Research Ethics for All:
Accessible Research Ethics Education for Community Research Partners

Literature Review References

Baumer, N. T., Becker, M. L., Capone, G. T., Egan, K., Fortea, J., Handen, B. L., Head, E., Hendrix, J. E., Litovsky, R. Y., Strydom, A., Tapia, I. E., & Rafii, M. S. (2022). Conducting clinical trials in persons with Down syndrome: summary from the NIH INCLUDE Down syndrome clinical trials readiness working group. *Journal of Neurodevelopmental Disorders*, *14*(22). https://doi.org/10.1186/s11689-022-09435-z

Boahen, G. (2015). Researching the Mental Capacity Act 2005: Reflections on governance, field relationships, and ethics with an adult who did not consent. *Ethics and Social Welfare*, *9*(4), 375-389. https://doi.org/10.1080/17496535.2015.1072571

Boettcher, N., Duque, C., & Lashewicz, B. M. (2022). Negotiating research participant consent with, for and by adults with developmental disabilities in interaction with their third-party consent providers. *International Journal of Qualitative Methods*, *21*, 1-15. https://doi.org/10.1177/16094069211054941

Bowler, J. E., & Rai, D. (2016). Letter from Bristol. *The National Medical Journal of India*, *29*(4), 238–239.

Boxall, K., & Ralph, S. (2009). Research ethics and the use of visual images in research with people with intellectual disability. *Journal of Intellectual & Developmental Disability*, *34*(1), 45–54. https://doi.org/10.1080/13668250802688306

Boxall, K., & Ralph, S. (2010). Research ethics committees and the benefits of involving people with profound and multiple learning disabilities in research. *British Journal of Learning Disabilities*, *39*(3), 173–180. https://doi.org/10.1111/j.1468-3156.2010.00645.x

Calveley, J. (2012). Including adults with intellectual disabilities who lack capacity to consent in research. *Nursing Ethics*, *19*(4), 558–567. https://doi.org/10.1177/0969733011426818

Carey, E., & Griffiths, C. (2017). Recruitment and consent of adults with intellectual disabilities in a classic grounded theory research study: ethical and methodological considerations. *Disability & Society*, *32*(2), 193–212. https://doi.org/10.1080/09687599.2017.1281793

Cascio, M. A., Weiss, J. A., Racine, E., & the Autism Research Ethics Task Force. (2020). Person-oriented ethics for autism research: Creating best practices through engagement with autism and autistic communities. *Autism*, *24*(7), 1676–1690. https://doi.org/10.1177/1362361320918763

Cascio, M. A., Weiss, J. A., & Racine, E. (2021). Empowerment in decision-making for autistic people in research. *Disability & Society*, *36*(1), 100-144. https://doi.org/10.1080/09687599.2020.1712189

Cithambaram, K., Duffy, M., & Courtney, E. (2019). End-of-life care research on people with intellectual disabilities: Challenges for proactive inclusion in an Irish context. *British Journal of Learning Disabilities*, *47*(2), 70–76. https://doi.org/10.1111/bld.12260

Clement, T., & Bigby, C. (2013). Ethical challenges in researching in group homes for people with severe learning difficulties: shifting the balance of power. *Disability & Society*, *28*(4), 486–499. https://doi.org/10.1080/09687599.2012.711245

Conroy, N. E., McDonald, K. E., Olick, R. S., & The Project ETHICS Expert Panel Members. (2021). A survey study of the attitudes and experiences of adults with intellectual disability regarding participation in research. *Journal of Intellectual Disability Research*, *65*(10), 941–948. https://doi.org/10.1111/jir.12877

Cook, T., & Inglis, P. (2012). Participatory research with men with learning disability: informed consent. *Tizard Learning Disability Review*, *17*(2), 92–101. https://doi.org/10.1108/13595471211218875

Coons, K. D., & Watson, S. L. (2013). Conducting research with individuals who have intellectual disabilities: Ethical and practical implications for qualitative research. *Journal on Developmental Disabilities*, *19*(2), 14–24. https://www.proquest.com/scholarly-journals/conducting-research-with-individuals-who-have/docview/1460847872/se-2

