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A Call-in for Allyship and Anti-Ableism in Intellectual Disability Research

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Running head: Anti-ableist intellectual disability research

Abstract

Provoked by decades of grassroots activism, anti-ableist work is underway to advance disability rights. Intellectual disability researchers can integrate these social changes into their work by interrogating and transforming the beliefs and practices that underpin intellectual disability research. We share actionable ideas to foster anti-ableism and allyship in intellectual disability research. These include: 1) Learn from and nurture long-term, mutual relationships with people with intellectual disability; 2) Amplify the voices of people with intellectual disability in institutional structures that influence research; 3) Infuse anti-ableist frameworks into our own research; and 4) Embody a career-long commitment to disability rights, reflexive practice, and growth.

Key words: anti-ableist, intellectual disability research, disability rights

Introduction

In the US, the scientific study of intellectual disability has roots in a time when disability epitomized deviance and incompetence. These beliefs resulted in people with disabilities being feared, provided charity, seen as inferior, and segregated and efforts to prevent people with disabilities from being born (McDonald, Fialka-Feldman, Barkoff, & Burgdorf, 2020; Shapiro, 1994; Trent, 2021; Wehmeyer, 2013). Today—thanks to decades of grassroot efforts by people with disabilities and their allies—we increasingly reject these ableist beliefs, beliefs that discriminated on the basis of disability, in favor of recognizing the inherent value and rights of people with disabilities (Charlton, 1998; Shapiro, 1994; United Nations, 2012). In turn, there is a focus on promoting disability rights and equal access by pursuing anti-ableist work, or efforts to dismantle the intentional and unintentional interpersonal, institutional, and structural dynamics that discriminate on the basis of disability and give rise to inequities (Berne, Morales, Langstaff, & Invalid, 2018; Bogart & Dunn, 2019; Invalid, 2017).

Likely all researchers today would broadly endorse disability rights. However, beliefs alone do not lead to changes in policy and practice. Moreover, ableism can be subtle and evade easy detection, especially within an ableist society. Researchers have a responsibility to intentionally work to bring disability rights into scientific research (Lakin & Turnbull, 2005; National Institute on Disability Independent Living, and Rehabilitation Research, 2019; Shogren, 2022). This includes interrogating the beliefs and practices that underpin intellectual disability research. And, when these beliefs and practices are found to perpetuate ableism, working towards shifting underlying frameworks. Importantly, this work must be continuous as progress towards greater integration of disability rights and new insights into ableism can reveal opportunities for further enhancement. For researchers without intellectual disability, this process

is one of allyship, or the lifelong, positive, and conscious actions undertaken to promote the inclusion of marginalized populations (Saad, 2020; The Anti-Oppression Network, n.d.).

We are US-based disabled and non-disabled researchers, activists, and allies with experience experimenting with how intellectual disability researchers can advance anti-ableism intellectual disability research. We have worked together for over a decade on research and other projects to promote disability rights. Over the course of our work, we have discussed and identified actionable ideas that can help researchers foster anti-ableism in intellectual disability research and be effective allies to people with intellectual disability. As a field, we are collectively called to continuously appraise ableist forces and, where indicated and possible, take actions to meet our commitments to accountability to people with intellectual disability, disability rights, and supporting people with intellectual disability to live full and meaningful lives.

Here, primarily for those without lived experience of disability, we share our ideas to further grow our common pursuit of research more fully reflecting anti-ableist practices. These ideas fall under four broad categories, all sharing an emphasis on learning from and working with people with intellectual disability: 1) Learn from and nurture long-term, mutual relationships with people with intellectual disability; 2) Amplify the voices of people with intellectual disability in institutional structures that influence research; 3) Infuse anti-ableist frameworks into our own research; and 4) Embody a career-long commitment to disability rights, reflexive practice, and growth. In Table 1 we provide self-reflection questions and ideas and resources for action within each of these areas. We share these ideas as a call-in—an invitation—to join us in the inner work that allows us to identify how we participate in ableism and the outer work that helps us more fully express disability rights in our research, with attention to

continuous improvement. In doing this work, discomfort and even risk may be encountered; it is therefore important to note that those with relatively greater privilege may be best positioned to take greater professional risks in advancing disability rights in research, and may bear a greater responsibility to doing so.

