FOCUS: RESEARCH AND CLINICAL ETHICS

Research Ethics and Intellectual Disability: Broadening the Debates

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This article examines the ethical issues surrounding the inclusion of people with intellectual disabilities as research subjects. It explores subject selection, competence, risk and benefits, and authority through three tensions that emerge when considering these concepts in the context of the Disability Rights Movement and critical disability scholarship. These tensions are defined as the double dangers of inclusion and exclusion; the challenges of defining competence and risk in terms of individuals vs. groups; and the conflicts that arise when pursuing the dual goals of amelioration and elimination of disabilities. Though these tensions are not resolved, they underscore the importance of researchers engaging with critical disability perspectives in order to navigate these complex ethical questions.

INTRODUCTION

Including people with intellectual and developmental disabilities (ID†) in medical research raises many ethical issues. Difficult questions emerge on multiple fronts: from determining competence to the problem of who should serve as a surrogate decision maker; from articulating appropriate definitions of risk and benefit to the larger social implications of medical research on disability; from the dangers of exploitation to the injustices of exclusion. Moreover, the category “intellectual disability” casts a wide net and encompasses individuals with a broad range of abilities and disabilities, thus complicating efforts to speak about “people with ID” as a single, uniform group. For the purposes of my discussion here, I will define ID as a category that encompasses a variety of conditions that are congenital or diagnosed in early childhood and that in some way af-

†Abbreviations: ID, intellectual disability; IRB, Institutional Review Board.

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fect the individual’s cognitive function. These include conditions like Down syndrome, Fragile X syndrome, autism, and individuals diagnosed with mental retardation.¹

Though some ethical and bioethical debates tend to dismiss this group as unworthy of philosophical attention [1], people with ID have, in fact, played a significant role in the very emergence of research ethics as a field of inquiry. Many of the codes and policies governing research on human subjects that have been articulated since the mid-20th century are a direct response to the abuses and exploitation suffered by people with disabilities at the hands of researchers.² Perhaps the most well-known case, following on the heels of the horrors of Nazi medicine, is the hepatitis study conducted at the Willowbrook State School for children with mental retardation in Staten Island, New York. Over the course of almost 2 decades, researchers deliberately infected children with the live hepatitis virus in order to study the effects of gamma globulin to treat it, violating numerous ethical principles in the process [2]. As Teresa Iacono writes, “Knowingingly or not, every researcher submitting a proposal to a research ethics committee does so in the shadow of the Willowbrook study …” [3].

The participation of people with ID in biomedical research continues today. A survey of current clinical trials involving people with ID on the National Institutes of Health registry of clinical trials reveals hundreds of studies involving subjects with a variety of conditions, ranging from broad designations like “mental retardation” and “intellectual disability” to specific conditions like Down syndrome and Fragile X syndrome. These studies, which include drug trials, observational studies, genetic research, and behavioral research, focus on both the nature and etiology of the disability itself and on related health conditions (e.g., Alzheimer’s, cancer, metabolic diseases, obesity, psychiatric disorders.)

In the wake of the blatant abuses and disregard for human dignity found in historical examples like Willowbrook, much attention has been focused on the necessity of protecting people with ID because of their vulnerability. At the same time, the past few decades have witnessed a sea change in which the assumption that people with ID are a vulnerable class in need of protection has come under scrutiny. The burgeoning, multi-faceted Disability Rights Movement [4,5] has exposed the discrimination and stigmatization experienced by people with disabilities and has worked toward the goals of justice, inclusion, and self-determination. In the case of ID, the vocal parental advocacy movement that emerged in the mid-20th century has been joined by a robust self-advocacy movement wherein people with ID are asserting their autonomy and arguing for social, political, and legal changes that will improve their quality of life and reverse the effects of stigma and social isolation. Accompanying these political movements, the birth of Disability Studies as a field of academic inquiry has produced a significant body of work by disability scholars in a broad range of fields, including literary theory, philosophy, history, the fine arts, the social sciences, and bioethics [6,7,8]. Together, these critical disability perspectives, as I have called them [1], challenge multiple assumptions about disability: that the quality of life with a disability is objectively and inevitably diminished; that having a disability is a tragedy and something to be pitied; and that people with ID are globally vulnerable and incapable of self-determination. In bringing their voices to political, legal, social, and bioethical debates, people with disabilities have broken the silence caused by their marginalization and have taken an active part in the process of self-definition and the fight for justice.

