The Ethics of Relying on Research Participants' Altruism

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Abstract: We examine the ethics of enrolling individuals in research that poses net health risks by appealing to their altruism. We argue that it is permissible to enroll individuals who are motivated by altruism when (i) they autonomously consent; and (ii) the net health risks are outweighed by the combination of (ii-a) the extent to which participation furthers their considered aims and thereby contributes to their wellbeing and agency and (ii-b) the study's social value. Further, it is permissible to enroll altruistic individuals who cannot consent when: (I) their surrogate consents and they assent, ideally because it furthers their aims; and (II) the net health risks are outweighed by the extent to which participation contributes to their wellbeing and agency. This account leads us to suggest a revision of consent forms to include more information about studies' social value and a reduction of barriers to the enrollment of participants who cannot consent.

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Introduction

Individuals enroll in clinical research for three principal reasons: to access clinical benefits, receive compensation, and help others. While the research ethics literature has extensively discussed the first two motives, altruism has received less attention.[1] This is regrettable because appealing to participants' altruism involves complex ethical considerations. One reason to do so

[1] On motivation by therapeutic benefit, see Paul Applebaum, Loren Roth, and Charles Lidz, "The therapeutic misconception: Informed consent in psychiatric research," *International Journal of Law and Psychiatry* 5, no. 3-4 (1982): 319-29, https://doi.org/10.1016/0160-2527(82)90026-7 and Jonathan Kimmelman, "The therapeutic misconception at 25: Treatment, research, and confusion," *The Hastings Center Report* 37, no. 6 (2007): 36-42, https://doi.org/10.1353/hcr.2007.0092. On financial motivation, see Christine Grady, "Payment of clinical research subjects," *The Journal of Clinical Investigation* 115, no. 7 (2005): 1681-87, https://doi.org/10.1172/JCI25694; and Christine Grady, Gabriella Bedarina, Ninet Sinaii, Mark Anthony Gregorio, and Ezekiel Emanuel, "Motivations, enrollment decisions, and socio-demographic characteristics of healthy volunteers in phase 1 research," *Clinical Trials* 14, no. 5 (2017): 526-36, https://doi.org/10.1177/1740774517722130. For a rare discussion of altruistic motivation, see Lynn Jansen, "The ethics of altruism in clinical research," *The Hastings Center Report* 39, no. 4 (2009): 26-36, https://doi.org/10.1353/hcr.0.0164.

is that it may increase the numbers willing to participate, thereby enabling socially valuable research. This is especially important for research that poses "net" health risks, that is, research whose prospective health benefits, if any, are exceeded by the prospective setbacks to participants' health. Participation in net risk research is contrary to individuals' prospective health interests, hence, clinical benefits do not provide participants with a reason to enroll. Moreover, research ethics norms limit monetary payment for studies that pose net health risks to avoid undue inducement and coercion and, for participants requiring surrogate consent, to prevent exploitation for others' monetary gain.[2] This leaves altruism as a key motivator for enrollment in studies with net health risks.

Appealing to participants' altruism in such cases raises concern that they might be exposed to excessive risks for others' benefit, thereby violating the Kantian injunction to always treat each person as an end in themselves and never merely as a means.[3] Since the Nuremberg Code of 1947, research regulations, guidelines, and standard practices have been designed to minimize the chances that participants are exploited in this sense. To this end, two conditions are standardly imposed on research with individuals who have decisional capacity. The first is *autonomous consent*—roughly, agreement that is given intentionally and freely by a capable

[2] Grady, "Payment of research subjects"; Joseph Millum and Michael Garnett, "How payment for research participation can be coercive," *The American Journal of Bioethics* 19, no. 9 (2019): 21–31, https://doi.org/10.1080/15265161.2019.1630497.

[3] Immanuel Kant, *Groundwork of the Metaphysics of Morals*, edited by Mary Gregor and Jens Timmermann, Cambridge University Press, 2012, G428-9.

individual who is adequately informed and who understands the pros and cons of enrolling.[4] The second is a *favorable risk-benefit ratio*.[5] This requires minimizing the risks to those that are necessary for the study's scientific and social value. It also requires an intrapersonal evaluation of the net expected effect on each participant's interests and judging whether any prospective setback to these interests is outweighed by the study's expected social value. Importantly, this balancing of individual net expected harm against prospective social value incorporates special concern for research participants. Consequently, researchers and ethics review committees tend to be very reluctant to expose participants to moderate, much less high net health risks, even when a study's prospective social value is considerable.[6]

We explore two questions arising from these tests when recruiting participants by appealing to their altruism. First, how should we understand the interests of altruistic individuals when conducting the intrapersonal balancing of prospective harms and benefits that is part of the *favorable risk-benefit ratio* test? In practice, review boards and researchers focus on individuals'

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[4] Tom L. Beauchamp, "Autonomy and consent," in *The Ethics of Consent: Theory and Practice*, edited by Frank Miller and Alan Wertheimer. Oxford University Press, 2010, https://doi.org/10.1093/acprof:oso/9780195335149.003.0003.