Anti-ableist Intellectual Disability Research Practices

1. Learn from and nurture long-term, mutual relationships with people with intellectual disability

Many intellectual disability researchers do not have lived experience with disability; those who do may still struggle to resist internalizing ableism and/or may not have broad experience with diverse individuals with intellectual disability (Shogren, 2022). As such, it is important to intentionally incorporate opportunities to learn about the history, acts of resistance, and contemporary experiences of people with intellectual disability as part of one's ongoing professional development, even though this information largely resides in non-academic sources. We can leverage rich, multi-media opportunities that center disability rights available in movies, books, social media, blogs, museums, disability rights organizations' websites, cultural events, and disability rights celebrations, especially those from people with disabilities. As we engage with this material, it is critical to have an open mind, attend to the many ways intellectual disability is experienced (e.g., by people from different racial and ethnic groups, with different gender identities, and with varying communication needs), and critically assess relics of ableism. For example, we might begin to identify ableist messages, such as an emphasis on charity, or how awareness campaigns are grounded in beliefs that disability is undesirable, rather than rights, or beliefs about disability as an aspect of human diversity that should be celebrated

(Kassiane, 2012) or gain insight into experiences of belonging to multiple minoritized communities (Annamma, Connor & Ferri, 2013).

Importantly, we must be vigilant for how perspectives change over time and are not one-dimensional or necessarily shared uniformly. That is, what is modern and accepted may evolve—for example, consider changes to language related to intellectual disability (Bersani, 2007), differing preferences for person-first or identify-first language (Bottema-Beutel et al, 2021), and cultural perspectives toward disability and autonomy (Annamma, Connor & Ferri, 2013). Intellectual disability researchers are well-advised to stay abreast of social developments so they can be responsive to them in their research. Through learning about disability history and the experiences of people with intellectual disability, we can better understand their needs, values, and priorities and leverage those insights to guide research endeavors.

This learning can have immediate practical implications. For example, if we are having difficulty with research participant recruitment, assessing *why* people with disabilities may mistrust researchers (i.e., due to a history of forgoing informed consent, harming people, and perpetuating information that asserted inferiority and inhumanity; D'Antonio, 2005; Freedman, 2001; Sabatello, 2018) may help us generate innovative approaches that demonstrate respect and responsiveness to community views. Strategies we have found useful include getting to know people, providing information that conveys the legitimacy of the research participation opportunity, and partnerships with self-advocacy groups.

As allies, having authentic, mutual, long-term relationships with people with intellectual disability is also an important aspect of being committed to disability rights. Fundamental to allyship, these relationships demonstrate commitment to respecting people with intellectual disability as full, valued members of society and create opportunities to serve as resources to

those who experience disparities in social capital. Of note, relationships grounded in disability rights principles affords opportunities to learn with and from people with intellectual disability and can decrease paternalism (McDonald & Keys, 2008). Critically, these relationships should reflect a genuine commitment to community building and mutuality and be free of deficit-and/or charity-based orientations centered on seeing disability as an individual-level problem and taking pity on those with disabilities. We can both model such relationships and help others build their own if they do not already have them or if they could benefit from stronger mutuality.

Building and sustaining authentic, mutual, long-term relationships requires deliberate effort. Due to long-standing marginalization, one may sometimes find that there are few people with intellectual disability in their communities. However, people with intellectual disability are—and should be—everywhere: they are our family members, neighbors, colleagues, providers of services to us, users of social service organizations we support, and fellow members of our religious organizations, concerned citizens also seeking community engagement and improvements in our communities, and users of community spaces and resources such as libraries, concert halls, and sports arenas. As we seek to deepen our understanding and commitments, we can assess our various settings and create or enhance relationships therein.

In attending to mutuality, we can be a friend and resource to people with intellectual disability and, in turn, receive these benefits as well. Examples from our relationships include being part of one another's Circle of Support and visioning processes, sharing meals, family time, special occasions, and social events, being an accountability partner for personal and professional goals, and contributing time and expertise to disabled people's organizations.

Collectively, these resources and relationships can be leveraged to yield rich insights, including implications for intellectual disability research. For example, researchers may learn

more about the historical underpinnings of guiding frameworks and practices in their fields and change processes underway in efforts to infuse disability rights into knowledge generation (Andrews et al, 2019; Wehmeyer, 2013). In contrast, others may find ways in which their field has experienced shortcomings in adopting anti-ableist perspectives or in re-aligning its prevailing frameworks with community priorities (Shogren, 2022)—these insights can subsequently be leveraged for change efforts.

2. Amplify the voices of people with intellectual disability in institutional structures that influence research

We can also enhance anti-ableist disability research by amplifying the voices of people with intellectual disability in institutional structures that influence intellectual disability research.

