

# Person-Oriented Research Ethics to Address the Needs of Participants on the Autism Spectrum

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**ABSTRACT** Research ethics scholarship often attends to vulnerability. People with autism may be vulnerable in research, but are also vulnerable to unjust exclusion from participation. Addressing the needs of participants with autism can facilitate inclusion and honor the bioethics principle of respect for persons while accounting for risk and vulnerability. Drawing from a review of the literature and informed by a moral deliberation process involving a task force of stakeholders (including autistic people and parents of autistic people), we use the model of person-oriented research ethics to identify several practical strategies researchers can use to address these needs and foster inclusion. Strategies include using multiple means of communication, addressing the sensory environment, preparing participants in advance, and accounting for social context. These practical strategies are not just methodological or design choices; they are inherently related to ethical issues. Method and design choices fulfill ethical aspirations by facilitating inclusion, reducing discomfort, and focusing on individuals.

**KEYWORDS** human subjects research, vulnerable populations, inclusion in research, autism spectrum, research design, person-oriented research ethics

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Over the past two decades, the amount of biomedical<sup>1</sup> and social science<sup>2</sup> research regarding autism has increased dramatically. Along with this growth in research comes a pressing need for understanding ethics issues in the autism research context.<sup>3</sup> People with autism may be vulnerable in research, yet existing ethics scholarship on other vulnerable populations—for example, children,<sup>4</sup> psychiatric patients,<sup>5</sup> people with neurodegenerative disorders,<sup>6</sup> people with intellectual disabilities,<sup>7</sup> and people with substance use diagnoses<sup>8</sup>—is not sufficient to address the potentially unique needs of individuals on the autism spectrum<sup>9</sup> or concerns about ethical research and treatments (such as whether it is ethical to research a cure for autism). Moreover, people with autism may be

vulnerable to unjust exclusion from biomedical and social science research studies.

Research ethics scholars have raised concerns about the exclusion of vulnerable people from research based on overly restrictive research ethics guidelines and narrow understandings of vulnerability.<sup>10</sup> People who have historically been excluded from research or from decision-making processes (for example, because parents or guardians consented on their behalf) arguably have a "right to science" (as enshrined in the Universal Declaration of Human Rights and of recent interest to bioethicists<sup>11</sup>). This phrase describes individuals' right to have their perspectives represented in research and a right to participate in research that might benefit them or their communities. Some individuals with mental or

intellectual disabilities who have been excluded from research might have more capacity to consent and participate than is often assumed.<sup>12</sup> This right to research inclusion complements, but does not replace, the right to be protected in research and to have risks and benefits of research participation appropriately balanced. From this perspective, the needs of people with autism should be met to facilitate their participation in research and honor the bioethics principle of respect for persons.

A recent proposal by two of us (Cascio and Racine) for person-oriented research ethics promotes inclusion in research by attending to the everyday and relational aspects of research ethics, some of which can impede participation.<sup>13</sup> This framework encourages researchers to reflect on ethics issues through the consideration of five guideposts: respect for holistic personhood, individualization, acknowledgment of individuals' "lived worlds," researcher-participant relationships, and empowerment in decision-making. Person-oriented research ethics moves beyond general considerations to focus on the needs of specific groups or individuals.

This article concentrates on how the guideposts of respect for holistic personhood and individualization can guide researchers to address the needs of autistic people as a group and as individuals. Addressing autism needs requires attention to the ethical aspects of how research studies are designed and the methodologies that are used. Method and design choices can fulfill ethical aspirations by facilitating inclusion, reducing discomfort, and focusing on individual persons. After discussing in more detail the guideposts of respect for holistic personhood and individualization, we describe the method of a literature review we conducted about autism research that addressed research ethics issues and the role of a project task force in the literature review process. We then summarize several themes from the literature we reviewed that identify ways in which researchers can address the needs of people with autism, both as a group and as individuals.

