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Person-oriented ethics for autism research: Creating best practices through engagement with autism and autistic communities

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Lay Abstract:

Research ethics means issues that concern the welfare and wellbeing of people who take part in research. It is important in all scientific studies. Ethics helps people who do research treat people who take part in research fairly and with respect. This paper is about day to day ethics when autistic people take part in research. We present tips for researchers who want to do this type of study.

We used two methods to make these tips. First, we wanted to know what other people said about this topic. We used a literature review to find out. Second, we wanted to know what autistic people, parents, and professionals thought, and had a working group meet to discuss it. The working group provided advice that researchers could consider around day to day ethics in research. This paper talks about these methods and advice. The advice fits into five big groups:

- (1) Tailor the research process for the unique needs of each person.
- (2) Think about the world in which people who take part in research live.
- (3) Make it easier for people to make their own choices.
- (4) Value what people who take part in research have to share and consider their needs and strengths.
- (5) Think about how researchers and people who take part in research work together.

This project shows why it is useful for researchers and communities to talk about research ethics together.

Abstract:

Research ethics is an important part of any study. Ethics goes beyond ethics committee approval and consent documents. It addresses broader issues of respect, inclusion, and empowerment in the everyday context of research. This paper focuses on everyday aspects of research ethics for studies involving autistic participants. It draws on a review of the literature and a process of ethical deliberation involving a task force of researchers, professionals, autistic self-advocates, and parents. These methods led to the creation of suggestions for researchers. This paper describes the community engagement process, briefly presents the task force suggestions, and provides more detailed discussion of select items for illustration. Suggestions are organized around five “person-oriented research ethics” guideposts: (1) individualization (e.g., providing individualized support for participants), (2) acknowledgment of lived world (e.g., acknowledging barriers to care that impact research ethics), (3) empowerment in decision-making (e.g., creating accessible consent processes that address specific communication needs), (4) respect for holistic personhood (e.g., addressing sensory and processing needs and strengths), and (5) focus on researcher-participant relationships (e.g., involving autistic people in ways other than research participants, including but not limited to via participatory research). This project highlights the value of researcher-community partnerships in discussions about research ethics.

Keywords: ethics, research ethics, community engagement, advocacy, informed consent

Introduction

Research ethics is an important component across all types of autism research. Many research ethics concerns for autistic participants¹ are not unique to this group, such as concerns about inaccessible consent processes or power imbalances in research, which are shared across almost all research contexts. However, autism introduces two specific considerations: (1) historical disenfranchisement of autistic people in research (e.g., Beresford, Tozer, Rabiee, & Sloper, 2004; Pellicano & Stears, 2011) that raises the need to explicitly re-articulate a commitment to high ethical standards; and (2) unique autistic experiences (such as individual and interpersonal experiences of anxiety, communication differences, and the double empathy problem) and histories and controversies around autism (such as a history of institutionalization and controversies about specific interventions, and conflicting social movements). These factors suggest the usefulness of tailoring research ethics to the context of autism.

Traditional approaches to research ethics discussions in autism appear to be often centered on risk. For instance, people with autism may face risks of coercion to consent to research (Fisher, 2003; Harris, 2003), lower ethical standards in research (Dawson, 2004, 2017), or particular discomfort in the research process that should be mitigated (Bellieni, Rocchi, & Buonocore, 2012; Kerns et al., 2016). Research ethics can instead be a forward-looking endeavor (Racine, Cascio, Montreuil, & Bogossian, 2019), empowering researchers and research participants to proactively consider ethical issues in relational terms, through person-oriented research ethics (Cascio & Racine, 2018). The focus on a person-oriented approach is meant to complement the strong existing focus on ethics review and oversight within research ethics (for

¹ In this manuscript, as well as the report it describes, we use person-first and identity-first language as well as the language of “on the spectrum,” in deference to the varying preferences of task force members and potential research participants (Kenny et al., 2016).

more discussion on regulatory and non-regulatory paradigms in research ethics, see Emanuel & Grady, 2007). As its name suggests, person-oriented research ethics is centrally about people, specifically potential or actual research participants. It is characterized by five guideposts derived from the literature, which can be applied to any study. “Individualization” invites the consideration the unique needs of each potential participant. “Acknowledgment of Lived World” designates things outside the research process that might affect the study, particularly social context and significant others such as family. “Empowerment in Decision-Making” refers to strategies to maximize potential participants’ decision-making abilities throughout the research process. “Respect for Holistic Personhood” invites respect and recognition of the value of all potential research participants, even those whose capacity to consent is limited, and includes strategies for determining and addressing the needs, preferences, and priorities of potential participants. Finally, “Focus on Researcher-Participant Relationships” attends to the relational aspects of research, including power dynamics.

While this model provides general guidelines for person-oriented research ethics, it also suggests that researchers “specify – in partnership with stakeholders – the specific contours of person-oriented research ethics in different clinical and societal contexts (Cascio & Racine, 2018, p. 22).” For instance, it has been applied in the context of dementia research ethics theory (Silva et al., in press) to highlight strategies for building relationships with participants and caregivers, avoiding stigma, and communicating comfortably. Recent studies have also used this model to justify the importance of investigating gamete donor and recipient views on consent to the use of embryos created by gamete donation in research (Baía, de Freitas, Samorinha, Provoost, & Silva, 2019), and to focus on maintaining participant dignity and avoiding harm in a study of people living with motor neuron disease (Remm, Halcomb, & Stephens, 2019).