First, as we engage in roles as educators and mentors, we can integrate the voices of people with intellectual disability in curriculum and course materials, thereby strengthening trainees' preparation to pursue anti-ableist research. For example, we can invite individuals with intellectual disability to teach or co-teach a class or course (Fialka-Feldman & Gill, 2021) and assign readings and media which privilege their voices. Similarly, we can invite people with intellectual disability to present or co-present at conferences and workshops. To ensure success, we must work with the person to prepare and practice, as presenting may be a new role for them. When providing support, we should monitor against speaking for the presenter with intellectual disability. It is essential that these voices include individuals with differing communication needs and from additionally minoritized groups, making sure to not always ask the same individuals so as to increase opportunities among a broader group.

Second, we can address institutional practices and structures to increase the feasibility of recruiting people with intellectual disability for educational and professional opportunities (e.g.,

degree or training programs, employment as research staff): Doing so increases representation in and enriches science itself (Andrews & Lund, 2015; Lund, Andrews, & Holt, 2016; Raymaker, 2017). Achieving this requires procedural changes such as developing practices to intentionally attract them, support them in the application process, reduce bias in candidate evaluation, and value lived experience. Purposively mentoring individuals with intellectual disability for such opportunities is one way to increase social capital and power of people with intellectual disability and reflects the presumption of competence, a critical component of disability rights.

Importantly, success in these areas requires further anti-ableist work centered on structural changes in higher education to create access to broader university functions such as required trainings (e.g., accessible means to learn and demonstrate knowledge of ethical issues in research with people), communications (e.g., administrative notices and required forms), and facilities (Dwyer, et al., 2021). We can use our institutional positions and social capital to advocate for policy changes, including those that prohibit the hiring or advancement of research staff without high school or higher education degrees, a challenge we have experienced.

Third, we can identify timely opportunities to work toward greater inclusion on decision-making and advisory bodies that impact research with people with intellectual disability. For example, we can advocate for inclusion on governing bodies that shape research funding priorities and awards; peer review processes; boards, including editorial boards, workgroups, or committees; journal editorials, insight pieces, or responses to published articles; and research projects (Lewis, Richards, Rice, & Collis, 2020; Lory, 2019; National Institutes of Health, Advisory Committee to the Director, Working Group on Diversity, Subgroup on Individuals with Disabilities, 2022; Nicolaidis, 2019). One strategy to increase representation is, anytime an invitation is issued to participate, to agree to serve only if joined by an individual with an

intellectual disability. Importantly, the contributions of people with intellectual disability should be fully and publicly acknowledged and they should be kept informed of the eventual outcomes.

In facilitating inclusion, we must continuously pursue authentic inclusion by creating accessible environments (e.g., re-imagining meeting structures, integrating multi-modal communication, prioritizing plain language) and dynamics that promote input and are receptive to the perspectives of people with intellectual disability so they can genuinely influence discussions and decisions. We must also be willing to interrogate the idea of what is legitimate knowledge and be prepared to acknowledge the value of and role for lived experience alongside empirical evidence. Building personal relationships, acknowledging power imbalances and past harms, earning trust, facilitating comfort, and providing universal accommodations are strong starting points; monitoring these dynamics and collecting feedback on them can help identify areas for further development (Garcia- Iriarte et al, 2009; Nicolaidis et al, 2019; McDonald & Stack, 2016).

Similarly, when encountering Institutional Review Board (IRB) challenges due to ableist assumptions, we can work with our IRBs to understand their concerns, discuss any inaccuracies that may contribute to their concerns, and identify mutually acceptable courses of action that address the concerns while minimizing compromises discordant with principles of disability rights. For example, if an IRB requests that individuals with intellectual disability be assessed by a physician for consent capacity for a not greater than minimal risk study or require proxy consent when the person with intellectual disability has legal capacity, we can discuss with them how this requirement may be discriminatory, make individuals feel that they are being tested, or lead to exclusion of people with intellectual disability from research (McDonald et al, 2016). We can work with our IRB to understand that the use of alternative approaches (e.g.,

accommodations to enhance understanding, supported decision-making, safeguards calibrated to study risks) can better reflect disability rights and foster the responsible inclusion of people with intellectual disability.

3. Infuse anti-ableist frameworks into our own research

We can often readily—albeit only with deliberate, sustained effort—transform our own research endeavors. Infusing anti-ableist frameworks into our research is multi-faceted, complex, and a long-term undertaking. The fields contributing to intellectual disability research have long traditions of epistemological and conceptual frameworks that may not be as apparent today or easily overturned. Yet incremental, conscious acts can create needed transformation.

