



Paradigm Shifts in Disability and Health: Toward More Ethical Public Health Research

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Disability is often considered a health outcome disproportionately experienced by minority groups. It is also possible to view people with disabilities as a minority group that itself experiences health disparities.

Calls to reduce these disparities necessitate the inclusion of people with developmental disabilities in research, although resulting ethical issues can thwart scientific progress. Using disability rights principles can help address ethical challenges and promote safe, respectful public health research. Examples include applying human rights frameworks, providing accommodations, attending to power, countering legacies of deficits-based models of disability, and transforming access to science more broadly.

Collectively, these strategies can encourage broader engagement in safe, respectful, inclusive public health research aimed at promoting the health and well-being of people with developmental disabilities. (*Am J Public Health*. 2013; 103:2165–2173. doi:10.2105/AJPH.2013.301286)

DISABILITY IS OFTEN CONSIDERED a health outcome that minority groups disproportionately experience; for example, African Americans and Native Americans are at greater risk for fetal alcohol syndrome, which can result in

developmental disability.^{1–3}

However, disability and health are not mutually exclusive. It is possible to view people with developmental disabilities as a minority group that itself experiences health disparities. Like other minorities, people with developmental disabilities experience marginalization and decreased expectations and opportunities. This results in inequalities in relationships, education, community access, health and health care, quality of life, and civic, economic, and political participation.⁴ These social conditions and their consequences as social determinants of health are similar to those that other marginalized groups experience.⁵

Developmental disabilities involve lifelong impairment in physical, learning, language, or behavioral conditions that begin before the age of 22 years and that affect functioning (e.g., intellectual disability, cerebral palsy, autism spectrum disorder, spina bifida, hearing loss). Almost 14% of children and 5 to 6 million people of all ages in the United States have a developmental disability.^{6–8}

Among children, attention-deficit/hyperactivity disorder and learning disabilities may be especially prevalent; what is known about adults is largely restricted to those with intellectual disability.^{8,9}

Like other minorities, individuals with developmental disabilities experience substantial preventable health disparities.

These disparities cast a wide net, covering preventable injuries, vulnerability in emergencies, health behaviors, health care experiences, health outcomes, and health service and health promotion program accessibility.^{5,10} For example, only about 50% of adults with developmental disabilities exercise compared with 75% of the general population¹¹; people with developmental disabilities experience increased rates of obesity^{11,12}; and autistic adults have about twice the odds of experiencing unmet health care needs and using the emergency department.¹³ As with reducing health disparities among other minorities, understanding the origins of these disparities and addressing them requires attention to the lived experience of developmental disability.

THE DISABILITY RIGHTS MOVEMENT

Many people with developmental disabilities in the United States have been denied basic civil rights, warehoused outside the community in institutions, and subjected to, among other things, forced sterilization and

living conditions devoid of dignity and self-determination (notable exceptions include those with access to specialized education or community, such as those who are blind or deaf).^{14–17} In response, and stimulated by previous civil rights movements, the disability rights movement has united people with disabilities and their allies to advocate inclusion, respect, and self-determination in education, vocation, community living, and policy.

Although there were earlier activists, especially for people with sensory and physical disabilities, the broader disability rights movement started in the 1970s and emphasized the importance of inclusion with the slogan “nothing about us without us.”^{14,15,17} Disability rights advocates have achieved critical civil rights wins, such as inclusive education provided in the 1975 Education for All Handicapped Children Act and the 1990 Americans with Disabilities Act, which prohibits discrimination in numerous settings and argues for disability-related accommodations to enable access to them.¹⁷ Despite these wins, individuals with higher support needs or more marginalized disabilities, including many with developmental disabilities, continue to struggle to fully benefit from the disability rights



movement; the fight for civil rights is ongoing.

IMPACT ON SCIENCE

Scientific advances are needed to reduce health disparities among people with developmental disabilities. We have learned from the exclusion of other groups from health research (e.g., women, children, people of color) that such practices leave these groups less able to benefit from scientific advancements.¹⁸ To address disparities and create more effective interventions, it is necessary to increase the inclusion of individuals with developmental disabilities in public health research. Shifts in society's perception of disability also encourage novel scientific endeavors. For example, there is increasing demand to move from biomedical research focused on preventing disability to public health research promoting health equity. However, the developmental disabilities population faces unique ethical and social challenges to participation, including unwillingness to participate because of distrust toward public health stemming from past transgressions.