[5] Ezekiel Emanuel, David Wendler, and Christine Grady, "What makes clinical research ethical?" *Journal of the American Medical Association* 283, no. 20 (2000): 2701-11, 2705, https://doi.org/10.1001/jama.283.20.2701.

[6] Annette Rid, "Setting risk thresholds in biomedical research: lessons from the debate about minimal risk," *Monash Bioethical Review* 32 (2014): 63–85, 64 https://doi.org/10.1007/s40592-014-0007-6.

interests in their health (and perhaps their monetary interests). And consent forms standardly provide exhaustive descriptions of the health risks and other ways in which the research might negatively affect participants. In contrast, the study's social value is minimally described. For example, the US National Institutes of Health (NIH) template consent form for intramural research directs researchers to describe the immediate and long-term foreseeable risks and discomforts to participants, including risks of physical, psychological, emotional, legal, economic, and privacy harms. Forms list many pages of risks—the template consent language for what will happen to participants' left-over blood samples alone contains more than 30 sentences. In contrast, the template description of the potential for the study to benefit others is 1-2 sentences.[7] An understanding of the interests of altruistic participants can help establish whether this way of presenting information to participants is warranted.

The second question is what the Kantian injunction not to treat research participants as mere means, but also always as ends in themselves, requires for potential participants with cognitive limitations. This question is especially challenging when the authenticity of the individuals' benevolent motives is in doubt because their altruism is associated with a medical condition. Such individuals may not be able to meet the requirement of autonomous, informed consent. How to conceive of their interests is a further challenge.

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[7] NIH, *Informed Consent Template for Use at the NIH Clinical Center*. version 13: 04-15-2024. https://irbo.nih.gov/confluence/display/ohsrp/Consent+Templates+and+Guidance. Also see WHO, *Informed Consent Form Template for Clinical Studies*, accessed 6 June, 2026. https://www.who.int/groups/research-ethics-review-committee/guidelines-on-submitting-research-proposals-for-ethics-review/templates-for-informed-consent-forms.

In this paper, we address these two questions and thereby offer an account of when it is permissible to appeal to the altruism of both people in the general population, and people with impaired agency, to enroll them in research. For concreteness, our consideration of participants who may not be able to consent focuses on individuals with Williams syndrome, who often have mild to moderate cognitive impairment and tend to be more altruistic than the general population.

Section 1 considers altruistic adults in the general population. It argues that when participation in research advances their considered, steady, final ends, it contributes to their wellbeing and agency. Section 2 introduces Williams syndrome. Section 3 argues that, although individuals with Williams syndrome often lack the capacity to consent, it remains the case that participation contributes to their wellbeing and agency when it serves their considered final ends. Further, enrollment of individuals who are unable to consent requires the permission of a surrogate and the participant's assent, which ideally is based on the participant's appreciation of why participation would be worthwhile. Section 4 argues that the association between the altruism of individuals with Williams syndrome and their medical condition does not undermine the ways in which participation can advance their wellbeing and agency. Section 5 considers policy implications. Section 6 concludes.

1. Altruism, wellbeing, and agency

A rational agent's interests are at least partly determined by the extent to which they achieve their final aims. A final aim is an end that an agent values in itself and not merely because it contributes to some further end. For example, a person with HIV may be motivated to participate

in research because they value improving the lives of people with HIV, and not merely because participating in research will enhance their reputation.[8] The values that determine a person's final ends have two characteristics. First, *endorsement*: the person can reflect on these values and, when doing so, regards it as right that they hold them. Second, *self-judgment:* the person assesses themselves, at least in part, by the extent to which they live up to these values.[9]

A considered, steady aim is one that an individual has given due thought to, expresses allegiance to, and takes into account in a variety of decisions over time to the extent that acting on it forms a part of their personality. Some such aims are primarily self-regarding, such as having good health. Others might be substantially other-regarding, such as that a cure is found for HIV. Importantly, even though their own welfare will not normally be the principal reason for which people pursue their other-regarding ends, many regard the achievement of their other-regarding ends as a determinant of how well their life goes for their own sake. For example, someone who volunteers for socially valuable research because they are motivated to advance medical knowledge might naturally regard contributing to such knowledge as promoting their own wellbeing.[10]

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[8] David Evans, "An activist's argument that participant values should guide risk–benefit ratio calculations in HIV cure research," *The Journal of Medical Ethics* 43 (2017): 100–03, https://doi.org/10.1136/medethics-2015-103120.

