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Empowerment in decision-making for autistic people in research

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ABSTRACT

Empowerment in research is important in many autism and autistic communities and an important part of 'nothing about us without us'. It is also an important component of person-oriented research ethics. This article reviews the literature on ethics in autism research for information related to decision-making empowerment for autistic people. A review of 81 articles reveals several themes and specific strategies. Empowerment is important for, but also goes beyond, establishing informed consent. Empowerment is a form of participant and community engagement, and necessarily shaped by specific context. The view of research ethics put forth in this article envisions ethics as a potential avenue for empowerment, where research participants are able to decide how to be involved and to shape research processes and contexts. This view of research ethics is aligned with the aspirations of many in advocacy communities, though it may not correspond to conventional understandings of research ethics.

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Research ethics; empowerment; autism; informed consent

Points of interest

- This article talks about ethics in autism research.
- It focuses on the importance of people with autism having the power to make choices about research.
- It describes what published articles have said about this issue.
- Making choices about research includes not only the choice to take part in a study or not, but also many other choices before, during, and after the study.
- The way that this article talks about research ethics helps achieve goals of many autistic people and disabled people to be included.

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Introduction

Empowerment generally describes the process of gaining greater control and exercising greater autonomy with respect to choices and life conditions (Perkins and Zimmerman 1995). Disability studies scholars have defined empowerment as 'a method by which individuals and communities exert influence and control over resources, events, and outcomes' (Block et al. 2011). Empowerment is tightly linked to concepts like self-advocacy and self-determination (Block et al. 2011; Clifford 2013; Morgan and Yoder 2012). The concept emerged in women's rights and civil rights movements and is also an important component of disability rights broadly. Empowerment is important in all aspects of life, and engaging with research studies is no exception. Empowerment is consistent with the goals of research ethics theory, even though research ethics practice may not always be fully empowering (Dresser 2016).

The purpose of this paper is to address relational and every day ethics of research involving participants on the autism spectrum, with a focus on empowerment in decision-making related to research. Research ethics is a field composed of both scholarship and practices that encompass a range of priorities, from protection of research participants to equitable distribution of the benefits of research. Research ethics can be viewed as a form of empowerment for research participants (including participants with disabilities), although this may be unclear based on an extant focus on regulatory and 'soft law' concerns such as forms, paperwork, rules, and guidelines. Research ethics, insofar as it derives from the field of ethics more broadly, is ideally an aspirational endeavor, striving toward the flourishing and well-being of individuals (Cascio and Racine 2018), including taking into account diverse forms of flourishing or 'the good life' (Rodogno, Krause-Jensen, and Ashcroft 2016). Research ethics as a field has the potential to empower participants to have productive, meaningful, and positive interactions with researchers (and vice versa).

Empowerment in the context of research is important for many within the autism and autistic communities. We use the term 'autism community' to refer to individuals with autism, parents, family members, and allies as well as service providers, researchers, and other professionals; and 'autistic community' to refer to communities of autistic people only. We use variously the phrases 'autistic person', 'person with autism', and 'person on the spectrum', in recognition of the diversity of preferences on this terminology. Autistic communities have taken up the disability rights call 'nothing about us, without us', importantly including a call for research participation in studies about autism. Autism and autistic communities are important stakeholders engaged in research collaborations around the world, such as Shaping Autism Research and the Participatory Autism Research Collective (PARC),

Autistica, and the Know Your Normal project in the UK; the Academic Autism Spectrum Partnership in Research and Education (AASPIRE) in the United States; and the Cooperative Research Centre for Living with Autism in Australia (Autism CRC). Such diverse groups engage in research in a variety of ways, and do not always agree within or between them. Autism and autistic communities are also involved in academic publishing, through journals such as *Autonomy, the Critical Journal of Interdisciplinary Autism Studies* (Arnold 2018) or *Autism in Adulthood*. In both the scholarly literature and important community spaces and web publications, people on the spectrum have stressed the importance of being empowered in research (Autistic Self Advocacy Network 2018b; Brown 2012; Annear 2013). Despite some promising developments in participatory autism research and guidelines on how to undertake it (Nicolaidis et al. 2011; Jivraj et al. 2014; Pellicano et al. 2017; Nicolaidis et al. 2019; Fletcher-Watson et al. 2018), there is no consensus on the steps that need to be taken to facilitate empowerment in research generally and throughout the research process. There is also limited reflection within bioethics about the theory and practice of empowerment in research particularly in the context of disability studies, which has often had a tense relationship with bioethics (Goering 2008; Asch 2001).

In contrast to research ethics approaches that might leave empowerment lacking, the model of person-oriented research ethics (Cascio and Racine 2018) states that empowerment in decision-making is an important component of every day research ethics. Empowerment calls for the recognition of research participants' interest in remaining agents of their own lives, including when participating or considering participation in research studies. Person-oriented research ethics describes guideposts for research ethics drawing from diverse applications of the concept of person-centeredness in research. The concept of person-centeredness emerges from a range of clinical and methodological literatures including participant-centered research (Kost et al. 2013), participatory research (Azzarito 2016), relational ethics (Meloni, Vanthuyne, and Rousseau 2015), and everyday ethics (Dresser 2015; Zizzo, Bell, and Racine 2016). The notion of empowerment in decision making used in this model draws from the understanding of empowerment in person-centered care, which focuses on supporting individuals' choices, promoting self-determination, and encouraging autonomy and self-confidence (Morgan and Yoder 2012). This understanding of empowerment is highly relational, concentrating on the responsibility of the healthcare provider to foster empowerment. Indeed, relational considerations are important in empowerment, especially where power imbalances exist such as the imbalance between researchers and research participants. However, disability studies scholars have criticized 'traditional' models of empowerment for implying a process by which professionals give or grant power to disabled people,

proposing instead 'transformative' rehabilitation models in which empowerment 'results […] from change in the attitudinal and built structures of the society in which the disabled person lives' (Schriner 2001). These attitudinal and structural changes can also emerge from relational and every day considerations, such as those outlined in this paper.

Research intersects with empowerment in complex ways. First, empowerment is consistent with the emphasis on autonomy encountered in formalized research ethics policies around the world, including the Belmont Report and Declaration of Helsinki. This emphasis is codified in processes like informed consent. The basic tenet of these policies is that potential participants have the right to determine what happens to them, including whether or not to participate in research. This ability is often limited to a passive role of giving permission, i.e. consenting, but autonomy has a deeper sense as an ability possessed by an agent and exercised within a given context (Racine and Dubljević 2016, 2017). An 'agent' is one who acts (not only consents); recognizing people's agency is a core component of the concepts of autonomy and empowerment. Conceptualizing people who take part in research as agents is especially important in contrast to the way such participants are often configured as passive, as 'research subjects' rather than agents (Dresser 2016).

Second, research as a knowledge-generating activity can be important for empowerment. Knowledge empowers and provides tools to promote flourishing and wellbeing. The United Nations Convention on the Rights of Persons with Disabilities (United Nations General Assembly 2007) specifically invokes obligations 'to undertake or promote research' in universal design and new technology to meet the needs of people with disabilities. These obligations overlap with the United Nations' 'right to science', which some scholars (Vayena and Tasioulas 2015; Scanlon, MacNaughton, and Sprague 2017) have interpreted to mean that people have a right not only to be free from the harms in research, but to direct the course of research as a way to impact policy, healthcare, and technology development and to advance social recognition. In these ways, empowerment is important both within research and surrounding it. Although many studies involving people with disabilities may not currently rise to this potential, the demonstrated possibility inspires our interest in the every day ethics of empowerment in research.

Both individual and social factors may impact autistic individuals' experiences with empowerment. Different scholars may focus on different characteristics of or theories about autism as more central or valid than others, but ethicists have pointed to differences in components of executive function as possibly impacting participants' comprehension of research choices (Richman 2019). These difficulties are relational, not necessarily individual.

Communication differences and the 'double empathy problem' (Milton 2012) may make it difficult for participants and researchers to communicate effectively (Richman 2019). There are also common social experiences that may impact research ethics. People with autism who have experience in institutional settings – used in the broad sense to include situations of institutional control including schooling and social services – may have learned an 'acquiescence to authority' that makes self-determination difficult, especially if saying yes to authority figures has become a rewarded and therefore adaptational strategy (Fisher 2003; Harris 2003). However, none of this is to say that people on the spectrum lack ability for self-determination and cannot benefit from empowerment processes. Self-advocacy is a skill included in many educational curricula for both students and older adults on the spectrum (Shore 2004, Sibley 2004). Autistic people are visible self-advocates politically, in local communities, and in daily self-determination settings (Brownlow and O'Dell 2006; Autistic Self Advocacy Network 2018a; Bagatell 2007; 2010). Our attention to research ethics is predicated on the premise that autistic people's rights to self-determination must be respected and not marginalized due to diagnosis, communication style, measured IQ, or any other characteristic.

In this paper, we tackle the question: how can the research process be designed to facilitate the empowerment of people with autism? To pursue this question, we present the results of a thorough narrative review of literature on empowerment in autism research ethics.

Research process

To elucidate empowerment strategies, we employed a systematic-interpretive narrative review of the literature and engagement with a deliberative task force of autism stakeholders. Results of the literature review were shared with a task force of seventeen individuals concerned with autism research, including the three authors of this paper, other researchers, autistic self-advocates, parents of people with autism, professionals who work with people with autism, and advocacy and service organization representatives associated with Autism Canada, Autism Ontario, Autism Speaks Canada, the Canada/Israel Autism Research Initiative, the Fédération Québécoise de l'autisme, H.A.L.E. Autism, SaskFEAT, and the Worktopia Project. More information about the task force can be found at our website (https://www.autismresearchethics.net/task-force), which we also use to connect with broader autism and autistic communities, share updates, and solicit feedback on the project. This led to further refinement and brainstorming. The Task Force collectively and iteratively developed a report of suggestions for researchers to use to include autistic people in studies, which is also

available on the website (https://www.autismresearchethics.net). This paper, written by the authors but drawing on the insights of the Task Force suggestion development process, expands upon one specific area of the broader Task Force report (empowerment in decision-making) and presents an in-depth report on the literature. We also submitted a draft of this paper to the Task Force for a 'member-checking' process (LeCompte and Schensul 2010, 62) to confirm its acceptability.

The literature review followed McDougall's (2015) critical-interpretive approach. In fall 2016, we searched ProQuest Philosopher's Index (which focuses on philosophy, including ethics), Web of Science (which includes both clinical and social sciences), and Ovid Medline (which focuses on basic and clinical sciences) for keywords related to autism spectrum conditions and research ethics, broadly defined. We chose these databases to get a cross-section of different disciplines, with different approaches and priorities. Search terms for ProQuest were autis* OR asperger* OR 'Fragile X' OR Rett. Search terms for Web of Science were TS=(autis* OR asperger* OR 'Fragile X' OR Rett) AND TS=(research ethics OR bioethic* OR neuroethic* OR consent* OR assent* OR dissent* OR confidential* OR privacy OR disseminat* OR decision-making OR vulnerab* OR autonom* OR rapport). Search terms for Ovid Medline were (exp Child Development Disorders, Pervasive/OR exp Fragile X Syndrome/OR exp Rett Syndrome/OR autis*.mp. OR asperger*.mp. OR fragile x.mp. OR rett.mp.) AND (exp Confidentiality/OR exp Informed Consent/OR exp Ethics/OR exp Research Design/OR research ethics.mp. OR bioethic*.mp. OR neuroethic*.mp. OR consent*.mp. OR assent*.mp. OR dissent*.mp. OR confidential*.mp. OR priva*.mp. OR disseminat*.mp. OR decision-making.mp. OR vulnerab*.mp. OR autonom*.mp. OR rapport.mp.)

As these terms show, we used a broad range of autism-related keywords. Given that we did not have a date limit on our search, we also included keywords and MeSH terms that were used in the former DSM-IV (and current ICD-10), namely Asperger's syndrome. We also searched for Rett syndrome in recognition of its similarity with autism spectrum conditions. Although there are important clinical and neurobiological differences between Rett syndrome and autism (Percy 2011), we recognize that several academic and popular sources considered Rett Syndrome to have been part of the autism spectrum (Cukier et al. 2012; Chien et al. 2011; Konstantareas 1998; Deweerdt 2011; Autism Support Network 2016; WebMD 2018) and therefore informative for understanding every day ethical issues. We similarly searched for Fragile X Syndrome, due to the wealth of genetic research on autism focused on Fragile X specifically, but excluded articles about Fragile X that were not associated with autism (e.g. Fragile X-associated tremor/ataxia syndrome). In this report, we specify if an article is specifically concerned with

Fragile X syndrome or Rett syndrome, when those articles are also informative for autism research ethics.

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). The vast majority of the identified articles were in English. While the majority of ultimately included articles report on studies that were conducted in the U.S., U.K., and Canada (or are conceptual papers written by authors working in these countries), our review in this paper also includes contributions from or concerning Australia (Leonard et al. 2013; Mathai, Bourne, and Cranswick 2005), France (Ben Said et al. 2014; Trehin 2003; Zorn and Puustinen 2015), India (Daley, Singhal, and Krishnamurthy 2013), Spain (Fuentes and Martin-Arribas 2007), Malaysia (Shamsuddin et al. 2014), Romania (Goldstein et al. 1989), Japan (Takahashi et al. 2003), and Belgium (Hens, Peeters, and Dierickx 2016a, 2016b).

After screening titles and abstracts, we conducted a full review of remaining articles to determine if they addressed our interests in autism research ethics. Common reasons to exclude articles at full review were that they did not discuss ethics at all, or only included minimal information on ethics (e.g. they had no information beyond noting that an ethics committee approved the project or that participants gave consent). We included articles that explicitly addressed research ethics, and those that contained 'hidden' ethics data (Dubois 2008) that were identified by our keywords, despite not being primarily about research ethics. Dubois defines 'hidden' ethics information as the useful empirical data (and we might add – normative, philosophical justifications) that are discussed in an article that 'is not published in a journal that [research ethics committee] members might regularly read', 'does not include any keywords or subject headings that pertain to research ethics', and/or 'when the authors of the study themselves either do not recognize or do not explicitly discuss the ethical significance of their findings' (Dubois 2008, 3).

This search yielded a total of 379 articles. Content related to the person-oriented research ethics guidelines was extracted from these articles. 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 was then condensed and reorganized iteratively until an outline of interrelated ideas, issues, and suggestions under each guidepost was created. This paper presents some of the extracted data regarding the

guideposts Empowerment in Decision-Making and Individualization, from 81 identified articles summarized in Table 1.