Bringing a critical disability perspective to bear upon debates in biomedical research is

¹*Mental retardation* is a highly contested term that has been replaced with “intellectual disability” by many professional organizations. Though I am in full support of retiring it, I include it here because it is still a clinical designation used in numerous contexts, including the NIH registry of clinical trials.

²These include the Nuremberg Code (1948), the Declaration of Helsinki (1964), the Belmont Report (1979), and the Federal Policy for the Protection of Human Subjects, or the “Common Rule” (1991).
valuable insofar as it problematizes many of the core concepts in research ethics. Thus, in what follows, I identify a series of key tensions that emerge when researchers consider concepts like vulnerability, competence, risk, and benefit in the context of critical disability scholarship. By exploring the tensions between inclusion and exclusion, the individual and the group, and amelioration and elimination, I demonstrate how a critical focus on intellectual disability can clarify, complicate, and inform broader debates in research ethics.

THE DOUBLE DANGER OF INCLUSION AND EXCLUSION

The dangers of including people with ID in research have been articulated in numerous ways, and many justifications have been given for their exclusion. First, in view of the many historical abuses of this population, this group has been defined as particularly vulnerable and in need of special attention and protection. Second, because of their cognitive limitations, the danger of people with ID being harmed through their participation in research may be more pronounced. Moreover, there can be challenges in determining competence and ensuring that individuals with ID understand the nature of the research and the attendant risks and benefits. In cases where individuals are not competent (and have never been competent), their reliance upon surrogate decision-makers makes their participation in research even more morally fraught, particularly if the research involves invasive medical procedures or if the study provides no clear and direct benefit to the subject (i.e., non-therapeutic research). For all of these reasons, the dominant assumption has been that people with ID require special consideration in the research context and that such protections intended to prevent abuse and harm to people with ID may be too stringent and that the exclusion of people with ID from research is unfair, unjustified, and may be equally harmful [9,10,11,12]. First, there is a concern that this exclusion amounts to another form of discrimination against people with ID. In some cases, they may be wrongly excluded from research based on the erroneous assumption that they cannot give consent when in fact they can [13]. In addition to errors regarding their incapacity, excluding disabled subjects from participating in clinical research can prevent people with ID from gaining important medical benefits from therapeutic research [3,12]. Finally, in considering other individuals’ interests and the broader advancement of knowledge, excluding individuals with ID from participating in research denies family members the potential benefits of increased knowledge about disability and its treatments and may more generally slow progress in understanding and treating intellectual disabilities or conditions that are associated with them.

While it can be argued that therapeutic research on people with ID has clear benefits, what about participation in non-therapeutic research? For those who are capable of making the decision themselves, there may be a number of reasons to want to participate: the desire to help advance knowledge, the interest in learning more about the research process itself, or the hope that this will lead to treatments or knowledge that may someday benefit the individual in the future. Denying autonomous subjects who have the capacity to understand and consent to this research, it has been argued, is unfair because it denies them the opportunity to engage in this form of altruism and to contribute to the advancement of knowledge. However, the participation of “never competent” subjects in non-therapeutic research leads into much thornier ethical and philosophical terrain, since it now involves the decision of a surrogate. Thus we must ask on what grounds a surrogate decision-maker

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3I focus here on “never competent” subjects because, unlike formerly competent subjects, there is no possibility of imagining what they would have wanted based on past preferences.
could justify enrolling an individual with an intellectual disability in a study that has no direct benefit to the subject and to which the subject herself cannot consent. The possibility for exploitation is even more pronounced in these cases, as the subject is incapable of understanding the reasons for participation and seems only to serve as a means to an end that will never directly benefit her. How, then, might one justify the participation of these subjects with ID in non-therapeutic research?