[9] Agnieszka Jaworska, "Respecting the margins of agency: Alzheimer's patients and the capacity to value," *Philosophy and Public Affairs* 28, no. 2 (1999): 105-38, 13-16, https://doi.org/10.1111/j.1088-4963.1999.00105.x.

[10] Evans, "An activist's argument."

By deferring to a person's informed, considered judgment of what makes their life go better for them, we respect their powers to formulate a view of the good life and set final ends for themselves.[11] It is commonly argued that such deference, and the concomitant reasons to further a person's welfare insofar as it is determined by the satisfaction of their ends, should be limited to cases in which the person's final aims are not in conflict with the foundational values that motivate such deference, namely, respect for persons and sympathy with their perspective.[12] This rules out, for example, counting the satisfaction of a person's sadistic ends as contributing to a conception of their welfare that others have reason to promote. Our arguments in this paper are consistent with this limitation. For we focus on cases in which individuals' aims are praiseworthy, such as advancing knowledge about a health condition and improving treatments for those who suffer from it. We conclude that, when an individual has such laudable, considered, steady, final aims that can be advanced by participation in research, and they see the degree to which they promote these aims as a determinant of how well their lives go for them, such participation contributes to their wellbeing.[13] Of course, this contribution needs to be

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[11] Matthew D. Adler, *Wellbeing and Fair Distribution: Beyond Cost-Benefit Analysis.* Oxford University Press, 2012, chap. 3; Roger Crisp, "Wellbeing," *The Stanford Encyclopedia of Philosophy*, edited by Edward N. Zalta, 2021, secs. 4.2 and 4.3. https://plato.stanford.edu/archives/win2021/entries/wellbeing/

[12] John C. Harsanyi, "Morality and the theory of rational behaviour," in *Utilitarianism and Beyond*, edited by Amartya Sen and Bernard Williams, Cambridge University Press, 1982; Adler, *Wellbeing and Fair Distribution*, chap. 3; Crisp, "Well-being," secs. 4.2 and 4.3.

[13] Jansen, "The ethics of altruism."

balanced against the ways in which participation may threaten their other interests, such as being healthy.

What about individuals whose altruistic aims are ill-considered, fleeting, suggestible, or highly context-dependent? In such cases, it is doubtful that satisfaction of their aims contributes significantly to their wellbeing. Such motives reflect transient inclination rather than stable values. It therefore seems unlikely that a person would, in a reflective mood, count their satisfaction as contributing significantly to their own welfare.[14]

Now consider a case in which achieving a firmly held, altruistic aim requires substantial personal sacrifice, such as when a person with HIV pauses antiretroviral treatment, and thereby risks increased infection, to contribute to research on a cure for HIV.[15] People may reasonably value the opportunity to improve others' lives in these ways, even when doing so sets back their own wellbeing on balance (that is, after accounting for the ways in which advancing their altruistic ends contributes to their wellbeing). Respect for people's agential capacities requires that, in considering the overall quality of a person's situation and opportunities, we take into account not merely their opportunities for well-being, but also their opportunities to pursue non-self-interested goals and thereby to shape the world to better fit their ideals.[16] This is a second way in which participation in research on altruistic grounds can be in participants' interest.

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[14] Derek Parfit, *Reasons and Persons*, Oxford University Press, 1984, Appendix I.

[15] Evans, "An activist's argument."

[16] Amartya Sen, "Wellbeing, agency and freedom: The Dewey Lectures 1984," *The Journal of Philosophy* 82, no. 4 (1985): 169-221, http://www.jstor.org/stable/2026184; Kimberley

The significance of a person's exercise of agency in service of their final aims depends on how considered and steady these aims are. The decision to pursue a considered, firmly held aim will generally be an important expression of a person's agency. In contrast, a choice to follow a fleeting desire will not be as valuable in this regard. Similarly, an opportunity to pursue a context-dependent or induced inclination is likely to generate actions that merely reflect happenstance or the person's pliability.

The foregoing establishes that the intrapersonal component of the *favorable risk-benefit ratio* test should be interpreted as encompassing the extent to which participation in research furthers people's steady, altruistic final ends and thereby advances their welfare and agency. By doing so, researchers treat participants' interests in their welfare and agency, as well as their altruistic ends, as reason-giving and thereby treat participants as ends in themselves.[17]

Even on this broader understanding of altruistic individuals' interests, a choice to enroll in research out of a considered altruistic motive can represent a net setback to their interests. For the risks of harm posed by the research might be so great that, even accounting for the ways it contributes to their wellbeing and agency, participation makes things go prospectively worse for them. It follows that the second part of the *favorable risk-benefit ratio* test, which requires balancing any prospective net loss to research participants against the social good of the research, remains pertinent for altruists. Still, recognizing the extent to which participation may be in their interest shapes where this test draws the line between permissible and impermissible

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Brownlee, "The lonely heart breaks: On the right to be a social contributor," *Aristotelian Society Supplemental Volume* 90, no. 1 (2016): 27-48, https://doi.org/10.1093/arisup/akw008.