To date, no scholarship has systematically applied the person-oriented framework to understanding how research aligns with the aforementioned guideposts around autism. This project emerged from discussions among an interdisciplinary group of Canadian autism researchers and stakeholders motivated to encourage reflective practice (Racine et al. 2011). It aimed to (1) identify the research ethics literature that addresses research involving autistic people; (2) understand how this literature intersects with the person-oriented research ethics framework; and (3) use stakeholder engagement to develop a resource for researchers to ethically and meaningfully include autistic people in research, not only as participants but as colleagues, knowledge users, and partners. To address these aims, we conducted a review of autism research ethics literature from multiple disciplines. We then convened an interdisciplinary group of Canadian autism stakeholders (researchers, self-advocates, parents of people with autism, professionals who work with people with autism, and advocacy organization representatives) who reviewed this literature and the person-oriented research ethics framework, and engaged in ongoing discussions and engagement (described further below) regarding how it could be integrated within autism research.

Methods

There were multiple iterative steps to our method. The first three authors conducted a systematic-interpretive literature review. We then shared its results with the task force (described below), who developed the process for broader community engagement. The task force then considered both the literature and feedback from the broader autism and autistic communities,² alongside their own lived experience, to develop a report and recommendations for autism-

² We use the term autism community to refer to family members, allies, and professionals; and the term autistic community to refer to autistic people and self-advocates.

informed person-oriented research ethics. These methods were chosen in order to incorporate expertise from intersecting and diverse sources – the published literature, experts with lived experience, and the broader public. Using these multiple sources allowed us to generate suggestions emerging from priorities of the literature, task force members, and broader communities. These suggestions are intended to serve as a resource for researchers conducting or planning studies involving participants on the spectrum, and a draft of the task force’s report has been made available to the broader community online. In the current paper, we present the core final original suggestions from this report and key examples, as well as a description of the process of creating it.

Literature Review

The goal of the literature review was to identify research ethics literature that addresses research involving autistic people, and critically examine it for content related to person-oriented research ethics. The literature review followed McDougall’s (2015) critical-interpretive approach, which merges a systematic literature search strategy with an inclusive sampling strategy (which does not exclude studies based on research design), followed by an interpretive analysis. Three databases, 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. These three databases include a broad range of fields from philosophy and the social and clinical sciences. Search terms for ProQuest were *autis* OR asperger* OR “Fragile X” OR Rett*.³ 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*

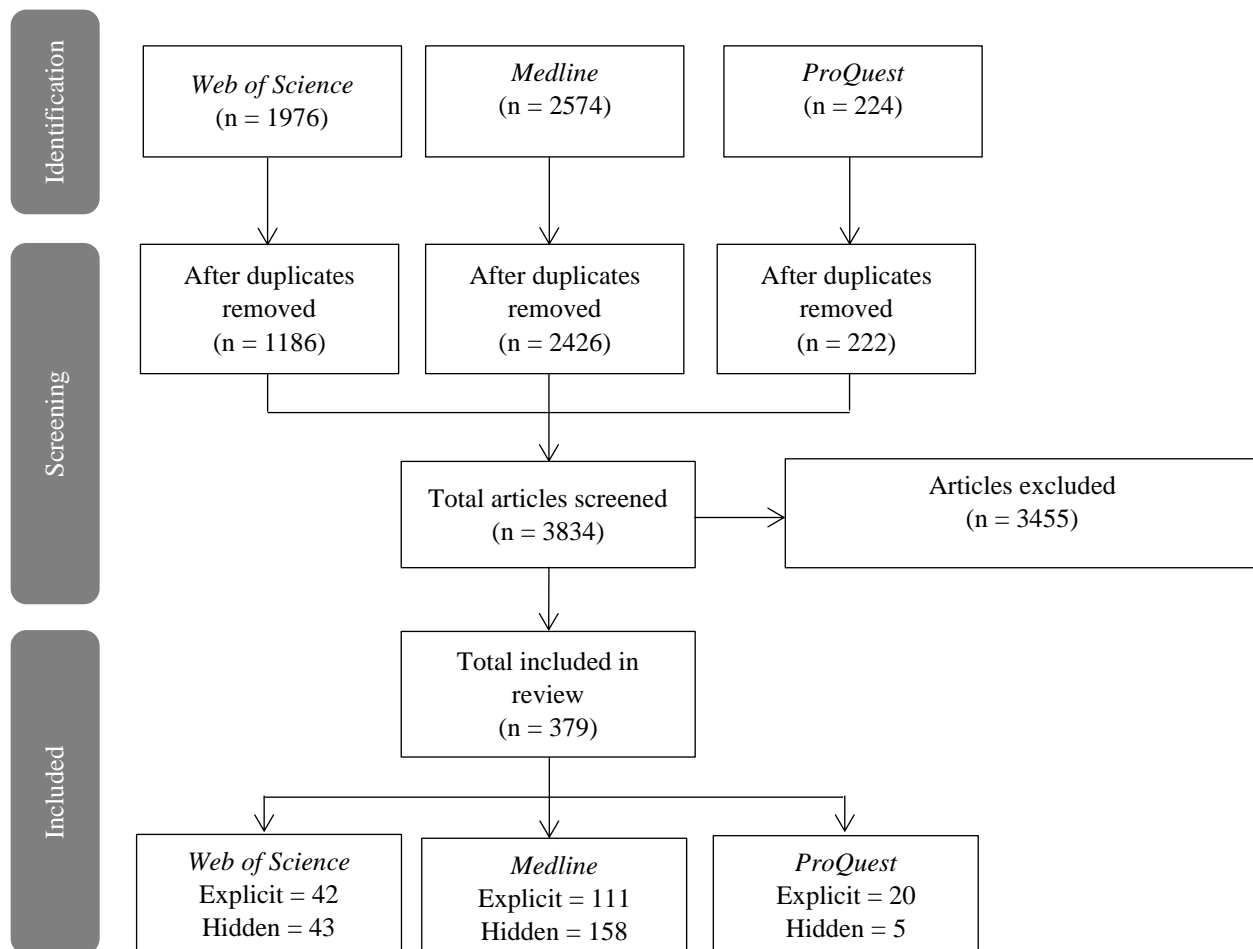
³ Search terms related to autism were used in ProQuest Philosopher’s Index because ethics (philosophy) was already the focus of the database.

assent* OR dissent* OR confidential* OR privacy OR disseminat* OR decision-making OR vulnerab* OR autonom* OR rapport). Search terms for Ovid Medline 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.)