Narrative review results

Unsurprisingly, informed consent was a major theme within discussions of empowerment in decision-making in the literature. Documenting informed consent is a highly visible and easy-to-track part of the research ethics process (Koenig 2013), as well as often very visible in articles about research. Themes in the literature include the right to accept or refuse to participate in research, diverse expressions of assent and dissent, consent as a process, accessible consent processes, and determining necessary specific information. While these themes center around the decision to take part in research or not, empowerment in decision-making also includes other decisions and is not only restricted to the act of giving permission. The subsequent sections therefore address empowerment in data collection and research design, and empowerment in dissemination and return of research results. Another important theme around empowerment centers on community empowerment, especially through community-based participatory research (CBPR). CBPR can be a mechanism for empowerment, but empowerment is also important *within* CBPR processes. This section highlights strategies participatory research teams have used to empower autistic team members, looking at empowerment for autistic people engaging in research as co-researchers, not participants. Finally, we conclude our results with findings from formal and informal 'evidence-based' research ethics.

All potential participants have a right to accept or refuse

Discussions of empowerment and decision-making in the literature on autism research ethics start from the very basic premise that people with autism have a right to participate in research, or to refuse to. Unfortunately, these rights, and research participant rights in general, are not always respected when participants are on the spectrum, with advocates expressing concerns about the standards applied to autism-related research and practice; autism-specific standards might mean lower standards (Salt 2019; Dawson 2004, 2017). Therefore, this basic premise does not go without stating and we must assert that the first step in autism research ethics is affirming human rights and refusing lesser standards. There are several factors that may complicate consent to research for autistic people, including the fact that many participants are children, who lack the legal authority to consent, or are adults who have been deemed legally unable to give consent or determined by researchers (e.g. through a capacity checklist) to lack the ability to give informed consent (Santosh et al. 2016).

Table 1. Literature reviewed.

References	Hidden or explicit?	Article type	Content relevant to empowerment	Part(s) of the research process
Bailey, D. B., et al. 2014. "Parent Ratings of Ability to Consent for Clinical Trials in Fragile X Syndrome." *Journal of Empirical Research on Human Research Ethics* 9 (3): 18–28	Explicit	Empirical Ethics	Study of parents on ability of their child with Fragile X to consent to clinical research found parents favorable to the idea that such individuals can participate in consent or assent process.	Consent
Baret, L., and B. Godard. 2011. "Opinions and Intentions of Parents of an Autistic Child Toward Genetic Research Results: Two Typical Profiles." *European Journal of Human Genetics* 19 (11):1127–1132.	Explicit	Empirical Ethics	Study of parents on preferences regarding return of genetic results; notes potential benefits and harms linked to receiving individual results which should be explained to participant at the beginning of the study.	Consent Dissemination
Barnes, R. E., and H. McCabe. 2012. "Should We Welcome a Cure for Autism? A Survey of the Arguments." *Medicine Health Care and Philosophy* 15 (3): 255–269	Explicit	Conceptual Paper	Asserts people with guardians have a right to proxy consent.	Consent
Barrow, W., and E. F. Hannah. 2012. "Using Computer-Assisted Interviewing to Consult with Children with Autism Spectrum Disorders: An Exploratory Study." *School Psychology International* 33 (4): 450–464.	Explicit	Qualitative Study	Agreed on a stop signal with participants, but also paid attention to other signs of not wanting to continue.	Consent
Ben Said, M., L. Robel, C. Messiaen, Y. Craus, J. P. Jais, B. Golse, and P. Landais. 2014. "Patient Information, Consents and Privacy Protection Scheme for an Information System Dedicated to Pervasive Developmental Disorders." *Studies in Health Technology & Informatics* 205: 755–9.	Explicit	Conceptual Paper	Describes a privacy protection scheme for an autism spectrum disorders information system, and describes modifications to the consent and information documents stressing voluntariness, non-opposition consent to secondary use of data, and special mention of genetic and neuroimaging data.	Consent
Bowdin, S., P. N. Ray, R. D. Cohn, and M. S. Meyn. 2014. "The Genome Clinic: A Multidisciplinary Approach to Assessing the Opportunities and Challenges of Integrating Genomic Analysis into Clinical Care." *Human Mutation* 35 (5): 513–519.	Explicit	Clinical/ Intervention Study	Gave patients and families choice about whether or not to receive information on 'medically actionable variants' identified in genetic testing; conducted qualitative interviews with patients and parents about participation with an eye toward revising consent forms and educational materials.	Return of Results Consent

(*continued*)

Table 1. Continued.

References	Hidden or explicit?	Article type	Content relevant to empowerment	Part(s) of the research process
Brendel, D. H. 2003. "Complications to Consent." *Journal of Clinical Ethics* 14 (1–2): 90–4	Explicit	Conceptual Paper	Tentatively considers that patients should be able to read case reports written about them before they are submitted to research journals and have more of a say about what is published, even considering the possibility of co-authorship.	Consent Dissemination
Brownlow, C., and L. O'Dell. 2002. "Ethical Issues for Qualitative Research in On-Line Communities." *Disability & Society* 17 (6): 685–694.	Explicit	Conceptual Paper	Extensive discussion of ethics for online research drawing from authors' experiences conducting research in online autistic spaces, including being transparent about researchers' presence and intentions, providing opportunities to ask questions, asking permission to use posted material in research reports, and taking a self-advocacy and community empowerment approach to the study.	Consent Data Collection Dissemination
Carlson, L. 2013. "Research Ethics and Intellectual Disability: Broadening the Debates." *Yale Journal of Biology & Medicine* 86 (3): 303–14	Explicit	Conceptual Paper	Debates the risks of both inclusion and exclusion of participants with intellectual disability (including who also have autism); debates who is the best person to provide proxy consent and by what standard; notes risk that institutional settings can be coercive; encourages individualization of informed consent process.	Recruitment Consent
Carter, J. 2003. "Looking into a Distorted Mirror." *Journal of Clinical Ethics* 14 (1–2): 95–100	Explicit	Participant Reflection	Suggests more precise definitions of 'informed consent' and 'thickly disguising' patients described in case reports, after being a patient in such report which turned out to be hurtful and confusing to read.	Consent Dissemination
Cermak, S. A., et al. 2015. "Feasibility of a Sensory-Adapted Dental Environment for Children with Autism." *American Journal of Occupational Therapy* 69 (3): 6903220020p1-10	Hidden	Clinical/ Intervention Study	Allowed families the option to complete the consent process and surveys with a research team member in their home, or upon arriving at the visit, recognizing that it might be difficult for participating children to wait through the consent process on-site; confirmed appointments a few days in advance and allowed rescheduling as needed.	Consent Data Collection

(*continued*)

Table 1. Continued.

References	Hidden or explicit?	Article type	Content relevant to empowerment	Part(s) of the research process
Charman, T., P. Howlin, C. Aldred, G. Baird, F. Degli Espinosa, T. Diggle, H. Kovshoff, J. Law, A. Le Couteur, J. MacNiven, I. Magiati, N. Martin, H. McConachie, S. Peacock, A. Pickles, V. Randle, V. Slonims and D. Wolke. 2003. "Research into Early Intervention for Children with Autism and Related Disorders: Methodological and Design Issues. Report on a Workshop Funded by the Wellcome Trust, Institute of Child Health, London, UK, November 2001." *Autism* 7 (2): 217–225.	Hidden	Conceptual Paper	Proposes strategies for successful randomized controlled trials involving 'patient preference trials (stratification of randomization)', offering participants access to alternative treatments, and communicating to participants the value of the randomization strategy.	Research Design Recruitment
Cridland, E. K., S. C. Jones, P. Caputi, C.A. Magee. 2015. "Qualitative Research with Families Living with Autism Spectrum Disorder: Recommendations for Conducting Semistructured Interviews." *Journal of Intellectual & Developmental Disability* 40 (1): 78–91	Explicit	Guidelines: Qualitative research	Extensive suggestions for conducting qualitative research with people with autism and families, including respecting right to assent/consent separately from parents, using checklists on consent forms to be more accessible, and using dissemination phase to provide resources to participants.	Consent Dissemination
Daley, T. C., N. Singhal, and V. Krishnamurthy. 2013. "Ethical Considerations in Conducting Research on Autism Spectrum Disorders in Low and Middle Income Countries." *Journal of Autism and Developmental Disorders* 43 (9): 2002–2014.	Explicit	Conceptual Paper	Describes ethical issues in autism research in low and middle income countries drawing from researcher experience in India, noting the possibility of coercion in low-resource environments, the problem of the therapeutic misconception, and the importance of not jeopardizing access to other services.	Consent
Danforth, A. L., C. M. Struble, B. Yazar-Klosinski, and C. S. Grob. 2016. "MDMA-Assisted Therapy: A New Treatment Model for Social Anxiety in Autistic Adults." *Progress in Neuro-Psychopharmacology & Biological Psychiatry* 64: 237–49	Hidden	Clinical/ Intervention Study	Suggests recruiting autistic adults who use speech or text-to-speech technologies instead of non-speaking children, in order to collect self-report, confirm assent, and communicate better.	Recruitment Consent Data Collection

(*continued*)

Table 1. Continued.

References	Hidden or explicit?	Article type	Content relevant to empowerment	Part(s) of the research process
Dunn-Geier, J., et al. 2000. "Effect of Secretin on Children with Autism: A Randomized Controlled Trial." *Developmental Medicine & Child Neurology* 42 (12): 796–802	Hidden	Clinical/ Intervention Study	Asserts that research into treatment empowers parents to make treatment decisions.	Dissemination
Elsabbagh, M., A. Yusuf, S. Prasanna, K. Shikako-Thomas, C.A. Ruff, and M.G. Fehlings. 2014. "Community Engagement and Knowledge Translation: Progress and Challenge in Autism Research." *Autism* 18 (7): 771–81	Explicit	Clinical/ Intervention Study	Reports that participants considered empowerment a critical goal of research; knowledge generated by research empowers affected individuals, families, and practitioners to make informed decisions.	Dissemination
Francois, D., S. Powell, and K. Dautenhahn. 2009. "A Long-Term Study of Children with Autism Playing with a Robotic Pet Taking Inspirations from Non-Directive Play Therapy to Encourage Children's Proactivity and Initiative-Taking." *Interaction Studies* 10 (3): 324–373.	Hidden	Clinical/ Intervention Study	Honored child's request to not be videotaped despite having permission from parents to do so; used method inspired by non-directive play therapy to encourage the child participant to be proactive in the study.	Data Collection
Fuentes, J., and M. C. Martin-Arribas. 2007. "Bioethical issues in Neuropsychiatric Genetic Disorders." *Child and Adolescent Psychiatric Clinics of North America* 16 (3): 649–661.	Explicit	Conceptual Paper	Suggests strategies to maximize ability to seek assent, including visual aids, augmentative and alternative community, and 'easy reading texts'; details specific considerations for genetic screening.	Consent
Goldstein, R., O. Joja, D. M. Psatta, M. Petrescu, I. Paraschiv, and M. Popa. 1989. "Vasotocin Improves Intelligence and Attention in Mentally Retarded Children." *Physiology & Behavior* 46 (6): 967–70.	Hidden	Clinical/ Intervention Study	Excluded children who expressed reluctance or resistance to the study, despite parent permission.	Consent
Hens, K., H. Peeters, and K. Dierickx. 2016a. "The Ethics of Complexity. Genetics and Autism, A Literature Review." *American Journal of Medical Genetics Part B-Neuropsychiatric Genetics* 171 (3): 305–316.	Explicit	Conceptual Paper	Suggests lay and autism-friendly consent form language, asserts right of children to assent while discussant complexity of inability to assent and choice of proxy consenter. Notes dissent may reflect anxiety rather than refusal, but that anxiety itself may be a reason to dissent. Also includes genetics-specific content suggestions for consent.	Consent

(*continued*)

Table 1. Continued.

References	Hidden or explicit?	Article type	Content relevant to empowerment	Part(s) of the research process
Hens, K., H. Peeters, and K. Dierickx. 2016b. "Shooting a Moving Target. Researching Autism Genes: An Interview Study with Professionals." *European Journal of Medical Genetics* 59 (1): 32–38.	Explicit	Empirical Ethics	Suggest using visuals in informed consent forms and information sheets, both for participants on the spectrum and proxy-consenting parents who may share some traits.	Consent
Hodgetts, S., J. Magill-Evans, and J. E. Misiaszek. 2011. "Weighted Vests, Stereotyped Behaviors and Arousal in Children with Autism." *Journal of Autism & Developmental Disorders* 41 (6): 805–14.	Hidden	Clinical/ Intervention Study	Changed data collection procedures to accommodate physical resistance demonstrated by some participants and requests made by parents.	Data Collection
Howe, E. G. 2003. "Lessons from "Jay Carter"." *Journal of Clinical Ethics* 14 (1–2): 109–17.	Explicit	Conceptual Paper	Provides scripts for care providers to create a space for patients to withdraw consent from having case studies published, or to proactively withdraw from publishing if it would cause harm even if the patient still does consent.	Dissemination
Huws, J. C., and R. S. Jones. 2008. "Diagnosis, Disclosure, and Having Autism: An Interpretative Phenomenological Analysis of the Perceptions of Young People with Autism." *Journal of Intellectual & Developmental Disability* 33 (2): 99–107.	Hidden	Qualitative Study	After interviewing participants, researchers debriefed participants and asked again if they were happy for their responses to be included in the study.	Consent
Jefferson, T. 2004. "Informed Choice and Balance are Victims of the MMR-Autism Saga." *The Lancet Infectious Diseases* 4 (3): 135–6.	Explicit	Conceptual Paper	Asserts that research evidence empowers medical decision-making.	Dissemination
Jivraj, J., L. A. Sacrey, A. Newton, D. Nicholas, and L. Zwaigenbaum. 2014. "Assessing the Influence of Researcher-Partner Involvement on the Process and Outcomes of Participatory Research in Autism Spectrum Disorder and Neurodevelopmental Disorders: A Scoping Review." *Autism* 18 (7): 782–93.	Explicit	Conceptual Paper	Reviews Nicolaidis et al. 2011 for collaborative strategies for doing community-based participatory research with autistic self-advocates; integrating text-based online media and a consensus-building process empowers self-advocates to contribute to the research team by accommodating diverse needs.	Research Design

(*continued*)

Table 1. Continued.