One defense for using “never competent” individuals in non-therapeutic research is another iteration of the discrimination argument: it is unfair to assume that, if competent and able to understand and make the choice themselves, “never competent” individuals with ID would not want to act altruistically and participate, and hence it is discriminatory to exclude them. Norman Cantor outlines this argument in his book, Making Medical Decisions for the Profoundly Mentally Disabled, but ultimately refutes it, claiming that it is simply illogical to impute something like a desire to act altruistically to individuals who have never been competent [10]. However, Cantor does put forth his own different justification for non-therapeutic research, one based upon a social-justice rationale. He states, “It does not seem intrinsically unfair or inhumane to extract some return from a never competent person who is receiving social benefits” [10]. In other words, because people with profound ID receive social benefits (e.g., housing, support services), it is not unjust to expect them to offer something in return. He writes, “Extraction of some sacrifice — even from a profoundly disabled person — seems consistent with the treatment that people get in a representative democracy” [10]. He does acknowledge that there must be a recognized standard to prevent exploitation, arguing that “the appropriate guideline in fixing maximum permissible risk (for a surrogate’s extraction of sacrifice) is intrinsic human dignity — meaning freedom from unconscionable exploitation. The boundary of that constraint has not definitively been established, but a minor increase over minimal risk has distinct promise” [10].

The idea that society is owed something from non-consenting individuals with ID in the form of a sacrifice through participation in non-therapeutic research is highly problematic for a number of reasons. First, there is the assumption that an equivalence exists between services that people with ID receive and the social benefit as payback that participation in non-therapeutic research would provide. What exactly would determine which services necessitate this “extraction of sacrifice,” and how would this be quantified? This very project seems to hark back to earlier tropes of the burdensome disabled person as a drain on society, of the undeserving “feeble-minded” incapable of contributing to society and who are simply objects of charity and benevolence rather than agents with fundamental human rights [14]. Second, even if one accepts this kind of quid pro quo rationale, who would make such determinations? Would Institutional Review Boards (IRBs) also be responsible for evaluating what kinds of services individuals were receiving and then determining that they would be proper candidates for recruitment? What roles would surrogates play in making these evaluations? Would individual researchers bear some responsibility to guard against exploitation of their subjects in these non-therapeutic protocols, and if so, what would this involve?

Cantor argues that “humane conditions” must be in place in order to justify exacting a sacrifice in return. Yet while some people with ID are currently living in such conditions, sadly many are not. Abuses in institutionalized and group home settings for people with ID persist4, and given the social and economic disenfranchisement of a large segment

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4There have been numerous reports of horrific abuses in institutional and community settings over the past few years. For some examples, see: http://www.nytimes.com/2011/03/13/nyregion/13homes.html; http://www.texastribune.org/library/data/abuse-neglect-texas-disabled-institutions/; http://www.courant.com/news/connecticut/group-home-deaths/hcp-dds-murphy-reaction-0305-20130304-1,0,5600814.story.
of this population, the more pressing concern regarding social justice is to ensure safe and humane conditions for all people with ID. I would argue this should take precedence over exacting sacrifices from this group for the benefit of a society wherein they continue to be marginalized. Finally, the non-disabled population also receives ample social benefits and supports of various kinds (arguably far more than individuals with ID) from a society that is expressly structured according to a standard of normalcy that they embody, and they are neither expected nor required to pay society back in the form of participation in non-therapeutic research. Thus it seems doubly unjust to compel people with ID to make this sacrifice when they are unable to consent to it.\footnote{Cantor responds to some of these counter-arguments in his book, though not convincingly, in my view.}

