The Autism Research Ethics Task Force
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Introduction

Overview

**Vision Statement:** We are a Task Force focused on autism research ethics. Our goal is to provide a range of recommended practices for how to design studies that take the specific strengths and needs of people on the autism spectrum into consideration.

A lot of people think of research ethics in terms of rules, regulations, paperwork, and standards. Research ethics certainly involves these things, but it also involves everyday interactions and relationships between researchers, participants, and communities. This report is about these everyday issues and how they impact the research process from the planning stages, when doing research, and when sharing results of research afterwards.

Our approach to research ethics is *person-oriented*. What is person-oriented research ethics? It is a model of thinking about research ethics that we developed based on insights from clinical ethics, such as person-centered care and supported decision-making, as well as research ethics concepts such as evidence-based research ethics and goodness-of-fit ethics. This model is described in more detail in Part 1. We are happy to be able to share this report with you and hope you will find it useful.

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**A note about language:** The debate on language and autism is ongoing, with many passionate defenders who argue both for and against medicalized terminology, person-first language, identity-first language, and normalization of autism through language. The heart of these debates is a single question: “How do we best talk about autism?” There is, as of yet, no consensus on the answer to this question, due to the diversity of experiences and perspectives within autism and autistic communities. For this reason, this report uses terms such as “autistic person”, “person with autism”, and “person on the spectrum” interchangeably to respect the range of valid and important views. This choice is in line with the person-oriented approach, which stresses respecting an individual’s preferences. Since these preferences vary, this document’s terminology will also vary.

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**Why autism?** Autism is the common ground that brings all of the members of the Task Force together. Some of us are autistic people, self-advocates, or people on the spectrum; some of us are parents of children diagnosed with autism; some of us are advocates; some of us do research with people on the spectrum or aspire to do so; and some of us are service providers. Many of us represent multiple categories.

Autism, beyond being our common focus, provides an especially promising motivation for pursuing person-oriented research ethics. Autism is an area in which a call for the recognition of diversity has been particularly strongly voiced – by the neurodiversity movement as well as by other self-
advocates, parent advocates, professionals, and advocacy organizations. The neurodiversity movement argues that autism should be understood not as a disease or disorder, but as a part of human diversity (namely, neurological diversity). We can learn from this call for diversity and use it as a launching point for the recommended practices we propose. Also, reported prevalence of autism is increasing in many countries, as is patient and family engagement in and support for research initiatives, leading to more research in clinical and social sciences that will or might involve participants on the spectrum. There are many types of research studies, including research drawing from literature reviews, research using surveys and other methods of directly interacting with autistic participants, research using information from databases without direct interaction, and research that is a combination of these types.

**What is autism?** Autism means many things to many people. The term is often used as shorthand for “Autism Spectrum Disorder” (ASD), the term used in the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) to refer to a neurodevelopmental condition that affects the way a person communicates and relates to people and the world across the lifespan. It is characterized by differences in social communication and social interaction, as well as restrictive and repetitive behaviours and interests although not everyone likes repetition. It can impact behaviour, social skills, understanding of non-verbal communication, thought processes in consuming and/or distributing information, self-care skills, and the processing of perception of sensory information. Some people do not like the use of “disorder” in the term ASD and opt instead for “autism spectrum conditions” (ASC) or simply “autism.” Disorder and related language uses a deficit-based approach that frames autistic people as less than non-autistic people. As mentioned above, neurodiversity advocates argue instead that autism can be understood as a difference in the wiring of the brain, or an experience of one’s inner and external worlds that is situated in unexpected and/or alternative social responses and bodily understandings of these worlds. The use of the word “spectrum” highlights the fact that while all people with autism will experience certain differences, the degree to which each person on the spectrum experiences these differences throughout their lifespan varies in intensity and frequency. Just like all people, each person with autism is different, and has unique strengths and passions.

**Why are our recommendations important?**

1. **Person-oriented research ethics protects participants.**

People with autism may be vulnerable in research. The research process itself might be overwhelming or confusing, some research procedures might by unpleasant, and some types of research include a potential risk for harm. Attention to person-oriented research ethics can ensure potential participants are more informed, protect research participants from harm or undue influence, and make the research process more pleasant.

2. **Person-oriented research ethics may lead to better science.**

Research ethics in research designs can improve clarity of results and allow for more relevant and widely applicable findings. When people are not included in research about things that concern them, it is hard to know if the results of a study apply to them. Therefore, including people with
autism leads to more relevant research findings. Diversity within autistic communities is also important, and including people with autism means including people of all ages (especially children and youth who are already profoundly excluded from many types of research), people from racialized minority groups including Indigenous populations, people of all genders, all diagnostic statuses, and people with a range of support needs.

(3) Person-oriented research ethics brings focus on social inclusion.

Reframing the research questions and designs allow translation to impact for autistic communities. The development of guidelines and recommended practices around autism have the potential to support and encourage more researchers to include people with autism, allowing autistic people to have their perspectives heard and their concerns researched. Inclusion in research is an important form of social inclusion for these reasons, but autistic people might be unjustly excluded, especially young people\(^1-3\), women\(^4\), and nonverbal communicators\(^5\). These guidelines will help address that exclusion and close the gap in both representation of perspectives and access to research on topics of concern.

**How are we accomplishing our task?** We are combining insights from the scholarly literature with insights from a Task Force and Community Engagement Process. The Task Force is composed of researchers, autistic people, parents of people with autism, service providers and other professionals, and autism advocacy organizations representatives. We are committed to a process of *co-constructing knowledge* whereby all of these important voices are involved in the discussion and writing of this report.
Background

Our work emerged from the desire to create a resource for researchers, to raise awareness about the importance of and possibilities for including autistic participants in their studies, which is applicable to those focused on research pertaining to autism and also for those who are interested in recruiting diverse populations.

While our project brings a unique focus on research ethics and an intentional broadness as to methods, approach, and topics of study, there are some earlier initiatives in autism research that relate to our project.

There are several participatory autism research groups working around the world including the Academic Autism Spectrum Partnership in Research and Education (USA), the Autistic Adults and Other Stakeholders Engage Together (AASET) PCORI-Funded Engagement Project (USA), the Autism Cooperative Research Centre (Australia), the Participatory Autism Research Collective (UK), and Shaping Autism Research in the UK (UK). The UK’s National Institute for Health Research INVOLVE national advisory group has also engaged in a public involvement process including people with autism. These initiatives are great models for doing participatory research. These participatory research models are not explicitly focused on ethics, although there are ethical justifications for participatory methods. However, we argue that both research that is participatory and that which is not needs to consider person-oriented research ethics. We focus on everyday issues that encompass all types of research.

Currently, there are some helpful pre-existing participant resources. Autism Speaks US publishes “A Participant’s Guide to Autism Drug Research” which is also hosted by Autism Speaks Canada, but it is limited to one type of medical research. The Canadian Tri-Council Panel on Research Ethics publishes a FAQ and brochure for research participants which provides questions participants could ask researchers in any study. We build on these resources with recommended practices that are specific to autism research or autistic participants.

The recommended practices we present in this report are innovative and unprecedented due to their explicit focus on ethics and autism and their aim of preparing researchers. We present these practices in order to make them accessible to all researchers, no matter their field or method. Often research ethics solutions are developed ad hoc, in the middle of a study when something arises, or in planning phases that are not widely discussed in research ethics literature specifically (“hidden” ethics issues). In this document, we synthesize the insights of researchers in a range of fields and bring their solutions to light. While the literature is often very detailed or specific to certain topics or approaches, we also reflect on our own experiences of interaction and our own perspectives to create solutions that reflect the big picture. The breadth of experiences represented on the task force and the reflections of task force and community members complements the published literature.
Details of Process & Methods

In this section we detail the process and methods we used to develop this report in three interrelated steps: the literature review, the task force, and the community engagement process.

Figure 1: Project Process

Literature Review

Ariel Cascio, Jonathan Weiss, and Eric Racine spearheaded the literature review as an early step in this process. We wanted to know what ethical issues had already been discussed in the literature, including what ethical issues researchers and research participants have written about, what problems they have encountered, and what solutions they have tried or proposed.

To identify relevant literature, we searched three databases. We included articles from the clinical sciences, social sciences, and humanities to avoid having a bias towards only certain types of research (e.g., only biomedical research or only anthropology research). Ovid’s Medline (which focuses on clinical sciences), Web of Science (which includes both clinical and social sciences), and ProQuest Philosopher’s Index (which focuses on philosophy, including ethics) were used. For Web
of Science and Ovid Medline, search terms related to autism and research ethics were used. For ProQuest, a smaller database, only autism search terms were used. Note that our definition of autism was intentionally broad, and we also included keywords for Asperger's, Fragile X, and Rett Syndrome.