[17] Onora O'Neill, *Constructions of Reason*, Cambridge University Press, 1990.

research. Keeping constant the prospective social value of a study, it can be acceptable to expose altruistic individuals who offer autonomous consent to greater research risks than would be acceptable if they did not have altruistic aims.[18] In what follows, we examine how this analysis extends to cognitively impaired individuals who are unable to consent.

2. Williams syndrome

Williams syndrome is a genetic neurodevelopmental disorder affecting roughly 1 in 7,500 individuals.[19] It leads to cardiovascular disease and a risk of sudden death that is 25-100 times higher than the general population.[20] Current treatments are limited largely to palliation of

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[18] Here, we agree with Jansen, "The ethics of altruism," 30, though only for partly overlapping reasons. Jansen focuses on the extent to which success at achieving altruistic aims can contribute to wellbeing. Our analysis adds the importance of people's opportunities to exercise agency. Note that since we focus on the intrapersonal element of the *favorable risk-benefit ratio* test, we make no claim about how, precisely, a net setback to an individual's interests, broadly understood, should be balanced against the social good of research. For discussion of competing views, see Nir Eyal, "Is there an ethical upper limit on risks to study participants?" *Public Health Ethics* 13, no. 2 (2020): 143-56, https://doi.org/10.1093/phe/phaa028.

[19] Beth Kozel, Boaz Barak, Chong Ae Kim, *et al*. "Williams syndrome," *Nature Reviews Disease Primers* 7, article 42 (2021), https://doi.org/10.1038/s41572-021-00276-z.

[20] Alessia Del Pasqua, Gabriele Rinelli, Alessandra Toscano *et al*. "New findings concerning cardiovascular manifestations emerging from long-term follow-up of 150 patients with the

cardiovascular symptoms.[21] To develop more effective treatments, it is crucial to better understand the molecular mechanisms underlying the cardiovascular symptoms associated with Williams syndrome.[22]

Individuals with Williams syndrome typically have a hypersocial, empathetic personality and a strong aversion to others' distress.[23] They display greater altruism than the general

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Williams-Beuren-Beuren syndrome," *Cardiology in the Young* 19, no. 6 (2009): 563-7, https://doi.org/10.1017/S1047951109990837.

[21] Armin Wessel, Verena Gravenhorst, Reiner Buchhorn, Angela Gosch, Carl-Joachim Partsch, and Rainer Pankau, "Risk of sudden death in the Williams-Beuren syndrome," *American Journal of Medical Genetics* 127A, no. 3 (2004): 234-7, https://doi.org/10.1002/ajmg.a.30012.

[22] Kozel *et al.*, "Williams syndrome."

[23] Osvanna Leyfer, Janet Woodruff-Borden, Bonita Klein-Tasman, Johanna Fricke, and Carolyn B. Mervis, "Prevalence of psychiatric disorders in 4 to 16-year-olds with Williams syndrome," *American Journal of Medical Genetics B: Neuropsychiatric Genetics* 141B, no. 6 (2006): 615-22, https://doi.org/10.1002/ajmg.b.30344.

population,[24] a reduced sense of "stranger danger", and a diminished sense of fear.[25] Finally, while typically of a cheery disposition, they experience relatively high levels of anxiety, possibly because of difficulties with social pragmatics.[26] Research that explores how they understand and respond to threats and social situations may help them and their carers to better navigate and manage their social environment. Trials are also needed to explore treatments for their anxiety.[27]

Williams syndrome is associated with mild to moderate cognitive impairment, with an average IQ of around 60.[28] Whether individuals with Williams syndrome can consent to research depends on the level of their cognitive function and the complexity of the research. Assessment

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[24] Teresa Doyle, Ursula Bellugi, Julie Korenberg, and John Graham, "'Everybody in the world is my friend.' Hypersociability in young children with Williams syndrome," *American Journal of Medical Genetics A* 124A, no. 3 (2004): 263-73, https://doi.org/10.1002/ajmg.a.20416; Wendy Jones, Ursula Bellugi, Zona Lai, *et al*. "Hypersociability in Williams Syndrome," *Journal of Cognitive Neuroscience* 12, no. 1 (2000): 30-46, https://doi.org/10.1162/089892900561968.

[25] Andreia Santos, Catarina Silva, Delphine Rosset, and Christine Deruelle, "Just another face in the crowd: evidence for decreased detection of angry faces in children with Williams syndrome," *Neuropsychologia* 48, no. 4 (2010): 1071-8, https://doi.org/10.1016/j.neuropsychologia.2009.12.006.