It seems clear from these considerations that neither a blanket prohibition nor a carte blanche for recruiting people with ID as subjects for research will do. When evaluating what is ethically at stake, the following distinctions are important to consider: the line between therapeutic and non-therapeutic research and the difference between research that is: a) focused specifically on some dimension of intellectual disability (e.g., investigating etiology or associated symptoms); b) investigating a health-related condition that is particularly relevant to this population (e.g., Alzheimer’s in people with Down syndrome); or c) a study in which the disability itself is not a factor. (In this last case, it is generally agreed that if there is no compelling reason to recruit individuals with ID, it is preferable to use subjects who do not have an intellectual disability.) Yet deciding when participation is appropriate in all of these cases depends upon the definition and clarification of concepts like competence, consent, risk, and benefit. It is to these issues that we now turn.

**DEFINING COMPETENCE AND RISK: THE INDIVIDUAL AND THE GROUP**

One of the cornerstones of research ethics is the concept of informed consent. While there can be challenges in obtaining informed consent from research subjects who do not have an intellectual disability, the inclusion of people with ID presents additional, unique concerns. These include determining which subjects are able to make the decision to partake in research, deciding who is best positioned to make this determination, and ensuring that fully informed consent has been obtained. While it might be an injustice to exclude all people with ID from participating in research because of these challenges, determining competence and specifically ensuring that an individual has the cognitive skills necessary for giving fully informed consent is not an easy or straightforward task. In some cases, it may be very clear that an individual is either fully competent or completely unable to give consent, but the broad range of conditions housed under the umbrella of ID and the variations even within a particular group prevent any facile assumptions or group-based designations.

One dimension of the debate has centered upon what standard or criteria should be used to determine the capacity to consent \[10,12,13\]. As Rebecca Dresser explains, though “there is general agreement that subjects should exhibit at least the ability to understand the significant information relevant to the choice about research participation,” the question of how to measure this and who is best equipped to do so remains \[15\]. In the case of ID, there are particular concerns regarding suggestibility, the desire to please clinicians and caregivers, and therapeutic misconception (the mistaken idea that the research will directly and personally benefit them.) Various approaches have been suggested in order to prevent coercion and exploitation. For example, Dresser defines a set of safeguards that, while placing additional requirements on researchers and IRBs and potentially adding costs to research, she defends as “manageable and ethically justified” \[15\]. Celia Fisher goes farther and argues for a “goodness-of-fit” ethic of informed consent, which may require addi-
tional creativity and engagement on the part of researchers. In adopting a relational approach, Fisher advocates for a context-based evaluation, rather than assuming that the evaluation of the individual’s capacities or deficits alone is sufficient. She explains: “Modifying the consent setting to reduce the perception of power inequities, to provide opportunities to practice decision-making, and to construct concrete ways of demonstrating that other services will not be compromised can strengthen the goodness-of-fit between person and consent setting” [16].

Yet even with such provisions and modifications in place, there may still be features of particular conditions that make it difficult to ensure full comprehension for consenting individuals. Deborah Barnbaum devotes a chapter to the ethical quandaries regarding autism research in her book, *The Ethics of Autism*, and though she sees value in Fisher’s model, she argues that “… the unique deficits that characterize autism may require researchers to be particularly careful when seeking informed consent from persons with autism. … Patience, understanding, and novel approaches to informed consent are required when obtaining consent from individuals who may have enormous difficulty in understanding alternative courses of action, or accessing their own values and preferences” [17]. This suggests that, beyond defining the particular elements that constitute consent, there may be additional challenges in providing the adequate means for communicating information between subject and researcher. Recognizing these impediments means attending to the specific features of the disability.

Given the group variation within a particular disability, compounded by the broad array of conditions that fall under the heading of “intellectual disability,” it is difficult to attribute any particular feature or definition of competence (or incompetence) to a single group. Moreover, as many critical disability theorists have pointed out, competence itself is a contested concept. One of the assumptions these theorists have challenged is the attribution of global incompetence to people with ID [18]. There is a long history of discounting and silencing the voices of people with ID as a group because of their perceived incompetence and incapacities, and this in turn has justified many of the oppressive practices to which they have been subjected at the hands of “the mentally accelerated” (to borrow James Trent’s term) [1,14]. In view of this history, it is both valuable and necessary to interrogate the very notions of competence and consent and consider alternative models of autonomy and decision-making that aim at fully enabling communication and comprehension [6,19].