Figure 2: Literature Review Search Terms

<table>
<thead>
<tr>
<th>ProQuest</th>
<th>Web of Science</th>
<th>Ovid Medline</th>
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<tr>
<td>autis* OR asperger* OR &quot;Fragile X&quot; OR Rett</td>
<td>TS=(autis* OR asperger* OR &quot;Fragile X&quot; 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)</td>
<td>1. exp Child Development Disorders, Pervasive/</td>
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<td>5. asperger*.mp.</td>
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<td>23. vulnerab*.mp.</td>
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<td>24. autonom*.mp.</td>
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<td>25. rapport.mp.</td>
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<td>26. 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25</td>
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<td>27. 8 and 26</td>
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We used a review method in bioethics called a critical-interpretive review which combines the systematic search strategy described above with an interpretive analysis. After determining keywords and using them to identify potential articles in these three databases, we reviewed their titles and abstracts to see if they were relevant to autism research ethics. Common reasons to exclude articles at this level were that they were not about humans, were not about people on the spectrum, they were only abstracts with no full paper (conference abstracts), or they were in a language other than those we read (English, French, and Italian).
Next, we read the remaining articles in full to determine if they addressed autism research ethics either explicitly or as “hidden ethics data.” Dubois and colleagues define hidden ethics data as an article which includes useful details or reflections on research ethics but “is not published in a journal that REC [research ethics committee] members might regularly read” or if “it does not include any keywords or subject headings that pertain to research ethics” or “when the authors of the study themselves either do not recognize or do not explicitly discuss the ethical significance of their findings.” In our review, articles were also included if they contained “hidden” ethics data (the title and abstract did not reveal a focus on ethics either through keywords, topics, or concepts). Common reasons to exclude articles at full read were that they did not discuss ethics (for example, they had human subjects but no mention of ethics or consent), or they included only minimal information on ethics (for example, they had no information beyond noting that an ethics committee approved the project or that participants gave consent). We did not exclude articles based on the research design nor did we limit the literature to research – we also included other types of articles such as journalism, biographies, and reflections of researchers and research participants. To analyze the articles, we read the full article and “extracted” sections of the article that addressed the five guideposts of person-oriented research ethics described below. This information was organized in spreadsheets with columns for each guidepost. 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 were then condensed and reorganized iteratively until an outline of interrelated ideas, issues, and suggestions under each guidepost was created.

The search was conducted in October 2016 and analysis continued through March 2018. Nearly 4000 articles were reviewed and almost 400 articles (explicit and hidden) were ultimately included. The figures on the next pages provide more detail.
Figure 3: Literature Screening Flowchart

- **Identification**
  - Articles identified through *Web of Science* database searching ($n = 1976$)
  - Articles identified through *Medline* database searching ($n = 2574$)
  - Articles identified through *ProQuest* database searching ($n = 224$)

- **Screening**
  - After duplicates removed ($n = 1186$)
  - After duplicates removed ($n = 2426$)
  - After duplicates removed ($n = 222$)

- **Total articles screened** ($n = 3834$)

- **Eligibility**
  - Articles excluded ($n = 3455$)

  - Common exclusion reasons at level of abstract and title review:
    a) Not about humans
    b) Not about people on the spectrum
    c) Only abstracts with no full paper
    d) Written in a language other than English, French, or Italian

  - Common exclusion reasons at level of full text review:
    e) Did not discuss ethics
    f) Included only minimal ethics information on ethics

- **Included**
  - *Web of Science*
    Explicit = 42
    Hidden = 43
  - *Medline*
    Explicit = 111
    Hidden = 158
  - *ProQuest*
    Explicit = 20
    Hidden = 5

- Total articles included in review ($n = 379$)
Figure 4: Articles Included by Database

ARTICLES INCLUDED

- MedLine (269): Explicit 111, Hidden 158
- Web of Science (85): Explicit 42, Hidden 43
- ProQuest (25): Explicit 20, Hidden 5

Figure 5: Articles Included by Year

NUMBER OF RELEVANT PUBLICATIONS PER YEAR

DATE OF PUBLICATION

NUMBER OF PUBLICATIONS


**Task Force**

Reviewing the literature is an important first step, but it’s not enough. We also wanted to know what researchers, service providers, people on the spectrum, and their families think about these issues. For this reason, we created a Task Force that combines these different “stakeholders” (people who have a “stake” in a topic – a particular reason to be concerned about it). We invited people to the Task Force based on our connections in the autism and autistic communities across Canada, including through professional colleagues (both on the spectrum and not), service organizations, and advocacy organizations. The table below summarizes the Task Force members. More detailed biographies can be found at [https://www.autismresearchethics.net/task-force](https://www.autismresearchethics.net/task-force).

In the work below, we also reference articles, websites, and other sources that came to our attention through other means such as Task Force members’ independent reading or recommendations from other people we know. These sources were not included in the literature view either because they were not indexed by the databases, they were published after the search, or they were not captured by the keywords.
The Task Force met in Montreal on December 14 and 15, 2017. The workshop agenda included a presentation of vision and goals, icebreakers, a presentation of the preliminary and emerging results of a literature review on autism research ethics, and a discussion of these results. We also had in-depth discussion of the five guideposts of person-oriented research ethics and how they apply to situations where autistic people participate in research. In small then large groups, we drafted an
outline for the recommended practices report. We also discussed the www.autismresearchethics.net website and how best to use it for community engagement.

The organizers of the event worked to include several strategies to make the workshop accessible and productive for all members: autistic and neurotypical people, researchers and non-researchers, people familiar with the building and unfamiliar with it, English speakers and French speakers. We drew from the Autism Cooperative Research Centre’s Inclusive Research Practice Guides and Checklists as well as our own experiences to do so. Strategies to increase accessibility included:

- using language and formatting that shows a focus on clarity

- sending detailed arrival instructions including maps and photographs of the airport arrival terminal from a first person point of view

- soliciting and sharing photographs and biographies of workshop attendees and staff, to increase familiarity and recognize-ability

- preparing presentation slides and narratives and distributing them in advance and day of, for participants who want to read along

- presenting and discussing guidelines for engagement and conversation during the workshop

- providing people 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

- reserving additional space in the building as a “quiet room” should any participant wish to take a break during the day

These strategies allowed task force members to be prepared and reduced the stress or not-knowing. The accommodating space allowed members to know that there was a lot of diversity in “voices” being represented. Small group meetings allowed opportunities for everyone to contribute. Members report feeling supported and valued and having a pleasant experience.

At the workshop, the Task Force discussed the five guideposts of person-oriented research ethics and drafted the initial outline for this report. We also revised the invitation for the Community Engagement Group and decided to have a forum available on the website for the broader community to respond to discussion questions.

Since the workshop, we have been collaborating online to write this report. First, the organizers of the workshop sent detailed notes for those who could not attend in person or who preferred to review the information. Drafts of the report outline, the report, and related documents have been circulated since. We have used a flexible format including options for document editing by both email and a web-based office suite; options for writing which are both open-ended (writing directly on a
draft) and closed-ended (responding to specific questions in a worksheet); and options for communicating with the project lead (Ariel) via email, on the phone, or in-person when feasible.

Community Engagement

Figure 7: Community Engagement Timeline

We also wanted to allow broader engagement with autism and autistic communities beyond the Task Force. We wanted this project to include the perspectives of many stakeholders, not just those who have the interest and availability to take part in a Task Force. Although it would be impossible to represent the interests and experiences of all researchers and all potential research participants, we did attempt to provide a platform for a more inclusive conversation. We did this primarily through our project website: [www.autismresearchethics.net](http://www.autismresearchethics.net)

The project website provides a brief description of and rationale for the project, short biographies of the Task Force members, a blog with project updates, a discussion forum inviting visitors to reflect on the five guideposts of person-oriented research ethics, multiple means of contact, and a resources page with links to other projects, tools, and articles about research ethics and participants on the spectrum.

Since the launch of the website in October 2017, Ariel has shared the web address at conferences. At the time of the Task Force meeting the website did not include a forum. Plans for the forum were discussed at the Task Force workshop and via email afterwards.