Crook, B., Tomlins, R., Bancroft, A., & Ogi, L. (2015). "So often they do not get recruited": Exploring service user and staff perspectives on participation in learning disability research and the barriers that inhibit it. *British Journal of Learning Disabilities*, *44*(2), 130-137. https://doi.org/10.1111/bld.12120

Daley, T. C., Singhal, N., & Krishnamurthy, V. (2013). Ethical considerations in conducting research on autism spectrum disorders in low and middle income countries. *Journal of Autism and Developmental Disorders*, *43*(9), 2002–2014. https://doi.org/10.1007/s10803-012-1750-2

Dorozenko, K. P., Bishop, B. J., & Roberts, L. D. (2016). Fumblings and faux pas: Reflections on attempting to engage in participatory research with people with an intellectual disability. *Journal of Intellectual & Developmental Disability*, *41*(3), 197–208. https://doi.org/10.3109/13668250.2016.1175551

Dowse, L. (2009). 'It's like being in a zoo.' Researching with people with intellectual disability. *Journal of Research in Special Educational Needs*, *9*(3), 141–153. https://doi.org/10.1111/j.1471-3802.2009.01131.x

Drozd, M., Chadwick, D., & Jester, R. (2021). Successful strategies for including adults with intellectual disabilities in research studies that use interpretative phenomenological analysis. *Nurse Researcher*, *29*(3), 34–41. https://doi.org/10.7748/nr.2021.e1778

Earle, S., Ledger, S., Tilley, E., Walmsley, J., Chapman, R., & Townson, L. (2020). A critical reflection on accessing women with learning disabilities to participate in research about sensitive subjects through organisational partnerships. *British Journal of Learning Disabilities*, *48*(2), 162–169. https://doi.org/10.1111/bld.12314

Feudtner, C., & Brosco, J. P. (2011). Do people with intellectual disability require special human subjects research protections? The interplay of history, ethics, and policy. *Developmental Disabilities Research Reviews*, *17*(1), 52–56. https://doi.org/10.1002/ddrr.139

Fudge Schormans, A., Wilton, R., & Marquis, N. (2019). Building collaboration in the co-production of knowledge with people with intellectual disabilities about their everyday use of city space. *Area*, *51*(3), 415-422. https://doi.org/10.1111/area.12492

Furberg, R. D., Ortiz, A. M., Moultrie, R. R., Raspa, M., Wheeler, A. C., McCormack, L. A., & Bailey, D. B. (2018). A digital decision support tool to enhance decisional capacity for clinical trial consent: Design and development. *JMIR Research Protocols*, *7*(6): e10525. https://doi.org/10.2196/10525

Gjermestad, A., Luteberget, L., Midjo, T., & Witsø, A. E. (2019). Preparing a dialogue conference together with persons with intellectual disabilities. *Nordic Social Work Research*, *10*(4), 343-355. https://doi.org/10.1080/2156857X.2019.1602558

Gjertsen, H. (2019). People with intellectual disabilities can speak for themselves! A methodological discussion of using people with mild and moderate intellectual disabilities as participants in living conditions studies. *Scandinavian Journal of Disability Research*, *21*(1), 141–149. https://doi.org/10.16993/sjdr.615

Haines, D. (2017). Ethical considerations in qualitative case study research recruiting participants with profound intellectual disabilities. *Research Ethics*, *13*(3–4), 219–232. https://doi.org/10.1177/1747016117711971

Hall, S. A. (2013). Including people with intellectual disabilities in qualitative research. *Journal of Ethnographic & Qualitative Research*, *7*(3), 128–142.