These challenges can discourage research and thwart efforts to promote well-being. To meet these challenges, attention to the complex relationships among multiple perspectives, especially the concerns and priorities of people with developmental disabilities, is needed so we do not unknowingly create or approve practices perceived as patronizing or harmful. In time, new knowledge may

encourage scientific advancements that lead to positive health outcomes.

We reviewed these key ethical issues and considered strategies to help foster safe, respectful public health research that includes people with developmental disabilities. Table 1 provides a summary of issues and solutions. These ideas are applicable to public health research focused on both the health of all individuals and the health of the subpopulation of those with developmental disabilities. We take a broad view of this goal; we hope that individuals with developmental disabilities will see increasing representation in public health research as study participants, members of the research team, and stakeholders in research policy and administration. Although these issues and strategies are presented sequentially, they are dynamically interrelated. We are in a unique position to examine these topics through our work as community and academic researchers active in developmental disabilities health and ethics research and through our experience on institutional review boards.

ETHICAL CHALLENGES AND RESPONSES IN PUBLIC HEALTH RESEARCH

Research holds a history of transgressions against minorities, among them using people with developmental disabilities in high-harm, low-benefit research sometimes without fully informed consent. Examples include

eugenics research and the deliberate infection of individuals with developmental disabilities with hepatitis.¹⁹

In response to these and other abuses, the US government intervened, establishing principles for ethical research and oversight.^{20,21} An unintended consequence has been a shift to overprotective attitudes toward individuals perceived as at risk for exploitation, which may exclude people with developmental disabilities from research.²²⁻²⁴ Coupled with institutional exclusion from research-related policy, public health research agendas often remain mismatched with the priorities of people with developmental disabilities.

At a crossroad with the disability rights movement's call for inclusion, the public health community must learn how to interpret and apply ethical principles in ways that protect human rights and respect inclusion. We believe this balance is best achieved not through further regulation but through strategies like those we have presented.^{25,26}

Like other minorities, many people with developmental disabilities harbor feelings of suspicion and distrust toward research, which may influence participation decisions.²⁷⁻²⁹ To address this, public health research practice needs to be brought in line with human rights frameworks.^{14,15,30} This means respecting the autonomy and dignity of people with developmental disabilities.^{27,31} Researchers must demonstrate that respect, and people must have opportunities for positive interactions with researchers, including

receiving appreciation such as compensation for their contributions.

Respect can be shown by entering into reciprocal relationships, including the community in research, and building visible opportunities for individuals and communities to benefit from research through, for example, opportunities for self-enrichment and life improvement. It can be shown by promoting indirect benefits, such as providing data to influence public health policy and advocate improved quality of life, for example, by using findings to advocate more inclusive health promotion programs. Lastly, respect can be shown by creating public health research aims and dissemination materials that promote disability rights principles and use respectful, community-supported language (e.g., framing participants in terms of strengths instead of deficits, using terms such as "intellectual disability" instead of "retarded").

Addressing Coercion and Comprehension

Including people with developmental disabilities as direct respondents in public health research means moving away from the invalid and, at times, ethically questionable practice of using proxy reports (having others respond for the person with the developmental disability).^{18,32} Still, people with developmental disabilities may experience comprehension challenges and vulnerability to coercion associated with their disability and reduced power over their lives.¹⁹