References	Hidden or explicit?	Article type	Content relevant to empowerment	Part(s) of the research process
Johannessen, J., T. Naerland, C. Bloss, M. Rietschel, J. Strohmaier, E. Gjevik, A. Heiberg, S. Djurovic, and O. A. Andreassen. 2016. "Parents' Attitudes Toward Genetic Research in Autism Spectrum Disorder." *Psychiatric Genetics* 26 (2): 74–80.	Explicit	Empirical Ethics	Surveys parent attitudes toward genetic research including decisions like use of collected DNA for future research; suggests cooperation between researchers and participants to help avoid misunderstandings and communicate risks; suggests explicit discussion during recruitment regarding potential benefits and harms not only to participants themselves but to implicated family members.	Recruitment Data Collection Consent Dissemination
Johnson, S. B., G. Whitney, M. McAuliffe, H. Wang, E. McCreedy, L. Rozenblit, and C. C. Evans. 2010. "Using Global Unique Identifiers to Link Autism Collections." *Journal of the American Medical Informatics Association* 17 (6): 689–95.	Explicit	Conceptual Paper	Describes a process for linking data between autism databases while maintaining confidentiality; stresses the importance of clarifying this process when obtaining informed consent.	Consent
Konstantareas, M. M. 1998. "Allegations of Sexual Abuse by Nonverbal Autistic People via Facilitated Communication: Testing of Validity." *Child Abuse & Neglect* 22 (10): 1027–1041.	Explicit	Legal Study	Describes expressions of dissent regarding testing of facilitated communication expressed using facilitated communication.	Data Collection
Langdon, P. E., G. H. Murphy, E. Wilson, L. Shepstone, D. Fowler, D. Heavens, A. Malovic, and A. Russell. 2013. "Asperger Syndrome and Anxiety Disorders (PAsSA) Treatment Trial: A Study Protocol of a Pilot, Multicentre, Single-Blind, Randomised Crossover Trial of Group Cognitive Behavioural Therapy." *BMJ Open* 3 (7).	Hidden	Clinical/ Intervention Study	Provided an 'easier to read' version of study information for potential participants with reading difficulties.	Consent
Langdon, P. E., G. H. Murphy, I. C. Clare, E. J. Palmer, and J. Rees. 2013. "An Evaluation of the EQUIP Treatment Programme with Men who have Intellectual or Other Developmental Disabilities." *Journal of Applied Research in Intellectual Disabilities* 26 (2): 167–80.	Hidden	Clinical/ Intervention Study	Allowed potential participants to have someone else present during the consent process.	Consent
Lappe, M. D. 2014. "Taking Care: Anticipation, Extraction and the Politics of Temporality in Autism Science." *Biosocieties* 9 (3): 304–328.	Explicit	Empirical Ethics	Qualitative study of parents' and researchers' perceptions of research participation, including motivations for participation and what people hoped families and broader communities would get out of participating in terms of accessing services and generating knowledge for future families.	Recruitment Dissemination

(*continued*)

Table 1. Continued.

References	Hidden or explicit?	Article type	Content relevant to empowerment	Part(s) of the research process
Leigh, M. J., D. V. Nguyen, Y. Mu, T. I. Winarni, A. Schneider, T. Chechi, J. Polussa, P. Doucet, F. Tassone, S. M. Rivera, D. Hessl, and R. J. Hagerman. 2013. "A Randomized Double-Blind, Placebo-Controlled Trial of Minocycline in Children and Adolescents with Fragile X Syndrome." *Journal of Developmental & Behavioral Pediatrics* 34 (3): 147–55.	Hidden	Clinical/ Intervention Study	Unblinded participants when they finished the study, not when the study was finished. This is identified as a weakness, but was done in order to allow parents to continue the treatment condition if their child benefited from it.	Research Design
Leonard, H., E. Glasson, A. Bebbington, G. Hammond, D. Croft, T. Pikora, J. Fairthorne, M. O'Donnell, C. O'Leary, M. Hansen, L. Watson, R. W. Francis, K. W. Carter, A. McKenzie, C. Bower, and J. Bourke. 2013. "Application of Population-Based Linked Data to the Study of Intellectual Disability and Autism." In *Using Secondary Datasets to Understand Persons with Developmental Disabilities and Their Families*, edited by R. C. Urbano, 281–327. Amsterdam, Netherlands: Elsevier.	Explicit	Conceptual Paper	Reports on a database that allowed some anonymous entries to account for parents who did not consent to have the child's identifying information given; despite the more limited amount of information, they report some successes in using the database for data linkage projects.	Consent Data Collection
Liu, E. Y., and C. T. Scott. 2014. "Great Expectations: Autism Spectrum Disorder and Induced Pluripotent Stem Cell Technologies." *Stem Cell Reviews and Reports* 10 (2): 145–150.	Explicit	Conceptual Paper	Reviews ethical issues in biobanking and induced pluripotent stems cells with respect to autism research; suggest researchers discuss current state of research with potential participants and realistic expectations for future applications; suggest participants have the right to refuse future contact by investigators using their samples.	Consent
Loyd, D. 2013. "Obtaining Consent from Young People with Autism to Participate in Research." *British Journal of Learning Disabilities* 41 (2): 133–140.	Explicit	Conceptual Paper	Detailed report of strategies used to obtain assent from students with autism, including using a visual information packet to ask for initial assent, partnering with the teacher, asking students again to assent each time they were recorded or interviewed, and using gestures to provide additional visual cues.	Consent Data Collection

(*continued*)

Table 1. Continued.

References	Hidden or explicit?	Article type	Content relevant to empowerment	Part(s) of the research process
Loyd, D. 2015. "Gaining Views from Pupils with Autism about their Participation in Drama Classes." *British Journal of Learning Disabilities* 43 (1): 8–15.	Explicit	Conceptual Paper	Detailed report of strategies used to collect data from students with autism, including collaborating with teachers and parents to ask for assent, re-affirming assent before video recording and interviews, giving participants a 'stop' card to use to end the session, giving participants ample time to prepare responses, and repeating responses back to confirm them.	Consent Data Collection
Mathai, J., A. Bourne, and N. Cranswick. 2005. "Lessons Learnt in Conducting a Clinical Drug Trial in Children with Asperger Syndrome." Australasian Psychiatry 13 (2):173–5.	Explicit	Conceptual Paper	Reports that children would not participate due to not wanting to have a blood test.	Data Collection
McLaughlin, D. M., and E. G. Carr. 2005. "Quality of Rapport as a Setting Event for Problem Behavior: Assessment and Intervention." *Journal of Positive Behavior Interventions* 7 (2): 68–91.	Hidden	Clinical/ Intervention Study	Terminated research sessions at the first sign of problem behaviors; the study itself was also about participant choice (of staff to work with).	Data Collection
Miller, F. A., R. Z. Hayeems, and J. P. Bytautas. 2010. "What is a Meaningful Result? Disclosing the Results of Genomic Research in Autism to Research Participants." *European Journal of Human Genetics* 18 (8): 867–871.	Explicit	Empirical Ethics	Reports parent reflection on the consequences of genetic results for participants' future decision-making.	Dissemination
Nicolaidis, C., D. Raymaker, K. McDonald, S. Dern, E. Ashkenazy, C. Boisclair, S. Robertson, and A. Baggs. 2011. "Collaboration Strategies in Nontraditional Community-Based Participatory Research Partnerships: Lessons from an Academic-Community Partnership with Autistic Self-Advocates." *Progress in Community Health Partnerships* 5 (2): 143–50.	Explicit	Conceptual Paper	Describes strategies to empower people with autism to contribute to community-based participatory research by deciding, for example, what to study and what to communicate to the public; strategies include a five-finger consensus-building method.	Research Design
Pellicano, E., A. Dinsmore, and T. Charman. 2014. "What Should Autism Research Focus Upon? Community Views and Priorities from the United Kingdom." *Autism* 18 (7): 756–770.	Explicit	Empirical Ethics	Expresses concern that lack of funding into priorities identified by the autism community means lack of evidence-based ways of addressing autism community needs.	Dissemination

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Table 1. Continued.

References	Hidden or explicit?	Article type	Content relevant to empowerment	Part(s) of the research process
Pellicano, E., and M. Stears. 2011. "Bridging Autism, Science and Society: Moving Toward an Ethically Informed Approach to Autism Research." *Autism Research* 4 (4): 271–282.	Explicit	Conceptual Paper	Raises concerns about the use of both individual and general research results; draws from empirical study suggesting that few autism families seem interested in genetic counseling sessions; suggests 'checks' on researchers to prevent them putting forth a cure/prevention mentality that could be used for undesirable purposes.	Dissemination
Perry, A. 2012. "Autism Beyond Pediatrics: Why Bioethicists Ought to Rethink Consent in Light of Chronicity and Genetic Identity." *Bioethics* 26 (5): 236–241.	Explicit	Conceptual Paper	Suggests using adaptive technologies to allow adults on the spectrum who do not communicate with speech to share their experiences and inform the design of the consent process for children with autism.	Consent
Porayska-Pomsta, K., C. Frauenberger, H. Pain, G. Rajendran, T. Smith, R. Menzies, M. E. Foster, A. Alcorn, S. Wass, S. Bernadini, K. Avramides, W. Keay-Bright, J. Chen, A. Waller, K. Guldberg, J. Good, and O. Lemon. 2012. "Developing Technology for Autism: An Interdisciplinary Approach." *Personal and Ubiquitous Computing* 16 (2): 117–127.	Explicit	Clinical/ Intervention Study	Notes that parents of children with autism are generally more interested to have their children participate in research as compared to other parents; stresses researchers' need to be flexible when working in school environments.	Recruitment Consent Data Collection
Preece, D., and R. Jordan. 2010. "Obtaining the Views of Children and Young People with Autism Spectrum Disorders about their Experience of Daily Life and Social Care Support." *British Journal of Learning Disabilities* 38 (1): 10–20.	Explicit	Qualitative Study	Told children they did not have to take part in the study even if their other family members participated; treated child's level of engagement during the meeting as a secondary sign of consent; stopped sessions at signs of distress; gave participants transcripts or audio of the interview, and an opportunity to delete responses or provide more information.	Consent Data Collection
Racine, E, E Bell, and M Shevell. 2013. "Ethics in Neurodevelopmental Disability." In Handbook of Clinical Neurology. Vol 118 (Ethical and Legal Issues in Neurology), 3rd ed., edited by J. L. Bernal and R. Beresford, 243–463. Amsterdam, Netherlands: Elsevier.	Explicit	Conceptual Paper	Stresses importance of children's assent and dissent in non-beneficial research where considerations of clinical interests do not come into play.	Consent

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Table 1. Continued.

References	Hidden or explicit?	Article type	Content relevant to empowerment	Part(s) of the research process
Rimland, B. 1998. "High Dose Vitamin B6 and Magnesium in Treating Autism: Response to Study by Findling et al." *Journal of Autism & Developmental Disorders* 28 (6): 581–2.	Hidden	Conceptual Paper	Observes that most children on the spectrum refuse to take Vitamin B6 for research due to its bitter taste, which may lead to high drop-out rates.	Data Collection
Rossi, J., C. Newschaffer, and M. Yudell. 2013. "Autism Spectrum Disorders, Risk Communication, and the Problem of Inadvertent Harm." *Kennedy Institute of Ethics Journal* 23 (2): 105–38.	Explicit	Conceptual Paper	Frames ethics of risk communication as an issue, in part, of the consequences of that communication for other decisions.	Dissemination
Ruef, M. B., and A. P. Turnbull. 2002. "The Perspectives of Individuals with Cognitive Disabilities and/or Autism on Their Lives and their Problem Behavior." *Research and Practice for Persons with Severe Disabilities* 27 (2): 125–140.	Hidden	Qualitative Study	Gave potential participants opportunities to meet individually with researchers to discuss study.	Recruitment
Rysavy, M. A., and J. R. Murph. 2015. "On Risks and Reality: Communicating the Difference between Autism Risks and Diagnosis." *AMA Journal of Ethics* 17 (4): 323–7.	Explicit	Conceptual Paper	Identifies ethical responsibility for autism researchers to avoid inflating validity or importance of research or results, because families use research and results to make important decisions.	Dissemination
Sandler, A. 2005. "Placebo Effects in Developmental Disabilities: Implications for Research and Practice." *Mental Retardation and Developmental Disabilities Research Reviews* 11 (2): 164–170.	Explicit	Conceptual Paper	Discusses ethics of placebo studies in light of studies of secretin and autism; stresses importance of adequately informing potential participants about the use of placebo conditions.	Consent
Santosh, P., J. Tarver, F. Gibbons, S. Vitoratou and E. Simonoff. 2016. "Protocol for the Development and Validation of a Questionnaire to Assess Concerning Behaviours and Mental Health in Individuals with Autism Spectrum Disorders: The Assessment of Concerning Behaviour (ACB) Scale." *BMJ Open* 6(3): e010693.	Explicit	Clinical/ Intervention Study	Used a capacity checklist with participants when the research team had doubts about capacity to consent.	Consent

(*continued*)

Table 1. Continued.

References	Hidden or explicit?	Article type	Content relevant to empowerment	Part(s) of the research process
Sarrett, J. C., and K. S. Rommelfanger. 2015. "Commentary: Attention to Eyes Is Present but in Decline in 2-6-Month-Old Infants Later Diagnosed with Autism." *Frontiers in Public Health* 3:272.	Explicit	Conceptual Paper	Discusses screening studies using eye-tracking, which might be predictive but not diagnostic for autism, and the importance of emphasizing this difference to parents and study participants.	Consent
Scahill, L., and C. Lord. 2004. "Subject Selection and Characterization in Clinical Trials in Children with Autism." *CNS Spectrums* 9 (1): 22–32.	Explicit	Conceptual Paper	Discusses sampling in interventional research; heterogeneous samples might be more difficult to interpret, but homogenous samples might be more difficult to recruit and have limited generalizability.	Recruitment Dissemination
Scahill, L., J. McCracken, C. J. McDougle, M. Aman, L. E. Arnold, E. Tierney, P. Cronin, M. Davies, J. Ghuman, N. Gonzalez, K. Koenig, R. Lindsay, A. Martin, J. McGough, D. J. Posey, N. Swiezy, F. Volkmar, L. Ritz and B. Vitiello. 2001. "Methodological Issues in Designing a Multisite Trial of Risperidone in Children and Adolescents with Autism." *Journal of Child & Adolescent Psychopharmacology* 11 (4): 377–388.	Explicit	Clinical/ Intervention Study	Researchers evaluated parents' impressions of the consent process using a questionnaire, but the results are not presented in this paper.	Consent
Schwartz, I. S., and D. M. Baer. 1991. "Social Validity Assessments - Is Current Practice State-Of-The-Art." *Journal of Applied Behavior Analysis* 24 (2): 189–204.	Explicit	Conceptual Paper	Suggest several signs that can be used to assess the social validity (acceptability) of an intervention, which do not rely on verbal communication, including a coding scheme for evaluating children with autism's enthusiasm; note that people with developmental disabilities are often more proactive about expressing concerns with an intervention program than others.	Data Collection
Shamsuddin, S., H. Yussof, S. Mohamed, and F. A. Hanapiah. 2014. "Design and Ethical Concerns in Robotic Adjunct Therapy Protocols for Children with Autism." *Procedia Computer Science* 42: 9–16	Explicit	Conceptual Paper	Stresses the importance of writing in parent consent form that child participants are allow to decline or discontinue participation.	Consent

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Table 1. Continued.