In April 2018, we formally invited individuals and groups to join our Community Engagement Group by emailing our individual contacts and autism organizations across Canada (in both English and
French). Our email invited people to visit our website and join our mailing list if desired. Mailing list subscribers received email notifications of updates posted on the website's blog. These updates invited people to comment in the forum or to reflect on forum questions and contact the Task Force in other ways.

This work is still in progress as this is a living document and we welcome your feedback. Such feedback will inform revisions of this report and our plans for future directions.
Part 1: Person-Oriented Research Ethics

Our suggestions are based on the model of person-oriented research ethics developed by Ariel Cascio and Eric Racine. The model is summarized in the figure below. This part of the report describes the model, defines its five guideposts, and provides an overview of some myths about research that we want to dispel.

Figure 8: Five Guideposts of Person-Oriented Research Ethics

What is person-oriented research ethics?

If you have ever conducted or participated in research, or given permission for a child to participate, you might be familiar with research ethics in terms of paperwork, perhaps most visibly consent forms. However, research ethics is not just about paperwork, it’s more importantly about relationships between researchers, participants, and broader communities. Therefore, we wanted to look instead at more relational and everyday things by focusing on what we call person-oriented research ethics.

As its name suggests, person-oriented research ethics is centrally about people, and most importantly about potential or actual research participants.

Person-oriented research ethics draws from insights in research ethics (like relational autonomy, evidence-based research ethics, everyday ethics, reflexive research ethics, and goodness-of-fit ethics) as well as clinical ethics (most notably, person- and family-centered care). We identified five guideposts derived from these literatures, which can be applied to any study. These guideposts are defined below:
Respecting participants, acknowledging lived world, and designing studies that take into consideration knowledge about diagnosis, cultural, and social factors that may influence research participants are all important. However, these factors should not overshadow the value of individual differences. The principle of individualization stresses the consideration of the unique needs and strengths of each person, but without reduction to characteristics of the population, be it diagnosis, ethnicity, gender, or religion. As much as possible given the study design, research should be open to individualization that takes into consideration the unique needs of specific individuals (beyond simply providing attention to the general needs of a particular population, e.g., people with autism). In short, person-oriented research provides a toolkit of strategies for involving participants inspired by characteristics like autism, but not a checklist that reduces them to such characteristics.

Although a focus on the particular individual is very important, our person-oriented research ethics approach also includes an awareness of the relational and contextual aspects of individuals’ lives. This principle requires respect for factors that influence 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 protocols and procedures that are culturally appropriate and non-stigmatizing. 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.

Regulatory research ethics focuses on participant decision-making primarily in the context of the consent form review, where participants must decide whether or not to participate in research. The important considerations in regulatory research ethics 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. In short, person-oriented research includes strategies to maximize the decision-making abilities of potential participants. This can include strategies for researchers to communicate with participants as well as structures and environments that provide better opportunities for participants to make informed decisions.
“Respect for persons” is a cornerstone of research ethics 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. It recognizes persons as individuals, but also as parts of communities. 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.

Research is always a social and interpersonal endeavor, whether or not the researcher and the research participants interact directly (e.g., biobanking; online or mailed survey research). Person-oriented research ethics stresses attention to the power dynamics involved in research. These power dynamics are perhaps most evident in discussions of vulnerability. 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 sociological, economic, and political factors.
Who are the people involved in person-oriented research ethics?

There are several people involved in person-oriented research ethics. There are researchers, participants, research funders, and broader communities. A few key terms are defined below:

We use the term “researcher” to refer to all of the people involved in conducting the study – including faculty, students, clinicians, service providers, and so on. Often researchers are allistic, or do not have autism, because autistic people have historically been disadvantaged from pursuing research training or conducting “citizen science” (research done outside of a research institution), although this is changing. It would be wrong to assume researchers are non-autistic. Many researchers also have autism, and many autistic people conduct research.

We use the term “participant” to refer to people who provide data that is used in a research study. This might mean doing an experiment, being interviewed, taking a survey, providing tissue or other biological samples, or having a researcher watch and take notes.

People with autism can take part in research in ways other than providing data. As mentioned above, people with autism can be researchers. People with autism also take part in research as collaborators or partners who work alongside other research staff; or as advisors who take part in committees that support researchers, raise important questions, decide what to study, and so on. These types of collaborators may or may not also be participants.

Another word we use in this report is “gatekeeper.” We use the term “gatekeeper” to mean someone who gives permission for the researcher to ask the potential participant if they want to take part. This does not necessarily mean the proxy who gives formal permission. The gatekeeper comes earlier than that. Gatekeepers can include parents, teachers, school principals, doctors, group home staff, employers, coaches, advocacy groups, listserv managers, webmasters, and so on.

We talk a lot below about “proxies.” We use the term “proxy” to mean a person that makes a decision about research participation on behalf of the participant. This person is often asked to provide a signature to give consent or permission for the participant to take part in the study. Often, but not always, the proxy is a parent or legal guardian.

We also talk a lot about different types of communities. In general, the “autism community” refers to parents, family members, and allies of people with autism as well as service providers, researchers, and other professionals; whereas the “autistic community” refers to communities of people with autism only.11

Figure 9: Myths about Person-Oriented Research Ethics

| Myth: Person-oriented research ethics only applies to research using participatory methods (like those described on p. 7), or patient advisory groups. |
| Actually: Person-centered or patient-oriented language is also often used in the context of advisory groups, participatory research, or community engagement. As the definitions above alludes to and Part 2 will make clearer, this kind of engagement is indeed important to person-oriented research ethics. However, when we talk about person-oriented research ethics we do not mean only patient advisory groups; we do not mean only participatory research; nor does we mean only during the time data is being colleted. We mean thinking about any of the different everyday interactions that go on when planning, doing, and sharing research. |
### Myth: Person-oriented research ethics only applies to social scientists. These suggestions just don’t apply to clinical research.

**Actually:** Several of the strategies we describe below emerge from clinical research, including several suggestions from the Centers for Children’s Environmental Health and Disease Prevention Research, ethical concerns raised in the context of pediatric pharmacological studies (or lack thereof), and specific suggestions regarding the use of social stories in preparing participants for research procedures. Several studies about clinical research informed these suggestions, which used interviews and observations of clinical researchers.

### Myth: Person-oriented research ethics only applies to clinical research involving patients.

**Actually:** The Canadian Institutes of Health Research (CIHR) has a “Strategy for Patient Oriented Research” that has a similar name to person-oriented research ethics. They define this strategy as “a continuum of research, from the initial studies in humans to comparative effectiveness and outcomes research, and the integration of this research into the health care system and clinical practice.” It is focused “on the needs of patients in the health care system as opposed to research focused on whole populations,” and “begins where basic biomedical research and pre-clinical studies end.” This is why we use a new term to describe our model. Person-oriented research ethics is broader and can be applied to any study involving participants on the spectrum: social research or clinical research, and clinical studies regardless of whether they are at the clinical or pre-clinical stages.

### Myth: Person-oriented research ethics is impossible when doing a controlled trial. Well-controlled studies cannot allow for a focus on individuals.

**Actually:** While a randomized controlled trial will look very different from a single-subject case design or person-centered ethnography, researchers conducting these studies can still reflect on the goals of person-oriented research ethics and implement many of the suggestions below, such as preparing participants for the experiment, consulting with autistic advocates, parents, and advocacy communities, and using non-stigmatizing language. Any research design can integrate these suggestions.

### Myth: There is no funding for person-oriented research projects.

**Actually:** CIHR’s Strategy for Person-Oriented Research can fund this type of research. The US National Institutes of Health also has a patient-oriented research career development award (the grant category is called “K23”). Small funders can provide useful support for small costs associated with suggestions in this report.

### Myth: Researchers can only ask adults with low levels of support needs to participate in studies.

**Actually:** Children and people with higher levels of support needs are often excluded from research, which scholars and advocates have criticized because these groups are therefore underrepresented and underserved by the results of research. Although researchers will have to take the needs of children and people with higher levels of support needs into consideration, including them as research participants or research collaborators is entirely possible.

### Myth: Research is planned by neurotypical people who recruit autistic participants.

**Actually:** Autistic people can be and have been involved in the planning of research, such as in Kevin Stoddart’s work. Autistic people conduct research on autism and other topics, which neurotypical researchers should also consult. Examples of autistic researchers and academics include Melanie Yergeau, Dinah Murray, Dawn Prince-Hughes, Temple Grandin, Michelle Dawson, Steven Kapp, Ibby Grave, Jean Kearns Miller, and Stephen Shore. When compared to research conducted by non-autistic people, there is a lack of research conducted by autistic people on autistic people. Many Task Force members are autistic researchers.