TABLE 1—Ethical Challenges and Responses in Public Health Research

Ethical Challenges	Responses	Recommendations for Action
<p>People with developmental disabilities have been exploited in and outside research. The disability rights movement challenges the ethics of using exclusion and autonomy-restricting practices as a means of protection.</p>	<p>Find ways to safely and respectfully include people with developmental disabilities in public research.</p>	<p>Learn about the disability rights movement. Include people with developmental disabilities as direct respondents in public health research.</p>
<p>Experiences with exploitation contribute to feelings of suspicion and distrust among people with developmental disabilities.</p>	<p>Use human rights frameworks to inform decision-making about ethical public health research practices and the treatment of people with developmental disabilities in research by respecting dignity and autonomy and promoting direct benefits associated with research participation.</p>	<p>Demonstrate respect for people with developmental disabilities. Provide people with developmental disabilities opportunities to get to know researchers before research participation decisions. Solicit and respond to participant needs and preferences. Teach participants desired skills. Share findings with participants. Produce findings or policy briefs for use in advocacy efforts. Create dissemination materials that promote respect and reduce negative stereotypes. Use respectful language in research materials and dissemination products. Be responsive to community priorities.</p>
<p>Coercion and comprehension challenges test foundational concepts of research ethics and require population-specific responses.</p>	<p>Modify materials, processes, and contexts to promote comprehension and accessibility and reduce power imbalances.</p>	<p>Simplify language. Make language more concrete and specific. Use visuals. Modify instrument delivery formats (e.g., oral instead of written administration). Provide materials in alternative formats such as Braille, text-to-speech, and electronic formats that interface with participants' assistive technology. Provide American Sign Language translation. Work collaboratively with people with developmental disabilities, including self-advocacy groups. Allow individuals to consult with a trusted other in making research participation decisions. Educate people in the lives of people with developmental disabilities about the value of self-determination.</p>
<p>Deficits-based models of disability linger in science, restricting ideas on the interests and abilities of people with developmental disabilities to contribute to research and the framing of appropriate research questions.</p>	<p>Apply disability rights principles to public health research.</p>	<p>Establish protocols for being alert to, and addressing coercion to, participate. Train research staff on power issues. Find ways to avoid or strengthen mandatory reporting of abuse. Maintain confidentiality of data. Allow more time for consent processes. Check in during data collection to make sure the participant still consents. Critically assess underlying assumptions of research aims and protocols, including whether people with developmental disabilities can lead healthy and fulfilling lives. Pursue research that illuminates the strengths and voices of people with developmental disabilities. Develop genuine relationships with people with developmental disabilities.</p>

Continued



TABLE 1—Continued

<p>Research practice and policy largely ignores accommodating functional limitations and enabling environmental access to public health research for people with developmental disabilities.</p>	<p>Modify measures, materials, practices, and policies to make them accessible to people with developmental disabilities without compromising, and possibly even improving, study reliability and validity. Establish policies that enable greater support for developing accessible public health research projects.</p>	<p>Make only changes necessary for accessibility, not for individual preference. Make minor modifications, e.g., to the instructions or by adding comment boxes that do not affect constructs. Make modifications that better present constructs to the population (similar to cultural tailoring or language translation). Offer instruments in alternative formats. Make physical modifications to the research environment, or meet with participants in the environment of their choosing. Pilot test instruments and protocols. Advocate in universities and at state and national levels for increased funding for projects to allow the resources and time required to include the input of people with developmental disabilities. Revise academic expectations to reflect the timeline required to make public health research accessible to people with developmental disabilities. Establish university and institutional review board policies and practices that allow the involvement and compensation of people with developmental disabilities.</p>
<p>People with developmental disabilities are marginalized from the broader context of public health knowledge production. As a result, public health research agendas may not include research perceived as worthwhile by people with developmental disabilities.</p>	<p>Increase the influence of people with developmental disabilities in public health-related science. Pursue public health-related research that meets the priorities and needs of people with developmental disabilities. Pursue community-engaged public health research.</p>	<p>Establish policies to include people with developmental disabilities on research teams, institutional review boards, advisory boards, and grant review boards and in peer review processes, academic and scientific occupations, policy positions, and other stakeholder settings. Create procedures for making inclusion in these bodies and roles accessible to people with developmental disabilities. Address research aims people with developmental disabilities perceive as relevant. Question whether interventions could risk further harming people with developmental disabilities, including because they may lead to efforts to prevent the birth of people with developmental disabilities or because they convey negative perceptions of people with developmental disabilities. Include members of the developmental disabilities community as members of the research team. Learn what people with developmental disabilities feel is important by communicating with them directly. Listen to what people with developmental disabilities feel are priorities in public health research and develop projects around community-identified needs. Work with people with developmental disabilities to improve their quality of life by supplying them with data or interventions they desire to live healthy lives.</p>