### RESPECT FOR HOLISTIC PERSONHOOD

Respect for holistic personhood builds from the principle of respect for persons, a cornerstone of research ethics.<sup>14</sup> This ethical guidepost, or practice principle, expands the discussion of respect for personhood by inviting an outlook on the entire person,

acknowledging biological, psychological, and social dimensions. Drawing on understandings of relational and contextual autonomy, this principle recognizes persons as individuals, but also as parts of communities.<sup>15</sup> It stresses the importance of recognizing the personhood and agency of all individuals, even those with potential or actual difficulties in decision-making, rather than having them avoid participating in research, as has often been the case.<sup>16</sup>

A key component of this respect is a strengths-based approach that focuses on capability and values the potential contributions of all individuals, even those who might be considered vulnerable by researchers, research

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**Involving people with autism in research design, development of recruitment materials, and other aspects of the research process respects the valuable perspectives and contributions that the lived experience of autism brings.**

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ethics boards, or others involved in the research process. In this way, it responds to the call "nothing about us without us," made by many in the disability rights community.<sup>17</sup> Concerns about some individuals' vulnerability are not unfounded, but these concerns should not necessarily be the basis for preventing people experiencing vulnerabilities from having their perspectives represented in research. The guidepost of respect for personhood encourages researchers to actively enhance the ability of people with autism to contribute to research by soliciting their feedback and by designing the research process to take into consideration their needs, preferences, or priorities.

### INDIVIDUALIZATION

While respect for holistic personhood focuses on designing studies that take into consideration characteristics and experiences of people with autism

that might affect the research process, the guidepost that focuses on individualization stresses the unique needs of each person and individual variation within the population of people with autism. A similar approach that focuses on individualization is person-centered care,<sup>18</sup> which in the medical context means individualization of treatment plans. This orientation is well justified in clinical practice but takes a different form in the context of research.

Much has been written about the differences between treatment and research, particularly when it comes to disability ethics.<sup>19</sup> The primary goal of care is the pursuit of the individual patient's well-being, whereas the primary goal of most research is the pursuit of a research question to obtain generalizable knowledge rather than to provide a benefit to each research participant. This key distinction leads to differences, for example, in standards for informed consent in the medical care and research contexts.<sup>20</sup> Some research designs, namely, randomized controlled trials, are particularly concerned with avoiding (and controlling for) variation between participants. Nonetheless, the ethical underpinnings of patient-centered care—respect and consideration for the unique individual—can still apply in research, as we will show below. Even for randomized controlled trials, scholars have advocated for greater individualization that respects the needs of unique participants, such as providing individualized support by tailoring the sequence of study components<sup>21</sup> or allowing options in how to complete a survey or interview.<sup>22</sup> Taking concerns about rigor seriously, such scholars have also proposed statistical strategies for addressing potential confounds raised by such adaptations.<sup>23</sup>

## LITERATURE REVIEW AND TASK FORCE DELIBERATION

With the importance of holistic personhood and individualization in mind, we approached the literature review with an emphasis on two questions: What common characteristics and experiences of people with autism might affect the research process? In everyday and relational ways, how can researchers address the needs of people with autism, as a group or as individuals? The methods for this project have also been detailed elsewhere.<sup>24</sup>

The literature review followed McDougall's<sup>25</sup> critical-interpretive approach. In the fall of 2016, we searched ProQuest Philosopher's Index, Web of Science, and Ovid Medline for keywords related to autism spectrum conditions and research ethics, broadly defined. We conducted a title and abstract review to determine which articles might contain information on research ethics and participants on the autism spectrum. Exclusion criteria eliminated articles that were not about humans, were not about people on the spectrum, were only abstracts with no full paper (conference abstracts), or were in a language other than those we read (English, French, and Italian). We then conducted a full review of remaining articles to determine if they addressed our interests in autism research ethics. Common reasons to exclude articles at the stage of full review were that they did not discuss ethics at all or included only minimal information on ethics (that is, they had no information beyond noting that an ethics committee approved the project or that participants gave consent). This review yielded a total of 379 articles.

We included articles that explicitly addressed research ethics, and those that contained "hidden" ethics data that were identified by our keywords, despite not being research ethics scholarship or even explicitly about research ethics.<sup>26</sup> Hidden ethics information is particularly important for addressing autism needs because, as we demonstrate below, ethics and methodology are often tightly intertwined.