### Myth: Autistic people cannot be managers.

**Actually:** While many autistic people do not have sufficient employment, this does not mean that all people with autism are unable to take on a range of jobs. In addition to being lead researchers, people on the spectrum can also serve as project managers.
<table>
<thead>
<tr>
<th>Myth: Autistic people do not go to conferences.</th>
<th>Actually: Autistic people may not always be invited to conferences organized by allistic researchers, but in fact people on the spectrum are listening, reading research, and attending conferences. The keynote of the International Society for Autism Research (INSAR) meeting in London, UK was interrupted by autistic adults who stood up and made their voices heard in research. INSAR and other key conferences are working to be more inclusive. Autistic people also organize and host conferences such as Autreat.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Myth: Interpersonal relationships have no impact on autism research.</td>
<td>Actually: A history of conflict between researchers and autism communities can generate mistrust that should be accounted for. When research studies have not taken the needs of participants on the spectrum into consideration (e.g., by forcing eye contact or participation in large groups without attending to sensory needs), participants and their parents have felt misunderstood and lost trust in the research process.</td>
</tr>
<tr>
<td>Myth: Autistic people are not empathic and/or lack “theory of mind.”</td>
<td>Actually: This is a common stereotype that might lead researchers to be concerned that autistic people cannot participate in research. However, the notions of a lack of empathy and of theory of mind have been challenged and reframed as instead a difference of empathy or theory of mind in which causes problems because of the contrast between two different ways of doing empathy or theory of mind, not because of a lack against a neurotypical standard (this has been referred to as the “double empathy problem”). In other words, people with autism may have differences in empathy and theory of mind, rather than absence of these things.</td>
</tr>
<tr>
<td>Myth: Autistic people may not be able to participate in social science-based research without being known to the researcher.</td>
<td>Actually: While building rapport can be an invaluable tool, it is not impossible for people on the spectrum to participate in studies with researchers they do not know yet. There are simply different rules of respect. It is especially important to not take any participant’s participation for granted, and to be clear about the possibility of deception in studies that rely on deception in their methods (like some psychology experiments).</td>
</tr>
<tr>
<td>Myth: All people on the spectrum like routine, visual supports, and so on.</td>
<td>Actually: There is a lot of diversity within the autism spectrum. While we provide suggestions based on common experiences, strengths, and preferences, these common experiences are not necessarily universal. For this reason, the individualization guidepost is important. Researchers should combine the general considerations in this report with their knowledge of specific participants.</td>
</tr>
<tr>
<td>Myth: Autistic people are too hard to accommodate.</td>
<td>Actually: This is the primary myth busted in this document. Researchers can accommodate people on the spectrum by thinking of accommodations as different parts of a toolbox of possible strategies, keeping an eye open for different options and continuously engaging autism and autistic communities.</td>
</tr>
</tbody>
</table>
Part 2: The Research Process

In this section, we provide suggestions for planning, doing, and sharing research involving participants on the autism spectrum. Summary tables are presented that link each guidepost to the phases of research (planning, doing, and sharing research) in an easy-to-read format, organized by research phase and guidepost. After the tables, each guidepost is reviewed in more detail, organized by phase (throughout research, planning research, doing research, and sharing research). Suggestions for researchers to follow are in colored boxes (yellow boxes contain recommendations for reflection, and green boxes contain recommendations for action). Several recommendations are discussed in more detail in bullet points below the boxes.

Research is a long process including deciding what to study, designing the exact methods with which to study it, recruiting participants, keeping participants interested and committed to the study ("retaining" participants), informing potential participants of the details of the study and asking if they want to take part ("consent"), collecting data, analyzing data, writing up the results of data, sharing the results with participants, sharing the results with the scientific community, and sharing the results with the broader public. We have divided these stages into three: Planning Research, Doing Research, and Sharing Research. We present ethical considerations for each in turn.

Obtaining ethics approval is of course an important part of any research involving human subjects. Our suggestions complement and expand requirements for such paperwork and permissions. These suggestions may be helpful for researchers in designing protocols for research ethics committees, or for directing research ethics committee members to resources that highlight the success previous researchers have had in conducting fruitful and ethical research with people on the spectrum. However, the purpose of our suggestions is to strengthen ethical reflection throughout the research process, not just when it comes to preparing paperwork. Many of the suggestions below go beyond what research ethics committees consider, focusing on every day and relational parts of doing research.32

Many of our suggestions could also apply to any research study, and are not necessarily specific to studies involving participants on the spectrum. We include these points because it is important that they be considered also in autism research. We have highlighted with a star things that are focused on autism-specific needs, histories, or controversies.
<table>
<thead>
<tr>
<th>Goals</th>
<th>Phase</th>
<th>Suggestions</th>
</tr>
</thead>
</table>
| **… consider the unique needs of each person?** | Throughout research | • Actions:  
  o 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:  
  o Individualize choices about what to study, because not all studies are meaningful for all people or groups. |
| | When doing research | • Actions:  
  o Individualize consent procedures.  
  o Individualize research design and data collection procedures (even in very standardized studies, in small ways).  
  o Individualize support for participants during the study.  
  o Tailor the language used (e.g., autistic person vs. person with autism) to each individual’s preference. |
| | When sharing research | • Actions:  
  o After a study, ask participants and researchers to reflect and report on how they felt during the research process; then follow-up as needed. |
# Table 2: Summary of Suggestions, Acknowledgment of Lived World

## Acknowledgement of lived world

<table>
<thead>
<tr>
<th>Goals</th>
<th>Phase</th>
<th>Suggestions</th>
</tr>
</thead>
<tbody>
<tr>
<td>How do I…</td>
<td>Throughout research</td>
<td>• Reflections: o Acknowledge stigma, stereotypes, and past experiences of having been excluded that impact the research process.</td>
</tr>
<tr>
<td>… respect the factors that influence participants’ needs and decisions, including individual, family, and community beliefs, norms, and values?</td>
<td></td>
<td>• Actions: o If participants want, involve significant others who play an important role in their lives, and may impact the research process.</td>
</tr>
<tr>
<td>… recognize my own beliefs, norms, and values and how they may impact the research encounter?</td>
<td>When planning research</td>
<td>• Reflections: o Acknowledge that many participants encounter research while striving to access care, treatment, and intervention which impacts research ethics. o Recognize broader autism and autistic communities such as advocacy groups or social movements, which have a stake in the research process. o Acknowledge that people with autism have historically been harmed in research and clinical settings, which may cause hesitance about research.</td>
</tr>
<tr>
<td>… use culturally appropriate and non-stigmatizing research protocols?</td>
<td></td>
<td>• Actions: o Integrate other demographic factors of participants that matter in research. o Address logistical challenges to participation.</td>
</tr>
<tr>
<td>… attend to present, past, and future experiences of participants?</td>
<td>When doing research</td>
<td>• Reflections: o Consider the important role the context or environment plays in research. o Know that the internet as an important social setting for many autistic people. o Reflect on the world in which researchers work, which also impacts the research process through logistical and regulatory barriers.</td>
</tr>
<tr>
<td>… be aware of the role of family and friends and the potential need or desire for their involvement?</td>
<td>When sharing research</td>
<td>• Reflections: o When writing up results, be mindful of findings or wording that might be stigmatizing.</td>
</tr>
</tbody>
</table>
### Table 3: Summary of Suggestions, Empowerment in Decision-Making