References	Hidden or explicit?	Article type	Content relevant to empowerment	Part(s) of the research process
Singh, J. S. 2015. "Narratives of Participation in Autism Genetics Research." *Science Technology & Human Values* 40 (2): 227–249.	Explicit	Qualitative Study	Qualitative study of parents whose children participate in autism genetic research; found that most parents were not seriously concerned about privacy and in fact favored sharing information.	Dissemination
Sokhadze, E. M., M. F. Casanova, A. Tasman, and S. Brockett. 2016. "Electrophysiological and Behavioral Outcomes of Berard Auditory Integration Training (AIT) in Children with Autism Spectrum Disorder." *Applied Psychophysiology & Biofeedback* 41 (4): 405–420.	Hidden	Clinical/ Intervention Study	Report moving away from a placebo control design because they had trouble recruiting families who would agree to participate in such a study.	Recruitment
Stein, Mark A, and Bryan H King. 2016. "Unequal Individual Risk and Potential Benefit Balanced by Benefits to the Population at Large in Autism Clinical Trials?" *The American Journal of Bioethics* 16 (4): 72–74.	Explicit	Conceptual Paper	Affirms that child participants must still be given the right to refuse to participate in a research study even if their parents moved the family to a new place in order to enroll.	Consent
Stokstad, E. 2008. "Medicine. Stalled Trial for Autism Highlights Dilemma of Alternative Treatments." *Science* 321 (5887): 326.	Explicit	Journalism	Presents argument that chelation trials should be held because if results show chelation is not effective, parents could use that result to make decisions about chelation.	Research Design
Szego, M. J., and M. H. Zawati. 2016. "Whole Genome Sequencing as a Genetic Test for Autism Spectrum Disorder: From Bench to Bedside and then Back Again." *Journal of the Canadian Academy of Child and Adolescent Psychiatry* 25 (2): 116–121.	Explicit	Conceptual Paper	Advocates for a database approach to studying whole genome sequences for autism research, requiring explicit consent from patients for the future use of their data in research; this additional consent process would require discussion of risks and benefits, notably privacy, and an assent process for pediatric patients that involves re-consent when these patients come of age.	Consent
Tabor, H. K., and M. K. Cho. 2007. "Ethical Implications of Array Comparative Genomic Hybridization in Complex Phenotypes: Points to Consider in Research." *Genetics in Medicine* 9 (9): 626–631.	Explicit	Conceptual Paper	Reviews ethical issues in array comparative genomic hybridization in autism research; questions if research on older samples involved a sufficient consent process; raises issues of implications for reproductive decision-making and possibility of incidental findings.	Consent Dissemination

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Table 1. Continued.

References	Hidden or explicit?	Article type	Content relevant to empowerment	Part(s) of the research process
Tabor, H. K., T. Brazg, J. Crouch, E. E. Namey, S. M. Fullerton, L. M. Beskow and B. S. Wilfond. 2011. "Parent Perspectives on Pediatric Genetic Research and Implications for Genotype-Driven Research Recruitment." *Journal of Empirical Research on Human Research Ethics* 6 (4): 41–52.	Explicit	Empirical Ethics	Qualitative study of parents' perceptions of return of genetic results. Finds parents want a choice due to consequences of results including possible negative psychological consequences, information for clinical decision-making, and information for reproductive decision-making; parents want results returned even if they do not understand results, because they provide hope and motivation to participate in future studies; suggests offering genetic counseling during return of results.	Dissemination
Takahashi, H., S. Suzumura, F. Shirakizawa, N. Wada, K. Tanaka-Taya, S. Arai, N. Okabe, H. Ichikawa, and T. Sato. 2003. "An Epidemiological Study on Japanese Autism Concerning Routine Childhood Immunization History." *Japanese Journal of Infectious Diseases* 56 (3): 114–117.	Explicit	Clinical/ Intervention Study	Epidemiological study on vaccination history and autism; researchers concerns that the informed consent process itself may have biased the sample.	Consent Recruitment
Torres, E. B., P. Yanovich, and D. N. Metaxas. 2013. "Give Spontaneity and Self-Discovery a Chance in ASD: Spontaneous Peripheral Limb Variability as a Proxy to Evoke Centrally Driven Intentional Acts." *Frontiers in Integrative Neuroscience* 7 (46.): 1–25	Hidden	Clinical/ Intervention Study	Research design demands that 'the child should lead', gives less active role to experimenter.	Research Design
Trehin, P. 2003. "Ethics of Research on Intellectual Disabilities and Autism: Point of View of a Parent." *Consensus in Child Neurology: Biological Bases and Clinical Perspectives in Autism,* edited by M. Elia, V. Romano, and P. Curatolo, pp. 17–23. Hamilon, ON: BC Decker.	Explicit	Conceptual Paper	Stresses using clear, lay language for consent forms. Encourages using alternative and augmentative communication, watching for nonverbal signs of discomfort, and using parent consent when necessary. Cautions that images and metaphor could be too abstract for people with autism.	Consent Data Collection

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Table 1. Continued.

References	Hidden or explicit?	Article type	Content relevant to empowerment	Part(s) of the research process
Vazquez, C. A. 1995. "Failure to Confirm the Word-Retrieval Problem Hypothesis in Facilitated Communication." *Journal of Autism & Developmental Disorders* 25 (6): 597–610.	Hidden	Clinical/ Intervention Study	Noted nonverbal signs that participants were interested in participating, such as seeking out test materials and refusing to leave after a session ended.	Data Collection
Vitiello, B., M. G. Aman, L. Scahill, J. T. McCracken, C. J. McDougle, E. Tierney, M. Davies, and L. E. Arnold. 2005. "Research Knowledge among Parents of Children Participating in a Randomized Clinical Trial." *Journal of the American Academy of Child and Adolescent Psychiatry* 44 (2): 145–149.	Explicit	Empirical Ethics	Assessed understanding of research protocols by parents giving permission for their children to participate in a randomized controlled trial; found good parent understanding and retention of main points.	Consent
Vosoughi, S., M. S. Goodwin, B. Washabaugh, D. Roy, and ACM. 2012. "A Portable Audio/Video Recorder for Longitudinal Study of Child Development." *ICMI '12: Proceedings of the ACM International Conference on Multimodal Interaction* (New York, NY, USA, October 20–26), 193–200.	Explicit	Conceptual Paper	Includes privacy management as an important component of instrument design; developed an 'oops' button for participants to delete materials they did not want stored and a 'consent' button to record photographs of which individuals consented in order to check photographs against video and delete non-consentors.	Data Collection
Warnell, F., B. George, H. McConachie, M. Johnson, R. Hardy, and J. R. Parr. 2015. "Designing and Recruiting to UK Autism Spectrum Disorder Research Databases: Do They Include Representative Children with Valid ASD Diagnoses?" *BMJ Open* 5 (9):e008625.	Explicit	Clinical/ Intervention Study	Despite concerns about asking parents for research consent during diagnostic of follow-up visits (which can be sensitive times), found that parents were open to it provided that researchers presented clear information about the study purpose.	Recruitment
Wible, J. R., and S. Dietrich. 2002. "Innovative Therapies, Suspended Trials, and the Economics of Clinical Research - Facilitated Communication and Biomedical Cases." *Philosophy of the Social Sciences* 32 (3): 275–309.	Explicit	Conceptual Paper	Asserts that people have the right to know if an intervention is considered impossible to evaluate scientifically.	Dissemination
Williams, J. L., W. A. Faucett, B. Smith-Packard, M. Wagner, and M. S. Williams. 2014. "An Assessment of Time Involved in Pre-test Case Review and Counseling for a Whole Genome Sequencing Clinical Research Program." *Journal of Genetic Counseling* 23 (4): 516–521.	Explicit	Empirical Ethics	Measured time spent on genetic counseling and pre-test case review in the context of a whole genome sequencing study, as well as consent/ non-consent rates; one family requested to speak with the genetic counselor before deciding whether or not to participate.	Recruitment Consent Dissemination

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Table 1. Continued.

References	Hidden or explicit?	Article type	Content relevant to empowerment	Part(s) of the research process
Wright, B., D. Marshall, D. C. Moore, H. Ainsworth, L. Hackney, J. Adamson, S. Ali, V. Allgar, L. Cook, L. Dyson, E. Littlewood, R. Hargate, A. McLaren, D. McMillan, D. Trepel, J. Whitehead, and C. Williams. 2014. "Autism Spectrum Social Stories In Schools Trial (ASSSIST): Study Protocol for a Feasibility Randomised Controlled Trial Analysing Clinical and Cost-Effectiveness of Social Stories in Mainstream Schools." *BMJ Open* 4 (7).	Explicit	Clinical/ Intervention Study	Co-designed leaflets and consent forms with patient and public involvement group.	Consent
Young, J. G., D. J. Cohen, S. E. Shaywitz, B. K. Caparulo, M. E. Kavanagh, R. D. Hunt, J. F. Leckman, G. M. Anderson, J. Detlor, D. Harcherik, and B. A. Shaywitz. 1982. "Assessment of Brain Function in Clinical Pediatric Research: Behavioral and Biological Strategies." *Schizophrenia Bulletin* 8 (2): 205–35.	Explicit	Conceptual Paper	List strategies for protecting participant rights and obtaining informed consent including not inviting families to participate during stressful or unstable periods, providing specially designed assent forms for children, encouraging parents to take forms home to read at their leisure, and training nurses who explain procedures step until both child and families understand.	Recruitment Consent Data Collection
Yudell, M., H. K. Tabor, G. Dawson, J. Rossi, C. Newschaffer, Communication Working Group in Autism Risk, and Ethics. 2013. "Priorities for Autism Spectrum Disorder Risk Communication and Ethics." *Autism* 17 (6): 701–22.	Explicit	Task Force Report	Discusses ethics of return of research results that contain risk information; results should be understandable to people with autism in order to further self-determination; results may have several benefits as well as implications for treatment and reproductive decision-making; aggregate results should also be communicated; when deciding whether to return results of limited clinical validity, researchers should consider what participants will likely do with the results.	Dissemination
Zheng, Z., E. M. Young, A. R. Swanson, A. S. Weitlauf, Z. E. Warren, and N. Sarkar. 2016. "Robot-Mediated Imitation Skill Training for Children With Autism." *IEEE Transactions on Neural Systems and Rehabilitation Engineering* 24 (6): 682–691.	Hidden	Clinical/ Intervention Study	Reports four participants with autism refusing to participate, two by refusing to sit in the experiment chair at all and two by 'exhibit[ing] mild distress' after beginning.	Data Collection Consent

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Table 1. Continued.

References	Hidden or explicit?	Article type	Content relevant to empowerment	Part(s) of the research process
Zorn, S., and M. Puustinen. 2015. "Recueillir des données auprès d'élèves avec troubles du spectre autistique en collège [Collecting Data from Students with Autistic Spectrum Disorders in Secondary School]." ICODOC 2015: Colloque Jeunes Chercheurs du Laboratoire ICAR, 20:01023 (unpaginated; 16 pages).	Explicit	Conceptual Paper	Conducted trial observation periods in classrooms before beginning the study, as an opportunity for students to meet the researchers and ask questions, in addition to getting permission from parents and teachers.	Consent
Zwaigenbaum, L., S. Scherer, P. Szatmari, E. Fombonne, S. E. Bryson, K. Hyde, E. Anognostou, J. Brian, A. Evans, G. Hall, D. Nicholas, W. Roberts, I. Smith, T. Vaillancourt, and J. Volden. 2011. "The NeuroDevNet Autism Spectrum Disorders Demonstration Project." *Seminars in Pediatric Neurology* 18 (1): 40–48.	Hidden	Clinical/ Intervention Study	Discusses plans to hold workshops to determine the best way to translate genetic research into application, including families and adults with ASD.	Dissemination

Laws and policies vary internationally and regionally, but for an overview in the U.S. see Wright (2019) and the UK see UK Department of Health and Social Care (2009). Our focus in this section is not the legal aspects which may vary substantially (e.g. at what age 'mature minor' doctrines take effect and how they might relate to research), but rather on the ethics scholarship (e.g. what *should* participation be and *why*) and every day aspects of research decisions (e.g. how to provide a space to say yes or no). Barnes and McCabe (2012) assert that people with autism who are unable to give consent 'should have the right for their guardians to consent on their behalf', rather than not being asked to participate in research at all (see also Carlson 2013). However, there are several questions about who the appropriate person might be to make decisions on behalf of such a person with autism (Carlson 2013; Perry 2012; Hens, Peeters, and Dierickx 2016b). Some argue that parents, who are often asked to make decisions about their children's research participation, may not be the best people to do so due in part to tensions between the priorities of many parents of people with autism and the priorities of many adults with autism themselves (Perry 2012). Perry (2012) suggests having adults with autism involved in designing consent forms for children with autism as part of an effort to empower them in this context. Patient and public involvement groups can also help with consent form design (Wright et al. 2014).

Regardless of who offers permission, several authors explicitly assert the right of children to assent (say yes) or dissent (say no) for themselves after permission has been given, and assert the obligation of researchers to honor a child's refusal to participate even when the parent has given permission (Stein and King 2016; Goldstein et al. 1989; Shamsuddin et al. 2014; Preece and Jordan 2010; Cridland et al. 2015). Empowering children to communicate these decisions might include preparing materials specifically for children (Loyd 2013). Researchers might also honor children's requests about specific activities during research, such as requests not to be videotaped despite having parents' permission to do so (Francois, Powell, and Dautenhahn 2009). Children's assent and dissent are particularly important in the case of non-beneficial research, whereas in beneficial research there may be some justification for overriding child's dissent if the decision impacts clinical welfare (Racine, Bell, and Shevell 2013).

Participants may express assent and dissent in diverse ways

Assent and dissent can be communicated in ways other than saying yes or no. Many sources in the literature stress the importance of researchers attending to both verbal and non-verbal indicators of assent and dissent (Trehin 2003; Preece and Jordan 2010; Hens, Peeters, and Dierickx 2016b; Barrow and Hannah 2012; Konstantareas 1998), which has also been noted

for participants with Rett syndrome (Larsson et al. 2013). Reviewed articles provide several examples of signs of assent or dissent they have observed. 'Soft no's' such as reluctance or resistance may need to be taken as signs of refusal (Goldstein et al. 1989), while a desire for engagement may also be demonstrated nonverbally (Preece and Jordan 2010), such as 'repeated attempts to open the cabinet door and grab the test materials, as well as their occasional refusal to leave the testing area after a session' (Vazquez 1995, 607). Opinions of parents and siblings about participants' responses can also help researchers to judge nonverbal cues (Preece and Jordan 2010).