The results of the literature review in progress were shared with a task force of seventeen individuals concerned with autism research: the three authors of this paper, other researchers, autistic self-advocates, parents of people with autism, professionals who work with people with autism, and representatives from advocacy organizations. More information on the composition of the task force is available on our project website,<sup>27</sup> which we also use as a portal to engage with the broader autism community and to solicit feedback on the project.

The task force engaged in a process of moral deliberation in which what constitutes ethical goals and conditions of research may be reenvisioned as part of an open and collegial process.<sup>28</sup> Moral deliberation is as much about the destination as the journey insofar as it constitutes a way to generate hypotheses about ethical

**Table 1.**  
**Summary of Practical Strategies to Address Autism Needs**

**Researchers can design recruitment strategies to address autism-specific needs of participants.**

- Use multiple and alternative avenues of communication.
- Choose language about autism that reflects the project's goal and stance.
- Evaluate the potential role of diagnostic accuracy as an issue in sampling and recruitment.

**Researchers can prepare participants on the spectrum for taking part in the study in accessible ways.**

- Provide explicit guidance and a predictable environment.
- Provide time for participants to familiarize themselves with the research space and personnel.
- Use social stories.
- Involve parents, staff, and other familiar figures in preparation.

**Data collection strategies can address the autism-specific needs of participants.**

- Pay attention to the environment of research.
- Pay attention to sensory, anxiety, and related needs.
- Use visual supports, being mindful of potential limitations.

**Research design strategies can address the autism-specific needs of participants.**

- Adapt specific tools, methods, or research designs.
- Involve people with autism in the development and pretesting of instruments and interview guides.
- Use autism-specific or modified research instruments that allow people with autism to more accurately show their strengths and weaknesses.
- Modify instruments to reduce verbal components.
- Address intersectional needs of participants, for example, those who are also Deaf or deaf.
- Reduce reliance on gaze or eye contact.
- Employ alternatives and complements to self-reporting without discounting self-reporting due to stereotypes about autism.

**Data collection procedures can be individualized (even in very standardized studies, in small ways).**

- Offer participants multiple ways to complete an interview, task, or procedure.
- Give participants the option of having support persons present, while taking into consideration the subsequent ethical issues of their involvement.
- Customize data collection devices.
- Adjust time, order, or pace of procedures.
- Allow participants to choose which sections of a study to complete.
- Individualize measures, targets, and goals.
- Individualize rewards and reinforcements used in studies.
- Individualize experimental conditions that bring about desired emotional states.
- Use different instruments or modifications to them for different people.

approaches to implement and also a way to foster ethical progress and the empowerment of stakeholders.<sup>29</sup> It represents a process where individuals are invited to become agents of their own growth.<sup>30</sup> Working with the task force led to further refinement and brainstorming.

We draw on the content from this literature review and the deliberative refinement in the analysis below. The final list of themes extracted from the data relevant

to addressing autism needs (falling within the guideposts of respect for holistic personhood and individualization) and reported in this paper are derived from 191 identified articles, listed in an online supplement.<sup>31</sup>

Our review of the literature revealed substantial, but often hidden, discussions about autism research ethics and specifically about ways to adapt the research process to better fit the needs and strengths of people on

the autism spectrum. The sections below present the insights and recommendations from this literature search, informed by task force deliberation. These recommendations, summarized in table 1, include strategies researchers can use in recruitment, in preparing individuals for participation, in addressing autism-specific needs during data collection, and in individualizing certain aspects of data collection to meet the needs of each person. After presenting practical strategies, we move into a discussion of the importance of these suggestions for broader ethics theory, namely, the importance of evidence-based ethics and moral deliberation involving stakeholders and the inseparability of practical, ongoing concerns about research methods and ethics.

### RECRUITMENT AND PREPARATION STRATEGIES

We identified autism-specific considerations in recruitment and sampling. With respect to recruitment, researchers can use multiple and alternative avenues of communication to avoid relying on modes that may be difficult—such as requiring potential participants to make phone calls.<sup>32</sup> The language used in recruitment materials when referring to autism (for example, “autistic adults/children/people,” “adults/children/people with autism,” or “adults/children/people on the autistic spectrum”) also affects recruitment because potential participants have diverse views on language use.<sup>33</sup> Some researchers find “adults on the autistic spectrum” to be a “less politicized term” that is useful for recruitment, while acknowledging that other research projects may want to use different language, depending on the audience and goals.<sup>34</sup> Members of our task force have suggested that researchers could individualize this language by asking individuals with autism how they prefer to be described.