<table>
<thead>
<tr>
<th>Goals</th>
<th>Phase</th>
<th>Suggestions</th>
</tr>
</thead>
<tbody>
<tr>
<td>How do I…</td>
<td></td>
<td></td>
</tr>
<tr>
<td>… enhance autonomy, self-confidence, and self-determination in the research process?</td>
<td>Throughout research</td>
<td>• Actions:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Use research on decision-making to develop “evidence-based” ethics practices.</td>
</tr>
<tr>
<td>… maximize the decision-making abilities of potential participants?</td>
<td>When planning research</td>
<td>• Actions:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Empower people with autism to contribute to research in ways other than providing data.</td>
</tr>
<tr>
<td>… use structures and environments that provide better opportunities for participants to make decisions?</td>
<td>When doing research</td>
<td>• Reflections:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Begin from the stance that people with autism have a right to participate in research, or to refuse to do so.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Consider ways in which the setting of a study can make free decision-making harder or easier.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Specific types of research might require sharing specific types of information.</td>
</tr>
<tr>
<td></td>
<td>When sharing research</td>
<td>• Actions:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Create a consent process which is accessible to people with autism.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Give potential participants a chance to meet researchers and ask questions and provide explicit opportunities for additional questions throughout the study.</td>
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<td></td>
<td>o If others are implicated in the study, include them in conversations about choosing to participate.</td>
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<tr>
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<td></td>
<td>o Collect information about who did not consent and why, in order to reflect on the consent process.</td>
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<tr>
<td></td>
<td></td>
<td>o Empower decision-making not only in deciding whether or not to participate but also in data collection and write-up.</td>
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<tr>
<td></td>
<td></td>
<td>• Reflections:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>o 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.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Actions:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>o 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.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Invite participants to be included in additional studies while still making it clear that one does not necessarily have to commit to further studies.</td>
</tr>
<tr>
<td>Goals</td>
<td>Phase</td>
<td>Suggestions</td>
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<td>----------------------------------------------------------------------</td>
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<td>--------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>How do I …</td>
<td></td>
<td><strong>Period throughout research</strong></td>
</tr>
</tbody>
</table>
| … recognize the personhood and agency of all participants, even those with potential or actual impairments of decision-making capacity? |                            | • Actions:                                                                                                                                  | o Use language which is non-judgmental and non-stigmatizing.  
  o Conduct empirical research about participants’ views of research and solicit feedback from participants and other stakeholders on research design. |
| … take a strengths-based approach that focuses on capability and values the potential contributions of all individuals to research questions that concern them? |                            | **Period when planning research**                                                                                                                                                                  |
| … respect and take into consideration the contributions of research participants? |                            | • Actions:                                                                                                                                  | o Make topics, measures, and outcomes meaningful (and understandable) to people with autism.  
  o Create research designs and data collection strategies that address the autism-specific needs of participants. |
| … solicit feedback of the target population?                           |                            | **Period when doing research**                                                                                                                                                                      |
| … design the research process to take into consideration needs, preferences, or priorities that might impact persons in this population? |                            | • Reflections:                                                                                                                            | o Evaluate the potential role of diagnostic accuracy as an issue in sampling and recruitment. |
|                                                                      |                            | • Actions:                                                                                                                                  | o Ensure participation is not overburdening.  
  o Actively include people with autism as participants themselves rather than just topics of research.  
  o Design recruitment strategies to address autism-specific needs of participants.  
  o Prepare participants on the spectrum for taking part in the study or for procedures in advance. |
|                                                                      |                            | **Period when sharing research**                                                                                                                                                                     |
|                                                                      |                            | • Actions:                                                                                                                                  | o Disseminate results in an accessible format for people with autism.  
  o Involve people with autism, stakeholders, and stakeholder organizations in the dissemination of findings.  
  o As always, respect privacy and confidentiality. |
<table>
<thead>
<tr>
<th>Goals</th>
<th>Phase</th>
<th>Suggestions</th>
</tr>
</thead>
</table>
| ... pay attention to the power dynamics involved in research? | Throughout research | • Action:  
  o Create and maintain open communication.  
  o Involve people with autism and their communities in research in other ways than as participants.  
  o Build relationships not just with participants, proxies, and gatekeepers, but also with broader communities. |
| ... build and maintain trust and rapport between myself, participants, and participant communities? | When planning research | • Reflection:  
  o Include attention to relationships in animal research on autism as well, because the research questions and study results impact autistic people and communities.  
  o Reflect on the role of researchers in the study.  
  o Account for any particular professional or personal connections with autism.  
  o Account for a history of conflict between researchers and autism communities that can generate mistrust. |
| ... recognize the sociological, economic, and political factors that influence these relationships? | When planning research | • Action:  
  o Build rapport before a study starts.  
  o Build relationships with people other than the participant, as necessary  
  o Be knowledgeable about or experienced with autism either professionally or personally. |
| | When doing research | • Reflection:  
  o Attend to power imbalances between researchers and participants which may make participants particularly vulnerable in the course of a study.  
  o Consider the value that relationships with researchers provide participants in terms of local community connections. |
| | When doing research | • Action:  
  o Maintain rapport, which has consequences for recruitment and data collection.  
  o Be prepared for and manage emotional experiences, as data collection can be emotional for participants.  
  o Take responsibility for communication of ethics information. |
| | When sharing research | • Action:  
  o 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.  
  o Read the writings of research participants about their experiences participating in research.  
  o Create research communities which can be a form of public engagement. |
Throughout Research

**Individualization**

**Suggestion (Action)**

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.

- Meetings can allow participants to take breaks, participate only for smaller lengths of time, sit at a distance from other meeting attendees, attend via Skype, contribute via writing rather than speaking, use assisted communication devices, evaluate key ideas with a thumbs-up/thumbs-down system, or work with a mentor or tutor.\(^{33,34}\)
- Multiple methods of contact (e.g., email or text message) may encourage more recruitment; for example, emails “may be less socially demanding on individuals with ASD.”\(^{35}\)
- Instructions can be individualized, as when Fage and colleagues designed photographic instruction sets of each child performing their task.\(^{36}\)
Acknowledgment of Lived World

**Suggestion (Reflection):**

**Acknowledge stigma, stereotypes, and past experiences of having been excluded that impact the research process.** It's important for researchers to consider their own cognitive biases and to avoid stereotyping.

- Questions should be phrased in a normalizing way that takes these experiences of stigma into account.\(^3\)
- Researchers must be aware of verbal and non-verbal communication differences (for example, some autistic people portray little to no facial expression), and not impose neurotypical stereotypes about what such communication means.
- Some people find that the language of prevention and cure expresses negative judgments about the value of the lives of people with autism.\(^3\) This has implications for research participation and partnership in participatory research, as people will work with researchers whose mission they believe in.\(^3\) For this reason, some scholars advocate avoiding language like “risk” which similarly implies a cure focus.\(^3\)

**Suggestion (Action)**

**If participants want, involve significant others who play an important role in their lives, and may impact the research process.**

**Discussion:**

- Parents, teachers, and staff can be important, especially when they are giving permission to participate. They may also be asked to provide data or information about research participants which can be helpful but also raises ethical issues such as if the person with autism needs to give permission for information to be shared about them.
- Participants may want significant others such as family members present during data collection for support or “translation,” but may also need privacy. Having an individual with autism as a member of the research team might also provide a source of interpersonal support for the participant.
- Other people might be implicated in data collection, such as when data is collected in a natural environment like school, or when participants are asked to bring a parent or friend to participate too.
  - Of particular concern, not all participants have a parent or friend to bring. This design therefore might exclude or discourage potential research participants.
- Others may be implicated in results, especially genetic results that might provide information about the genetics of non-participating family members.
Empowerment in Decision-Making

Suggestion (Action):

Use research on decision-making to develop “evidence-based” ethics practices. Studies have already been conducted on participant opinions on different ways empowering decision-making, providing suggestions for researchers on what to include in consent forms, what procedures to avoid if possible, and what to include in return of results. These studies include:

- Participants' and/or proxies' understandings of consent forms and procedures, finding parents very knowledgeable of key components but prone to the common “therapeutic misconception” of thinking that the treatment arm placement was personalized to their child, rather than being a random decision.40
- Experiences with the consent process (planned study, findings not yet reported).41
- Opinions about asking children to participate or consent to research,42 finding parents to generally be in favor.
- Opinions on storing data for later use, which more than half of parents surveyed supported but requested confidentiality of data, being informed about the purpose of research, and being updated about its progress.42
- Opinions on return of individual genetic results, which many parents having their children with autism participate in research strongly desire,44 but which may not be a common goal for parents not participating in research.45
- Specific things that might make participants, especially children, refuse to or being concerned about participating, such as having a blood test or taking bitter substances.47
### Respect for Holistic Personhood

**Suggestion (Action):**

*Use language which is non-judgmental and non-stigmatizing,* that recognizes that autistic people are listening, and considers the needs and values of the target population with sensitivity and empathy. This applies to writing, speaking, and video. Avoid presenting people with autism in voyeuristic ways. Demonstrate that the information collected in research is cherished, and be open to follow-up.

**Suggestion (Action):**

*Conduct empirical research about participants’ views of research and solicit feedback from participants and other stakeholders on research design.* Stakeholders can be consulted about what studies should be done (or not done!) and how studies should be designed and conducted. It would be ideal if research in autism took on a more person-centered approach, taking the needs of the person and community into account in the design of the research. Stakeholders include both people with autism and other advocates. Engaging stakeholders has been done through participatory research, by inviting advisory committees, and by paying community members (people with autism and parents) as consultants.