Reviewed articles also reveal ways in which researchers can proactively empower participants to express non-verbal decisions. Loyd (2015) gave participants a 'stop' card to indicate if they wanted to discontinue a session. Schwartz and Baer (1991) suggest several indicators of assent or willingness to participate that do not rely on verbal communication, including a coding scheme for evaluating children with autism's enthusiasm. They also note that people with developmental disabilities are often more proactive about expressing concerns with an intervention program than others because they are not as hindered by neurotypical preoccupations with 'courtesy' that might make them hesitate (Schwartz and Baer 1991, 200).

Dissent is tensely debated in research ethics, especially for beneficial research. It can be difficult to determine if signs of dissent are an actual refusal to participate, or simply a fear of anxiety that might be induced during the study. Others note, however that the fear response itself might 'be considered higher than minimal risk and is a sufficient reason to allow children to dissent to participate in research' (Hens, Peeters, and Dierickx 2016b) and so the idea of 'simply a fear' may indeed be worth taking as dissent. This point importantly contrasts with situations where researchers often conclude it might be considered ethical to 'persuade or cajole' neurotypical child participants (Nuffield Council on Bioethics 2015).

Consent is a process, not a one-time event or form

Research ethics scholars have long maintained that consent is a process, not a one-time signature on a form (Lahman et al. 2011). The literature we identified provides several suggestions for how to practice 'process consent'. Loyd (2013) had the teacher involved in her study of classroom experiences ask the class for consent every time she (the researcher) was present, there was video recording, and for individual interviews. Furthermore, 'When a young person commented on the camera directly, the comment was used as an opportunity to ensure that young person was happy with being recorded' (Loyd 2013, 135). Another strategy to ensure consent as an ongoing process is to reaffirm it at the end of a study, as Huws and Jones (2008, 101) did by

providing a debriefing after each interview 'during which the participants were informed that the research formed part of a larger study that involved interviewing other people about their views on autism. Participants were then asked to indicate whether they were still happy for their responses to be included in the study'. Note that both of these quotations rely on the idea of 'being happy' rather than 'consenting', a more accessible and less jargon-laden term. Other strategies to promote the process include providing overt opportunities for additional questions in in-person (Cridland et al. 2015) and online (Brownlow and O'Dell 2002) research, as well as giving potential participants a chance to meet researchers and ask questions (Zorn and Puustinen 2015; Ruef and Turnbull 2002). In keeping with the individualization guidepost of person-oriented research ethics (Cascio & Racine 2018), the consent process can also be individualized to the unique needs of each person in certain ways (Cridland et al. 2015; Carlson 2013; Howe 2003; Cermak et al. 2015; Leigh et al. 2013).

Consent processes can be more accessible for autistic people

Another finding from the literature review holds that the consent process should be accessible by considering common needs and strengths of people on the spectrum. One concrete example of this is designing 'autism-friendly' consent forms (Hens, Peeters, and Dierickx 2016a, 2016b; Trehin 2003; Fuentes and Martin-Arribas 2007). Autism-friendly strategies might include using visuals (Fuentes and Martin-Arribas 2007; Loyd 2013; Hens, Peeters, and Dierickx 2016a), accounting for literal thinking (Hens, Peeters, and Dierickx 2016a), accounting for difficulty foreseeing implications (Hens, Peeters, and Dierickx 2016a), using alternative and augmentative communication (Trehin 2003; Fuentes and Martin-Arribas 2007), using text-to-speech communication (Danforth et al. 2016), using a checklist format especially with children (Cridland et al. 2015), using gestures to provide additional visual cues (Loyd 2013), mixing written and verbal description (Huws and Jones 2008), and using 'easy reading texts' (Fuentes and Martin-Arribas 2007) or 'easier to read' formats (Langdon, Murphy, Wilson, et al. 2013). These strategies draw on common characteristics of people with autism, although they may not work for everyone. The Task Force Workshop participants agreed that while many autistic people are good with images, this is not true for everyone, and over-stressing it may ignore the diversity of need. Moreover, communication styles can be heavily shaped by context. Therefore, it can also be helpful to design consent communication in ways that are consistent with the ways participants are used to communicating, such as in Loyd's (2013) use of 'widgets' and social stories, which her participants already

used. Another way the consent process can be autism-friendly is by providing multiple ways for participants to communicate consent (e.g. by speech, by graphics, or by gesture) (Loyd 2013) and repeating participants' responses back to them to confirm understanding (Loyd 2015). Empowering consent processes might also allow supportive involvement of other parties. Some researchers gave participants the opportunity to have another person present during the consent process (Langdon, Murphy, Clare, et al. 2013), while others advocate for the use of legally authorized representatives to consider 'goodness of fit' between the potential participant and the study (Fuentes and Martin-Arribas 2007).

Accessibility concerns not only needs related to individual characteristics, but also social context. Another important lesson from the literature is that the setting of a study can make free decision-making harder. Institutional settings such as large residential services or group homes might make potential participants vulnerable to coercion from staff who have given researchers access (Carlson 2013). In family settings, some researchers have suggested avoiding inviting families to participate in research during times of 'unusual family stress' (Young et al. 1982) but others have found that families can easily process a request during 'a sensitive time' (Warnell et al. 2015). Attention to time and place can therefore be an important part of empowerment in decision-making

Specific types of research might require sharing specific information

Another consideration of empowerment is to determine the kind of information that must be shared with potential participants in order to empower decisions about the specific study at hand. This question arises with reference to research involving electronic communications such as email or web forums (Brownlow and O'Dell 2002), research on therapeutic interventions (Wible and Dietrich 2002; Fuentes and Martin-Arribas 2007; Daley, Singhal, and Krishnamurthy 2013; Scahill and Lord 2004) and research in which the researcher is also a therapist to the participant (Carter 2003; Howe 2003; Brendel 2003), screening and other genetic research – which might also implicate family members of participants (Johannessen et al. 2016; Williams et al. 2014; Fuentes and Martin-Arribas 2007; Baret and Godard 2011; Liu and Scott 2014; Sarrett and Rommelfanger 2015, see also Bell et al. 2015), studies involving placebos (Sandler 2005), as well as research databases and similar situations where data might be used in later studies (Warnell et al. 2015; Tabor and Cho 2007; Hens, Peeters, and Dierickx 2016b; Szego and Zawati 2016; Lappe 2014; Johnson et al. 2010; Ben Said et al. 2014; Liu and Scott 2014).

Empowerment, data collection, and research design

While deciding whether or not to participate in a particular study is a key decision-making moment, it is not the only decision participants make. Empowerment in decision-making about data collection and write-up is also important. Participants can consent to some but not all components of a study, such as sharing or not sharing identifying details in a database (Leonard et al. 2013). Recording devices used for data collection can have an 'oops' button to give users control over what recordings are kept (Vosoughi et al. 2012). Similarly, Preece and Jordan (2010) allowed participants to delete responses. While some participants may be concerned about sharing too much data, other participants might very much want to share it (Singh 2015). Another way participants can be empowered during the data collection process is if researchers stop data collection at signs of distress such as 'problem behavior' (McLaughlin and Carr 2005), refusal to sit in the experiment chair (Zheng et al. 2016), or resistance to using study tools like a heart-rate monitor (Hodgetts, Magill-Evans, and Misiaszek 2011). Informal observations can also inform researchers as to what participants find palatable; for example, one study found that 'many children would not participate because they were averse to having a blood test' (Mathai, Bourne, and Cranswick 2005); other researchers report that 'Vitamin B6 is very bitter; most autistic children refuse to take it' (Rimland 1998).

Sometimes empowering participants to make choices can be vital to research design, when the design is about such choices. For example, McLaughlin and Carr specifically studied the role of rapport with staff with respect to problem behavior, and were able to identify who had good rapport with a particular participant, by asking participants who they wanted to work with. Torres, Yanovich, and Metaxas (2013) stress the importance of letting the participant guide the process of a child-computer interface study, giving the experimenter a less active role. Although these designs are more inherently individualistic, even RCTs can take into consideration participant preference through things like stratification of randomization (Charman et al. 2003). Participants can also be empowered in the process of writing up research results. This point was discussed in the literature review around the controversial case study of 'Jay Carter', (pseudonym) whose psychiatrist asked to write a case report about their psychotherapy sessions. Carter gave his permission. After the psychiatrist published the piece, he gave it to Carter to read. Carter was hurt and distressed, in part by the tone of the piece, in part by its focus on Asperger's which had not been a focus of the psychotherapy, and in part by the embellishments taken to 'thickly disguise' his identity. The resulting case of this ethically fraught situation was then featured in *Journal of Clinical Ethics* (Howe 2003; Carter 2003; Brendel 2003) where editor-in-chief Howe (2003) commented, suggesting that in some

situations where care providers write case studies, they should let patients read the work paragraph by paragraph and 'they should stop writing, if patients request it'. While this is a clinical case and concern for Carter as a patient also played into this suggestion, non-clinical researchers such as anthropologists do sometimes encourage their research participants to read results and provide input before publication, such as in the process of 'member checking' (LeCompte and Schensul 2010).

Empowerment, dissemination, and return of research results

Empowerment in decision-making is also important with respect to dissemination of research findings and returning individual results to participants. The results of a research study may have implications for treatment decisions (Stokstad 2008; Rysavy and Murph 2015; Dunn-Geier et al. 2000; Jefferson 2004; Elsabbagh et al. 2014). Disseminating results, especially 'risk' information and genetic information, can have consequences for medical and reproductive decision making (Tabor et al. 2011; Rossi, Newschaffer, and Yudell 2013; Yudell et al. 2013; Hens, Peeters, and Dierickx 2016b; Johannessen et al. 2016; Miller, Hayeems, and Bytautas 2010; Bowdin et al. 2014). A review dedicated to the ethics of the return of genetic results has already been published (Bell et al. 2015). Because of the impact of research results on other decisions, participants may therefore need to be empowered to use them. For instance, Zwaigenbaum et al. (2011) planned a 'series of workshops aimed at determining optimal approaches to translation of genomic discoveries' to engage people with autism and families in determining the best way to share what researchers learn. In order to empower participants to continue the treatment condition if they found it helpful, Leigh and colleagues (2013) unblinded the Fragile X treatment condition they used to each family upon completion, rather than at the end of the study, so that families could use that information to decide whether or not to continue the treatment. Funding decisions are also important for empowering participants, as lack of research funding relevant to the concerns of the autism community can lead to a lack of knowledge about the topics most pressing for the community, leading to disempowerment (Pellicano, Dinsmore, and Charman 2014).

Community empowerment and community-based participatory research

Researchers can also empower people with autism to contribute to research in ways other than as participants. Perhaps the most notable research approach to do so is community-based participatory research (CBPR). CBPR has also been used in the context of autism research in

participatory research groups such as AASPIRE (Jivraj et al. 2014; Nicolaidis et al. 2011). Newer articles on these approaches have been published since we completed this review (e.g. Fletcher-Watson et al. 2018; Nicolaidis et al. 2019), demonstrating the timeliness of considering these issues. In these approaches, people with autism work alongside researchers to set research priorities and to design, publicize, execute, and write up research studies. CBPR and related movements (e.g. Participatory Action Research) make explicit claims about empowerment, namely that empowerment can occur *through* CBPR. It is also important to consider empowerment *within* CBPR, namely how to empower autistic collaborators in these projects. Researchers have reported on strategies to do so, such as setting rules about email use, and the 'five finger' method of voting, where participants can hold up fingers corresponding to a five-point scale of preferences on an action item (Jivraj et al. 2014; Nicolaidis et al. 2011). Even non-CBPR research can have implications for community empowerment beyond a medical or treatment-oriented model. Research can also be an opportunity to inform people about local autism community groups or support services they may not have accessed (Cridland et al. 2015).

Evidence-based practices: Who consents and why

Our literature review also indicates that research on decision-making can be used to develop 'evidence-based' empowerment practices (Anderson and Sieber 2009; Kalichman 2009). Several studies have reported on the perspectives of parents who are asked to give permission for their children to participate in research. Vitiello and colleagues (2005) investigated how parents of children with autism understood consent forms in a placebo-controlled trial (see also Scahill et al. 2001). They found that parents were very knowledgeable of key components, such as the purpose of the study and the right to withdraw, but did express the common 'therapeutic misconception' of thinking that the treatment arm placement was personalized to their child, rather than being a random decision (Vitiello et al. 2005). There have also been qualitative studies on parents' perspectives on research participation (Lappe 2014; Tabor et al. 2011) that suggest that some may be motivated to participate in research to obtain assessments in order to receive needed services, or to develop relationships with autism researchers and experts. Researchers have also asked parents their opinions on whether or not their children with autism should be asked to participate in research (Johannessen et al. 2016), and whether or not their children with Fragile X Syndrome would be able to give consent (Bailey et al. 2014), with parents being generally in favor. Similar studies investigating the perspectives of both parents and children have been planned to help develop 'evidence-

based standards for informed consent and educational materials' (Bowdin et al. 2014). Such studies can also provide information on specific ethical issues, like genetic counseling and genetic research (Pellicano and Stears 2011).

Recording and reflecting on who chooses not to consent to research can inform best practices for an empowering research process by revealing the impact of the consent process on the study. Some studies note that parents of people with autism may be more inclined to give permission for their children to participate in research than parents of neurotypical children (Porayska-Pomsta et al. 2012), but there may still be recruitment challenges. Researchers have reflected that their informed consent process may have itself influenced their decision-making, inadvertently discouraging families from enrolling children whose immunization history was poor or incomplete (Takahashi et al. 2003). The rate of non-consent was also a concern and consideration in a study of the time researchers needed to spend on genetic counseling prior to genetic testing (Williams et al. 2014). Researchers have reported moving away from a placebo control design because they had trouble recruiting families who would agree to participate in such a study (Sokhadze et al. 2016). Researchers can take the lessons from these studies to empower participants by providing information that is relevant to them, using designs that address their needs, and dedicating sufficient time to the recruitment and consent process. As the reviewed articles almost exclusively focus on the motivations and perspectives of parents as gatekeepers, more research is needed including the perspectives of participants (of any age) themselves.

Discussion

Empowerment can be considered a central component of research ethics (Cascio and Racine 2018), including in the context of autism research. The autistic community has raised empowerment as a key issue. The results above describe many ways in which empowerment is important throughout the research process, and suggestions for researchers to use to empower participants. The articles included in this review come from a variety of sources – some explicitly addressing ethics and others reflecting on ethics implicitly or incidentally. The reviewed articles include clinical studies, qualitative research, philosophical and conceptual papers taking a range of lenses, and a few narratives from participants and parents. Some draw from a medical model, some a social model, and some a combination or another model between or beyond that binary. This range has the benefit of generating a wealth of discussion and placing into conversation scholarship that might otherwise be disconnected, although it also has the limitation of lacking a

consistent approach. In this discussion, we highlight overarching trends and connect the reviewed articles to broader literature. Overall, this review reveals four main understandings of empowerment: empowerment as consent, empowerment as a developing process, empowerment as engagement, and empowerment in context.