There are also ethical dimensions to sampling strategies,<sup>35</sup> notably in the context of diagnostic accuracy and its importance for interpreting results.<sup>36</sup> Diagnostic accuracy and precision needs may vary from study to study. These needs must be balanced against the resources required to evaluate diagnoses.<sup>37</sup> Given data protection and confidentiality needs, researchers may not always be able to access diagnostic information.<sup>38</sup>

Many people with autism prefer to be prepared for changes in routine to reduce uncertainty.<sup>39</sup> Thus, they may need more explicit guidance about what will hap-

pen during the research process<sup>40</sup> and have a greater need for a predictable research environment than do others who participate in research.<sup>41</sup> Short sequences of information or instructions<sup>42</sup> and introductory statements before interviews may be especially helpful.<sup>43</sup> Researchers should provide time for participants to familiarize themselves with the room where study procedures are conducted, with research equipment, and with research personnel,<sup>44</sup> or have a practice phase to help individuals become familiar with details about the study.<sup>45</sup> Because some aspects of a study might be particularly challenging for participants who are often “sensitive to taste and to change in routine,” implementing a practice phase may be useful in taking an unpleasant tasting pill<sup>46</sup> or for dealing with other difficulties in taking pills.<sup>47</sup> “Social stories” are also common tools for providing social information to people with autism, taking into consideration the reader’s perspective, often in the format of short stories composed of short phrases that explicitly lay out what will happen in a certain situation.<sup>48</sup> Social stories can be used before arriving at a study site or initiating the study to prepare children with autism for data collection.<sup>49</sup>

Parents, staff, and other familiar figures can also help with preparation. Verbal instructions can be reinforced with a demonstration by research staff.<sup>50</sup> Parents can participate first, demonstrating the activity their child will participate in<sup>51</sup> or providing details to them about the research procedures prior to data collection,<sup>52</sup> perhaps using social stories created by the research team.<sup>53</sup> Even the simple presence of parents and other reassuring persons can be valuable for children with autism.<sup>54</sup> Beyond these specific preparatory strategies, a general flexibility in scheduling can help with preparation.<sup>55</sup>

### CONDUCTING THE RESEARCH

Research design and data collection strategies can address the autism-specific needs of participants at the point of data collection. These suggestions focus on attention to the environment in which research is conducted; attention to sensory, anxiety, and related needs; strategies related to research design; and the use of specific research tools.

**Attention to the environment.** The physical and social environment of research can be particularly distressing and can warrant the additional time suggested

above for participants to familiarize themselves with the setting.<sup>56</sup> The environment can impact performance, and the effects of environmental factors should be measured.<sup>57</sup> Strategies for creating a more accessible environment include using blackout curtains, turning off fluorescent lamps, playing calming music, using tactile deep-pressure wraps,<sup>58</sup> using soft lighting, providing comfortable seating, and minimizing noise.<sup>59</sup> Research settings may also generate associations that can affect the research process. For example, if the same room is used to draw blood and conduct other study procedures, participants may be anxious about the blood draws during other data collection sessions.<sup>60</sup> For this reason, it may be easier to conduct some research procedures in familiar settings. When children are involved in social science research conducted in school settings, it may be helpful to use a familiar room with their usual teacher or other educator present but standing outside the participant's line of sight.<sup>61</sup> Modifications undertaken and researched in clinical settings could also be applicable to research settings more broadly.<sup>62</sup>

Researchers themselves are part of the environment and can take action to increase accessibility. Researchers can give participants options about where to sit in relation to the researcher<sup>63</sup> or can position themselves unobtrusively.<sup>64</sup> Researchers can also pay particular attention to issues of time, by being punctual, avoiding researcher-initiated changes, being flexible with participant-initiated changes, and scheduling study visits for times when participants are less stressed.<sup>65</sup>