- Examples include the James Lind Alliance in the UK, which has created a process which was used by Autistica in the UK to define a list of research priorities, and in Ontario by the Ontario Brain Institute to engage stakeholders, including those with autism, in research priority setting for Neurodevelopmental Disorders. The James Lind **Priority Setting Partnership process** aims to generate Top 10 research priorities in medical research, bringing patients, carers, and clinicians together on an equal footing. For Autistica, this meant forming a steering committee of charity and health organization representatives and partner organizations, conducting a survey to collect research questions (“raw questions”) from stakeholders, sorting those raw questions into a smaller number, inviting voting on the most frequently submitting questions, and discussing the top 25 at a workshop involving autistic adults and youth, parents, and professionals.

**Discussion:**

- Feedback from participants can highlight opinions about research including research priorities, motivations for participating, views on what research procedures are feasible or acceptable, and views on what should be included in consent forms.
- It can provide information on why people decline to participate or withdraw from a study.
- It can shed light on people’s opinions about research including their views on privacy in sharing results.
**Focus on Researcher-Participant Relationships**

**Suggestion (Action):**

Create and maintain open communication.

**Suggestion (Action):**

Involve people with autism and their communities in research in other ways than as participants, such as throughout the whole process in participatory research, 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, dissemination and applying results, or being quoted as scholarly sources. AASPIRE's work is particularly instructive. We recommend:

- Have someone with autism on the research team so that the participant doesn’t feel alone.
- Recognize that autistic people also lead research and could be important colleagues or collaborators.
- Although it may be challenging, engage community members and ensure girls, women, and non-binary people, individuals with different communication styles, and children are included. It’s important to avoid tokenism and strive for genuine participation. Specific communication strategies can help mixed autistic/allistic research teams work well together (see p. 44).
- Provide special training to community members when needed. For example, Jivraj and colleagues summarize a study where the researchers trained people with intellectual disability in their research methods and framework so that they could conduct focus groups, help select a name for the project, review the consent process with each participant, analyze data, develop the questionnaire, and disseminate findings via a report and a plain language summary. Similar training could be used to involve people with autism, with and without intellectual disability, in research.
- Studies could involve a charter or partnership agreement that outlines the expectations and values for each party. This 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 website of the Canadian Institutes of Health Research provides some models and examples for developing them. Such models can be combined with suggestions about autism-friendly communication in this report, to create empowering documents for autistic partners.
**Suggestion (Action):**

Build relationships not just with participants, proxies, and gatekeepers, but also with broader communities.

**Discussion:**

- These broader communities may need pre-research information, results, and related information.
- Attending to the importance of community helps to develop more accepting and welcoming communities.
Individualization

**Suggestion (Action):**

Individualize choices about what to study, because not all studies are meaningful for all people or groups.

**Discussion:**

- This concern has been specifically highlighted for research into early intervention for children with autism, because interventions that might be appropriate for one group would not be appropriate for others and therefore needs to be tailored to the particular group involved in the study.⁵⁰
Acknowledgment of Lived World

Suggestion (Reflection):

Acknowledge that many participants encounter research while striving to access care, treatment, and intervention which impacts research ethics because:

Discussion:

- Often this context 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 treatment when other treatments have not been helpful. People might also participate in research in order to access diagnoses and assessments that would otherwise be prohibitively expensive, which might mean recruitment was unintentionally coercive. Genetic research might entail access to information or services for study participants that are absent for non-participants, leading to ethical tensions for researchers. Daley suggests researchers collaborate with service providers to maximize benefit, but recognizes that this is not always possible, especially in low-resource countries. 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 want out of it.

- Weighing risks and benefits is an essential part of any study, and in the context of 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.

- The desire to help other families affected by autism may be a motivation for families to participate, in order to contribute to the larger autism community by generating knowledge that might not provide a direct benefit to participants, but whose findings could be applied to help other families affected by autism in the future.

- Participating in research can give people access to otherwise expensive diagnoses, evaluations, and interventions. Sometimes ethicists are concerned about the “therapeutic misconception” where people who are participating in research think it is clinical care, not research. This misconception is an important concern in any clinical research, which is why it is important for researchers to explain the distinction clearly from the beginning. In this case, however, it’s both. Participating in research does give people access to care they would not otherwise get. Participating in research may also give people the benefit of learning from the study, not necessarily a direct treatment.

- Also, participants might need clinical care as a result of research participation (for example, if researchers find something in genetic results that needs care).
Suggestion (Reflection):

Recognize broader autism and autistic communities such as advocacy groups or social movements, which have a stake in the research process including also NGOs, the neurodiversity movement, and engagement with informal networks of stakeholders.

Discussion:

- Sometimes research also creates autism communities, such as communities of participants.
- Communities of participants can lead to the same people being asked to participate in many studies. Researchers need to broaden their participant base beyond specific communities. Participants need to reflect on how many studies they can be included on at one time.
- Autism communities are not homogenous and there are important conflicts between different groups and individuals in terms of their opinions on research.

Suggestion (Reflection):

Acknowledge that people with autism have historically been harmed in research and clinical settings, which may cause hesitance about research. People might not be willing to engage with researchers if they have had bad experiences in the past or have heard of bad experiences that others have had.

Discussion:

- This history of harm can include not only specific research scandals (such as the Willowbrook Hepatitis study exploiting youth with intellectual and developmental disabilities), but also broader harms resulting from research (such as the “refrigerator mother” theories that said autism was caused by bad parenting, or a history of links between genetics research and eugenics measures). It also includes individual trauma some people experienced from research or treatment. Harm in treatment is especially relevant to clinical research or research on treatments and interventions as the settings and procedures might be similar. It is also important in that even non-clinical research on autism sometimes replicates clinical language, which can be seen as deficit-focused and discriminatory. Non-clinical research may also ask participants to reflect on personal experiences with autism that can bring up strong positive or negative emotions.
- This history of harm is linked not only to autism, but also made worse in communities who have had bad experiences with researchers, such as indigenous communities and low-income countries.
- Some bad experiences comes from lack of cultural sensitivity or language skills on the part of researchers. As such, communities or individuals may not have been completely informed about what the research entailed.
Suggestion (Action):

Integrate other demographic factors of participants that matter in research, such as sex and gender, age, intellectual disability and other indicators of “severity,” communication styles, fixations if any, race, ethnicity, geography, language, and socioeconomic status. Researchers should see beyond only autism by taking these factors into consideration.

- These factors impact who tends to be able to participate.
- Researchers can use “culture-free tests” and cultural competency to make research more accessible.
- Researchers can partner with particular communities, such as Indigenous communities leadership.

Suggestion (Action):

Address logistical challenges to participation, such as being asked to take part in many studies, being otherwise overburdened or busy, difficulties with location, modes of transportation, and time it takes to do the study (especially travel time), and similar problems. The planning stage should attempt to account for these challenges and provide accommodation.
Empowerment in Decision-Making

Suggestion (Action):
Empower people with autism to contribute to research in ways other than providing data.

- Examples include participatory research, involving autistic people in the design of the study, citizen science done by family members and self-advocates.
- Autistic self-advocates can be empowered in this process through strategies such as the “five finger method” of reaching consensus by holding up a number of fingers corresponding to a short and clear scale of opinions on choices up for discussion.38
Respect for Holistic Personhood

Suggestion (Action):

Make topics, measures, and outcomes meaningful (and understandable) to people with autism.

- This isn’t necessarily limited to research that provides benefits or daily life applications, but research that addresses something autistic people are interested in seeing researched.
- Some topics of particular interest include transition to adulthood and studies of girls and women, as well as studies of services and service delivery.