Empowerment as consent

Many of the discussions about empowerment center on consent. Much of the literature highlights consent as a process and as an ongoing decision whether or not to participate in a study. Other research focused on consent for specific aspects of the study or on the use of results. Empowering consent can mean creating autism-friendly or individualized consent processes, and alerting researchers to the importance of different types of (often non-verbal) communication. Debate on the consent process has also centered on how to empower consent for people who do not have the legal authority to do so by virtue of age or guardianship. Some of these debates are informed by empirical research on consent and other research ethics issues, almost always concerning genetic or clinical research (e.g. Bailey et al. 2014; Johannessen et al. 2016; Tabor et al. 2011). Future research could examine potential participants' perspectives on ethics beyond genetics, such as what has occurred in other areas of clinical research (Coors 2015). Other topics of interest might include what information participants want about funding, what participants understand or want to understand about anonymization in qualitative research or case studies (which has been discussed in some dramatic cases gone wrong such as the Jay Carter case described above), or how participants think about issues of confidentiality and privacy.

Empowerment as a process

The review of the literature also alludes to the fact that empowerment is a process. First, empowerment designates the ability to be an active agent in one's own life, and thus implies the changing and non-static experience of decision-making capacity. The ability to make decisions can be developed, and several articles provide concrete suggestions for tailoring communication, providing facilitating environments, and consulting with autistic stakeholders. Second, empowerment needs to develop across the lifespan. While some studies focus on parents' perspectives as proxies or permission-givers for research, fewer focus on the perspectives of children and youth themselves about the research process, asking questions such as: *What would empower children in the research process?, What would make free decision-making easier?, What would make it harder?, or What kinds of information do*

children need and in what formats?, or What are children's perspectives on tensions between children and their parents? While the prevalence of autism research involving children necessitates attention to such questions, it is also important to note that not all autism research involves children, and that the perspectives of adult participants are also important to understand.

Empowerment as engagement

While much of the literature focuses on empowerment in terms of consent and participation in research, still others consider how to empower people with autism in research in roles other than as participant. One important avenue is through community-based participatory research. We would also be remiss if we did not mention that there are many autistic researchers, both who study autism (Kapp et al. 2013; Dawson et al. 2007; Salt in press) and who study other topics (Prince-Hughes 2004; Grandin and Johnson 2009). It is important to stress that discussions of autism research ethics are not limited to discussions about neurotypical researchers and participants on the spectrum. Autistic people are also researchers and research-users who may read articles and attend conferences to learn about completed and ongoing studies. As this project stresses, people with autism are also important stakeholders in conversations about research ethics.

Empowerment in context

Our literature review revealed the way that empowerment occurs within various broader contexts of people's lives. While empowerment has been discussed in the general ethics literature, our focus on autism specifically suggests that certain common characteristics or experiences of people with autism might particularly influence empowerment and decision-making in the research process, including a history of institutionalization and differences in communication styles. Even these communication styles can be shaped by context, prompting the recommendation that researchers use styles of communication that are already familiar to participants (e.g. only using Social Stories if participants are already using them). The literature also highlights that relationships (such as with parents) and settings (such as educational institutions) impact empowerment. Research itself is a social context, and this paper has highlighted some ways in which this research context can be adapted to empower people on the spectrum to make informed, voluntary decisions.

Conclusion

Research ethics can be envisioned as a field where research participants are empowered not only to make decisions (and provide consent) but to actually

shape research and the contexts in which it takes place. This view of research ethics is aligned with the aspirations of many in the autism and autistic communities, although it may not correspond to conventional understandings of research ethics. Person-oriented research ethics offers a framework where research participants are deemed to be active agents. In this paper we have presented some key issues related to one of the key guideposts of this framework, empowerment in decision making, for participants with autism. We have reviewed some concrete suggestions for autism-friendly decision-making strategies and suggested issues for researchers to keep in mind not only around consent (the most prominent theme), but also data collection, research design, dissemination, return of results, and working with autistic communities in CBPR and other ways. We have brought together explicit and hidden ethics data from articles published in the social sciences, clinical sciences, humanities, and more. We have identified cross-cutting themes of empowerment as consent, as a process, and as a form of engagement, and the importance of considering empowerment in historical, relational, and structural context.

Through this work, we advance discussion on theories and concepts of empowerment in research by arguing that empowerment is accomplished both *through* research (research can empower people in other areas of life) and *within* research (research participants can be empowered); and by highlighting that although empowerment is key to deciding whether or not to take part in a study, it is also important *throughout* research through process consent, data collection and research design, dissemination and return of results, and participatory and collaborative approaches to research. We also hope that this review paper will help researchers include people with autism in research as participants and/or as partners and reflect upon the challenges and opportunities of doing so.

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Data availability statement

The data supporting the development of this article are the articles referenced in Table 1.

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References

Anderson, E. E., and J. E. Sieber. 2009. "The Need for Evidence-Based Research Ethics." *The American Journal of Bioethics* 9 (11): 60–62. doi:10.1080/15265160903234060.

Annear, K. 2013. "Nothing about us without us: A research agenda." August 12. http://www.asan-au.org/2013/08/nothing-about-us-without-us-a-research-agenda/

Arnold, L. 2018. "Autonomy, the Critical Journal of Interdisciplinary Autism Studies." Open Journal Systems. Accessed 5 November 2011. http://www.larry-arnold.net/Autonomy/index.php/autonomy/index

Asch, A. 2001. "Disability, Bioethics and Human Rights." In *Handbook of Disability Studies*, edited by G. L. Albrecht, K. D. Seelman, and M. Bury, 297–326. Thousand Oaks, CA: Sage.

Autism Support Network. 2016. "What is Rett syndrome? | Autism Support Network." Autism Support Network. Accessed 6 November 2018. http://www.autismsupportnetwork.com/news/what-rett-syndrome

Autistic Self Advocacy Network. 2018a. "Autistic Self Advocacy Network | Nothing About Us Without Us." Autistic Self Advocacy Network. Accessed 5 November 2018. https://autisticadvocacy.org/?theme=active

Autistic Self Advocacy Network. 2018b. "Operational policy on research inquiries." Autistic Self Advocacy Network. Accessed 5 November 2018. https://autisticadvocacy.org/about-asan/operational-policy-on-research-inquiries/

Azzarito, L. 2016. "Moving in My World: From School PE to Participants-Centered Art Exhibitions." *Journal of Teaching in Physical Education* 35 (1): 38–53. doi:10.1123/jtpe.2014-0189.

Bagatell, N. 2007. "Orchestrating Voices: Autism, Identity and the Power of Discourse." *Disability & Society* 22 (4): 413–426. doi:10.1080/09687590701337967.

Bagatell, N. 2010. "From Cure to Community: Transforming Notions of Autism." *Ethos* 38 (1): 33–55. doi:10.1111/j.1548-1352.2009.01080.x.

Bailey, D. B., M. Raspa, A. Wheeler, A. Edwards, E. Bishop, C. Bann, D. Borasky, and P. S. Appelbaum. 2014. "Parent Ratings of Ability to Consent for Clinical Trials in Fragile X Syndrome." *Journal of Empirical Research on Human Research Ethics* 9 (3): 18–28. doi:10.1177/1556264614540591.

Baret, L., and B. Godard. 2011. "Opinions and Intentions of Parents of an Autistic Child toward Genetic Research Results: Two Typical Profiles." *European Journal of Human Genetics* 19 (11): 1127–1132. doi:10.1038/ejhg.2011.106.

Barnes, R. E., and H. McCabe. 2012. "Should we Welcome a Cure for Autism? A Survey of the Arguments." *Medicine, Health Care and Philosophy* 15 (3): 255–269. doi:10.1007/s11019-011-9339-7.

Barrow, W., and E. F. Hannah. 2012. "Using Computer-Assisted Interviewing to Consult with Children with Autism Spectrum Disorders: An Exploratory Study." *School Psychology International* 33 (4): 450–464. doi:10.1177/0143034311429167.

Bell, E., E. Racine, M. Carter, N. D. Pietro, J. Iles, and L. Zwaigenbaum. 2015. *Returning Genetic Research Results in Neurodevelopmental Disorders: Report and Review*. Montreal, QC: NeuroDevNet and Institut de recherches cliniques de Montréal.

Ben Said, M., L. Robel, C. Messiaen, Y. Craus, J. P. Jais, B. Golse, and P. Landais. 2014. "Patient Information, Consents and Privacy Protection Scheme for an Information System Dedicated to Pervasive Developmental Disorders." *Studies in Health Technology and Informatics* 205: 755–759.

Block, P., E. L. Rodriguez, M. C. Milazzo, W. S. MacAllister, L. B. Krupp, A. Nishida, A. M. Broughton, and C. B. Keys. 2011. "Building Pediatric Multiple Sclerosis Community Using a Disability Studies Framework of Empowerment." In *Disability and Community*, edited by R. K. Scotch and A. C. Carey, 85–112. Bingley, UK: Emerald Group Publishing Limited.

Bowdin, S., P. N. Ray, R. D. Cohn, and M. S. Meyn. 2014. "The Genome Clinic: A Multidisciplinary Approach to Assessing the Opportunities and Challenges of Integrating Genomic Analysis into Clinical Care." *Human Mutation* 35 (5): 513–519. doi:10.1002/humu.22536.

Brendel, D. H. 2003. "Complications to Consent." *The Journal of Clinical Ethics* 14 (1-2): 90–94.

Brown, L. X. Z. 2012. "Include us in the conversation: What "nothing about us without us" means." Accessed 5 November 2018. https://www.autistichoya.com/2012/03/include-us-in-conversation-what-nothing.html

Brownlow, C., and L. O'Dell. 2002. "Ethical Issues for Qualitative Research in on-Line Communities." *Disability & Society* 17 (6): 685–694. doi:10.1080/0968759022000010452.

Brownlow, C., and L. O'Dell. 2006. "Constructing an Autistic Identity: As Voices Online." *Mental Retardation* 44 (5): 315–321. doi:10.1352/0047-6765(2006)44[315:CAAIAV.2.0.CO;2]

Carlson, L. 2013. "Research Ethics and Intellectual Disability: Broadening the Debates." *The Yale Journal of Biology and Medicine* 86 (3): 303–314.

Carter, J. 2003. "Looking into a Distorted Mirror." *The Journal of Clinical Ethics* 14 (1-2): 95–100.

Cascio, M. A., and E. Racine. 2018. "Person-Oriented Research Ethics: Integrating Relational and Everyday Ethics in Research." *Accountability in Research* 25 (3): 170–197. doi:10.1080/08989621.2018.1442218.

Cermak, S. A., L. I. Stein Duker, M. E. Williams, C. J. Lane, M. E. Dawson, A. E. Borreson, and J. C. Polido. 2015. "Feasibility of a Sensory-Adapted Dental Environment for Children with Autism." *American Journal of Occupational Therapy* 69 (3): 6903220020p1–690322002010. doi:10.5014/ajot.2015.013714.

Charman, T., P. Howlin, C. Aldred, G. Baird, F. Degli Espinosa, T. Diggle, H. Kovshoff, et al. 2003. "Research into Early Intervention for Children with Autism and Related Disorders: Methodological and Design Issues. Report on a Workshop Funded by the Wellcome Trust, Institute of Child Health, London, UK, November 2001." *Autism: The International Journal of Research and Practice* 7 (2): 217–225. doi:10.1177/1362361303007002008.

Chien, I. C., C. H. Lin, Y. J. Chou, and P. Chou. 2011. "Prevalence and Incidence of Autism Spectrum Disorders among National Health Insurance Enrollees in Taiwan from 1996 to 2005." *Journal of Child Neurology* 26 (7): 830–834. doi:10.1177/0883073810393964.

Clifford, S. A. 2013. "A Narrative Inquiry of a Self-Advocacy Meeting: Rethinking Empowerment from Sovereignty to Spontaneity." *Disability Studies Quarterly* 33 (3). doi: 10.18061/dsq.v33i3.3244. https://dsq-sds.org/article/view/3244/3264.

Coors, M. E., K. M. Raymond, S. K. McWilliams, C. J. Hopfer, and S. K. Mikulich-Gilbertson 2015. "What Adolescents Enrolled in Genomic Addiction Research Want to Know About Conflicts of Interest." *Drug and Alcohol Dependence*, 147 (1): 272–275.

Cridland, E. K., S. C. Jones, P. Caputi, and C. A. Magee. 2015. "Qualitative Research with Families Living with Autism Spectrum Disorder: Recommendations for Conducting Semistructured Interviews." *Journal of Intellectual and Developmental Disability* 40 (1): 78–91. doi:10.3109/13668250.2014.964191.

Cukier, H. N., J. M. Lee, D. Ma, J. I. Young, V. Mayo, B. L. Butler, S. S. Ramsook, et al. 2012. "The Expanding Role of MBD Genes in Autism: Identification of a MECP2 Duplication and Novel Alterations in MBD5, MBD6, and SETDB1." *Autism Research* 5 (6): 385–397. doi:10.1002/aur.1251.

Daley, T. C., N. Singhal, and V. Krishnamurthy. 2013. "Ethical Considerations in Conducting Research on Autism Spectrum Disorders in Low and Middle Income Countries." *Journal of Autism and Developmental Disorders* 43 (9): 2002–2014. doi:10.1007/s10803-012-1750-2.

Danforth, A. L., C. M. Struble, B. Yazar-Klosinski, and C. S. Grob. 2016. "MDMA-Assisted Therapy: A New Treatment Model for Social Anxiety in Autistic Adults." *Progress in Neuro-Psychopharmacology and Biological Psychiatry* 64: 237–249. doi:10.1016/j.pnpbp.2015.03.011.

Dawson, M.. 2004. "The misbehaviour of behaviourists." Accessed May 2008. http://www.sentex.net/nexus23/naa_aba.html.

Dawson, M. 2017. "What history tells us about autism research, redux." *The Autism Crisis: Science and Ethics in the Era of Autism Advocacy*, November 10. http://autismcrisis.blogspot.com/2017/11/what-history-tells-us-about-autism.html

Dawson, M., I. Soulières, M. Ann Gernsbacher, and L. Mottron. 2007. "The Level and Nature of Autistic Intelligence." *Psychological Science* 18 (8): 657–662. doi:10.1111/j.1467-9280.2007.01954.x.