MAC designed and conducted the literature review, with help from research assistants. JW and ER advised on the literature review design and resolved uncertainties and disagreements. 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 eliminate articles that were not about humans, were not about people on the spectrum, were only abstracts with no full paper (conference abstracts), were in a language other than those we read (English, French, and Italian), or were duplicates from within or between databases. The remaining articles were reviewed fully to determine if they addressed autism research ethics. Common reasons to exclude articles at the stage of full review were that they did not discuss ethics at all, or only included minimal information on ethics (e.g., just noting that an ethics committee approved the project or that participants gave consent). We included articles that explicitly addressed research ethics, and those that contained “hidden” ethics data (Dubois, 2008) that were identified by our keywords, despite not being primarily about research ethics. “Hidden” ethics information refers to the useful empirical data (and normative, philosophical justifications) 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). Including these articles brings to light everyday ethical practices that might otherwise only be read by researchers working in the same field or on the same topic.

This search yielded a total of 4774 articles, of which 379 were ultimately included (see Figure 1). Content related to the person-oriented research ethics was extracted verbatim and organized by guidepost, then reviewed in a more holistic fashion to identify themes. Themes were then condensed and reorganized iteratively into an initial outline of interrelated ideas, issues, and suggestions.

Figure 1: Literature Screening Flowchart

Task Force

The goal of the task force was to model person-oriented autism research ethics based on stakeholder engagement. Preliminary literature review results served as a starting point for discussion of research ethics issues by the task force. The task force brought together different experts – credentialed (researchers), practicing (professionals and advocacy organization representations), and experts by experience (autistic self-advocates and parents of people with autism) – listed in the table below. At the same time as compiling the task force, we created a

website (<https://www.autismresearchethics.net/>) to summarize the project and the mandate of the task force, and to encourage input from broader communities.

Table 1: Task Force Members & Affiliations/Connections at Time of Meeting

Name	Connection to the topic	Location
Pascal Franco	Coordonnateur de projets Communication à la Fédération Québécoise de l'autisme	Quebec
Esther Rhee	National Program Director, Autism Speaks Canada	Ontario
Margaret Spoelstra	Educator Executive Director, Autism ONtario	Ontario
Nancy Noseworthy	Inclusive Schooling Consultant and Autism Advocate; Dehcho Divisional Education Council	Northwest Territories
Arden C. Fiala	Parent and Advocate	Saskatchewan
Connie Putterman	Parent advisor to autism research, family engagement in research, MHsc (c) in translational research at U of T	Ontario
Zari Yaraghi	Parent; Member of the Board of Directors of Autism Canada	Ontario
Franco Carnevale	Researcher Ethicist	Quebec
Ariel Cascio	Postdoctoral Researcher Pragmatic Health Ethics Research Unit, Institut de recherches cliniques de Montréal	Quebec
Malvina Klag	Research Fellow HEC Montréal	Quebec
Eric Racine	Researcher Pragmatic Health Ethics Research Unit, Institut de recherches cliniques de Montréal	Quebec
Jonathan Weiss	Researcher York University	Ontario
Mathieu Dubois	Postdoctoral Researcher, HEC Montréal Self-advocate	Quebec
Jessica Pigeau	Self-advocate	Alberta
Kristian Hooker	Self-Advocate Entrepreneur of Autism Services H.A.L.E. Autism	Manitoba
Wendy Mitchell	Service Provider Researcher	Alberta
Bei Evelyn	Undergraduate Student at McGill University Self-Advocate	Ontario/Quebec

The task force met in Montreal in December 2017. The researchers involved in the literature review (MAC, JW, and ER) presented a slide deck of literature review results, with slides also distributed in writing and in advance (see Box 1). This meeting used a process of ethical deliberation (Racine, 2016) to discuss the five guideposts of person-oriented research ethics and draft an initial outline for a report of suggestions for researchers. Deliberation – or reflective discussion on an issue – engages those concerned by a given issue within a climate that allows critical reflection on the formulation of a given problem and, ultimately, participation in a creative effort to generate action scenarios, with a focus on the analysis of key ethical principles (in this case, the five guideposts). For this workshop, we had a two-day agenda including a vision and goals presentation, icebreakers, a presentation of the literature review, a reflect-and-share or pair-and-share discussion on “what’s missing,” small group discussions focused on each guidepost, large group discussion for each small group to share their discussion, small group meetings to outline the report, large group discussion to generate consensus on outline, and a large group session to plan the website/community engagement component. The task force also developed a community engagement strategy, deciding to have a forum available on the website for the broader community to respond to discussion questions about person-oriented research ethics and autism, and revised an invitation to send to Canadian autism organizations inviting them to follow the project online. We strove to facilitate access and inclusion for all members: autistic and neurotypical people, researchers and non-researchers, and English and French speakers (see Box 1). These strategies drew from the Autism Cooperative Research Centre’s Inclusive Research Practice Guides and Checklists (Autism CRC, 2016), the principles of universal design for learning, and our own experiences working with autistic and autism communities.