Discussion:

- This is an important part of respect for holistic personhood which aims to develop studies which are centered on the needs of participants rather than being “variable-oriented”/“variable-centered,” “protocol centered,” or “laboratory based.” Agreement on goals and the tasks needed to reach those goals can create an alliance and shared bond.
- It is also respectful in the sense that it empowers autistic people to feel like real people, in contrast to research which others or alienates autistic people by treating autism as an object of fascination or confusion.
- However, it might not always be feasible because there may be some topics that are integral to understanding autism but which on the surface may not look meaningful or be judged to be meaningful to some. There are also concerns that making all decisions about research based on popular opinion is not the best way to decide what is important. Researchers should be able to decide what is important and interesting to them. Mechanisms such as peer review for funding applications is another way in which decisions about what to study are made. Nonetheless, people may not be interested in supporting research which is not meaningful to them or which they oppose (e.g., some people oppose cure-oriented research or genetic research).
- This suggestion is further complicated by diversity within stakeholder communities (see Acknowledgment of Lived World above): not all people with autism find the same topics, measures, and outcomes meaningful.
Suggestion (Action):

Create research designs and data collection strategies that address the autism-specific needs of participants, such as:

- 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.
- If in-person data collection is not necessary, video-chat programs could be easier for some participants.
- Getting to know the participant before data collection can help researchers understand what would work best.
- 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 in order to use participation time wisely, and having someone present to explain the study.
- Some methods may not be useful for participants on the spectrum, such as un-adapted round table discussions. There are resources for adapting these methods discussed in more detail elsewhere in this report.\textsuperscript{35,56}
- Researchers should be proactive about offering accommodations or options, or asking participants what they need; the onus shouldn’t always be on the autistic person to adapt or make accessibility requests.

Discussion:

- Visual supports can be helpful during data collection, but may also be limiting. 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.
Focus on Researcher-Participant Relationships

Suggestion (Reflection):

Include attention to relationships in animal research on autism as well, because the research questions and study results impact autistic people and communities.

Suggestion (Reflection):

Reflect on the role of researchers in the study.

- Researchers should reflect on how and why they choose their approaches. This is an important lesson from interpretive research.5

Suggestion (Reflection):

Account for any particular professional or personal connections with autism.

Suggestion (Reflection):

Account for a history of conflict between researchers and autism communities that can generate mistrust.

Suggestion (Action):

Build rapport before a study starts. Rapport means getting to know people and developing positive relationships with them. Researchers have discussed several strategies for building rapport and keeping in touch, including:

- Having a “get-to-know-you” period.
- Joining participants in favored activities.
- Having multiple projects to build long-term relationships.
- Sending newsletters.
- Sending birthday cards in long-term studies.
- Workshop participants discussed general friendliness, getting to know the researcher in advance, and making a video that potential participants could watch beforehand that shows the lab, the tasks, and what participants receive.
**Suggestion (Action):**

**Build relationships with people other than the participant, as necessary,** such as teachers, parents, and health care professionals who share genetic results. Researchers can involve this broader group of relevant people, either as the focus of the research or as a stakeholder in the process.

**Discussion:**

- Other people may influence or pressure participants. Therefore, it’s important for the researcher to form a direct relationship with the participant and not just the parent or teacher. It is also important to make sure participation is the participant’s choice, not the teacher or parent’s choice.
- Nonetheless, parents and teachers can be great advocates for individuals with autism. Some participants require significant supports from others, and therefore researchers will need to have relationships with them as well.

**Suggestion (Action):**

**Be knowledgeable about or experienced with autism either professionally or personally.**

- Take time to be in autism spaces and get to know the community, in order to develop knowledge that shows respect for autistic people.
- Researchers should not be or act surprised when meeting people on the spectrum, and should allow people to act in “atypical” ways, should avoid interrupting people or completing their sentences.
- More than other study populations, autism is a spectrum and there are more gray areas. Researchers need to know how to support that range, which can be an overwhelming thing to learn.
Individualization

Suggestion (Action):

Individualize consent procedures.

- For example, let people fill out forms at home vs. at the study site; be flexible in whether or not written assent needs to be provided, and communicate information in individually tailored ways.
- There are some “fallacies” that impact decision-making like “foot in the door effect” (“if people feel committed, they may feel hesitant to withdraw”) and “lab coat effect” (“symbol of authority may make us less likely to withdraw”). The need to minimize these effects makes it especially important to regularly stress “no punishment or judgement attached” to withdrawing from the study.

Suggestion (Action):

Individualize research design and data collection procedures (even in very standradized studies, in small ways), such as:

- Individualized rewards/reinforcements.
- Individualized stress/relaxation/baseline conditions.
- Individualized targets/measures/goals.
- Different (but non-individualized) measures for different people.
- Individualized or customizable devices used for data collection.
- Offering multiple ways to complete an interview/task/procedure.
- Individualizing timing, order, or pace of procedures such as allowing people to participate at their best time of day, allowing participants to complete only some parts of the study, or even accounting for individual difference in analysis.

Discussion:

- Many of these suggestions are especially important in non-collaborative, non-iterative designs such as randomized controlled trials.
- Some study designs, especially “single-case designs” or designs where the interviewee does the leading, explicitly focus on individualization because each participant has their own research trajectory.
- While many of the above examples are forms of individualization that might be particularly relevant for autistic people, this is also an opportunity to look beyond autism – for example, by offering different languages or considering additional mental health challenges or co-existing diagnoses.
Suggestion (Action):

**Individualize support for participants during the study** such as:

- Allow support persons or objects (“comfort items”, fidget toys, etc.) during the research procedures.
- Provide clarifications as needed.
- Plan for support in case of distress.
- 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: things on heads, temperature, smells such as perfume, voice level, or number of questions.
- Let participants assess the room ahead of time and give participants a chance to talk about needs and sensitivities and to say some variation on “I will come but…” followed by what they need.
- Create a form to make this easier for participants, or include a pre-interview for participants to talk about these issues and ask questions such as: “what can we do to remove any barriers for your participation?” “Would you prefer reading or listening?” “Would you prefer this or that?”

Suggestion (Action):

**Tailor the language used (e.g., autistic person vs. person with autism) to each individual’s preference.** Ask people how they prefer to talk about autism.
Suggestion (Reflection):

**Consider the important role the context or environment plays in research.** This includes places such as home, school, or institutional settings. Consider if the context is best matched to the intent of the study, and particularly the way that more autism-friendly or less autism-friendly environments might impact participants’ experiences.

Suggestion (Reflection):

**Know that the internet as an important social setting for many autistic people** who use the internet to connect to resources and to each other. Several studies take place “online” not only as a method of data collection (e.g., online surveys) but as the “site” under investigation such as certain forums or communities.57-59

Suggestion (Reflection):

**Reflect on the world in which researchers work, which also impacts the research process through logistical and regulatory barriers,** through things such as constraints of money, time, and training; the role of funders; regulations; the perspectives and biases of researchers; and the role of researchers in advocacy.
Empowerment in Decision-Making

**Suggestion (Reflection):**

Begin from the stance that people with autism have a right to participate in research, or to refuse to do so, and need to have freedom from pressure or constraints to choose to participate in research.

**Suggestion (Reflection):**

Consider ways in which the setting of a study can make free decision-making harder or easier. Some things that make a bad environment for decision making include stress, anxiety, pressure, influence (parents or others), peer pressure (for example, in a discussion group), a noisy, unsuitable environment, and a lack of time.

**Suggestion (Reflection):**

Specific types of research might require sharing specific types of information with potential participants to enable them to make decisions.

**Suggestion (Action):**

Create a consent process which is accessible to people with autism.

- For example, use visuals or allow alternative and augmentative communication, 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. These strategies foster an ability to understand consequences of different decisions.
- As always, it’s important to make the decision-making process non-judgmental by making it explicit that the participant won’t be penalized and practicing “unconditional positive regard” in equally supporting all decisions.

**Suggestion (Action):**

Give potential participants a chance to meeting researchers and ask questions and provide explicit opportunities for additional questions throughout the study. Consent is a process, not just a one-time form.

**Suggestion (Action):**

If others are implicated in the study, include them in conversations about choosing to participate.
Suggestion (Action): Collect information about who did not consent and why, in order to reflect on the consent process. This can be done formally or informally.

Suggestion (Action): Empower decision-making not only in deciding whether or not to participate but also in data collection and write-up and (as discussed in the next section), sharing results.
Respect for Holistic Personhood

Suggestion (Reflection):

Evaluate the potential role of diagnostic accuracy as an issue in sampling and recruitment. This means being clear on who you want to include in research and how to describe their diagnosis.

Discussion:

- Validity of the diagnosis is often the foundation both of recruitment (who participants) and of the researchers’ credibility in terms of claims about autism.

Suggestion (Action):

Ensure participation is not overburdening. Although inclusion in research is important, participation should not be overburdening. In other words, it is not always right to ask people to participate. Reasons discussed in the literature include: avoiding undue risk, avoiding burdening participants in non-risky ways (e.g., wasting time, discomfort, annoyance), and of course people refusing to do particular things.