Deweerdt, S. 2011. "Reclassification of Rett syndrome diagnosis stirs concerns." *Spectrum News*. https://www.spectrumnews.org/news/reclassification-of-rett-syndrome-diagnosis-stirs-concerns/

Dresser, R. 2015. "What Subjects Teach: The Everyday Ethics of Human Research." *Wake Forest Law Review* 50: 301–41.

Dresser, R. 2016. *Silent Partners: Human Subjects and Research Ethics*. New York, NY: Oxford University Press.

Dubois, J. M. 2008. "Hidden Data for Research Ethicists: An Introduction to the Concept and a Series of Papers." *Journal of Empirical Research on Human Research Ethics* 3 (3): 3–5. doi:10.1525/jer.2008.3.3.3.

Dunn-Geier, J., H. H. Ho, E. Auersperg, D. Doyle, L. Eaves, C. Matsuba, E. Orrbine, B. Pham, and S. Whiting. 2000. "Effect of Secretin on Children with Autism: A Randomized Controlled Trial." *Developmental Medicine & Child Neurology* 42 (12): 796–802. doi:10.1111/j.1469-8749.2000.tb00692.x.

Elsabbagh, M., A. Yusuf, S. Prasanna, K. Shikako-Thomas, C. A. Ruff, and M. G. Fehlings. 2014. "Community Engagement and Knowledge Translation: Progress and Challenge in Autism Research." *Autism* 18 (7): 771–781. doi:10.1177/1362361314546561.

Fisher, C. B. 2003. "Goodness-of-Fit Ethic for Informed Consent to Research Involving Adults with Mental Retardation and Developmental Disabilities." *Mental Retardation and Developmental Disabilities Research Reviews* 9 (1): 27–31. doi:10.1002/mrdd.10052.

Fletcher-Watson, S., J. Adams, K. Brook, T. Charman, L. Crane, J. Cusack, S. Leekam, D. Milton, J. R. Parr, and E. Pellicano. 2018. "Making the Future Together: Shaping Autism Research through Meaningful Participation." *Autism* 23 (4): 943–953. doi:10.1177/1362361318786721.

Francois, D., S. Powell, and K. Dautenhahn. 2009. "A Long-Term Study of Children with Autism Playing with a Robotic Pet: Taking Inspirations from Non-Directive Play Therapy to Encourage Children's Proactivity and Initiative-Taking." *Interaction Studies* 10 (3): 324–373. doi:10.1075/is.10.3.04fra.

Fuentes, J., and M. C. Martin-Arribas. 2007. "Bioethical Issues in Neuropsychiatric Genetic Disorders." *Child and Adolescent Psychiatric Clinics of North America* 16 (3): 649–661. doi:10.1016/j.chc.2007.02.003.

Goering, S. 2008. "You Say You're Happy, but … ': Contested Quality of Life Judgments in Bioethics and Disability Studies." *Journal of Bioethical Inquiry* 5 (2-3): 125–135. doi:10.1007/s11673-007-9076-z.

Goldstein, R., O. Joja, D. M. Psatta, M. Petrescu, I. Paraschiv, and M. Popa. 1989. "Vasotocin Improves Intelligence and Attention in Mentally Retarded Children." *Physiology & Behavior* 46 (6): 967–970. doi:10.1016/0031-9384(89)90199-6.

Grandin, T., and C. Johnson. 2009. *Animals in Translation: Using the Mysteries of Autism to Decode Animal Behavior*. New York, NY: SUNY Press.

Harris, J. 2003. "Time to Make up Your Mind: Why Choosing is Difficult." *British Journal of Learning Disabilities* 31 (1): 3–8. doi:10.1046/j.1468-3156.2003.00181.x.

Hens, K., H. Peeters, and K. Dierickx. 2016a. "Shooting a Moving Target. Researching Autism Genes: An Interview Study with Professionals." *European Journal of Medical Genetics* 59 (1): 32–38. doi:10.1016/j.ejmg.2015.12.009.

Hens, K., H. Peeters, and K. Dierickx. 2016b. "The Ethics of Complexity. Genetics and Autism, a Literature Review." *American Journal of Medical Genetics Part B: Neuropsychiatric Genetics* 171 (3): 305–316. doi:10.1002/ajmg.b.32432.

Hodgetts, S., J. Magill-Evans, and J. E. Misiaszek. 2011. "Weighted Vests, Stereotyped Behaviors and Arousal in Children with Autism." *Journal of Autism and Developmental Disorders* 41 (6): 805–814. doi:10.1007/s10803-010-1104-x.

Howe, E. G. 2003. "Lessons from 'Jay Carter'." *The Journal of Clinical Ethics* 14 (1-2): 109–117.

Huws, J. C., and R. S. Jones. 2008. "Diagnosis, Disclosure, and Having Autism: An Interpretative Phenomenological Analysis of the Perceptions of Young People with Autism." *Journal of Intellectual & Developmental Disability* 33 (2): 99–107. doi:10.1080/13668250802010394.

Jefferson, T. 2004. "Informed Choice and Balance Are Victims of the MMR-Autism Saga." *The Lancet Infectious Diseases* 4 (3): 135–136. doi:10.1016/S1473-3099(04)00934-X.

Jivraj, J., L. A. Sacrey, A. Newton, D. Nicholas, and L. Zwaigenbaum. 2014. "Assessing the Influence of Researcher-Partner Involvement on the Process and Outcomes of Participatory Research in Autism Spectrum Disorder and Neurodevelopmental Disorders: A Scoping Review." *Autism* 18 (7): 782–793. doi:10.1177/1362361314539858.

Johannessen, J., T. Naerland, C. Bloss, M. Rietschel, J. Strohmaier, E. Gjevik, A. Heiberg, S. Djurovic, and O. A. Andreassen. 2016. "Parents' Attitudes toward Genetic Research in Autism Spectrum Disorder." *Psychiatric Genetics* 26 (2): 74–80. doi:10.1097/YPG.0000000000000121.

Johnson, S. B., G. Whitney, M. McAuliffe, H. Wang, E. McCreedy, L. Rozenblit, and C. C. Evans. 2010. "Using Global Unique Identifiers to Link Autism Collections." *Journal of the American Medical Informatics Association* 17 (6): 689–695. doi:10.1136/jamia.2009.002063.

Kalichman, M. 2009. "Evidence-Based Research Ethics." *The American Journal of Bioethics* 9 (6-7): 85–87. doi:10.1080/15265160902923457.

Kapp, S. K., K. Gillespie-Lynch, L. E. Sherman, and T. Hutman. 2013. "Deficit, Difference, or Both? Autism and Neurodiversity." *Developmental Psychology* 49 (1): 59–71. doi:10.1037/a0028353.

Koenig, B. A. 2013. "Fixing Research Subjects Protection in the United States: Moving beyond Consent." *Mayo Clinic Proceedings* 88 (5): 428–430. doi:10.1016/j.mayocp.2013.03.010.

Konstantareas, M. M. 1998. "Allegations of Sexual Abuse by Nonverbal Autistic People via Facilitated Communication: Testing of Validity." *Child Abuse & Neglect* 22 (10): 1027–1041. doi:10.1016/S0145-2134(98)00082-9.

Kost, R. G., L. M. Lee, J. Yessis, R. A. Wesley, D. K. Henderson, and B. S. Coller. 2013. "Assessing Participant-Centered Outcomes to Improve Clinical Research." *New England Journal of Medicine* 369 (23): 2179–81. doi:10.1056/NEJMp1311461.

Lahman, M. K. E., M. R. Geist, K. L. Rodriguez, P. Graglia, and K. K. DeRoche. 2011. "Culturally Responsive Relational Reflexive Ethics in Research: The Three Rs." *Quality & Quantity* 45 (6): 1397–1414. doi:10.1007/s11135-010-9347-3.

Langdon, P. E., G. H. Murphy, I. C. Clare, E. J. Palmer, and J. Rees. 2013. "An Evaluation of the EQUIP Treatment Programme with Men Who Have Intellectual or Other Developmental Disabilities." *Journal of Applied Research in Intellectual Disabilities* 26 (2): 167–180. doi:10.1111/jar.12004.

Langdon, P. E., G. H. Murphy, E. Wilson, L. Shepstone, D. Fowler, D. Heavens, A. Malovic, and A. Russell. 2013. "Asperger Syndrome and Anxiety Disorders (PAsSA) Treatment Trial: A Study Protocol of a Pilot, Multicentre, Single-Blind, Randomised Crossover Trial of Group Cognitive Behavioural Therapy." *BMJ Open* 3 (7): e003449. doi:10.1136/bmjopen-2013-003449.

Lappe, M. D. 2014. "Taking Care: Anticipation, Extraction and the Politics of Temporality in Autism Science." *Biosocieties* 9 (3): 304–328. doi:10.1057/biosoc.2014.14.

Larsson, G., P. O. Julu, I. Witt Engerstrom, M. Sandlund, and B. Lindstrom. 2013. "Normal Reactions to Orthostatic Stress in Rett Syndrome." *Research in Developmental Disabilities* 34 (6): 1897–1905. doi:10.1016/j.ridd.2013.02.027.

LeCompte, M. D., and J. J. Schensul. 2010. *Designing & Conducting Ethnographic Research: An Introduction, Ethnographer's Toolkit*. 2nd ed. Lanham, MD: AltaMira Press.

Leigh, M. J., D. V. Nguyen, Y. Mu, T. I. Winarni, A. Schneider, T. Chechi, J. Polussa, et al. 2013. "A Randomized Double-Blind, Placebo-Controlled Trial of Minocycline in Children

and Adolescents with Fragile X Syndrome." *Journal of Developmental & Behavioral Pediatrics* 34 (3): 147–155. doi:10.1097/DBP.0b013e318287cd17.

Leonard, H., E. Glasson, A. Bebbington, G. Hammond, D. Croft, T. Pikora, J. Fairthorne, et al. 2013. "Application of Population-Based Linked Data to the Study of Intellectual Disability and Autism." In *Using Secondary Datasets to Understand Persons with Developmental Disabilities and Their Families*, edited by R. C. Urbano, 281–327. Amsterdam, Netherlands: Elsevier.

Liu, E. Y., and C. T. Scott. 2014. "Great Expectations: Autism Spectrum Disorder and Induced Pluripotent Stem Cell Technologies." *Stem Cell Reviews and Reports* 10 (2): 145–150. doi:10.1007/s12015-014-9497-0.

Loyd, D. 2013. "Obtaining Consent from Young People with Autism to Participate in Research." *British Journal of Learning Disabilities* 41 (2): 133–140. doi:10.1111/j.1468-3156.2012.00734.x.

Loyd, D. 2015. "Gaining Views from Pupils with Autism about Their Participation in Drama Classes." *British Journal of Learning Disabilities* 43 (1): 8–15. doi:10.1111/bld.12078.

Mathai, J., A. Bourne, and N. Cranswick. 2005. "Lessons Learnt in Conducting a Clinical Drug Trial in Children with Asperger Syndrome." *Australasian Psychiatry* 13 (2): 173–175. doi:10.1080/j.1440-1665.2005.02183.x.

McDougall, R. 2015. "Reviewing Literature in Bioethics Research: Increasing Rigour in Non-Systematic Reviews." *Bioethics* 29 (7): 523–528. doi:10.1111/bioe.12149.

McLaughlin, D. M., and E. G. Carr. 2005. "Quality of Rapport as a Setting Event for Problem Behavior: Assessment and Intervention." *Journal of Positive Behavior Interventions* 7 (2): 68–91. doi:10.1177/10983007050070020401.

Meloni F., K. Vanthuyne, and C. Rousseau. 2015. "Towards a Relational Ethics: Rethinking Ethics, Agency and Dependency in Research with Children and Youth." *Anthropological Theory* 15 (1): 106–23. doi:10.1177/1463499614565945.

Miller, F. A., R. Z. Hayeems, and J. P. Bytautas. 2010. "What is a Meaningful Result? Disclosing the Results of Genomic Research in Autism to Research Participants." *European Journal of Human Genetics* 18 (8): 867–871. doi:10.1038/ejhg.2010.34.

Milton, D. E. M. 2012. "On the Ontological Status of Autism: The 'Double Empathy Problem." *Disability & Society* 27 (6): 883–887. doi:10.1080/09687599.2012.710008.

Morgan, S., and L. H. Yoder. 2012. "A Concept Analysis of Person-Centered Care." *Journal of Holistic Nursing* 30 (1): 6–15. doi:10.1177/0898010111412189.

Nicolaidis, C., D. Raymaker, S. K. Kapp, A. Baggs, E. Ashkenazy, K. McDonald, M. Weiner, J. Maslak, M. Hunter, and A. Joyce. 2019. "The AASPIRE Practice-Based Guidelines for the Inclusion of Autistic Adults in Research as co-Researchers and Study Participants." *Autism* 23 (8): 2007–2019. doi:10.1177/1362361319830523.

Nicolaidis, C., D. Raymaker, K. McDonald, S. Dern, E. Ashkenazy, C. Boisclair, S. Robertson, and A. Baggs. 2011. "Collaboration Strategies in Nontraditional Community-Based Participatory Research Partnerships: Lessons from an Academic-Community Partnership with Autistic Self-Advocates." *Progress in Community Health Partnerships: Research, Education, and Action* 5 (2): 143–150. doi:10.1353/cpr.2011.0022.

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

Pellicano, E., L. Crane, K. Gaudion, and The Shaping Autism Research Team. 2017. *Participatory Autism Research: A Starter Pack*. London: UCL Institute of Education.

Pellicano, E., A. Dinsmore, and T. Charman. 2014. "What Should Autism Research Focus upon? Community Views and Priorities from the United Kingdom." *Autism* 18 (7): 756–770. doi:10.1177/1362361314529627.

Pellicano, E., and M. Stears. 2011. "Bridging Autism, Science and Society: Moving toward an Ethically Informed Approach to Autism Research." *Autism Research* 4 (4): 271–282. doi:10.1002/aur.201.

Percy, A. K. 2011. "Rett Syndrome: Exploring the Autism Link." *Archives of Neurology* 68 (8): 985–989. doi:10.1001/archneurol.2011.149.

Perkins, D. D, and M. A. Zimmerman. 1995. "Empowerment Theory, Research, and Application." *American Journal of Community Psychology* 23 (5): 569–579. doi:10.1007/BF02506982.

Perry, A. 2012. "Autism beyond Pediatrics: Why Bioethicists Ought to Rethink Consent in Light of Chronicity and Genetic Identity." *Bioethics* 26 (5): 236–241. doi:10.1111/j.1467-8519.2011.01952.x.

Porayska-Pomsta, K., C. Frauenberger, H. Pain, G. Rajendran, T. Smith, R. Menzies, M. E. Foster, et al. 2012. "Developing Technology for Autism: An Interdisciplinary Approach." *Personal and Ubiquitous Computing* 16 (2): 117–127. doi:10.1007/s00779-011-0384-2.