[26] Leyfer *et al.*, "Prevalence of psychiatric disorders."

[27] Kozel *et al.*, "Williams syndrome."

[28] Carolyn Mervis and Caroline Greiner de Magalhães, "Williams syndrome," in *Pediatric Neuropsychology: Research, Theory, and Practice*, edited by Miriam Beauchamp *et al.* Guilford Press, chap. 17, https://www.jstor.org/stable/10.1521/jj.41115370.20.

of whether individuals with Williams syndrome have decisional capacity is complicated by the fact that they often have strong oral communication abilities, which can lead to an overestimation of their cognitive function.[29]

Many participants with Williams syndrome cite a desire to help others with the syndrome as a reason to enroll in research. And some express a willingness to participate in research with more than minimal risks. Appealing to the altruism of individuals with Williams syndrome as part of the enrollment process could therefore increase recruitment for research that might yield significant benefits for others with Williams syndrome. This raises the question of how their consent should be obtained.

3. Altruism, wellbeing, and agency for people with Williams syndrome

Consider Molly (a pseudonym), a 30-year-old with Williams syndrome. She has mild to moderate intellectual disability and the typical Williams syndrome personality: gregarious and interested in others and their welfare. As is common, she experiences difficulties with social pragmatics and struggles with anxiety. She completed school in a mainstream setting for the first

[29] Carolyn Mervis and Angela E. John, "Cognitive and behavioral characteristics of children with Williams syndrome: implications for intervention approaches," *American Journal of Medical Genetics C:* 154C, no. 2 (2010): 229-48, https://doi.org/10.1002/ajmg.c.30263; Daniel Miezah, Melanie Porter, Adriana Rossi, Christina Kazzi, Jennifer Batchelor, and Jennifer Reeve, "Cognitive profile of young children with Williams syndrome," *Journal of Intellectual Disability Research* 65, no. 8 (2021): 784-94, https://doi.org/10.1111/jir.12860.

six years, then moved to a special school. She works three days a week in sheltered employment. In discussion, Molly commented on her situation as follows:

> "Interviewer: What are the good things about having Williams syndrome?
> Molly: I make people laugh and feel good. (…) I love older people and their stories. I love to hear what they were up to back in the day.
> Interviewer: What are the not so good/hard things about having Williams syndrome?
> Molly: Lots of people don't know about Williams syndrome. Most doctors don't know about Williams syndrome. When I go to the hospital, I always take an information sheet [about Williams syndrome]. I get bullied a lot. I think because of the way … oh this makes me feel sad … I think because of the way I act some people don't realize it is hard to always be happy."[30]

Molly's responses reveal some of her values: she thinks it is good that she makes others happy and that she is curious about others' lives. She also regards as bad others' ignorance about her condition and the harm to which this ignorance leads. Her answers also indicate a basis for self-judgment, e.g., pride in making others feel good and in combating ignorance about her condition. Though the interviewer did not ask the question, it is natural to think that, on reflection, Molly would regard her life as going better for herself when she is able to make others feel good and contribute to improving knowledge about Williams syndrome.

[30] Kozel *et al.*, "Williams syndrome," Box 1.

To give informed consent, individuals need to understand the study's risks, potential benefits, and alternatives to participation. Depending on the complexity of the study, Molly may be able to understand these things and consent. For example, she might be able to consent to a study that involves answering questions about the symptoms she experiences and her quality of life, or to a study that involves a single blood draw to obtain samples for research. If she is, consenting to enrollment offers the same opportunities as it does for altruistic individuals in general: to promote her other-oriented ends and thereby to advance her wellbeing and exercise her agency.

If the complexity of the study is such that Molly is unable to consent, current regulations in the US and around the world rightly require researchers to obtain the permission of a surrogate, along with the individual's assent. For individuals like Molly, who have life-long impairments, surrogates need to take into account the individual's best interests when making decisions for them. How should surrogates conceive of these interests?

Surrogates might assume that the relevant interests are limited to the potential participant's health, the quality of their experience, and their economic interests. As remarked in our Introduction, they seem to be supported in this assumption by the current structuring of consent forms, which emphasize the potential impact on participants' health. However, when individuals have capacities to value, endorse what they value, and set final ends for themselves, this would be too narrow an understanding of their interests. Respect for these capacities requires

taking their welfare to be determined at least in part by the attainment of their final ends, when they do so too, and assigning agency value to opportunities to pursue these ends.[31]

Naturally, individuals without the capacity to consent lack aspects of agency. For example, some may lack the ability to judge how to pursue their final aims most effectively or how to weigh risks. But this does not imply that they do not possess rational agency at all. It merely follows that, to a somewhat greater extent than competent agents, they need assistance making decisions and also protection from research risks, in the form of a surrogate decision maker who looks out for them. Where such individuals have considered, altruistic final aims, their wellbeing and agency can be advanced when they achieve these aims, including when others, taking their values as their guide and in dialogue with them, help them to do so.[32]