Hamilton, J., Ingham, B., McKinnon, I., Parr, J. R., Tam, L. Y.-C., & Le Couteur, A. (2017). Mental capacity to consent to research? Experiences of consenting adults with intellectual disabilities and/or autism to research. *British Journal of Learning Disabilities*, *45*(4), 230–237. https://doi.org/10.1111/bld.12198

Hart, S. M., Pascucci, M., Sood, S., & Barrett, E. M. (2020). Value, vulnerability and voice: An integrative review on research assent. *British Journal of Learning Disabilities*, *48*(2), 154–161. https://doi.org/10.1111/bld.12309

Herron, D., Priest, H. M., & Read, S. (2015). Working alongside older people with a learning disability: informing and shaping research design. *British Journal of Learning Disabilities*, *43*(4), 261–269. https://doi.org/10.1111/bld.12147

Hills, K. J., Clapton, J., Dorsett, P., & Andersen, K. (2020). Conducting research with people with nonverbal autism: An inclusive methodological approach. *Journal of Social Inclusion*, *11*(1), 5-23. https://doi.org/10.36251/josi.162

Ho, P., Downs, J., Bulsara, C., Patman, S., & Hill, A.-M. (2018). Addressing challenges in gaining informed consent for a research study investigating falls in people with intellectual disability. *British Journal of Learning Disabilities*, *46*(2), 92–100. https://doi.org/10.1111/bld.12217

Hopkins, R., McGrath, J., Hogan, B., Skehan, P., & Acheson, L. (2022). In response to "'Ethno…graphy?!? I can't even say it': Co-designing training for ethnographic research for people with learning disabilities and carers." *British Journal of Learning Disabilities*, *50*(1), 61-65. https://doi.org/10.1111/bld.12452

Horner-Johnson, W., & Bailey, D. (2013). Assessing understanding and obtaining consent from adults with intellectual disabilities for a health promotion study. *Journal of Policy and Practice in Intellectual Disabilities*, *10*(3), 260-265. https://doi.org/10.1111/jppi.12048

Inglis, P., & Cook, T. (2011). Ten top tips for effectively involving people with a learning disability in research. *Journal of Learning Disabilities and Offending Behaviour*, *2*(2), 98–104. https://doi.org/10.1108/20420921111152441

Irvine, A. (2010). Conducting qualitative research with individuals with developmental disabilities: Methodological and ethical considerations. *Developmental Disabilities Bulletin*, *38*(1–2), 21–34.

Jepson, M. (2015). Applying the Mental Capacity Act to research with people with learning disabilities. *British Journal of Learning Disabilities*, *43*(2), 128–134. https://doi.org/10.1111/bld.12122

Johnson, H., Douglas, J., Bigby, C., & Iacono, T. (2011). The challenges and benefits of using participant observation to understand the social interaction of adults with intellectual disabilities. *Augmentative and Alternative Communication*, *27*(4), 267–278. https://doi.org/10.3109/07434618.2011.587831

Kaley, A., Hatton, C., & Milligan, C. (2019). More than words: The use of video in ethnographic research with People with intellectual disabilities. *Qualitative Health Research*, *29*(7), 931–943. https://doi.org/10.1177/1049732318811704

Kidney, C. A., & McDonald, K. E. (2014). A toolkit for accessible and respectful engagement in research. *Disability & Society*, *29*(7), 1013–1030. https://doi.org/10.1080/09687599.2014.902357

Kuri, E., & Fudge Schormans, A. (2022). Pivotal care practices: Care ethics in inclusive arts-based research with people labelled/with intellectual disability during the COVID-19 pandemic. *The Arts in Psychotherapy*, *80*, 101920. https://doi.org/10.1016/j.aip.2022.101920

Maes, B., Nijs, S., Vandesande, S., Van Keer, I., Arthur-Kelly, M., Dind, J., Goldbart, J., Petitpierre, G., & Van der Putten, A. (2021). Looking back, looking forward: Methodological challenges and future directions in research on persons with profound intellectual and multiple disabilities. *Journal of Applied Research in Intellectual Disabilities*, *34*(1), 250–262. https://doi.org/10.1111/jar.12803

Manning, C. (2009). 'My memory's back!' Inclusive learning disability research using ethics, oral history and digital storytelling. *British Journal of Learning Disabilities*, *38*(3), 160–167. https://doi.org/10.1111/j.1468-3156.2009.00567.x