Ableist conceptual frameworks in research—which inform research questions, methods, and interpretations of findings—influence policy and practice and can lead to justifications for segregating people with disabilities and an (over)emphasis on individual-focused medical or rehabilitation interventions. A key starting point is interrogating the conceptual frameworks underpinning our research, with a focus on the model of disability operating therein. This framework—explicitly and implicitly—guides us in identifying research questions, specifying a design, and interpreting findings; and can sometime be unquestionably accepted. Narrow and archaic medical models of disability have historically lead researchers to pathologize disability and to cure, normalize, fix, and rid individuals of their disability (Walmsley, 2001; Wehmeyer, 2013).

Eradicating the legacies of medical and charity models that perceive disability as inherently problematic can be challenging. Thanks largely to insights from disabled people, recent discourse has identified how popular interventions, research approaches (including those that compare people with intellectual disability to those without), and outcomes that center

curing, fixing, and changing people with disabilities to be more like people without disabilities are in fact detrimental to people with disabilities (Bottema-Beutel, Kapp, Lester, Sasson, & Hand, 2021; En ligneRose, 2007; Feldman, Bosett, Collet, & Burnham-Riosa, 2013; Hacking, 2006; Interagency Autism Coordinating Committee, 2017; Spong & Bianchi, 2018; Walker & Raymaker, 2021). Related, there is increasing concern for how the medical model contributes to using biomedical advances to prevent disability and reduce the perceived caregiving burden of people with disabilities (Bersani et al, 2007; de Graaf, Buckley, & Skotko, 2015; Parens & Asch, 2003; Peace & Roy, 2014; Yeo-The & Tang, 2022), rather than improving the quality of life of people with intellectual disability in ways that are community-supported.

In contrast, biopsychosocial and life course models inclusive of disability rights and neurodiversity principles position disability as a natural element of human diversity emergent from dynamic processes between individuals and environments (Walker & Raymaker, 2021; World Health Organization, 2011). Biopsychosocial models can counter individual-focused models that locate problems as within individuals to instead emphasize oppressive and disabling systems and highlight approaches acceptable to and topics important to people with disabilities. Adoption of such models is an important step towards anti-ableist research. For example, a biopsychosocial perspective may drive researchers to study prenatal genetics screening from the perspective of identifying needed structural interventions such as social supports and resources for families (Janvier, Farlow & Wilfond, 2012). This model also drives a team of researchers with and without intellectual disability to explore relationships, housing, and interactions with doctors (Salmon et al., 2019; Tuffrey-Wijne, 2009)—all topics identified by and important to the disability community. Similarly, life course models are aiding researchers in recognizing the need for services and supports across the lifespan leading to transitions from a single focus on

parents to one dually focused on the desires of children and adults with intellectual disability. For recommendations on how to make one's conceptual framework more explicit and avoiding ableist language, see Bottema-Beutel and colleagues (2021).

A second critical step to transforming the lingering impacts of ableist origins is by critically examining the social and historical forces that shape beliefs about who can contribute to and generate knowledge. Constructivist approaches implore us to reconsider the historic practice of limiting knowledge generation to individuals with advanced scientific education. While not a cure-all, nor without ethical concerns, pursuing community-engaged research—research done in partnership with people with intellectual disability—can foster anti-ableist intellectual disability research by acknowledging gaps in non-disabled scientists' knowledge and integrating the views of people with disability. Community-engaged research positions lived experience as a valid form of knowledge that can inform all aspects of the scientific process. Importantly, we can extend community engagement to places where it may seem less possible. For example, adults with intellectual disability can guide researchers working with young children or provide support to team members who use pictorial or behavioral methods for communication. Moreover, engagement of people with intellectual disability can provide guidance for handling emergent, complex issues, such as safeguards in genomics research (Sabatello et al, 2022). The growing literature on community-engaged research with people with intellectual disability provides insight into common challenges and effective practices (Bigby, Frawley, & Ramcharan, 2014; Nicolaidis et al., 2019; Schwartz et al., 2019; Stack & McDonald, 2014).

Third, dominance of positivism and ableist assumptions has led some researchers to broadly adopt proxy-report methodologies. When relevant for the research question, anti-ableist

researchers make the assumption that individuals with intellectual disability are able to provide valid information in qualitative *and* quantitative research, and, design their research to engage people with intellectual disability as primary respondents by maximizing accessibility.

