention Study*					x	• Honored one child's request not to be videorecorded despite permission for recording from parents.				x		
Glasson & Wray 2004 *Explicit Clinical/ Intervention Study*		x		x		• Evaluated protocol for obtaining consent from parents to allow data about their child with autism to be forwarded to a register. • Urban/rural residence, intellectual disability, birth country, and first language were associated with lower consent rates.		x				
Goldstein et al. 1989 *Hidden Clinical/ Intervention Study*					x	• Excluded children who expressed reluctance or resistance to participation, even against parents' desires.			x			

Citation / Type							Description						
Hens, Peeters, & Dierickx 2016 *Explicit* *Conceptual Paper*			x		x		• Noted problems with lack of skills professionals needed for certain tasks in low and middle income countries. • Reflected on appropriate proxies for consent.			x			
Johannessen et al. 2016 *Explicit* *Empirical Ethics*	x	x					• Demographic factors affected parents' attitudes towards genetic research involving their children with autism. • Parents of boys were less positive to genetics. • Parents of people with infantile autism were more positive than parents of people with Asperger's syndrome. • Effects were small.		x				
Johnson et al. 2010 *Explicit* *Conceptual Paper*			x				• Described issues related to the use of identifies in autism databases, including confidentiality and data management. • Particular attention to multi-national studies involving different ethics review processes, laws, and regulations.		x		x	x	
Johnson et al. 2009 *Explicit* *Conceptual Paper*			x				• Identified and criticized lack of inclusion of Native American and African American perspectives in research.	x	x				
Krahn & Fenton 2012 *Explicit* *Conceptual Paper*	x						• Identified and criticized the lack of inclusion of female participants in autism research.		x				
Lajonchere, et al. 2010 *Hidden* *Conceptual Paper*		x					• Described the database's philosophy to include a broad range of autism spectrum disorders.		x				
Lappe 2014 *Explicit* *Empirical Ethics*					x		• Presented ethnographic data on the experiences and motivations of parents who enroll their children in autism research studies.		x		x		x

Citation						Notes						
Leonard et al. 2013 *Explicit Conceptual Paper*			x			• Described issues related to secondary datasets on intellectual disability and autism. • Attended to ethico-legal differences in different countries.				x	x	x
Lord et al. 2005 *Explicit Conceptual Paper*	x		x			• Stressed the need for recruitment of diverse under-represented populations including those living in rural areas, ethnic minorities, and non-English speakers.		x				
Loyd 2013 *Explicit Conceptual Paper*	x	x			x	• Identified and criticized lack of research on first-person perspectives that includes children and youth on the spectrum. • Identified and criticized lack of inclusion of people who communicate non-verbally. • Stressed the importance of empowering children to assent or dissent.	x	x	x			
Loyd 2015 *Explicit Conceptual Paper*	x	x				• Identified and criticized lack of inclusion of people who communicate non-verbally in research.	x	x				
Nicolaidis et al. 2011 *Explicit Conceptual Paper*		x		x		• Described strategies for participatory research involving autistic partners, particularly to address communication differences. • Identifies lack of internet access as a barrier. • Raises concerns about how to better include people who do not communicate in writing.	x					
Pasiali et al. 2014 *Hidden Clinical/ Intervention Study*			x			• Reported that one eligible participant was unable to complete the task due to language barriers, and therefore was excluded.				x		
Pellicano et al. 2014 *Explicit Empirical Ethics*		x				• Cautioned against tokenism when including autistic people as community partners in research.	x					

						Notes						
Perry 2012 *Explicit* *Conceptual Paper*					x	• Considered the ethics of proxy consent for research involving children with autism. • Questioned the appropriateness of parents as proxies given conflicts between parents of children with autism and autistic adults on questions of treatment and identity.			x			
Persico et al. 2015 *Explicit* *Conceptual Paper*					x	• Identified and criticized lack of pharmacological research specifically concerning children.	x	x				
Pierce et al. 2014 *Explicit* *Conceptual Paper*				x		• Identified and criticizes lack of ethnicity reporting in autism research.						x
Preece & Jordan 2010 *Explicit* *Qualitative Study*		x	x		x	• Identified and criticized the lack of inclusion in research of children and people who communicate non-verbally.	x	x				
Racine et al. 2013 *Explicit* *Conceptual Paper*					x	• Stressed the importance of ensuring children can assent or dissent even if they aren't formally consenting.			x			
Scahill & Lord 2004 *Explicit* *Conceptual Paper*		x				• Debated subject selection and characterization needs, particularly diagnosis and clinical rating scales.	x					
Scahill et al. 2001 *Explicit* *Clinical/* *Intervention Study*					x	• Identified and criticized lack of pharmacological research specifically concerning children.	x	x				
Shefcyk 2015 *Explicit* *Conceptual Paper*	x		x			• Identified and criticized lack of autism research involving women and girls.		x				

Study	S/G	LVL	COM	R/E/G/L	SES	AGE		RD	REC	CON	DC	DM	DISS
Singh 2015 *Explicit Qualitative Study*						x	• Presented ethnographic data on the experiences and motivations of parents who enroll their children in autism research studies.	x		x			x
Stein & King 2016 *Explicit Conceptual Paper*						x	• Evaluated ethical issues in a clinical trial for participants with autism. • Asserted the right of participants to withdraw from research even if their parents have relocated in order to participate.					x	
Tabor et al. 2011 *Explicit Empirical Ethics*						x	• Presented results of a study on parent perspectives on pediatric genetic research involving children with autism and children with diabetes.		x				
Tierney et al. 2007 *Explicit Clinical/ Intervention Study*	x		x	x			• Family socioeconomic status, children's behavioral difficulties and IQ, and ethnicity impacted parent satisfaction with a trial involving children with autism.		x				
Warnell et al. 2015 *Explicit Clinical/ Intervention Study*			x	x			• Noted underrepresentation of families with a first language other than English in a UK autism research database.		x				
Zamora et al. 2016 *Explicit Conceptual Paper*				x			• Presented strategies for recruitment and retention of Latino families in autism research. • Partnered with a Latino community-based organization. • Used word of mouth. • Flexibility with rescheduling. • Provided transportation or transportation costs.		x				

Legend: S/G = Sex and Gender; LVL = Level of Support Needs; COM = Communication Modes; R/E/G/L = Race, ethnicity, geography, and language; SES = Socioeconomic Status; AGE = Age; RD = Research Design; REC = Recruitment; CON = Consent; DC = Data Collection; DM = Data Management; DISS = Dissemination