Marshall, K., & Tilley, L. (2013). Life stories, intellectual disability, cultural heritage and ethics: Dilemmas in researching and (re)presenting accounts from the Scottish Highlands. *Ethics and Social Welfare*, *7*(4), 400–409. https://doi.org/10.1080/17496535.2013.842304

Marshall, Z. (2012). Navigating risks and professional roles: research with lesbian, gay, bisexual, trans, and queer young people with intellectual disabilities. *Journal of Empirical Research on Human Research Ethics*, *7*(4), 20–33. https://doi.org/10.1525/jer.2012.7.4.20

McClimens, A., & Allmark, P. (2011). A problem with inclusion in learning disability research. *Nursing Ethics*, *18*(5), 633–639. https://doi.org/10.1177/0969733011404588

Mcclimens, A., & Evans, J. (2013). Credit where it's due: clients' contribution to academic research. *Learning Disability Practice*, *16*(7), 26–28. https://doi.org/10.7748/ldp2013.09.16.7.26.e1474

McCormack, L. A., Wylie, A., Moultrie, R., Furberg, R. D., Wheeler, A. C., Treiman, K., Bailey, D. B., & Raspa, M. (2019). Supporting informed clinical trial decisions: Results from a randomized controlled trial evaluating a digital decision support tool for those with intellectual disability. *PloS One*, *14*(10), 1-21. https://doi.org/10.1371/journal.pone.0223801

McDonald, K. E., Conroy, N. E., Olick, R. S., & The Project ETHICS Expert Panel. (2017). What's the harm? Harms in research with adults with intellectual disability. *American Journal on Intellectual and Developmental Disabilities*, *122*(1), 78–92. https://doi.org/10.1352/1944-7558-122.1.78

McDonald, K. E. (2012). "We want respect": adults with intellectual and developmental disabilities address respect in research. *American Journal on Intellectual and Developmental Disabilities*, *117*(4), 263–274. https://doi.org/10.1352/1944-7558-117.4.263

McDonald, K. E., Conroy, N. E., Kim, C. I., LoBraico, E. J., Prather, E. M., & Olick, R. S. (2016). Is safety in the eye of the beholder? Safeguards in research with adults with intellectual disability. *Journal of Empirical Research on Human Research Ethics*, *11*(5), 424–438. https://doi.org/10.1177/1556264616651182

McDonald, K. E., Conroy, N. E., Olick, R. S., & the Project ETHICS Expert Panel. (2016). Is it worth it? Benefits in research with adults with intellectual disability. *Intellectual and Developmental Disabilities*, *54*(6), 440–453. https://doi.org/10.1352/1934-9556-54.6.440

McDonald, K. E., Conroy, N. E., Olick, R. S., & Project ETHICS Expert Panel. (2018). A quantitative study of attitudes toward the research participation of adults with intellectual disability: Do stakeholders agree? *Disability and Health Journal*, *11*(3), 345–350. https://doi.org/10.1016/j.dhjo.2017.12.004

McDonald, K. E., Gibbons, C., Conroy, N., & Olick, R. S. (2022). Facilitating the inclusion of adults with intellectual disability as direct respondents in research: Strategies for fostering trust, respect, accessibility and engagement. *Journal of Applied Research in Intellectual Disabilities*, *35*(1), 170–178. https://doi.org/10.1111/jar.12936

McDonald, K. E., & Kidney, C. A. (2012). What is right? Ethics in intellectual disabilities research. *Journal of Policy and Practice in Intellectual Disabilities*, *9*(1), 27–39. https://doi.org/10.1111/j.1741-1130.2011.00319.x

McDonald, K. E., Kidney, C. A., Nelms, S. L., Parker, M. R., Kimmel, A., & Keys, C. B. (2009). Including adults with intellectual disabilities in research: Scientists' perceptions of risks and protections. *Journal of Policy and Practice in Intellectual Disabilities*, *6*(4), 244–252. https://doi.org/10.1111/j.1741-1130.2009.00225.x