Respectful and valid research practices may be best accomplished by creating *de novo* or adapting existing self-report measures, and engaging people with intellectual disability to collect data, enhancing universal accommodations (e.g., text-to-speech for online surveys, use of plain language in all materials, screen-reader compatible materials, etc.) while simultaneously offering tailored approaches to participate in data collection (e.g., Milner and Frawley, 2019; Nicolaidis et al., 2019; Sabatello, Chen, Zhang, & Appelbaum, 2019; Schwartz et al., 2019). Researchers and participants may spend extended time together to establish effective ways of communicating, rather than excluding those who do not communicate in the way(s) preferred by non-disabled researchers. In some cases, this may mean pursuing more interactive or transactional approaches (Caldwell, 2014; Milner & Frawley, 2019; Ormston, Spencer, Bernard, & Snaper, 2014) or alternative forms of communication. Such adaptations are *strengths* of research protocols, rather than protocol deviations or inconsistencies, as they enhance representation and validity.

Infusion of anti-ableist frameworks also requires us to consider our work through an intersectional lens, acknowledging that the experience of disability is but one aspect of identity. Taking an intersectional approach and giving equal importance to other labels or experiences such as gender, race, ethnicity, sexual orientation, etc., demonstrates an understanding of the humanity and complexity of people with intellectual disability, is the right thing to do, and may have synergistic positive outcomes with other efforts to promote rights more broadly across different social identities and experiences. To achieve this, we must infuse intersectionality into intellectual disability research, which will require, for example, enhancing anti-racist intellectual

disability research (Annamma et al, 2013; Johnson et al, 2021) and sharing our expertise to enhance the representation of people with intellectual disability in general population research, such as clinical trials (Feldman et al., 2013; McDonald, Schwartz, & Sabatello, 2022).

4. Embody a career-long commitment to disability rights, reflexive practice, and growth

Being an ally is a long-term process. Social conditions and trends—and therefore what’s needed and possible—will change over time. Commitment to anti-ableist intellectual disability research entails a continual process of listening, reflecting, learning, and growing. It requires us across all career stages to de-center our own experience, take responsibility for our missteps, and take action to improve. It is possible that some of us may reflect on how research earlier in our career may have caused harm or operated from an ableist perspective; sharing these reflections is important to model and encourage this same commitment from others (Shogren, 2022). Taking on anti-ableist work as a career-long commitment implores honest reflection, accountability, genuine openness to change, corrective actions, rebuilding of trust, and plans for change, while allowing for professional growth and opportunities to establish new practices and an identity as a researcher.

Reflexive practice can be institutionalized into one’s work in a variety of ways. For example, we can establish an external group that holds us accountable to anti-ableist research (by constructively critiquing research proposals, research protocols, and dissemination products), regularly assessing participatory work by using tools to identify who did what work (Garcia-Iriarte, Kramer, Kramer, & Hammel, 2009), obtaining feedback on what is working well and what needs to be targeted for improvement (McDonald & Stack, 2016; Nicolaidis et al., 2019; Stack & McDonald, 2014), or participating in a peer mentoring group (Daniell, 2006) focused on accountability to anti-ableist intellectual disability research.

Whatever the means, we encourage everyone to commit to the career-long pursuit of continuously learning and improving and foster the same in their students and mentees. One frame that helps us is the notion of speaking in draft, in which missteps and feedback are expected. This framework emphasizes the continual, never-ending process of deepening our understanding, identifying bias, and taking action toward anti-ableism. Future readers of this manuscript will likely perceive it as naive and ableist in ways we don't yet see—this will be welcome as it will indicate progress and demonstrate the synergistic benefits of collective efforts toward social justice. For example we have helped each other identify times when our initial reaction that something wasn't possible was driven by ableist thinking, rather than genuine feasibility.

Conclusion

Although work remains, society is making important advances toward disability rights. Children with intellectual disability are more likely now to live with their families and receive effective, integrated education, young adults with intellectual disability have new opportunities to pursue higher education, and adults with intellectual disability are increasingly engaged in meaningful employment and satisfying careers and experience a sense of belonging to their community. Research in intellectual disability can help facilitate these social improvements and be a powerful partner by strengthening commitments to anti-ableist intellectual disability research with a focus on weeding out scientific paternalism (Ayers, 2021).

To have this positive effect, we must actively work as a community and with genuine openness to learning and changing. We write this piece to invite us all to leverage our shared commitment to demolishing ableist systems of oppression. We encourage each of us to do the work of anti-ableist intellectual disability research every day and urge you to start doing so or

increase the intentionality of ongoing efforts by *writing down and committing to undertake 2-4 short-term actions that will help you better infuse disability rights into your research*. These commitments may be uncomfortable. They may entail personal risk. But we have a shared responsibility to undertake them as part of our accountability to marginalized people. Make a regular practice of writing out your commitments to this work, building in supports to help you in this pursuit, and seeking to do better with each new act. It takes a village to build and enact a culture of anti-ableist intellectual disability research. Let's work together.