To illustrate, consider the following fictional case:

> **Nora's Possible Participation:** To develop interventions to address the anxiety of individuals with Williams syndrome, researchers are investigating how they respond to threatening or distressing social situations. They plan to present participants with menacing or upsetting images and short films and then draw blood to check their levels of stress hormones. Participation will cause moderate, temporary anxiety. It offers no health benefits. The study includes people who can

[31] Jaworska, "Margins of agency"; Dana Howard and David Wendler, "Beyond instrumental value: Respecting the will of others and deciding on their behalf," in *The Oxford Handbook of Philosophy and Disability*, edited by Adam Cureton and David Wasserman, Oxford University Press, 2020. https://doi.org/10.1093/oxfordhb/9780190622879.013.31.

[32] Jaworska, "Margins of agency."

consent as well as those who lack decisional capacity, provided a surrogate authorizes their enrollment and they assent. During the consent process, the researchers determine that Nora, a thirty-two-year-old with Williams syndrome, cannot consent. Nora's mother, who is her surrogate decision-maker, indicates that Nora has always wanted to help others with Williams syndrome.

If Nora's surrogate considers only the health-related risks and the quality of her experience, they would conclude that participation is not in Nora's interests and would not agree to her enrollment. However, widening the assessment to include her steady, final aims reveals that participation could promote her interests, on balance. In making this assessment, it is important to consider not only Nora's aims, but also her will. Enrollment best reflects Nora's rational agency when she agrees to it because it helps realize her altruistic ends. In that case, participation is an expression of her character and her understanding of key aspects of her options. But it is conceivable that she might agree to participate on mistaken grounds. For example, suppose that the case continues as follows:

Nora's Misconceived Assent: When asked whether she wishes to participate, Nora answers that she believes it will help her anxiety. When advised not to expect any such benefit (and that she is likely to experience an increase in anxiety during the study), she responds that she wants her anxiety to go away and hopes this will help.

When an altruistic individual assents based on a mistake—here, the "therapeutic misconception"[33]—their agency departs in two respects from an ideal of practical rationality according to which a person forms correct beliefs about the reasons they have to choose (or forgo) particular options and, in choosing, they are guided by their final ends. First, their beliefs about their reasons are inaccurate. Second, their will is not guided by an appreciation of the reasons they genuinely have to participate. Instead, in such instances, the alignment of what they want to do and their final ends is a mere accident; it just so happens that the way they misperceive the situation leads them to assent to something that serves their aims.

These shortcomings of their agency can affect whether enrollment is in their interest. Suppose that, if Nora were to participate out of an appreciation for the altruistic reasons for enrollment, the promotion of her wellbeing and agency interests through advancing her final aims would only just exceed the disvalue of the prospective harms to her. Given that misconceived assent somewhat weakens the extent to which enrollment expresses her rational agency, it might then, in the final reckoning, not be in her interest to enroll if, instead, her assent were misconceived. In such cases, a surrogate would have good grounds to consent to Nora's enrollment only if she assents for the right reasons.

Of course, it might be that enrollment would, in expectation, very substantially further Nora's altruistic aims at minimal cost. Then enrollment might be in Nora's interests, on balance, even if her assent was misconceived, and even if her misconception was resistant to correction. If attempts to clear up Nora's misunderstanding and secure assent out of an appreciation of the pertinent altruistic reasons fail, her surrogate could then, in good conscience, consent because

[33] Applebaum *et al*., "Therapeutic misconception."

enrolling her would advance her aims without contradicting her will. Recognizing this, we propose that, while assent for the right reasons is valuable, it is not always necessary for participation to be ethical.

Now consider:

Nora's Refusal: As in Nora's Misconceived Assent, except that Nora understands she will not benefit clinically and, on that basis, declines to participate.

In this instance, Nora's dissent might stem from a failure to understand how participating would help achieve her aims. If it is likely that she would assent if she understood this, then it would be valuable for the researchers to engage in a dialogue with her and her surrogate to explain the potential for participation to promote her goal of helping people with Williams syndrome. Naturally, this dialogue should not stray into pressuring her. Should Nora persist in her dissent, then it would be unethical to enroll her. Being enrolled against her will would likely increase the distress that the study would cause. It would also undermine Nora's sense of control over her life, which is a contributor to wellbeing.[34] Furthermore, just as her considered, final ends are one element of her agency, her will is another. Thwarting her will would therefore set

[34] Reed Larson, "Is feeling "in control" related to happiness in daily life?" *Psychological Reports* 64, no. 3 (1989): 775-84, https://doi.org/10.2466/pr0.1989.64.3.775; Francesco Pagnini, Katherine Bercovitz, and Ellen Langer, "Perceived control and mindfulness: Implications for clinical practice," *Journal of Psychotherapy Integration,* 26, no. 2 (2016): 91–102, https://doi.org/10.1037/int0000035.

back one aspect of her agency. These are compelling grounds for a surrogate to give their permission only if Nora assents. But, even if Nora's surrogate does consent, the researchers, out of respect for Nora's will, should not enroll her without her assent.