There is a tension, then, between the need to make provisions for groups that are perceived as vulnerable (like “people with ID”) on the one hand and the fact that when determining something as crucial as the ability to give informed consent, the internal heterogeneity of this very group and the fluidity and contextual nature of concepts like consent [12] resist overly generalized determinations. This same tension between group identification and the particularities of the individual can also be seen in the attempt to define and assess risks. As mentioned earlier, the notion that as a class people with ID should be excluded from research has been rejected on the grounds that it is based upon unjustified and erroneous assumptions about global incapacity. As long as the proper safeguards are in place, some argue, the worry that this group will assume greater risks is unwarranted. In her article, “Rethinking Research Ethics,” bioethicist Rosamond Rhodes argues that too much emphasis has been placed on this issue, overlooking the specific challenges faced by each individual within the group.

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6Fisher elaborates on what this entails: “Investigators must be willing to reconfigure experimental procedures to reduce or eliminate research vulnerability. This may include re-conceptualizing traditional assumptions regarding the standards by which an individual is considered competent to give informed consent and the role of guardians in consent decisions” (p. 30).

7In the case of autistic persons, Barnbaum argues, their lack of a theory of mind directly impacts their ability to make some of the cognitive moves required to fully appreciate the nature and goals of research.
been placed on protectionism and concludes that, “As a general rule, if it would be acceptable for a capacitated patient to choose, or for a surrogate to authorize or forgo an innovative therapeutic intervention, then it should also be reasonable to enroll a subject who lacks decisional capacity in a trial of that therapy when research involves only reasonably small additional burdens” [9].

But can risks be defined in equivalent ways for people with ID and non-disabled individuals? In the context of pediatric research, “minimal risk” is defined as “the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests” [20]. Yet there are debates as to whether this criterion should be viewed as objectively defined or relative to the child’s context and situation [21]. In a similar vein, it is important to consider the distinct nature of physical and psychological risks that may accompany medical research on people with ID (who, in some instances, may actually be children).

In the case of some people with ID, an inability to fully understand the study’s purpose and practices may exacerbate what would ordinarily be considered minimal risk. If someone has had negative experiences in clinical settings or negative associations with medical care, what would ordinarily be considered minimal or negligible risk (e.g., a minimally invasive procedure like a blood draw) might be a more traumatic experience since it may not be experienced in the same way. Moreover, the stipulation that if any evidence of discomfort is present the subject can withdraw [10] does not necessarily protect individuals who are incapable of certain forms of expression and who may not be able to communicate their negative feelings or pain. Even if there are ways to mitigate these dangers, it is not clear that an exact equivalence can be drawn between the risks that may be assumed by people with decisional capacities and those for whom these capacities are affected by their disability.

Because research on ID sometimes involves the participation of the families of people with ID, risks to these individuals must be considered as well. For example, family members are often recruited in genetic research on autism, raising the question of what risks attend this kind of non-therapeutic research. In discussing the use of twins or siblings, for example, Chen, Miller, and Rosenstein raise the question of whether it is ethical to subject children to these studies: “Choosing to recruit only family members as research participants, and particularly targeting siblings at birth, has the potential to place unfair burdens on families with a child with autism and take advantage of their desperation. Thus, investigators designing studies that target family members for research participation must carefully consider alternative strategies and justify the scientific advantage of the chosen study design” [22]. In addition to concerns regarding justice and therapeutic misconception, the issue is further complicated by the fact that the health status of siblings of autistic children is unclear. If they are “at risk” for autism, the authors ask, should they be considered a “healthy” population or a group that “has a condition” in some sense? This designation affects the assessment of risks and benefits, as well as the kinds of safeguards and restrictions that govern medical research on healthy versus “disabled” children [22]. This ambiguity again highlights the challenges inherent in invoking vulnerable groups in discussions of risk, as in some cases the very definition of group membership may be at issue.