References

- Advisory Committee to the Director Working Group on Diversity, Subgroup on Individuals with Disabilities, National Institutes of Health (2022). Report.
- Andrews, E. E., Forber-Pratt, A. J., Mona, L. R., Lund, E. M., Pilarski, C. R., & Balter, R. (2019). # SaytheWord: A disability culture commentary on the erasure of “disability”. *Rehabilitation Psychology*, 64(2), 111.
- Andrews, E. E., & Lund, E. M. (2015). Disability in psychology training: Where are we? *Training and Education in Professional Psychology*, 9(3), 210.
- Annamma, S. A., Connor, D., & Ferri, B. (2013). Dis/ability critical race studies (DisCrit): Theorizing at the intersections of race and dis/ability. *Race Ethnicity and Education*, 16(1), 1-31.
- Ayers, K. (March, 2021). *Opening Remarks*. PCORI Workshop on Methodologic Challenges in Intellectual and Developmental Disabilities Research.
- Berne, P., Morales, A. L., Langstaff, D., & Invalid, S. (2018). Ten principles of disability justice. *WSQ: Women's Studies Quarterly*, 46(1), 227-230.
- Bersani Jr, H. (2007). President's Address 2007-The Past is Prologue:“MR,” Go Gentle Into That Good Night. *Intellectual and Developmental Disabilities*, 45(6), 399-404.
- Bersani Jr, H., Rotholz, D. A., Eidelman, S. M., Pierson, J. L., Bradley, V. J., Gomez, S. C., . . . Morin, D. (2007). Unjustifiable non-therapy: Response to the issue of growth attenuation for young people on the basis of disability. *Intellectual and Developmental Disabilities*, 45(5), 351-353.

- Bigby, C., Frawley, P., & Ramcharan, P. (2014). Conceptualizing inclusive research with people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 27(1), 3-12.
- Bogart, K. R., & Dunn, D. S. (2019). Ableism special issue introduction. *Journal of Social Issues*, 75(3), 650-664.
- Bottema-Beutel, K., Kapp, S., Lester, J. N., Sasson, N., & Hand, B. (2021). Avoiding ableist language: Suggestions for autism researchers. *Autism in Adulthood*, 3(1), 18-29.
- Caldwell, K. (2014). Dyadic interviewing: A technique valuing interdependence in interviews with individuals with intellectual disabilities. *Qualitative Research*, 14(4), 488-507.
- Charlton, J. (1998). *Nothing about us without us: Disability oppression and empowerment*. Berkeley: University of California Press.
- D'Antonio, M. (2005). *The state boys rebellion*: Simon and Schuster.
- Daniell, E. (2006). *Every other Thursday: Stories and strategies from successful women scientists*: Yale University Press.
- de Graaf, G., Buckley, F., & Skotko, B. G. (2015). Estimates of the live births, natural losses, and elective terminations with Down syndrome in the United States. *American Journal of Medical Genetics*, 167a(4), 756-767.
- Dwyer, P., Acevedo, S. M., Brown, H. M., Grapel, J., Jones, S. C., Nachman, B. R., ... & Williams, Z. J. (2021). An Expert Roundtable Discussion on Experiences of Autistic Autism Researchers. *Autism in Adulthood*, 3(3), 209-220.
- En ligneRose, N. (2007). Politics of Life Itself. Biomedicine, Power, and Subjectivity in the Twenty-First Century, Princeton et Oxford. In: Princeton University Press.

- Fialka-Feldman, M., & Gill, M. (2021). Teaching Disability Studies Together: The Importance of Having Instructors with Labels of Intellectual Disabilities. *Canadian Journal of Disability Studies*, 10(3), 275-284.
- Feldman, M. A., Bosett, J., Collet, C., & Burnham-Riosa, P. (2013). Where are persons with intellectual disabilities in medical research? A survey of published clinical trials. *Journal of Intellectual Disability Research*, 58(9), 800-809. doi:10.1111/jir.12091
- Foucault, M. (1973). The birth of the clinic: an archaeology of medical perception, trans. AM Sheridan Smith, New York: Pantheon.
- Freedman, R. I. (2001). Ethical challenges in the conduct of research involving persons with mental retardation. *Mental Retardation*, 39(2), 130-141.
- Garcia-Iriarte, E., Kramer, J. C., Kramer, J. M., & Hammel, J. (2009). "Who did what?": A participatory action research project to increase group capacity for advocacy. *Journal of Applied Research in Intellectual Disabilities*, 22, 10-22.
- Hacking, I. (2006). Making Up People. *London Book of Reviews*, 28.
- Hens, K., Peeters, H., & Dierickx, K. (2016). Shooting a moving target. Researching autism genes: an interview study with professionals. *European Journal of Medical Genetics*, 59(1), 32-38.
- Interagency Autism Coordinating Committee. (2017). 2016-2017 Interagency Autism Coordinating Committee Strategic Plan For Autism Spectrum Disorder.
- Invalid, S. (2017). Skin, Tooth, and Bone - The Basis of Movement is Our People: A Disability Justice Primer. *Reproductive Health Matters*, 25(50), 149-150.
- Janvier, A., Farlow, B., & Wilfond, B. S. (2012). The experience of families with children with trisomy 13 and 18 in social networks. *Pediatrics*, 130(2), 293-298.