We can now turn to the *favorable risk-benefit ratio* test for individuals with Williams syndrome. For individuals with decisional capacity, this test permits balancing any net setback to their interests against the social value of research. For individuals who lack decisional capacity, strict safeguards are required to protect against using them in a way that sacrifices their overall interests for the social good. Outside of emergency situations, this involves narrowing the test to the intrapersonal balancing of harms and benefits, and rules out enrolling individuals who cannot consent when it represents a net loss to them. But, because their interests are broadly conceived to include the contribution that achievement of their altruistic aims makes to their wellbeing and agency, this is consistent with enrolling individuals who cannot consent in research that poses net *health* risks. Indeed, holding constant the positive social value of the research, it is permissible, on the proposed version of this test, for a study to expose benevolent individuals who cannot consent to greater net health risks than would be acceptable if they were not altruistic.

4. Medical conditions and authentic aims

This reasoning is open to the following doubt. Might the association between the altruism of individuals with Williams syndrome and their medical condition undermine the extent to which satisfying their altruistic aims contributes to their wellbeing and agency? After all, in some cases, the association of individuals' aims with their medical condition renders these aims pathological.

For instance, some have argued that it is not in the interests of individuals with anorexia nervosa to attain their goal of being extremely thin.[35] We will now argue that Williams syndrome differs in crucial ways from such cases of pathological motivation.

Researchers report four key findings about anorexia patients' pursuit of extreme thinness.[36] (a) *Unrecognized high risk:* This pursuit involves a high likelihood of severe harm to health, which is frequently grossly underestimated or denied by patients.[37] (b) *Undervaluing health:* Due to depression and low self-esteem, patients often assign unduly low value to their health and life.[38] (c) *Dubious beliefs about how things they value relate to each other:* The justifications proffered by patients for the overwhelming value they assign to thinness appeal to questionable beliefs about the connection between their weight and their other values. For example, many believe that "being fat" would represent an indictment of their entire personality and would render them unworthy of being loved.[39] (d) *Lack of endorsement:* On reflection, some patients are ambivalent about, or even reject, the supreme importance they place on being thin.[40]

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[35] Jacinta Tan, Tony Hope, Anne Stewart, and Raymond Fitzpatrick, "Competence to make treatment decisions in anorexia nervosa: thinking processes and values," *Philosophy, Psychiatry, & Psychology* 13, no. 4 (2006): 267-82, https://doi.org/10.1353/ppp.2007.0032.

[36] Tan *et al.* "Competence in anorexia."

[37] Tan *et al.* "Competence in anorexia," 271.

[38] Tan *et al.* "Competence in anorexia," 273-4.

[39] Tan *et al.* "Competence in anorexia," 273.

[40] Tan *et al.* "Competence in anorexia," 274.

These factors should affect our judgment of what furthers anorexia patients' wellbeing and agency as follows. Factors (a) and (b)—unrecognized high risks and lack of self-worth—establish that their quest for extreme thinness is likely to harm them in ways that they are unable to fully appreciate. These factors can, in principle, be addressed by appointing a surrogate who has accurate information and can give due weight to their health. A further question is whether in making decisions on behalf of an anorexia patient, their surrogate ought to balance these harms against the satisfaction of the patient's preference for extreme thinness. In our view, factors (c) and (d)—these patients' misjudgments about how other things they value, such as being loveable, are related to being thin, as well as their lack of endorsement of the importance they find themselves placing on thinness—count against such balancing. For these factors undermine the extent to which thinness is part of a coherent conception of the good life that they have affirmed after consideration.

Now consider individuals with Williams syndrome. Their lack of fear, diminished sense of "stranger danger", and their limited cognitive capacity mean they may underappreciate the risks of research enrollment. Moreover, around 10% of individuals with Williams syndrome have depression.[41] This highlights the need to clarify the risks to them and their surrogates and to ensure these are not undervalued. The most important contrast with anorexia is that people with Williams syndrome do not seem to have systematic misperceptions about how helping others connects to other things they value, such as being loveable. Nor do people with Williams

[41] R. Royston, C. Oliver, P. Howlin, *et al*. "The profiles and correlates of psychopathology in adolescents and adults with Williams, Fragile X and Prader–Willi syndromes," *Journal of Autism and Developmental Disorders* 50 (2020): 893–903, https://doi.org/10.1007/s10803-019-04317-1.

syndrome experience ambivalence regarding, or disavow their altruism. Rather, their altruism is described as an integral part of their sociable and empathetic personality.[42] This suggests that individuals with Williams syndrome generally endorse their altruistic motivations.