#### **Attention to sensory, anxiety, and related needs.**

Due to sensory sensitivities and similar issues, some common procedures might be more distressing to some participants with autism than to other participants, thereby warranting autism-specific protocols and forms and specific training for new researchers.<sup>66</sup> Several sources indicate that people with autism may find procedures and devices such as blood draws, mouth swabs, brain imaging, tympanometry, gel electrodes, cold pressor tests, cardiorespiratory monitoring devices, blood pressure cuffs, and pill swallowing more painful or difficult than do people without autism and thus may require special attention to risk-benefit analysis, pain management, and crisis management.<sup>67</sup> For example, some researchers argue that “sedation may be approvable for brain imaging studies for children with autism,

but not for the children that are used as controls.”<sup>68</sup> Others have suggested alternatives such as using dry electrodes<sup>69</sup> or supports such as providing a motivational toy during cold pressor tests.<sup>70</sup> Researchers have even designed new technologies for data collection specifically aimed at reducing sensory burden.<sup>71</sup>

People with autism often report high levels of anxiety,<sup>72</sup> and many sources describe strategies aimed at reducing anxiety around data collection. Suggestions include allowing time for participants to settle in at the research site,<sup>73</sup> not enforcing a time limit on completing research tasks,<sup>74</sup> choosing “weakly stressful” stimuli for studies requiring minor stressor conditions,<sup>75</sup> and using visual timers,<sup>76</sup> as people with autism may also have timing and pacing needs.<sup>77</sup>

**Visual supports.** Visual supports can also be helpful during data collection.<sup>78</sup> Pairing text and visual information can aid people with limited reading skills,<sup>79</sup> and many people with autism have strong visual skills.<sup>80</sup> People with autism who have lower levels of support needs can inform the design of visuals aimed at participants with higher levels of support needs.<sup>81</sup> However, there is some concern that using images can be constraining, that a small number of available images may limit what participants can express visually.<sup>82</sup> Participants with concrete and literal ways of thinking, characteristics associated with autism,<sup>83</sup> may interpret visual supports more narrowly, limiting how they talk about them.<sup>84</sup>

## **RESEARCH DESIGN STRATEGIES**

Several suggestions from the literature focus on how researchers can attend to the needs of people with autism by adapting in various ways interviews,<sup>85</sup> focus groups,<sup>86</sup> participant observation,<sup>87</sup> questionnaires,<sup>88</sup> psychometric testing,<sup>89</sup> studies of social interaction or rapport,<sup>90</sup> online research,<sup>91</sup> psychoanalytic research,<sup>92</sup> or pediatric psychopharmacology studies.<sup>93</sup> Some suggestions also focus on issues specific to particular research designs, such as finding appropriate comparison groups. Cross-cutting themes regarding research design include involving people with autism in the development and pretesting of instruments and interview guides<sup>94</sup> and using autism-specific or modified research instruments that allow people with autism to more accurately show their strengths and concerns.<sup>95</sup>

The need for specific tools is especially pronounced for certain commonly measured concepts such as IQ<sup>96</sup> and anxiety,<sup>97</sup> in line with long-standing concerns about bias and variability within and between different IQ tests.<sup>98</sup> Even within the population of people with autism, there is much variation, especially regarding intellectual disability and verbality, which necessitates different evaluation instruments for different people<sup>99</sup> or modifications to reduce verbal components.<sup>100</sup> Multiple tests of cognitive function are often used within the same study, which is a form of individualization.<sup>101</sup> A small amount of literature also addresses the needs of autistic research participants who are Deaf or deaf.<sup>102</sup> Instruments that rely on gaze or eye contact might prove particularly problematic for people with autism, thus requiring modification.<sup>103</sup> Instrument choice is a methodological decision but can also be considered an ethical choice, given that inappropriate instruments may mischaracterize people with autism.<sup>104</sup>

Some studies ask people with autism to self-report their experiences or complete self-reporting instruments. Many people have raised concerns that self-reporting may be particularly difficult for individuals with autism, particularly regarding emotional experiences. Researchers have used several strategies to address this difficulty. Some studies pair self-reports with reports of others,<sup>105</sup> sometimes individualized based on participant characteristics such as age and level of verbal communication or the availability of willing “informants.” Another possibility is to pair self-reporting with physiological data.<sup>106</sup> Others use physiological measures or observation of verbal and nonverbal behavior without necessarily requiring self-reporting. Such observation not only informs data collection but can also be used to identify adverse events that participants may not be able to verbalize.<sup>107</sup>