- Johnson, K. R., Bogenschutz, M., & Peak, K. (2021). Propositions for Race-Based Research in Intellectual and Developmental Disabilities. *Inclusion*, 9(3), 156-169.
- Kassiane S. (2012). Acceptance vs. Awareness. Retrieved from <https://autisticadvocacy.org/2012/04/acceptance-vs-awareness/>
- Kirby, A., McDonald, K., Cusack, J., Maddox, B., Mangan, C., Morgan, L., Roux, A., Singhal, N. & Zener, D. (2021). An expert discussion on knowledge translation in autism in adulthood research. *Autism in Adulthood*, 3(1), 11-17.
- Lakin, K. C., & Turnbull, A. P. (Eds.). (2005). *National goals and research for people with intellectual and developmental disabilities*. American Association on Mental Retardation.
- Lewis, B., Richards, S., Rice, S., & Collis, A. (2020). A response to Bates, C et al (2020) “Always trying to walk a bit of a tightrope”: The role of social care staff in supporting adults with intellectual and developmental disabilities to develop and maintain loving relationships. *British Journal of Learning Disabilities. British Journal of Learning Disabilities*, 48(4), 269-271.
- Lory, B. (2019). For the Love of Science? *Autism in Adulthood*, 1(1), 12-14.
- Lund, E. M., Andrews, E. E., & Holt, J. M. (2016). A qualitative analysis of advice from and for trainees with disabilities in professional psychology. *Training and Education in Professional Psychology*, 10(4), 206.
- McDonald, K., Conroy, N., Olick, R., Kim, C., LoBraico, E. & Prather, E. & The Project ETHICS Expert Panel (2016). Is safety in the eye of the beholder? Safeguards in research with adults with intellectual disability. *Journal of Empirical Research in Human Research Ethics*, 11, 424-438.

- McDonald, K., Fialka-Feldman, M., Barkoff, A. & Burgdorf, M. . (2020). Legal, Ethical, and Social Issues Affecting the Lives of People with Intellectual and Developmental Disabilities. In A. L.M. Glidden, L.J., McIntyre, L.L. & Tasse, M. J., (Ed.), *American Psychological Association Handbook on Intellectual and Developmental Disabilities*. Washington, DC: American Psychological Association
- McDonald, K. & Keys, C. (2008). How the powerful decide: Access to research participation for those at the margins. *American Journal of Community Psychology*, 42, 79-93.
- McDonald, K., Schwartz, A. & Sabatello, M. (2022). Eligibility criteria in clinical trials funded by the National Institutes of Health: Can adults with intellectual disability get in? *Disability and Health Journal*, 15(4), 101368.
- McDonald, K. E., & Stack, E. (2016). You say you want a revolution: An empirical study of community-based participatory research with people with developmental disabilities. *Disability and Health*, 9(2), 201-207.
- Milner, P., & Frawley, P. (2019). From ‘on’ to ‘with’ to ‘by.’ People with a learning disability creating a space for the third wave of inclusive research. *Qualitative Research*, 19(4), 382-398.
- National Institute on Disability IL, and Rehabilitation Research. (2019). 2018-2023 Long-Range Plan.
- Nicolaidis, C. (2019). Autism in adulthood: The new home for our emerging field. *Autism in Adulthood*, 1, 1-3.
- Nicolaidis, C., Raymaker, D., Kapp, S. K., Baggs, A., Ashkenazy, E., McDonald, K., . . . Joyce, A. (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.