Box 1: Some strategies used by workshop organizers to facilitate access and inclusion

- Use clear language and formatting.
- Send detailed arrival instructions including maps and photographs of the airport arrival terminal from a first person point of view.
- Solicit and share photographs and biographies of workshop attendees and staff.
- Prepare read-along copies of presentations, distributed in advance and during the workshop.
- Present and discuss guidelines for engagement and conversation during the workshop.
- Provide multiple ways to engage such as attending one, both, or neither days; having large group and small group discussion; attending by teleconference; or providing written commentary.
- Make available a “quiet room.”

After the workshop, task force members collaborated via email, on the phone, or in-person one-on-one with the project lead (MAC) to finalize the list of suggestions and develop a detailed report to share with the broader community. The project lead provided multiple ways to contribute (open-ended text editing, structured feedback worksheets, dialogue) and recirculated drafts incorporating all contributions for further rounds of commentary and approval.

The task force contributed both professional expertise and lived experience to the co-construction of knowledge. In building the current suggestions, the task force synthesized the insights of research in a range of fields, including clinical research, social research, and philosophy. Task force members also reflected on their own experiences of interactions with research, and their own perspectives, to create solutions that reflect the big picture, and complement the published literature.

Community Engagement

The website (<https://www.autismresearchethics.net/>) was designed to facilitate a community engagement process, to allow broader engagement with autism and autistic communities beyond the task force and include the perspectives of many stakeholders. It provides brief descriptions of the project and task force members, updates, a discussion forum, multiple means of contact, and a resources page. It is available in both official languages of Canada, English and French.

In April 2018, we activated the website forum and emailed the invitation drafted and revised by the task force to individual contacts and autism organizations across Canada. The project leader (MAC) met with a small number of interested individuals (researchers, parents, and people who are both) via phone or in person and received feedback which was circulated anonymously to the task force. The task force read these comments and integrated them into the suggestions presented in the next section, for example by expanding certain bullet points, and into website design. These suggestions in turn were circulated in draft form to the broader community via the website and its subscribers' mailing list, to allow further feedback and refinement. This feedback is ongoing.

Summary of Suggestions

The suggestions are intended to serve as a resource for researchers. Each guidepost is operationalized as a list of "How do I..." question(s) (Tables 2 to 6) followed by suggested "actions" or "reflections". The "How do I..." questions derive from the five guideposts and are intentionally generic and open-ended in order to encourage flexibility and reflexivity (instead of providing rigid recommendations). Our approach is therefore an invitation to self-reflection in which the answers will be tailored to the individual researcher's project, context, and situation.

The suggested actions and reflections are intended to be more autism-specific, although they also include reinforcing basic rights that all research participants are owed, and derive from the literature review and task force deliberation. These actions and reflections are reported according to how they relate to four phases of research: (1) throughout research; (2) when planning research; (3) when doing research; and (4) when sharing research. Each table is followed by an illustration drawing from one particular bullet point and discussion of each guidepost. The full-length task force report expands on each bullet point found in Table 1 to 5, supported by further detail, examples, justifications, and debates or tensions regarding the suggestion. Readers interested in learning more about a bullet point not discussed in detail in this manuscript are invited to view the full report available on the project website (<https://www.autismresearchethics.net/>). The purpose of this paper is not to be exhaustive, but rather to outline priorities from the literature, task force, and broader community; and to demonstrate the value of a broad, community-engaged approach.

Individualization

This guidepost stresses the consideration of the unique needs and strengths of each person, without reduction to characteristics of the population (i.e., autism). It holds that research should be open to individualization that takes into consideration the unique needs of specific individuals, as much as possible within the research design. For example, in large and/or long-distance studies (e.g., online research) it may not be feasible to respond to each individual, but could still be possible to offer a range of options. It provides a toolkit of strategies for involving participants inspired by characteristics like autism, but not a checklist that reduces them to such characteristics.

Table 2: Individualization: Summary of Suggestions

Individualization		
Goals	Phase	Suggestions
How do I... ... consider the unique needs of each person?	Throughout research	Actions: <ul style="list-style-type: none"> ○ Individualize communication about the study (e.g., when including people with autism in the design of the study, when recruiting participants, and when telling people about results) to meet the diverse needs of people on the spectrum.
	When planning research	Actions: <ul style="list-style-type: none"> ○ Facilitate priority setting with autism and autistic communities, or draw on existing literature, to identify studies that can be most meaningful to particular people or groups (e.g., some individuals are more concerned with interventions, others with mental health, others with employment, etc.).
	When doing research	Actions: <ul style="list-style-type: none"> ○ Individualize consent procedures. ○ Individualize research design and data collection procedures (even in very standardized studies, in small ways). ○ Individualize support for participants during the study. ○ Tailor the language used (e.g., autistic person vs. person with autism) to each individual's preference.
	When sharing research	Actions: <ul style="list-style-type: none"> ○ After a study, ask participants and researchers to reflect and report on experiences (positive and negative) with the research process; then follow-up as needed.