McDonald, K. E., Kidney, C. A., & Patka, M. (2013). "You need to let your voice be heard": research participants' views on research. *Journal of Intellectual Disability Research, 57*(3), 216–225. https://doi.org/10.1111/j.1365-2788.2011.01527.x

McDonald, K. E., & Raymaker, D. M. (2013). Paradigm shifts in disability and health: Toward more ethical public health research. *American Journal of Public Health*, *103*(12), 2165–2173. https://doi.org/10.2105/AJPH.2013.301286

McDonald, K. E., Schwartz, N. M., Gibbons, C. M., & Olick, R. S. (2015). "You can't be cold and scientific": Community views on ethical issues in intellectual disability research. *Journal of Empirical Research on Human Research Ethics*, *10*(2), 196–208. https://doi.org/10.1177/1556264615575512

McDonald, K., & Patka, M. (2012). "There is no black or white": Scientific community views on ethics in intellectual and developmental disability research. *Journal of Policy and Practice in Intellectual Disabilities*, *9*(3), 206–214. https://doi.org/10.1111/j.1741-1130.2012.00348.x

Mietola, R., Miettinen, S., & Vehmas, S. (2017). Voiceless subjects? Research ethics and persons with profound intellectual disabilities. *International Journal of Social Research Methodology*, *20*(3), 263–274. https://doi.org/10.1080/13645579.2017.1287872

Mulhall, P., Taggart, L., Coates, V., & McAloon, T. (2020). Using a Delphi survey to gain an international consensus on the challenges of conducting trials with adults with intellectual disabilities. *Clinical Trials*, *17*(2), 138–146. https://doi.org/10.1177/1740774519887168

Mulhall, P., Taggart, L., McAloon, T., & Coates, V. (2021). Challenges to conducting randomised controlled trials with adults with intellectual disabilities: Experiences of international experts. *Journal of Applied Research in Intellectual Disabilities*, *34*(3), 891–904. https://doi.org/10.1111/jar.12838

Nicolaidis, C., Raymaker, D., Kapp, S. K., Baggs, A., Ashkenazy, E., McDonald, K., Weiner, M., Maslak, J., Hunter, M., & Joyce, A. (2019). The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism: The International Journal of Research and Practice*, *23*(8), 2007–2019. https://doi.org/10.1177/1362361319830523

Northway, R., Howarth, J., & Evans, L. (2015). Participatory research, people with intellectual disabilities and ethical approval: making reasonable adjustments to enable participation. *Journal of Clinical Nursing*, *24*(3–4), 573–581. https://doi.org/10.1111/jocn.12702

Nosan, G., Bertok, S., Vesel, S., Yntema, H. G., & Paro-Panjan, D. (2014). Correspondence. *Croatian Medical Journal*, *55*(1), 78. https://doi.org/10.3325/cmj.2014.55.78a

Østby, M. (2020). Recruitment of research participants with intellectual disability in a Norwegian context – a response to Williams. *European Journal of Special Needs Education*, *35*(1), 21–22. https://doi.org/10.1080/08856257.2019.1687559

Peuravaara, K. (2014). Reflections on collaborative research: to what extent and on whose terms? *Scandinavian Journal of Disability Research*, *17*(3), 272-283. https://doi.org/10.1080/15017419.2013.859178

Post, S. G., Pomeroy, J., Keirns, C., Cover, V. I., & Dorn, M. L. (2017). A grassroots community dialogue on the ethics of the care of people with autism and their families: The Stony Brook Guidelines. *HEC Forum*, *29*(2), 93–126. https://doi.org/10.1007/s10730-017-9320-9

Riggs, N. R., Hepburn, S. L., Pinks, M. E., & Fidler, D. J. (2022). A prevention science approach to promoting health and quality of life for individuals with intellectual and developmental disabilities. *Infant and Child Development*, *31*(1), e2278. https://doi.org/10.1002/icd.2278