This presents novel challenges to foundational concepts of ethical research²¹ and may require specific strategies to obtain informed consent from people whose difficulties may be linguistic or social (e.g., low literacy or a tendency to take instructions too literally). Known barriers include comprehensibility and accessibility of consent materials and instruments, issues with communicating decisions, and struggles around power dynamics, including coercion to participate and mandatory reporting of abuse.^{27,28,33–36} Of note, there is disagreement on how to proceed because of different ideas about how to balance inclusion, autonomy, and safety, and people with developmental disabilities are rarely included in the conversation.^{27,28,31,35,37–43}

There are ways to address barriers to comprehension, accessibility, and self-determination in informed consent by modifying language to be simpler or more concrete, demonstrating research procedures, changing instrument delivery formats (e.g., oral administration, computer-assisted tools use), using visuals, working with people with developmental disabilities to design research materials, affording opportunities for potential participants to consult with those whom they trust, and so on.^{27,28,33–37,44} We can improve accessibility by providing study materials in alternative formats (e.g., Braille, electronic formats with text-to-speech capability or that interface with participants' assistive technology), translating materials into American Sign Language, and asking participants what will enable them to make



informed decisions. It may also be useful to spend extra time in the consent process or to ask participants if they wish to continue after the study has started.

These methods recognize that many people with developmental disabilities are able to make their own decisions and express their preferences and broaden opportunities for more people to do so. Moreover, these models can decouple autonomy from consent capacity so that self-determination, or people's freedom to make their own choices about research participation, is preserved even when decisional incompetence is present and there is thus a need for another person to legally sign research consent. These models can also be used to show that diminished comprehension does not always indicate decisional incompetence.⁴⁵

Mitigating coercion challenges requires researcher sensitivity to power issues affecting self-determination. Researchers can help those who work with people with developmental disabilities appreciate the value of assisting them to make their own participation decisions and encourage acts that support autonomy and direct access to the population. Related, researchers can use meaningful assent procedures (including honoring participants' decisions), if appropriate, and monitor for compromised voluntariness by attending to nonverbal cues, seeking explicit signs of agreement, and privileging the preferences of the person with the developmental disability.^{37,46–48}

Because some may worry about the consequences of their honest responses to research questions,

researchers can devise data collection strategies that minimize the need for mandatory reporting (e.g., using computer-assisted tools, not pressuring participants to answer questions), promote self-determination in mandatory reporting, and help everyone understand that participant responses are private.^{36,37,44} These strategies may require study-specific protocols and the (ongoing) training of research personnel.

Respecting Disability Rights in Public Health Research

Similar to revised understandings of health determinants among other minority communities, paradigmatic shifts in the understanding of disability are challenging entrenched models and practices, although their uptake in mainstream public health is slow.⁵ Early medical models viewed disability as a defect to be remediated or prevented. More recent models advance disability as a limitation in function. Countering both views, social models frame disability as something barriers embedded in social, political, and built environments have created; for example, whereas accessible buildings and public transportation do not remove all barriers, they have reduced limitations in function and greatly improved available opportunities. Today, public health increasingly reflects integrated models of disability that take into account function and environment.^{5,49,50}

Despite advances, deficits-based models of disability remain pervasive in society. People with developmental disabilities are perceived as tragic or pitiable,

requiring charity and protection, or as broken and incomplete, made whole only by therapy or medicine.^{14,15,17} These culturally entrenched mental models are particularly difficult to recognize and overcome because of their pervasiveness and social normativeness.⁵¹ The legacy of deficits-based thinking permeates health research,⁵ producing low expectations of interest and ability to participate, including narrower views of who can consent and what constitutes harm.^{24,52,53}

This can lead to the belief that anyone able to consent and participate in research is not “really disabled” enough to represent the population. This belief fails to account for advances in attitudes, community supports, assistive technology, and life opportunities that have changed the implications of living with developmental disability.^{15,32}

As society broadens its idea of what people with developmental disabilities can do, these ideas need to penetrate science. Indeed, people with developmental disabilities emphasize the importance of inclusion in research generally and as a civil right.^{27,28,54} Uptake of these ideas among researchers can foster data collection strategies that allow people to share their perspectives, focus on their strengths, foster direct and indirect benefits, and secure privacy and confidentiality.^{18,27,31,35,38,41,54–62} Moreover, these shifts require the public health community to understand that disability and health can coexist, to address disability prevention in ways that promote dignity, and to focus public health interventions on

removing social and environmental barriers.^{5,49}

As noted, respecting disability rights principles in science may bring about a change in mindset and behavior for some researchers, including environmental changes to augment decisional competency. There is no step-by-step guide for how to become more focused on disability rights; however, getting to know people with developmental disabilities in informal settings, learning about the disability rights movement, and being aware of disability models can all foster a shift of thinking.