Example

The bullet point “Individualize support for participants during the study” emerges from a wealth of examples of how to implement individualization in studies involving participants on the autism spectrum, as a way of addressing autism needs and accounting for variation among people with autism. Researchers can encourage participants to play with fidget toys, if they want to, during data collection (Sokhadze, Casanova, Tasman, & Brockett, 2016) or bring their favorite toys with them to the research visit (Baranek et al., 2002). Some studies allow participants to have support persons (friends, family members, or staff) present during the study (Barrow & Hannah, 2012; Ruef & Turnbull, 2002), although other researchers assert the importance of allowing participants confidentiality from others by interviewing alone (Cridland, Jones, Caputi, & Magee, 2015) and raise the concern that the presence of others might limit opportunities for the participant to interact with the researcher (Preece & Jordan, 2010). Other types of support that can be individualized include providing clarifications to participants as needed (De Silva et al., 2009; Falkmer, Granlund, Nilholm, & Falkmer, 2012; Orsmond & Cohn, 2015), providing breaks when needed (Baranek et al., 2002; Happe, 1994), and planning for support in case of participant distress (Wright et al., 2014). Task force members noted that sensory sensitivities or fears can be an important area in which to individualize, as people may have a range of concerns related but not limited to having things on their heads, temperature, smells such as perfume, voice level, or the number of questions. These considerations are especially important when the research takes place in a dedicated space (rather than when the researcher travels to spaces of a participants’ choice). Task force members encouraged researchers to let participants assess the room ahead of time and give participants a chance to talk about their unique needs and sensitivities. Researchers can create a form to make this easier for participants, or include a pre-interview for participants to talk about these issues.

Acknowledgment of Lived World

Although a focus on the particular individual is very important, person-oriented research ethics also includes an awareness of the relational and contextual aspects of individuals' lives. The guidepost of Acknowledgment of Lived World requires respect for factors that shape participants' needs and decisions, including family and community beliefs, norms, and values, as well as a recognition of the researcher's beliefs, norms, and values and how they may impact the research encounter. It stresses culturally appropriate and non-stigmatizing procedures. It includes, as relevant to the research topic and individual participant, present, past, and even future experiences, and awareness of the role of family and friends and the potential need or desire for their involvement in decision-making. In short, person-oriented research considers the role of social context and significant others in the participants' lives.

**Table 3: Acknowledgment of Lived World: Summary of Suggestions**

Acknowledgement of lived world		
Goals	Phase	Suggestions
<p>How do I...</p> <ul style="list-style-type: none"> ... respect the factors that influence participants' needs and decisions, including individual, family, and community beliefs, norms, and values? ... recognize my own beliefs, norms, and values and how they may impact the research encounter? ... use culturally appropriate and non-stigmatizing research protocols? ... attend to present, past, and future experiences of participants? ... be aware of the role of family and friends and the potential need or desire for their involvement? 	Throughout research	<p>Reflections:</p> <ul style="list-style-type: none"> ○ Acknowledge stigma, stereotypes, and past experiences of having been excluded that impact the research process.
	When planning research	<p>Actions:</p> <ul style="list-style-type: none"> ○ If participants want, involve significant others who play an important role in their lives, and may impact the research process.
		<p>Reflections:</p> <ul style="list-style-type: none"> ○ Acknowledge that many autistic participants are more focused on striving to access care, treatment, and intervention, which impacts motivation to take part in research. ○ Recognize broader autism and autistic communities such as advocacy groups or social movements, which have a stake in the research process. ○ Acknowledge that people with autism have historically been harmed in research and clinical settings, which may cause hesitation about research.
	When doing research	<p>Actions:</p> <ul style="list-style-type: none"> ○ Integrate other demographic factors of participants that matter in research. ○ Address logistical challenges to participation.
		<p>Reflections:</p> <ul style="list-style-type: none"> ○ Consider the important role the context or environment plays in research. ○ Know that the internet is an important social setting for many autistic people. ○ Reflect on the world in which researchers work, which also impacts the research process through logistical and regulatory barriers.
	When sharing research	<p>Reflections:</p> <ul style="list-style-type: none"> ○ When writing up results, be mindful of findings or wording that might be stigmatizing (e.g., "at risk of autism").

Example

One important example in autism research is addressed in the suggestion (Table 2) “acknowledge that many autistic participants encounter research while striving to access care, treatment, and intervention which impacts research ethics.” This is an integral consideration in autism research, as the autistic community is known to have multiple varying unmet needs across the lifespan (Lai & Weiss, 2017), which serve to accentuate an experience that may otherwise seem common to many clinical groups who participate in research. Often this context of seeking care is high-stress and high-expectations, where people are facing difficulty accessing services. Some scholars describe this as a context of “desperation” which might pressure people to participate in research in order to try a new autism-related intervention when other interventions have not been helpful (Lord et al., 2005). Participating in research can give people access to otherwise expensive autism diagnoses, evaluations, and interventions (Lappe, 2014; Singh, 2015), which introduces the possibility of coercion. The broader social context of access to autism-related care is therefore important for researchers to consider. Genetic research might entail access to information or services for study participants that are absent for non-participants, leading to ethical tensions for researchers (Hayeems, Miller, Bytautas, & Li, 2013). Daley and colleagues suggests researchers collaborate with service providers to maximize benefit, but recognizes that this is not always possible, especially in low-resource countries (Daley, Singhal, & Krishnamurthy, 2013). While researchers cannot usually control what access participants have outside the study, they can determine that access when planning research and consider it in risk-benefit analyses. It is also important to understand these motivations to participate because people might withdraw from a study if they are not getting what they expect of it. Weighing risks and benefits is an essential part of any study, and in autism research the context of care available outside the study must be included too. There are ethical concerns with using placebos, waitlists,

and other types of non-treatment controls where some participants would not get treatment; many designs are considered unethical for this reason.