Robotham, D., & Hassiotis, A. (2009). Randomised controlled trials in learning disabilities: a review of participant experiences. *Advances in Mental Health and Learning Disabilities*, *3*(1), 42–46. https://doi.org/10.1108/17530180200900008

Robotham, D., King, M., Canagasabey, A., Inchley-Mort, S., & Hassiotis, A. (2011). Social validity of randomised controlled trials in health services research and intellectual disabilities: a qualitative exploration of stakeholder views. *Trials*, *12*, 144. https://doi.org/10.1186/1745-6215-12-144

Sammet Moring, N., Parish, S. L., Mitra, M., & Alterio, N. A. (2019). After disclosure: A research protocol to respond to disclosures of abuse and sexual violence in research with adults with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *16*(4), 254–263. https://doi.org/10.1111/jppi.12292

Snipstad, Ø. I. M. (2022). Concerns regarding the use of the vulnerability concept in research on people with intellectual disability. *British Journal of Learning Disabilities*, *50*(1), 107–114. https://doi.org/10.1111/bld.12366

Strnadová, I., & Walmsley, J. (2018). 5004 - Peer-reviewed articles on inclusive research: Do co-researchers with intellectual disabilities have a voice? *Journal of Applied Research in Intellectual Disabilities*, *31*(1), 132–141. https://doi.org/10.1111/jar.12378

Sutton, B. (2021). "I like you being here": To understand and be understood through illustration. *HAU: Journal of Ethnographic Theory*, *11*(2), 675–692. https://doi.org/10.1086/717106

Swaine, J., Parish, S. L., Luken, K., & Atkins, L. (2011). Recruitment and consent of women with intellectual disabilities in a randomised control trial of a health promotion intervention. *Journal of Intellectual Disability Research*, *55*(5), 474–483. https://doi.org/10.1111/j.1365-2788.2011.01399.x

Taua, C., Neville, C., & Hepworth, J. (2014). Research participation by people with intellectual disability and mental health issues: an examination of the processes of consent. *International Journal of Mental Health Nursing*, *23*(6), 513–524. https://doi.org/10.1111/inm.12079

Tilley, E., Strnadová, I., Ledger, S., Walmsley, J., Loblinzk, J., Christian, P. A., & Arnold, Z. J. (2021). 'Working together is like a partnership of entangled knowledge': exploring the sensitivities of doing participatory data analysis with people with learning disabilities. *International Journal of Social Research Methodology*, *24*(5), 567–579. https://doi.org/10.1080/13645579.2020.1857970

Tuffrey-Wijne, I., & Butler, G. (2010). Co-researching with people with learning disabilities: an experience of involvement in qualitative data analysis. *Health Expectations*, *13*(2), 174–184. https://doi.org/10.1111/j.1369-7625.2009.00576.x

Wagner, L., Frisch, M., Turner-Brown, L., Andrews, S., Edwards, A., Moultrie, R., Alvarez Rivas, A., Wheeler, A., & Raspa, M. (2020). Preferences for the research use of electronic health records among young adults with fragile X syndrome or autism spectrum disorder. *Disability and Health Journal*, *13*(4), 100927. https://doi.org/10.1016/j.dhjo.2020.100927

Watchman, K. (2016). Investigating the lived experience of people with down syndrome with dementia: Overcoming methodological and ethical challenges. *Journal of Policy and Practice in Intellectual Disabilities*, *13*(2), 190–198. https://doi.org/10.1111/jppi.12167

Van der Weele, S., & Bredewold, F. (2021). Shadowing as a qualitative research method for intellectual disability research: Opportunities and challenges. *Journal of Intellectual & Developmental Disability*, *46*(4), 340-350. https://doi.org/10.3109/13668250.2021.1873752

Weksler-Derri, D., Shwed, U., & Davidovitch, N. (2019). Ethical challenges in participatory research with autistic adults in Israel. *Journal of Empirical Research on Human Research Ethics*, *14*(5), 447–451. https://doi.org/10.1177/1556264619858524

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