A final consideration in doing genetic testing on family members for the purposes of research into the etiology of disabilities has to with the value and impact of genetic knowledge itself. Acquiring genetic knowledge can have serious psychological and practical consequences for individuals and must be taken into consideration as a potential harm [22]. Despite these possible risks, however, some would claim the eventual benefits of genetic research into intellectual disabilities ultimately outweighs the potential harms to individuals, since an under-
standing of the genetic bases for disabilities like autism will lead to the improved treatments and the possibility of curing and preventing them. Yet can we assume that the goals of prevention and cure are objectively desirable and universally shared?

**CUI BONO? AMELIORATION AND ELIMINATION**

The foregoing discussion has outlined a number of the benefits that medical research may have for people with ID. In the case of therapeutic research, there are potential health-related benefits to the subject. And even in non-therapeutic research, the subject may derive personal benefits [13]. In addition to the direct benefits to the individual subject, family members, other groups (e.g., people with the same disability, both present and future), and society more broadly may all benefit from biomedical research.

Yet the question “cui bono?” or whose interests are being served, raises other critical questions that must be addressed when identifying the benefits of research: Who determines what constitutes a benefit and from what position of expertise or authority? Are there underlying normative judgments and values that shape how such benefits are defined? In answering these questions, many in the disability community (including self-advocates, advocates, and scholars) have challenged assumptions regarding the very nature of disability, the quality of disabled lives, and what is at stake in the discourses of prevention and cure. These critiques highlight another tension that emerges in research ethics between the goals of amelioration and elimination. By amelioration, I mean the desire and aim to improve the lives of people with ID through improved health care and treatment as a result of biomedical research, as well as through social, political, and structural changes. By elimination, I mean the desire and aim to eliminate particular conditions through research into cures, individual therapies, and various forms of prevention. How and why might these goals come into conflict?

In “Respecting Persons with Disabilities and Preventing Disability: Is there a Conflict?” Asch, Gostin, and Johnson formulate this tension as follows: “The field of public health faces a dilemma in the area of disability prevention. The mandate of public health has traditionally been read to embrace the prevention of disabilities. However, this mandate also includes a duty to enhance the well-being of persons with disabilities. Essential to this latter duty is increasing the respect of society for persons with disabilities.” This problem emerges when “public health simultaneously tries to prevent disability and elevate the status of persons with disabilities within our society” [23]. Though their focus is primarily on forms of prevention like prenatal screening, versions of this problem can be found in the context of research as well. Consider how this tension between amelioration and elimination has played out in debates regarding autism research.

One of the arguments for including people with ID in research is that they may benefit both as individual subjects and as members of a group. This is true in the case of research that is focused on their particular disability (regarding treatment for symptoms associated with it or investigations into etiology), but it is also arguably true for other health-related conditions that may have a direct bearing upon this particular population (e.g., cardiac research for people with Down syndrome). Yet in the case of autism, some have asked whether the attempt to “cure” autism in adults would amount to a fundamental change to the individual’s personal identity that would be unwelcome and even potentially harmful.

In *The Ethics of Autism*, Barnbaum argues that it may not, in fact, benefit autistic adults to be cured of their autism: “It is not clear that adults who have always lacked a theory of mind would be benefited by gaining a theory of mind in mid-life: who they are would be compromised tremendously by gaining a theory of mind. … Any suggestion of re-making the world of an adult with autism — an adult with his own personality, beliefs, and preferences — is a failure to recognize him as his own person” [17]. Her answer is to preserve what she calls autistic integrity: “adults with autism should be al-
owed to live out the lives the way they are. Respect for a life without a theory of mind, and a notion of autistic integrity, is called for” [17]. In setting up this opposition between curing and respecting people with autism, Barnbaum echoes the views of many in the growing self-advocacy movement who view autism as a form of neurodiversity rather than as an objectively undesirable pathology that should be cured. (“Neurotypicals” — those without autism — often hold this latter view.) But does the researcher who is investigating the genetic basis of autism (or other intellectual disabilities) and who hopes to cure the condition someday necessarily fail to respect the dignity and personhood of individuals who have autism? Must a search for a cure imply the devaluation of or lack of respect for those who have the condition?