- Ormston, R., Spencer, L., Bernard, M., & Snaper, D. (2014). The foundations of qualitative research. In J. Ritchie, C. Lewis, N. McNaughton, & R. Ormston (Eds.), *Qualitative research practice: A guide for social science students and researchers* (pp. 2-25): sage.
- Parens, E., & Asch, A. (2003). Disability rights critique of prenatal genetic testing: Reflections and recommendations. *Mental Retardation and Developmental Disabilities Research Review*, 9(1), 40-47.
- Park, K. (2006). *Secrets of women: gender, generation, and the origins of human dissection*: Zone Books New York.
- Peace, W. J., & Roy, C. (2014). Scrutinizing Ashley X: Presumed medical “solutions” vs. real social adaptation. *The Journal of Philosophy, Science & Law*, 14(3), 33-52.
- Raymaker, D. M. (2017). Reflections of a community-based participatory researcher from the intersection of disability advocacy, engineering, and the academy. *Action research*, 15(3), 258-275.
- Saad, L. F. (2020). *Me and White Supremacy: Combat Racism, Change the World, and Become a Good Ancestor*: Sourcebooks, Inc.
- Sabatello, M. (2018). Cultivating inclusivity in precision medicine research: disability, diversity, and cultural competence. *Journal of Community Genetics*, 10(3), 363-373.
- Sabatello, M., Chen, Y., Zhang, Y., & Appelbaum, P. S. (2019). Disability inclusion in precision medicine research: a first national survey. *Genetics in Medicine*, 21(10), 2319-2327.
- Sabatello, M., Martschenko, D. O., Cho, M. K., & Brothers, K. B. (2022). Data sharing and community-engaged research. *Science*, 378(6616), 141-143.

- Salmon, N., Garcia Iriarte, E., Donohoe, B., Murray, L., Singleton, G., Barrett, M., & Dillon, M. (2019). Our Homes: An inclusive study about what moving house is like for people with intellectual disabilities in Ireland. *British Journal of Learning Disabilities*, 47(1), 19-28.
- Schwartz, A. E., & Durkin, B. (2020). "Team is everything": Reflections on trust, logistics and methodological choices in collaborative interviewing. *British Journal of Learning Disabilities*, 48(2), 115-123.
- Schwartz, A. E., Kramer, J. M., Cohn, E. S., & McDonald, K. E. (2019). "That Felt Like Real Engagement": Fostering and Maintaining Inclusive Research Collaborations With Individuals With Intellectual Disability. *Qualitative Health Research*, 30(2), 236-249.
- Shapiro, J. (1994). *No pity: People with disabilities forging a new civil rights movement*. New York: Three Rivers Press.
- Shogren, K. A. (2022). Presidential Address, 2022—Dismantling Systemic Barriers: Re-envisioning Equity and Inclusion. *Intellectual and Developmental Disabilities*, 60(6), 520-529.
- Spong, C. Y., & Bianchi, D. W. (2018). Improving public health requires inclusion of underrepresented populations in research. *JAMA*, 319(4), 337-338.
- Stack, E., & McDonald, K. (2014). Nothing about us without us: Does action research in developmental disabilities research measure up? *Journal of Policy and Practice in Intellectual Disabilities*, 11(2), 83-91.
- Straus, S. E., Tetroe, J., & Graham, I. (2009). Defining knowledge translation. *Cmaj*, 181(3-4), 165-168.
- The Anti-Oppression Network. (n.d.). allyship. Retrieved from <https://theantioppressionnetwork.com/allyship/>

- Trent Jr, J. W. (2021). Historical foundations of the field of intellectual and developmental disabilities. In L.M. Glidden, Abbeduto, L.J., McIntyre, L.L. & Tasse, M. J. (Eds.). *American Psychological Association Handbook on Intellectual and Developmental Disabilities*. Washington, DC: American Psychological Association.
- Tuffrey-Wijne, I. B., Gary. (2009). Co-researching with people with learning disabilities: An experience of involvement in qualitative data analysis. *Health Expectations*, 13, 174-784.
- United Nations. (2012, October 11). *Convention on the Rights of Persons with Disabilities and Optional Protocol*. Paper presented at the Convention on the Rights of Persons with Disabilities.
- Walker, N., & Raymaker, D. M. (2021). Toward a neuroqueer future: An interview with Nick Walker. *Autism in Adulthood*, 3(1), 5-10.
- Walmsley, J. (2001). Normalisation, emancipatory research and inclusive research in learning disability. *Disability & Society*, 16 (2), 187-205
- Wehmeyer, M. L. (2013). The story of intellectual disability. *Paul H. Brookes*.
- World Health Organization. (2011). *World report on disability*. Retrieved from Geneva:
- Yeo-Teh, N. S. L., & Tang, B. L. (2022). Moral obligations in conducting stem cell-based therapy trials for autism spectrum disorder. *Journal of Medical Ethics*, 48(5), 343-348.