Accessibility and Scientific Practice in Public Health

Civil rights legislation,^{63,64} disability rights advocacy, and shifting attitudes have resulted in increased community access for individuals with disabilities.^{14,15,17} To achieve these changes, people with disabilities ask for better treatment as do other minorities, but they also need accommodations to address functional limitations and enable environmental access. Likewise, accommodations are often necessary to safely and consensually involve people with developmental disabilities in public health research. Scientific practice is not always conducive to accommodating needs and rarely considers making disability accommodations an ethical imperative.^{37,65} Moreover, expectations and common practices among universities, institutional review boards, and funding agencies can apply pressures or create restrictions that challenge the provision of accommodations.



Making a study accessible may involve modifying previously validated instruments, including their delivery^{13,44}; offering instruments in alternative formats; making physical changes to the research setting; allowing people who support those with developmental disabilities access to research settings; and finding ways to remove those supporters in situations in which their presence may increase risk, for example in violence research in which the supporter may be the perpetrator.^{33,36}

Fortunately, compromises to scientific quality may not be as much of a concern as it first seems. Small wording or formatting changes or the inclusion of items such as comment boxes to reduce participant frustration can improve accessibility without negatively affecting reliability or validity. In these cases and cases in which more substantial modification is needed, careful pilot testing, or repiloting and revalidation, can help ensure materials are accessible while retaining reliability and validity.^{13,44,65} In rare cases in which modifications may compromise validity, finding alternative methods is generally preferable to exclusion or to presenting materials participants cannot understand, as occurs when an English measure is presented to a Spanish-reading participant.

Systemic barriers to accessible research may require changes in policy or practice. Projects that include stakeholder input, community engagement, or translation and cultural tailoring to ensure that modifications are helpful (rather than what researchers think would be helpful) require

more time, larger funding, and different development processes. This reality requires adjustments in funding levels, academic productivity expectations, acceptable research methodologies, and university and institutional review board practices for community member involvement and compensation.^{38,58,66} Although the need for greater fiscal resources is not a justification for ignoring ethical directives, it is worth noting that many modifications to enable access for people with disabilities are low or no cost.⁶⁷ Critical review of current systems can facilitate changes to better support research with minorities.

Broader Impacts and Community Engagement

Power, policy, funding, dissemination, and public perception. Thus far we have primarily addressed ethical considerations with including people with developmental disabilities as research participants. However, ethical public health research practice extends to questions of who makes research decisions about what is studied and funded and what is presented in dissemination.^{23,24,68} Scientific knowledge can influence decision-making in society, what is decided on, and what is considered important to address.⁶⁹ Research influences public policy, funding priorities, and public perception.

People with developmental disabilities are frequently excluded from the larger context of public health knowledge production—for example, gubernatorial research advisory boards, grant review boards, and journal peer review

processes. Furthermore, individuals with developmental disabilities are underrepresented in academic and scientific occupations, public office, and other settings in which stakeholder input is solicited and respected.^{70,71} And, whereas family members or developmental disability professionals may be included in some of these settings, they cannot always predict others' perspectives,^{72–78} and their priorities and agendas can conflict with those individuals with developmental disabilities hold.^{65,68,79}

Coupled with the legacy of deficits-based thinking, this generates a great risk of public health research priorities being at odds with the goals of the population as well as research that may further stigmatize, marginalize, and disempower people,⁴ including a focus on potentially profitable biomedical research at the expense of research on quality of life.⁶⁸

The solution to many of these issues lies in the increased presence of people with developmental disabilities in the larger milieu of knowledge production. Again, to improve representation on institutional review boards, on grant review committees,⁸⁰ and in public health occupations, attention to accessibility and accommodations is needed. In addition, policy changes requiring the representation of individuals with developmental disabilities in stakeholder settings and to provide support and incentives for inclusion could be useful. Research findings must be made accessible to self-advocates for effective use in policy, advocacy, and community-based interventions, for example,

producing a plain language research brief or policy briefs along with academic articles.⁸¹ Community-engaged research may also prove beneficial to these aims.