Observation-based collection methods may also include passive telemetric monitoring<sup>108</sup> or audio-visual data collection.<sup>109</sup> This type of data collection also raises new ethical concerns about data security and data sharing.<sup>110</sup> While there are concerns that data must be protected, parents of participants may be less concerned with risks of data sharing and, in fact, may find being able to access and share data a motivator for research participation.<sup>111</sup> Information on the perspectives of

participants themselves is lacking and worthy of further investigation.

Beyond privacy, the use of technological devices to collect data raises issues related to sensory needs and motor skills. It can be difficult to get training data when using technological devices.<sup>112</sup> Designs should be comfortable, noninvasive, or require few to no wearable parts<sup>113</sup> or should rely less on fine motor skills.<sup>114</sup> Devices should also be resilient to aggressive behavior and safe in case participants put them in their mouths.<sup>115</sup>

Despite concerns about self-reporting and the use of alternative strategies, the self-reports of both adults and children with autism is valuable and valid information. The self-reports of participants should not be discounted or excluded due to stereotypes about autism.<sup>116</sup>

There are also multiple ways that researchers can make research more accessible and comfortable for individuals, beyond the broad accessibility strategies listed above. “Everyday acts of individualizing” such as those described here “facilitate the ongoing tasks of the study, while also producing those tasks as potential resources for participants.”<sup>117</sup> Studies with the flexibility to do so can offer participants multiple ways to complete an interview, task, or procedure. They can provide answers in written or oral formats<sup>118</sup> and online or by phone or on paper.<sup>119</sup> Researchers can provide to participants the option of reading survey questions or having the questions read to them.<sup>120</sup> Participants could also be offered different ways to complete a protocol, such as choosing between two topics of conversation in a study of conversational reciprocity,<sup>121</sup> giving either blood or saliva samples,<sup>122</sup> or choosing how a medication is delivered.<sup>123</sup> There can be group or individual settings for completing questionnaires or interviews.<sup>124</sup> Participants can be given the choice to complete some components at home or at the research site.<sup>125</sup> Researchers can create individualized visual supports<sup>126</sup> and the option to use or not use them at all.<sup>127</sup> Participants can also use individualized “adaptive technologies” (such as computers with screen readers).<sup>128</sup> Participants may have idiosyncratic needs such as wearing headphones and verbalizing intrusive thoughts.<sup>129</sup> Such individualization can also be accounted for in the analysis phase.<sup>130</sup> Researchers can also give participants the option of having support persons present.<sup>131</sup> However, this option raises concerns

about whether support persons are also research participants.<sup>132</sup>

The need for standardized research methods is not necessarily a barrier to accommodating the individual needs of people with autism. Standardized research methods can be individualized while maintaining rigor and integrity. For example, data collection devices can be customized to better appeal to each participant,<sup>133</sup> or the timing, order, or pace of procedures can be adjusted to make a study more appealing and comfortable.<sup>134</sup> Additionally, some studies permit participants to choose which sections to complete, allowing a customization of content.<sup>135</sup> A large number of studies demonstrate individualizing measures, targets, and goals;<sup>136</sup> the kinds of rewards or reinforcements that are used; or the experimental contexts that can bring about desired emotional states.<sup>137</sup> Some studies also varied<sup>138</sup> or modified the study instruments.<sup>139</sup>

### THE ETHICS OF ADDRESSING AUTISM NEEDS

The needs of people with autism should be met to promote their inclusion in research. The findings of our literature review highlight several broad strategies that can be useful for responding to these needs. Several of these strategies, across a range of study types, address common traits associated with autism or social contexts important to autistic people. Many of the suggestions in the literature revolve around providing multiple or alternative means of communication that are in line with various communication styles of people with autism. This may mean using visuals alongside text, although some concerns about relying on visual communication have been raised. Aside from using visuals, communication needs can be addressed by providing multiple ways to contact the researcher, using social stories to explain what will happen during research, and providing a variety of communication options for data collection based on the needs of each person. Other suggestions revolve around sensory sensitivities that are common in autism, anticipating research procedures that might trigger such sensitivities, and attending to the sensory aspects of the environment in which research is conducted. Researchers have also accommodated preferences for routine or familiarity that are common among people with autism, especially through helping participants prepare for studies.