Empowerment in Decision-Making

Empowerment in Decision-Making focuses on participant decision-making, including but not limited to the consent process. The important considerations in regulatory research ethics around informed consent are information, comprehension, and voluntariness. In person-oriented research ethics, these considerations are not all-or-nothing. Person-oriented research ethics draws on person-centered priorities of autonomy, self-confidence, and self-determination – and how to enhance them. They are also not limited only to consent, but also everyday decisions in research. In short, person-oriented research includes strategies to maximize the decision-making abilities of potential participants. This includes strategies for researchers to communicate with participants as well as environments that provide better opportunities for participants to make informed decisions.

Table 4: Empowerment in Decision-Making: Summary of Suggestions

Empowerment in decision-making		
Goals	Phase	Suggestions
<p>How do I...</p> <p>... enhance autonomy, self-confidence, and self-determination in the research process?</p> <p>... maximize the decision-making abilities of potential participants?</p> <p>... use structures and environments that provide better opportunities for participants to make decisions?</p>	Throughout research	<p>Actions:</p> <ul style="list-style-type: none"> ○ Use research on decision-making to develop “evidence-based” ethics practices (e.g., studies on participants’ understandings of consent forms).¹
	When planning research	<p>Actions:</p> <ul style="list-style-type: none"> ○ Empower people with autism to contribute to research in ways other than providing data, e.g. using autism-friendly communication methods in participatory research.
	When doing research	<p>Reflections:</p> <ul style="list-style-type: none"> ○ Begin from the stance that people with autism have a right to participate in research, or to refuse to do so. ○ Consider ways in which the setting of a study can make free decision-making harder or easier. ○ Specific types of research might require sharing specific types of information.
		<p>Actions:</p> <ul style="list-style-type: none"> ○ Create a consent process which is accessible to people with autism (e.g., using visuals, asking autistic people for feedback on consent forms). ○ Give potential participants a chance to meet researchers and ask questions and provide explicit opportunities for additional questions throughout the study. ○ If others are implicated in the study, include them in conversations about choosing to participate. ○ Collect information about who did not consent and why, in order to reflect on the consent process. ○ Give participants choices beyond just whether or not to participate, such as choices about how data are collected or how results are written.
	When sharing research	<p>Reflections:</p> <ul style="list-style-type: none"> ○ Consider ways in which the research process can empower or disempower people in other parts of their lives. For example, results of research can have implications for treatment decisions and genetic results can have implications for reproductive decisions.
		<p>Actions:</p> <ul style="list-style-type: none"> ○ Empower participants to make decisions at the end of a study, such as what individual results to access if any, and whether or not to read published results. ○ Invite participants to be included in additional studies while still making it clear that one does not necessarily have to commit to further studies.

¹“Evidence-based research ethics” describes the practice of applying the results of social science research that examines research ethics issues (Kalichman, 2009).

Example

The suggestion to “create a consent process which is accessible to people with autism” (Table 3) involves using clear communication strategies and attention to the research environment which are useful for any stage of the research process. Taking an autism-specific lens means considering the diverse ways that autistic people understand and communicate, which by definition of their diagnosis requires more support than in many other conditions or in the general population. An accessible consent process could, for example, use visuals (Fuentes & Martin-Arribas, 2007; Hens, Peeters, & Dierickx, 2016; Loyd, 2013), acknowledge and support the use of alternative and augmentative communication (Fuentes & Martin-Arribas, 2007; Trehin, 2003), use video to explain the research process, pay attention to the non-verbal communication of people on the spectrum, and ask adults with autism for feedback on consent forms (Perry, 2012). These strategies foster an ability to understand consequences of different decisions and create conditions for comfort and authenticity. As always, it’s important to make the decision-making process non-judgmental by making it explicit that the participant will not be penalized and practicing what one task force member described as “unconditional positive regard” in equally supporting all decisions. Similar strategies can be used to empower other decisions in research – not just whether to participate or not – including decisions about data collection, receiving results of research, or being involved as a partner in models such as participatory research described below (see also Cascio et al. in press).

Respect for Holistic Personhood

“Respect for persons” is a cornerstone of research ethics (Beauchamp & Childress, 2009) and endures throughout all aspects of person-oriented research ethics described in this section. Respect for holistic personhood maintains that it is important to recognize the rights and self-determination abilities of all participants, even those with potential or actual impairments of decision-making capacity. This principle involves a strengths-based approach that focuses on capability, and values the potential contributions of all individuals to research questions that concern them. It is holistic in the sense that it acknowledges biological, psychological, and social dimensions of personhood. In short, person-oriented research recognizes value in the contributions of all potential research participants, even those in situations of vulnerability. Person-oriented research is designed to respect and take into consideration the contributions of research participants by soliciting feedback of the target population and designing the research process to take into consideration needs, preferences, or priorities that might impact persons in this population.