Questions of benefits. Ethical public health research with people with developmental disabilities also means pursuing research they feel is worthwhile, important, and needed.²⁸ Ethical research means asking research questions people with developmental disabilities feel are relevant (which may or may not reflect the values and priorities of the general population) and delivering interventions the recipients desire—which may be, as with other minorities, different from what outsiders think is appropriate.^{27,28,65,68,82,83}

Ethical research also means questioning the potential for harm in research traditionally thought of as beneficial, such as studies focusing on prevention of disability to improve population health. Although the full complexities of the following example are outside the scope of this article, it provides a particularly clear example of how ethics can shift with perspective and why many self-advocates with developmental disabilities find prevention research troubling. With the discovery of biomarkers for Down's syndrome, an estimated 92% of potential Down's syndrome births are aborted.⁸⁴ Because of this and similar practices in biomedical research that can lead to questionable public health practices, self-advocates are concerned that this type of genetic research could lead to a new kind of normative, rather than law-driven, eugenics.^{79,83,85,86}



The community has also raised concerns about interventions with intent to remediate or “normalize” disability characteristics to make a person appear less disabled, as opposed to focusing on quality of life and accepting behavior that may improve functioning. To some, these normalizing therapies further marginalize and oppress.^{87,88} Others express concern over the lack of research on their possible long-term side effects, such as loss of self-esteem, depression, or suicidality.⁸⁹ Ironically, such interventions may further fuel health disparities. Again, community-engaged research can help address these concerns.

Community-engaged research. Participatory approaches to research were created in part in response to ethical issues minorities face in research, including those discussed here. These approaches change the relationship between a minority community and the scientists who study it by placing members of the community in the role of coinvestigators. There are a variety of approaches to community-engaged research,^{82,90–98} from informal collaborations to more formal approaches such as community-based participatory research.^{99,100} In community-engaged research, there may be explicit and implicit policy or social justice aims to the research. As is true elsewhere, effectively including people with developmental disabilities as members of a research team requires attention to accommodations.^{44,65}

There are substantial benefits to community-engaged research, particularly for individuals with

disabilities.^{90,101–103} In alignment with “nothing about us without us,” community-engaged practice includes people in research about them. It assists with developing research aims and interventions that the recipients feel are relevant and useful. It helps promote public health research that is respectful and mindful of human dignity, and it incorporates civil rights framing.

Having community input on study materials can make substantial improvements in comprehensibility and accessibility, including to informed consent and dissemination materials. Community-engaged practice enables people with developmental disabilities to benefit from participating in the research process itself and helps ensure disseminated materials do not perpetuate stigma and oppression. And community-engaged practice has the potential to produce better science because of increased access to the population, better designed studies, more trustworthy conclusions, and a pool of participants who are motivated to take part because they trust the investigators and are invested in the study’s outcomes.^{13,65,90,101–104}

But even as participatory research helps promote ethics, it introduces new ethical concerns.^{65,69,102–104} For example, scientists are compensated financially for their work, but what about community members? Power sharing requires constant vigilance, and facilitating it may require scientists to give up more control than they find comfortable or have been trained to allow. Community-engaged projects risk tokenism, in which community

members have little or no power or do not fully represent the interests and priorities of the larger community. The question of who can speak for whom has no easy answers.

CONCLUSIONS

In line with principles of ethical public health practice, our goals are to encourage public health science that is sensitive to the ethical and social dimensions of research with an important and underattended minority group and to include this group more in public health research and knowledge production more generally. We hope the ideas advanced herein contribute to the development of more effective, ethical means of facilitating participation by people with developmental disabilities in science, thereby advancing the reduction of health disparities.

On a related note, we hope the number of public health researchers who take up these ideas, particularly by using community-engaged science, grows as we identify ways to navigate ethical minefields. These strategies can improve the ability of the public health community to work with people with developmental disabilities to monitor their health status (e.g., in the new field of disability epidemiology), intervene to promote health and well-being in ways that preserve respect and dignity, and promote inclusion in general population studies. ■

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