While these considerations address characteristics commonly associated with autism, other strategies attend to the social context in which people with autism live. The language used to talk about autism (for example, “autistic people,” “people with autism” or “people on the spectrum”) in different communications about research is an important part of social context that researchers need to carefully consider. Involving people with autism in research design, development of recruitment materials, and other aspects of the research process also respects the valuable perspectives and contributions that the lived experience of autism brings. Many of these strategies can be individualized based on the specific needs and preferences of the participant with respect to visual reasoning, language preference, and so on. For example, preparticipation questionnaires proactively provided by the research team could anticipate participants’ needs and create an inviting space for participants to signal what would work best for them.

These practical strategies are important for broader ethics methodology and theory. Methodologically, they demonstrate the importance of evidence-based ethics and moral deliberation involving stakeholders. Evidence-based research ethics aims to use empirical research to inform thinking about more normative research ethics issues.<sup>140</sup> Using both a systematic-interpretive review of the literature and a process of moral deliberation to understand everyday ethical issues in practice, we showed how empirical literature can help substantiate higher-level ethics principles. The inclusion of “hidden” ethics data—although difficult and complex—brings together everyday experiences of researchers working in diverse fields on diverse questions, but with similar participants.

From a theory standpoint, the practical strategies we reviewed demonstrate the ethical dimensions of research design choices and day-to-day methods concerns. Even strategies that seem to belong more strictly in the domain of research design—such as the choice of standardized research instruments in clinical research—have important ethical dimensions. Instrument choice is important not only for study validity (arguably itself an ethics issue<sup>141</sup>) but also because inappropriate instruments may lead to results that represent participants in inaccurate or stigmatizing ways, or simply cause participants undue frustration and discomfort. Designing



studies and choosing methods that facilitate inclusion, reduce discomfort, and focus on individual persons fulfills ethical aspirations of justice (inclusion and representation), respect, and person centeredness.

The suggestions presented in this article are extensive, and some are easier to implement than others. Researchers face barriers such as time, cost, and regulations. There are also barriers integrated into long-standing cultures of research. These are especially prominent when considering individualization, which is central to person-centered care but intimidating for many researchers to consider in person-oriented research. Protocols that require standardization may seem limited in how much they can be individualized. Our review of the literature questions this entrenched belief by showing several options for individualization and strategies for accounting for it within studies that rely on standardization and control.

Despite potential barriers, taking steps to meet the needs of research participants with autism remains a worthwhile goal. A person-oriented research ethics framework can give researchers tools to plan studies and deal with new ethical issues raised in new design strategies.

## CONCLUSION

Addressing the needs of participants with autism involves practice strategies that take into consideration common characteristics of people with autism, the broader sociopolitical context of autism research, and the unique needs of individual participants—which are shaped by intersecting aspects of their identities and multifaceted life experiences, including living with autism. Addressing autism needs is not only a methodological and design choice but also an ethical issue because it facilitates inclusion, reduces discomfort, and respects persons. Our survey of the literature shows that there are many ways that researchers already address autism needs, across many disciplines and study types, even when they do not frame such strategies within the lens of research ethics. Here, we have brought these strategies to light for all human subjects researchers and research ethics committee members, highlighting their importance within key ethical frameworks of respect and inclusion. ♦

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## ERRATUM

In the July-August 2020 issue, the disclaimer statement was incorrect for the article "The Pathway Forward: Insights on Factors that Facilitate Research with Pregnant Women," by Anna C. Mastroianni, Robert Franceschini, Sarah L. Wicks, and Leslie Meltzer Henry (*Ethics & Human Research* 42, no. 4 [2020]: 2-16, doi:10.1002/eahr.500058). This is the correct statement, and it should have been labeled "Disclaimer": "The content of this manuscript is solely the responsibility of the authors and does not necessarily represent the official views of BluePath Health, Goodwin Procter LLP, or any of their clients."

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