Preece, D., and R. Jordan. 2010. "Obtaining the Views of Children and Young People with Autism Spectrum Disorders about Their Experience of Daily Life and Social Care Support." *British Journal of Learning Disabilities* 38 (1): 10–20. doi:10.1111/j.1468-3156.2009.00548.x.

Prince-Hughes, D. 2004. *Songs of the Gorilla Nation: My Journey through Autism*. Crown. New York, NY: Three Rivers Press.

Racine, E., E. Bell, and M. Shevell. 2013. "Ethics in Neurodevelopmental Disability." In *Handbook of Clinical Neurology, Vol. 118 (Ethical and Legal Issues in Neurology)*, 3rd ed., edited by J. L. Bernal, and R. Beresford, 243–463. Amsterdam, Netherlands: Elsevier.

Racine, E., and V. Dubljević. 2016. "Porous or Contextualized Autonomy? Knowledge Can Empower Autonomous Moral Agents." *American Journal of Bioethics* 16 (2): 48–50.

Racine, E., and V. Dubljević. 2017. "Behavioral and Brain-Based Research on Free Moral Agency: Threat or Empowerment?" In: *Neuroethics: Anticipating the Future*, edited by J. Illes and S. Hossain, 388–410. Oxford. UK: Oxford University Press.

Richman, K. 2019. "Autism, Autonomy, and Research." In *Research Involving Participants with Cognitive Disability & Differences: Ethics, Autonomy, Inclusion, and Innovation*, edited by M. Ariel Cascio and E. Racine, 53–63. New York, NY: Oxford University Press.

Rimland, B. 1998. "High Dose Vitamin B6 and Magnesium in Treating Autism: Response to Study by Findling et al." *Journal of Autism and Developmental Disorders* 28 (6): 581–582.

Rodogno, R., K. Krause-Jensen, and R. E. Ashcroft. 2016. "Autism and the Good Life': A New Approach to the Study of Well-Being." *Journal of Medical Ethics* 42 (6): 401–408. doi:10.1136/medethics-2016-103595.

Rossi, J., C. Newschaffer, and M. Yudell. 2013. "Autism Spectrum Disorders, Risk Communication, and the Problem of Inadvertent Harm." *Kennedy Institute of Ethics Journal* 23 (2): 105–138. doi:10.1353/ken.2013.0006.

Ruef, M. B., and A. P. Turnbull. 2002. "The Perspectives of Individuals with Cognitive Disabilities and/or Autism on Their Lives and Their Problem Behavior." *Research and Practice for Persons with Severe Disabilities* 27 (2): 125–140. doi:10.2511/rpsd.27.2.125.

Rysavy, M. A., and J. R. Murph. 2015. "On Risks and Reality: Communicating the Difference between Autism Risks and Diagnosis." *AMA Journal of Ethics* 17 (4): 323–327. doi:10.1001/journalofethics.2015.17.4.nlit1-1504.

Salt, M. 2019. "REB/IRB Variability and Other Ethical Challenges in Multi-Site Research Involving Participants on the Autism Spectrum." In *Research Involving Participants with Cognitive Disabilities & Differences: Ethics, Autonomy, Inclusion, and Innovation*, edited by M. Ariel Cascio, and E. Racine, 77–86. New York, NY: Oxford University Press.

Sandler, A. 2005. "Placebo Effects in Developmental Disabilities: Implications for Research and Practice." *Mental Retardation and Developmental Disabilities Research Reviews* 11 (2): 164–170. doi:10.1002/mrdd.20065.

Santosh, P., J. Tarver, F. Gibbons, S. Vitoratou, and E. Simonoff. 2016. "Protocol for the Development and Validation of a Questionnaire to Assess concerning Behaviours and Mental Health in Individuals with Autism Spectrum Disorders: The Assessment of concerning Behaviour (ACB) Scale." *BMJ Open* 6 (3): e010693. doi:10.1136/bmjopen-2015-010693.

Sarrett, J. C., and K. S. Rommelfanger. 2015. "Commentary: Attention to Eyes is Present but in Decline in 2-6-Month-Old Infants Later Diagnosed with Autism." *Frontiers in Public Health* 3: 272. doi:10.3389/fpubh.2015.00272.

Scahill, L., and C. Lord. 2004. "Subject Selection and Characterization in Clinical Trials in Children with Autism." *CNS Spectrums* 9 (1): 22–32. doi:10.1017/S1092852900008336.

Scahill, L., J. McCracken, C. J. McDougle, M. Aman, L. E. Arnold, E. Tierney, P. Cronin, et al. 2001. "Methodological Issues in Designing a Multisite Trial of Risperidone in Children and Adolescents with Autism." *Journal of Child and Adolescent Psychopharmacology* 11 (4): 377–388. doi:10.1089/104454601317261555.

Scanlon, M. L, G. MacNaughton, and C. Sprague. 2017. "Neglected Population, Neglected Right: Children Living with HIV and the Right to Science." *Health and Human Rights* 19 (2): 169–181.

Schriner, K. 2001. "A Disability Studies Perspective on Employment Issues and Policies for Disabled People: An International View." *Handbook of Disability Studies*, edited by G. L. Albrecht, K. D. Seelman, and M. Bury, 642–662. Thousand Oaks, CA: Sage.

Schwartz, I. S., and D. M. Baer. 1991. "Social Validity Assessments - Is Current Practice State-of-the-Art." *Journal of Applied Behavior Analysis* 24 (2): 189–204. doi:10.1901/jaba.1991.24-189.

Shamsuddin, S., H. Yussof, S. Mohamed, and F. A. Hanapiah. 2014. "Design and Ethical Concerns in Robotic Adjunct Therapy Protocols for Children with Autism." *Procedia Computer Science, Special Issue: Medical and Rehabilitation Robotics and Instrumentation*, edited by H. Yussof, 42:9–16. doi:10.1016/j.procs.2014.11.027

Shore, S. 2004. "Using the IEP to Build Skills in Self-Advocacy and Disclosure." In *Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum*, edited by S. Shore, 65–105. Shawnee Mission, KS: Autism Asperger Publishing.

Sibley, K. 2004. "Help Me Help Myself: Teaching and Learning Self-Advocacy." In *Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum*, edited by S. Shore, 33–63. Shawnee Mission, KS: Autism Asperger Publishing.

Singh, J. S. 2015. "Narratives of Participation in Autism Genetics Research." *Science Technology & Human Values* 40 (2): 227–249. doi:10.1177/0162243914542162.

Sokhadze, E. M., M. F. Casanova, A. Tasman, and S. Brockett. 2016. "Electrophysiological and Behavioral Outcomes of Berard Auditory Integration Training (AIT) in Children with Autism Spectrum Disorder." *Applied Psychophysiology & Biofeedback* 29: 29.

Stein, M. A., and B. H. King. 2016. "Unequal Individual Risk and Potential Benefit Balanced by Benefits to the Population at Large in Autism Clinical Trials?" *The American Journal of Bioethics* 16 (4): 72–74. doi:10.1080/15265161.2016.1145298.

Stokstad, E. 2008. "Medicine. Stalled Trial for Autism Highlights Dilemma of Alternative Treatments." *Science* 321 (5887): 326–326. doi:10.1126/science.321.5887.326.

Szego, M. J., and M. H. Zawati. 2016. "Whole Genome Sequencing as a Genetic Test for Autism Spectrum Disorder: From Bench to Bedside and Then Back Again." *Journal of the Canadian Academy of Child and Adolescent Psychiatry* 25 (2): 116–121.

Tabor, H. K., T. Brazg, J. Crouch, E. E. Namey, S. M. Fullerton, L. M. Beskow, and B. S. Wilfond. 2011. "Parent Perspectives on Pediatric Genetic Research and Implications for Genotype-Driven Research Recruitment." *Journal of Empirical Research on Human Research Ethics* 6 (4): 41–52. doi:10.1525/jer.2011.6.4.41.

Tabor, H. K., and M. K. Cho. 2007. "Ethical Implications of Array Comparative Genomic Hybridization in Complex Phenotypes: Points to Consider in Research." *Genetics in Medicine* 9 (9): 626–631. doi:10.1097/GIM.0b013e3181485688.

Takahashi, H., S. Suzumura, F. Shirakizawa, N. Wada, K. Tanaka-Taya, S. Arai, N. Okabe, H. Ichikawa, and T. Sato. 2003. "An Epidemiological Study on Japanese Autism concerning Routine Childhood Immunization History." *Japanese Journal of Infectious Diseases* 56 (3): 114–117.

Torres, E. B., P. Yanovich, and D. N. Metaxas. 2013. "Give Spontaneity and Self-Discovery a Chance in ASD: Spontaneous Peripheral Limb Variability as a Proxy to Evoke Centrally Driven Intentional Acts." *Frontiers in Integrative Neuroscience* 7: 46. doi:10.3389/fnint.2013.00046.

Trehin, P. 2003. "Ethics of Research on Intellectual Disabilities and Autism: Point of View of a Parent." *Consensus in Child Neurology: Biological Bases and Clinical Perspectives in Autism*, edited by M. Elia, V. Romano, and P. Curatolo, 17–23. Hamilon, ON: BC Decker.

UK Department of Health and Social Care. 2009. The Mental Capacity Act – Fact sheet for social scientists. Electronic document. https://webarchive.nationalarchives.gov.uk/20120106063901/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@pg/documents/digitalasset/dh_106217.pdf

United Nations General Assembly. 2007. *Convention on the Rights of Persons with Disabilities: Resolution/Adopted by the General Assembly. A/RES/61/106, Annex 1*. New York: United Nations.

Vayena, E., and J. Tasioulas. 2015. ""We the Scientists": A Human Right to Citizen Science." *Philosophy & Technology* 28 (3): 479–485. doi:10.1007/s13347-015-0204-0.

Vazquez, C. A. 1995. "Failure to Confirm the Word-Retrieval Problem Hypothesis in Facilitated Communication." *Journal of Autism & Developmental Disorders* 25 (6): 597–610.

Vitiello, B., M. G. Aman, L. Scahill, J. T. McCracken, C. J. McDougle, E. Tierney, M. Davies, and L. E. Arnold. 2005. "Research Knowledge among Parents of Children Participating in a Randomized Clinical Trial." *Journal of the American Academy of Child & Adolescent Psychiatry* 44 (2): 145–149. doi:10.1097/00004583-200502000-00006.

Vosoughi, S., M. S. Goodwin, B. Washabaugh, D. Roy, and ACM. 2012. "A Portable Audio/Video Recorder for Longitudinal Study of Child Development." ICMI '12: Proceedings of the ACM International Conference on Multimodal Interaction (New York, NY, USA, October 20–26), 193–200. doi:10.1145/2388676.2388715.

Warnell, F., B. George, H. McConachie, M. Johnson, R. Hardy, and J. R. Parr. 2015. "Designing and Recruiting to UK Autism Spectrum Disorder Research Databases: Do They Include Representative Children with Valid ASD Diagnoses?" *BMJ Open* 5 (9): e008625. doi:10.1136/bmjopen-2015-008625.

WebMD. 2018. "Rett Syndrome Symptoms, Causes, and Treatments." WebMD. Accessed 6 November 2018. https://www.webmd.com/brain/autism/rett-syndrome#1

Wible, J. R., and S. Dietrich. 2002. "Innovative Therapies, Suspended Trials, and the Economics of Clinical research - Facilitated Communication and Biomedical Cases." *Philosophy of the Social Sciences* 32 (3): 275–309. doi:10.1177/004839310203200301.

Williams, J. L., W. A. Faucett, B. Smith-Packard, M. Wagner, and M. S. Williams. 2014. "An Assessment of Time Involved in Pre-Test Case Review and Counseling for a Whole

Genome Sequencing Clinical Research Program." *Journal of Genetic Counseling* 23 (4): 516–521. doi:10.1007/s10897-014-9697-4.

Wright, B., D. Marshall, D. C. Moore, H. Ainsworth, L. Hackney, J. Adamson, S. Ali, et al. 2014. "Autism Spectrum Social Stories in Schools Trial (ASSSIST): Study Protocol for a Feasibility Randomised Controlled Trial Analysing Clinical and Cost-Effectiveness of Social Stories in Mainstream Schools." *BMJ Open* 4 (7): e005952. doi:10.1136/bmjopen-2014-005952.

Wright, M. 2019. "Who Decides? Legal Changes to Facilitate Inclusion of Participants with Impaired Cognition in Research." In *Research Involving Participants with Cognitive Disability and Differences: Ethics, Autonomy, Inclusion, and Innovation*, edited by M. Ariel Cascio, and Eric Racine, 15–26. New York, NY: Oxford University Press.

Young, J. G., D. J. Cohen, S. E. Shaywitz, B. K. Caparulo, M. E. Kavanagh, R. D. Hunt, J. F. Leckman, et al. 1982. "Assessment of Brain Function in Clinical Pediatric Research: Behavioral and Biological Strategies." *Schizophrenia Bulletin* 8 (2): 205–235. doi:10.1093/schbul/8.2.205.

Yudell, M., H. K. Tabor, G. Dawson, J. Rossi, C. Newschaffer, Communication Working Group in Autism Risk, and Ethics. 2013. "Priorities for Autism Spectrum Disorder Risk Communication and Ethics." *Autism* 17 (6): 701–722. doi:10.1177/1362361312453511.

Zheng, Z., E. M. Young, A. R. Swanson, A. S. Weitlauf, Z. E. Warren, and N. Sarkar. 2016. "Robot-Mediated Imitation Skill Training for Children with Autism." *IEEE Transactions on Neural Systems and Rehabilitation Engineering* 24 (6): 682–691. doi:10.1109/TNSRE.2015.2475724.

Zizzo, N., E. Bell, and E. Racine. 2016. "What Is Everyday Ethics? A Review and a Proposal for an Integrative Concept." *The Journal of Clinical Ethics* 27 (2): 117–128.

Zorn, S., and M. Puustinen. 2015. "Recueillir des données auprès d'élèves avec troubles du spectre autistique en collège [Collecting Data from Students with Autistic Spectrum Disorders in Secondary School]." ICODOC 2015: Colloque Jeunes Chercheurs du Laboratoire ICAR, 20:01023 (unpaginated; 16 pages). doi:10.1051/shsconf/20152001023

Zwaigenbaum, L., S. Scherer, P. Szatmari, E. Fombonne, S. E. Bryson, K. Hyde, E. Anognostou, et al. 2011. "The NeuroDevNet Autism Spectrum Disorders Demonstration Project." *Seminars in Pediatric Neurology* 18 (1): 40–48. doi:10.1016/j.spen.2011.02.003.