Table 5: Respect for Holistic Personhood: Summary of Suggestions**Respect for holistic personhood**

Goals	Phase	Suggestions
<p>How do I ...</p> <p>... recognize the personhood and agency of all participants, even those with potential or actual impairments of decision-making capacity?</p> <p>... take a strengths-based approach that focuses on capability and values the potential contributions of all individuals to research questions that concern them?</p> <p>... respect and take into consideration the contributions of research participants?</p> <p>... solicit feedback of the target population?</p> <p>... design the research process to take into consideration needs, preferences, or priorities that might impact persons in this population?</p>	Throughout research	<p>Actions:</p> <ul style="list-style-type: none"> ○ Use language which is non-judgmental and non-stigmatizing about autism. ○ Conduct empirical research about participants' views of research and solicit feedback from participants and other stakeholders on research design.
	When planning research	<p>Actions:</p> <ul style="list-style-type: none"> ○ Make topics, measures, and outcomes meaningful (and understandable) to people with autism. ○ Create research designs and data collection strategies that address the autism-specific needs of participants.
	When doing research	<p>Reflections:</p> <ul style="list-style-type: none"> ○ Determine if it is important to recruit based on precise diagnosis and how to describe diagnoses.
		<p>Actions:</p> <ul style="list-style-type: none"> ○ Ensure participation is not overburdening by avoiding undue risk or discomfort, or unnecessary studies; draw on existing autism research and resources. ○ Actively include people with autism as participants themselves (rather than relying only on third person reports, though they can be helpful). ○ Design recruitment strategies to address autism-specific needs of participants. ○ Prepare participants on the spectrum for taking part in the study or for procedures in advance.
	When sharing research	<p>Actions:</p> <ul style="list-style-type: none"> ○ Disseminate results in an accessible format for people with autism. ○ Involve people with autism, stakeholders, and stakeholder organizations in the dissemination of findings. ○ As always, respect privacy and confidentiality.

Example

Respect for Holistic Personhood encompasses a range of suggestions all aimed at discerning and addressing the needs, preferences, and priorities of people on the spectrum (e.g., Pellicano, Dinsmore, & Charman, 2014). One suggestion with several implications is to “create research designs and data collection strategies that address the autism-specific needs of participants.” This is integral because of the tremendous heterogeneity in etiology and presentation of autism (National Institute of Mental Health, 2018), which requires considerations of how to address diverse autism-specific needs of participants. Such strategies include reducing the sensory burden of research setting (e.g., noise, volume, light), avoiding unnecessary experiences that might be upsetting for some participants (e.g., using an elevator to reach the research location), involving people with autism in the development of instruments, using autism-specific or modified research instruments that allow people with autism to more accurately show their strengths and concerns, and offering participation by video-chat if in-person data collection is not necessary. Some types of communication that might work for some people with autism include picture systems, not bombarding people with questions, providing the option to read something, sending questions to the participant ahead of time.

There are some tensions regarding the best strategies for addressing autism needs in research design. Notably, visual supports are often suggested (Arborelius, Fors, Svensson, Sygel, & Kristiansson, 2013; Fage, Pommereau, Consel, Balland, & Sauzeon, 2016; Roldan-Alvarez et al., 2014), but they may also be limiting (Loyd, 2015; Preece & Jordan, 2010). Moreover, while many autistic people are good with images, this is not true of everyone and over-stressing it may ignore the diversity of needs. This is why individualization, described above, is so important. Getting to know the participant before data collection can help researchers understand what would work best. Researchers should be proactive about offering accommodations or options, or

asking participants what they need; the onus should not entirely be on the autistic person to adapt or make accessibility requests.

Focus on Researcher-Participant Relationships

Research is always a social and interpersonal endeavor. Person-oriented research ethics stresses attention to the power dynamics involved in research. These power dynamics are perhaps most evident in discussions of vulnerability (e.g., Howe, 2003). Attention to researcher-participant relationships also relates to building and maintaining trust and rapport between researcher, participant, and participant community. In short, person-oriented research considers carefully the relationship between researchers and participants and how it is shaped by social, economic, and political factors.

Table 6: Focus on Researcher-Participant Relationships: Summary of Suggestions

Focus on researcher-participant relationships		
Goals	Phase	Suggestions
<p>How do I...</p> <p>... pay attention to the power dynamics involved in research?</p> <p>... build and maintain trust and rapport between myself, participants, and participant communities?</p> <p>... recognize the sociological, economic, and political factors that influence these relationships?</p>	Throughout research	<p>Actions:</p> <ul style="list-style-type: none"> ○ Create and maintain open communication. ○ Involve people with autism and their communities in research in other ways than as participants. ○ Build relationships not just with participants, proxies, and gatekeepers, but also with broader communities.
	When planning research	<p>Reflections:</p> <ul style="list-style-type: none"> ○ Include attention to relationships in animal research on autism as well, because the research questions and study results impact autistic people and communities. ○ Reflect on the role of researchers in the study. ○ Reflect on any particular professional or personal connections with autism (often called “positionality”) and how it contributes to the research. ○ Account for a history of conflict between researchers and autism communities that can generate mistrust.
		<p>Actions:</p> <ul style="list-style-type: none"> ○ Build rapport before a study starts, e.g. by engaging in participants’ topics or activities of interest, which may be especially important for allistic (i.e., non-autistic) researchers seeking to collaborate across the spectrum of neurological difference. ○ Build relationships with people other than the participant, as necessary. ○ Be knowledgeable about or experienced with autism either professionally or personally.
	When doing research	<p>Reflections:</p> <ul style="list-style-type: none"> ○ Attend to power imbalances between researchers and participants which may make participants particularly vulnerable in the course of a study. ○ Consider the value that relationships with researchers provide participants in terms of local community connections.
		<p>Actions:</p> <ul style="list-style-type: none"> ○ Maintain rapport, which has consequences for recruitment and data collection. ○ Be prepared for and manage emotional experiences, as data collection can be emotional for participants. ○ Take responsibility for communication of ethics information.
	When sharing research	<p>Actions:</p> <ul style="list-style-type: none"> ○ Attend to important relationship concerns when a study is over, about returning results to participants, formalizing a good-bye, and maintaining good relations after. Follow up by sharing impacts of research. ○ Read the writings of research participants about their experiences participating in research. ○ Create research communities which can be a form of public engagement.