Chloe Silverman, in her comprehensive analysis of the history of autism and autism research, Understanding Autism, argues that this binary between curing autism on the one hand and refusing a cure in the name of respecting people with autism on the other is too stark. She argues that the importance of research into treatments for the symptoms and conditions associated with autism will be obscured by setting up this false dichotomy between cure and respect. In tracing the complex and contested contributions that parents of children with autism have made in the field of autism research (including the heated debates that surround vaccines and autism), she also shows how divided the community of advocates are when it comes to questions of treatments and cures, thus underscoring that it is impossible and irresponsible to assume that this community speaks in one voice [24]. When considering the benefits of research to the community of people with ID, it is important to recognize that not all members of this group (and their advocates) view cures or treatments through the same lens. What may seem like a benefit to the non-disabled population may in fact be perceived as a potential harm to people with disabilities, a point that has been made by multiple disability theorists and activists [25].

This tension between amelioration and elimination generates questions regarding resource allocation as well. Is there an imbalance between the funding for research into cures and the prevention of disabilities and the resources available for research aimed at ameliorating the lives of people with disabilities? (This question has been raised regarding Down syndrome, for example, where the elimination of this condition has become standard practice through prenatal screening and selective abortion [26].) What do the decisions regarding resource allocation say about the kinds of lives that are valued and judgments that are made about the quality of life for people with ID? And do people with ID and their advocates have a voice in this world of biomedical research? While answering these questions is beyond the scope of this paper, it is important to recognize that these questions are being asked by many in the disability community, to acknowledge the ways that people with disabilities and their advocates have already shaped the direction of research and to consider how these voices can be a part of current and future biomedical and bioethical debates regarding the nature and value of research.

These claims inevitably raise questions about authority and expertise. What place should individuals who are not scientists and researchers, who are not recognized as “experts” in biomedicine and bioethics, have in conversations about research ethics? In “Trusting Experts and Epistemic Humility in Disability,” bioethicist Anita Ho argues for epistemic humility in the relationship between health care providers and people with intellectual disabilities: “Epistemic humility is a disposition as well as a commitment. It arises out of professionals’ acknowledgment of the boundary of their expert domain as well as their fallibility. … Not only do we acquire and/or build knowledge on what others have previously discovered, but our methodology and accuracy can also be sharpened when we respond to critiques and challenges posed by others inside and outside our specialized domain” [27]. Ho is speaking primarily about clinical encounters
between health care providers and people with ID, yet these ideas can be transposed into the research setting as well. By virtue of their expertise and the work that they do, researchers play a gatekeeper function with respect to certain forms of knowledge generated about intellectual disability. Therefore, there is value in both acknowledging this epistemic authority and critically examining the moral responsibilities that accompany it [28].

CONCLUSION

Though my aim in this article has not been to offer explicit guidelines or policies, I will conclude with some suggestions as to how a critical disability perspective can inform ethical deliberations with respect to researchers, research subjects, and the nature of research itself. The above analysis has shown that many of the core concepts in research ethics are both value-laden and contested, a point that is valuable for researchers and clinicians to recognize for a number of reasons. First, defining risks, benefits, and competence involves normative judgments and reflects values that may not necessarily be shared by the individuals with ID who are directly affected by these definitions or by those in their immediate and broader communities. Second, in an effort to make the research encounter more respectful and transparent, it is important to consider how stereotypes and assumptions regarding ID may shape the interactions between people with ID and those involved in research (this includes clinicians, surrogate decision-makers, members of IRBs, researchers, and bioethicists). Finally, it is imperative to recognize the power dynamics between clinicians/researchers and subjects, surrogate decision-makers, and clients and to consider structural factors that may influence the voluntariness of participation. For example, as the debates regarding research on prisoners indicate, the processes of recruitment and obtaining consent are considerably more complex when individuals reside in institutional settings [29]. In the case of ID, this could include larger residential facilities or group homes, where the staff act as “gatekeepers” and where the potential for coercion may be more pronounced [30].