Suggestion (Action):

Actively include people with autism as participants themselves rather than just topics of research. Autistic people should have their perspectives represented in research.

- There are many ways of communicating, and spoken language shouldn’t limit “voices” from being heard. People who communicate differently might need more resources in order to participate (for example: communication boards, text-to-speech, pen and paper, tools for non-verbal responses included in sterile rooms).
- Inclusion of individuals should reflect diversity across the spectrum, lifespan, and life experience.
- Within this diversity, researchers should always interact directly with the person being researched, not a third person.

Discussion:

- Exclusion of certain autistic people from research (based on, for example, age, measured IQ, sex, or communication style) has been criticized.
**Suggestion (Action):**

**Design recruitment strategies to address autism-specific needs of participants** and manage expectations. Strategies include:

- Allowing people to text the researcher about their interest rather than making a phone call.
- Scheduling research around individuals' lives.
- Being flexible about scheduling.
- Explaining and validating why a person’s participation is valuable.

**Suggestion (Action):**

**Prepare participants on the spectrum for taking part in the study or for procedures in advance.** Examples include:

- Visual aids in instructions.
- Social stories.
- Pre-assessments.
- Supporting parents to prepare their own children for the research.
Focus on Researcher-Participant Relationships

Suggestion (Reflection):

Attend to power imbalances between researchers and participants which may make participants particularly vulnerable in the course of a study. This includes also the perception of power and expectations around power.

Discussion:

➢ Often researchers are neurotypical and participants are on the spectrum, and neurotypical people are generally given more power in society at large.
➢ As always, researchers who are also clinicians or psychotherapists have two roles and might create undue influence.
➢ Power imbalances are starker when research is done by researchers from high-income countries in low-income countries

Suggestion (Reflection):

Consider the value that relationships with researchers provide participants in terms of local community connections.

Suggestion (Action):

Maintain rapport, which has consequences for recruitment and data collection.

Discussion

Relationships between researchers and participants could impact the interpretation of data and the results in a variety of ways.

➢ Getting to know participants helps with data collection, builds trust, and reduces anxiety.
➢ Gender differences might impact participants’ responses as some participants might be more or less comfortable with a particular gender.
➢ One the other hand, some advocate for keeping the researcher consistent, to avoid variation due to who collected the data.
➢ The tone and style of the researcher can influence performance of the participant.
➢ Researcher biases can influence participants.
➢ How close the researcher feels to the participants could impact how the researcher interprets or discusses results, for better or worse.
Suggestion (Action):
Be prepared for and manage emotional experiences, as data collection can be emotional for participants.

Suggestion (Action):
Take responsibility for communication of ethics information.
Individualization

Suggestion (Action):

After a study, ask participants and researchers to reflect and report on how they felt during the research process; then follow-up as needed.

- This reporting can be ongoing in the form of a journal or diary throughout the study, rather than only at the end.
- It should only be done when it provides participants an opportunity to share reflections that they want to share; it should not be used to create additional emotional labor for participants.
- Some people on the spectrum have difficulty recognizing feelings, so this may be difficult.
- Follow-up studies are important. It is crucial that all participants have their voices heard and respected. If there is indication that a participant's input has been compromised, secondary inquiries should be considered.
- Researchers have the responsibility to repair any negative or unpleasant experiences for participants, or at least outline areas where support is available.

Discussion:

- This strategy recognizes that in order to continue to make the research process a positive experience of participants, we need to reflect on the process and not consider it "done" after one meeting.
- Paying attention to participant needs even after the completion of the research encourages participation in future studies.
Acknowledgment of Lived World

Suggestion (Reflection):
When writing up results, be mindful of findings or wording that might be stigmatizing.

Discussion:

- For example, in a study of bully victimization, the authors identified characteristics of the child (including neurodevelopmental characteristics of autism) that were associated with the child being bullied. The authors explicitly acknowledged “the ethical dilemma in pointing out presumed individual traits as risk factor for being bullied” and the potential for “blaming the victim.” Rather than let this possibility stand without comment, they wrote, “Bullying happens in a social context and it is also influenced by contextual factors, which are likely to greatly influence both the prevalence of bully victimization and the consequences of bully victimization for the individual child. However, individual factors also influence this risk and need to be addressed to maximize the effort of reducing bully victimization.” This example shows that the possibility that results might blame the victim or in other ways stigmatize participants does not mean not reporting those results, but it does mean reporting them carefully and in context.
Empowerment in Decision-Making

Suggestion (Reflection):
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.

Suggestion (Action):
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.

- Also ask participants to report back on at which stages throughout the process they would have liked to have more support.

Discussion:
- It may be easier for some people, who may have felt too shy to speak up during the process, to share this kind of information after the end of the study. Giving one last chance to open up can be very empowering.
- Paying attention to participants’ needs even after the completion of the research encourages participation in future studies.

Suggestion (Action):
Invite participants to be included in additional studies while still making it clear that one does not necessarily have to commit to further studies. This can create a feeling of empowerment for participants.
Respect for Holistic Personhood

Suggestion (Action):

Disseminate results in an accessible format for people with autism. Accessible formats include:

- Written reports of assessments along with clinical interpretations.
- Bullet points.
- Other suggestions mentioned throughout this report such as including visuals and using plain language.

Discussion:

- Disseminating results back to participants has been considered an ethical obligation, although there are some arguments against doing so in the context of unclear genetic results specifically.

Suggestion (Action):

Involve people with autism, stakeholders, and stakeholder organizations in the dissemination of findings.

- Participants can talk about their work at conference workshops.
- Community groups and advocacy organizations can be a good avenue for dissemination of results back to the participant community.
- Participatory research also has the benefit of helping share results with research partners' communities.

Suggestion (Action):

As always, respect privacy and confidentiality. There are some particular concerns in autism research around the common use of databases for sharing information between researchers, as well as the fact that even non-medical research implies collecting potentially medical information about diagnosis and so on.
Focus on Researcher-Participant Relationships

**Suggestion (Action):**

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.

**Discussion:**

- This creates confidence.
- Take this opportunity to reassure participants that their concerns will be taken into consideration “next time” – this study is not just an end but also a beginning for future research and implementation.

**Suggestion (Action):**

Read the writings of research participants about their experiences participating in research.

**Suggestion (Action):**

Create research communities which can be a form of public engagement.

- Encourage participants to share their experience with others in their community.
Part 3: Conclusion and Implications

Summary

As Part 2 has demonstrated, there are many ways that researchers planning and conducting a range of studies can implement person-oriented research ethics suggestions. Some of these suggestions are more appropriate to controlled trials, others to interview studies, others to participatory research, and so on. There may be many ways to have a person-oriented study, or many levels of being person-oriented in research ethics.

Next Steps

Our next steps will consider how to evaluate these guideposts. We plan to implement them in practice and ask participants and researchers to reflect on their experiences with them and level of satisfaction.

To implement these guideposts, we also need to encourage the research community to implement suggestions from the toolkit. There are many people involved in the research community, including:

1. Researchers – can consult these suggestions when planning, doing, and sharing research.
2. Research Ethics Committees – can consult these suggestions when evaluating protocols submitted for ethics review.
3. Journal Editors – can review prospective authors to these suggestions when submitting manuscripts for consideration.
4. Peer Reviewers for articles and grants – can consult these suggestions when evaluating the content and style of articles and the planned protocols in grants.
5. Funders – can encourage applicants to use these tools.

We plan to share these suggestions with these communities in several ways:

1. This report!
2. Create online tutorials for researchers, families, and participants.
3. We could make ourselves available for webinars or in-person seminars.
4. Create a template of our seminars for distribution of this information through online videos and more.

Although this report was written with researchers in mind, potential research participants might also be interested in these suggestions. Therefore, we are considering creating a guide for research participants as well.

We are also interested in understanding what stakeholders want to see from this report. If you have any ideas, please get in touch with the researchers via email (ariel.cascio@ircm.qc.ca or pragmatic.health.ethics@ircm.qc.ca), by phone (514-987-5500 extension 3249), or online (www.autismresearchethics.net).
References


After the workshop and revision of the Community Engagement Group invitation email, we applied for and received ethics approval from the Institut de recherches cliniques de Montréal and York University. We were uncertain if we wanted or needed to pursue ethics review due to the ambiguous nature of the project. Although we were asking people questions about the project and wanted to use their feedback, this project is not exactly research but more a community engaged reflection about research. Nonetheless, we determined that it would be worthwhile to consult our research ethics boards and pursue review specifically for the Community Engagement Group invitation and forum questions.