Example

One way to focus on researcher-participant relationships is to challenge the line between researcher and participant following the suggestion to “involve people with autism and their communities in research in other ways than as participants.” Involvement can take many forms. It can be done throughout the entire research process through things like community-based participatory research (CBPR) which several research groups successfully do with autistic community partners. Recent publications (e.g., Autism CRC, 2019; Fletcher-Watson et al., 2018; National Institute for Health Research, 2015; Nicolaidis et al., 2019) comprehensively highlight how to do participatory research in autism, as well as providing general guidelines for including autistic research participants. People with autism and autism communities can be involved in setting research priorities, in recruitment and managing databases or biobank, on advisory groups and committees, as a part of the research team or analyzing data, evaluating the success of an intervention, disseminating and applying results, or being quoted as scholarly sources. Having someone with autism on the research team can help the participant not feel alone. Quoting autistic people as scholarly sources recognizes that autistic people also lead research and could be important colleagues or collaborators.

Diversity within the autistic community is important to consider for this involvement, which means ensuring girls, women, and non-binary people, individuals with different communication styles, and children are included, despite often being excluded (Beresford et al., 2004; Krahn & Fenton, 2012; Loyd, 2015; Persico et al., 2015; Preece & Jordan, 2010). It is important to avoid tokenism and strive for genuine participation. Specific communication strategies can help mixed autistic/allistic research teams work well together (Nicolaidis et al., 2011). Providing special training to community members can help (Jivraj, Sacrey, Newton, Nicholas, & Zwaigenbaum, 2014). When involving community partners, studies could involve a

charter or partnership agreement that outlines the expectations and values for each party. Task force members suggested that this agreement could be co-written and posted on the wall of the study location, stating: “you have a right to X, Y, Z and a responsibility to X, Y, Z.” Such partnership agreements are commonly recommended for research involving participants as partners, and the Canadian Institutes of Health Research provides some models and examples for developing them (Parry, Salt, & Macaulay, 2015). Such models can be combined with suggestions about autism-friendly communication mentioned above, to create empowering documents for autistic partners.

Discussion & Conclusion

Research ethics is evolving to reflect the need to attend to everyday and relational aspects of ethics *in research* (person-oriented research ethics) and not only ethics *of research* (regulatory research ethics). This paper examines the broad principles of research ethics, especially ‘everyday’ ethics that often go undiscussed, and presents suggestions that can be helpful for researchers who aim to incorporate these topics into their research methodologies. It presents the work of a task force dedicated to modeling person-oriented research ethics in the context of autism. The examples presented above provide an overview of strategies researchers can use to include people with autism in their studies ethically and meaningfully, balancing the risks of participation with the risks of exclusion. While these suggestions derive from literature and personal experience often bound to one field (e.g., education) or one topic of study (e.g., student perspectives on drama class), the suggestions themselves are broad enough to provide a fruitful starting point for any researcher whether in the clinical sciences, social sciences, or humanities. As the examples briefly presented show, the suggestions are not necessarily simplistic or one-size-fits-all. There are tensions, for example, regarding the role of support persons or the value of visual communication strategies. The model of person-oriented research ethics equips

researchers to consider these tensions grounded in the five guideposts. As the examples briefly described above demonstrate, the guideposts can focus researchers' attention to everyday and relational issues which are essential to ethics in research, not just research ethics committee applications, consent forms, or dramatic ethical dilemmas.

Our endeavor to focus conversations about research ethics on everyday and relational aspects of research overlaps with recent efforts in participatory autism research, i.e., studies involving autistic people as both participants and research partners. Several research teams in many countries have engaged in participatory research with autistic people, and have published reports or guidelines for how to conduct such studies (Autism CRC, 2016; Fletcher-Watson et al., 2018; Nicolaidis et al., 2019), including ethical considerations. The participatory research movement, with roots in models like Participatory Action Research and Community-based Participatory Research (Schensul & LeCompte, 2016), makes ethical claims – most notably that participatory research seeks to address and redress power differences between researchers and participants by seeking collaboration and empowering marginalized communities. These goals served as a foundation for the community-engaged approach that was used to develop the current project. While our project pulled from participatory models (or at least stakeholder engagement models), our outcome differs from guidelines for participatory research due to our focus on the everyday experiences of ethics in research. While our summary of suggestions certainly overlaps with others' (highlighting the inseparability of research ethics from any research design or methods discussion), ours differ through our focus on the five guideposts of person-oriented research ethics. In line with this focus, we did not address the broader methodological details necessary for undertaking participatory research. Rather, we intend these guideposts to be applicable even to researchers who are not taking a participatory approach.

Several key figures within the research community can help to implement these practices. Researchers can consider these suggestions when planning, doing, and sharing research. Research Ethics Committees can consult these suggestions when evaluating protocols submitted for ethics review. Journal editors can direct prospective authors to these suggestions when submitting manuscripts for consideration. Peer reviewers for articles and grants can find inspiration in these suggestions when evaluating the content and style of articles and the planned protocols in grants. Funders can encourage applicants to use these tools.

To connect with these actors, the project's next steps include dissemination of the suggestions through peer-review publication, an accessible and visually engaging report, formal and informal communication with researchers through professional networks, and availability for seminars and webinars. The suggestions created by the task force should also be validated and refined through active testing. Therefore, the lead researchers are collaborating to implement select suggestions in an active research project, and solicit feedback from research participants on these elements of the study. This validation study will focus on the experiences of real research participants in the everyday context of an ongoing research study, thus contributing to the empirical study of human research ethics by identifying participate perspectives and feeding those perspective back into the development of research ethics theory and practice.

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