These concerns highlight the importance of ensuring appropriate, effective, and respectful modes of communication in recruitment, consent procedures, and clinical encounters for all subjects. Because it cannot be assumed that individuals with ID are uniform in their abilities to understand research and offer informed consent or assent, it is crucial to attend to the particularities of each individual or group of participants and to be open to creative and novel approaches that enable communication and active participation. This requires an inclusive approach to research that affirms the importance of engaging and respecting the voices and perspectives of people with ID (and, when appropriate, their advocates, surrogates and/or families).

This leads to the larger question of what kinds of biomedical research should be permitted when subjects with ID are involved. In the case of therapeutic research, subjects with ID should not be excluded simply by virtue of being a member of this group, as it is clear that over-generalizations about global incapacity and vulnerability are unwarranted and that preventing participation in certain forms of research may deprive people with ID from beneficial treatments and care. However, it does seem useful to distinguish between research that is focused on improving the health of people with ID (e.g., studies on cancer treatments or Alzheimer’s disease) and studies that are focused on addressing the disability itself. While both forms of research may benefit people with ID in various ways, there may be good reason to resist conflating disability and disease when considering the aims of research. For example, there is a difference between people with Down syndrome participating in clinical trials for chemother-

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8I realize that this distinction may be blurred in certain cases where health issues are related directly to the disability.
apy or drugs to treat heart disease and research involving cosmetic facial surgery that is not health-related but is intended solely to lessen the stigma associated with the appearance of Down syndrome. The question of whose good is being served and how that good is defined must be kept in the foreground, since there may be instances where the values of the researcher and the definition of what constitutes a benefit do not align with the subjects’ own perceptions of their disability and quality of life.

In the case of non-therapeutic research, questions of consent and the appropriateness of assuming risk for the purpose of benefitting others must be given careful attention. While it may be appropriate to include people with ID who are able to give informed consent in non-therapeutic research, a surrogate decision-maker placing someone incapable of consenting in harm’s way for the sake of others is more morally troubling. As disability historians have shown, it was not long ago that people with ID were viewed as social pariahs who were incapable of contributing to society. This historical context, coupled with the forms of marginalization and abuse that many people with ID still suffer today, should make one especially wary of arguments that maintain that participation in non-therapeutic research is a way for these individuals to somehow pay their social debt or give back to society.

Finally, insofar as biomedical research may be aimed at preventing and eliminating certain intellectual disabilities, it is imperative that researchers remain attentive to the ways in which the discourses surrounding prevention and cure directly or indirectly express judgments regarding the quality and value of disabled lives. It is important that erroneous assumptions and harmful stereotypes are not perpetuated in the process of developing and implementing research and to acknowledge that research is taking place in a broader social context in which justice for people with ID is still being sought. People with ID live in a society that has only recently begun to affirm their right to inhabit a shared world alongside the non-disabled.

In returning to the opening example, Willowbrook rightly serves as a reminder of how grotesquely distorted the aims and justifications of research can become. Yet as significant as these cases of abuse have been in defining the boundaries of ethical research, the critical disability perspectives emerging from the Disability Rights Movement and disability scholarship have an equally important role to play in shaping the landscape of research ethics. Just as all research takes place in the shadow of Tuskegee and Willowbrook, my hope is that the accomplishments of the Disability Rights Movement and the voices of people with disabilities will become equally familiar to researchers. The value of engaging in this dialogue extends beyond research on ID, as it points to fundamental questions regarding the aims of medicine and science, the meaning of a good life, and the possibility of solidarity, community, and justice.

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