Our contrasting judgments about the importance of satisfying some (apparent) final ends of individuals with anorexia and Williams syndrome are explained by the following principles. Where, due to a medical condition, a person cannot fully appreciate risks to their health, measures such as the use of a surrogate should be in place to make sure the risks are properly weighed. Furthermore, when their illness is associated with unreasonable assumptions about how their core values are connected or with ambivalence about, or rejection of, what they find themselves pursuing, this undermines the extent to which the satisfaction of these purported final aims contributes to their wellbeing and agency. However, when their final aims flow from things they truly care about, advancing these aims promotes their wellbeing and agency, even when their motives and their medical condition are associated.

5. Regulating altruistic participants' exposure to risk

We now examine what follows from our arguments for existing guidelines and practice. Consent forms, and discussions between researchers, participants and, where relevant, their surrogates, should accessibly describe the contributions to knowledge that participation may make and their value. One piece of information that may be pertinent in this regard is that an independent review committee has determined that the study's social value is such that its net health risks to

[42] Doyle *et al.*, "Everybody is my friend"; Kozel *et al.*, "Williams syndrome."

participants are morally acceptable. Naturally, participants should also be apprised of the possibility that participation may fail to make a socially valuable difference.[43] This means that the practice (discussed in our Introduction) of devoting only a sentence or two to a study's social value should be reformed, as this does not provide individuals or their surrogates with the information they need to appreciate the expected social value of a study.

We now turn to implications that are specific to altruistic individuals who are unable to consent due to cognitive impairment, but whose values ground their final ends. Such individuals commonly face comparatively limited opportunities to pursue non-self-interested goals.[44] For example, they frequently do not have the opportunity to work in a caring profession, donate significant money to charitable causes, or develop better ways to treat diseases. The occasion to participate in socially valuable research is therefore likely to be especially important to them. Moreover, we owe people recognition of the ways in which they can be social contributors, and such recognition is particularly important when their potential contributions are at risk of being overlooked because they constitute a marginalized minority.[45]

These considerations provide reason to reconsider current guidelines and regulations that bar individuals who cannot consent from participating in research that offers no prospect of

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[43] Jake Earl, Liza Dawson, and Annette Rid, "The social value misconception in clinical research," *The American Journal of Bioethics* 25, no. 8 (2025): 61-77, https://doi.org/10.1080/15265161.2024.2371119.

[44] Kozel *et al.*, "Williams syndrome," Fig. 6.

[45] Brownlee, "The lonely heart."

direct medical benefit unless the risks are minimal (or a minor increase over minimal).[46] These guidelines may actually set back their interests. If a person is strongly motivated to help others, participating in a research study that has the potential to generate socially valuable data can promote their wellbeing and agency, even when it poses more than minimal net risks.

At the same time, it is uncertain that any given study will have significant positive social impact. The contribution that any individual participant makes is likewise uncertain and typically modest. This suggests that, under ordinary circumstances, the potential to promote the ability of individuals who cannot consent to further their altruistic ends through enrollment in research cannot justify exposing them to more than moderate net health risks.

Our arguments also imply the rejection of some other proposed restrictions. Commentators have argued that vulnerable individuals should be enrolled in research that does not offer them clinical benefits only when the research concerns their own condition.[47] By ensuring that research that has net health risks and that is carried out on vulnerable participants will benefit similarly vulnerable others, this approach forestalls concerns that they are being used for the benefit of the general population. It thereby obviates the concern that they are being recruited because their health is considered less important. (Indeed, that research is undertaken for the benefit of similar patients shows that people with their vulnerabilities are valued.)

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[46] 45 CFR 46. 2018. HHS Policy for Protection of Human Subjects, §46.404-406. https://www.hhs.gov/ohrp/regulations-and-policy/regulations/45-cfr-46/index.html

[47] This view is consistent with US pediatric regulations, see Seema Shah and David Wendler, "Interpretation of the subjects' condition requirement: A legal perspective," *Journal of Law, Medicine, & Ethics* 38, no. 2 (2010): 365–73, https://doi.org/10.1111/j.1748-720X.2010.00495.

Moreover, the proposed limitation offers some assurance that enrollment serves individuals' altruistic aims because people often have a particular interest in their own condition and sympathy for others in their situation.

These reasons count in favor of permitting the enrollment of altruistic participants who cannot consent in studies that concern the participants' condition. Nonetheless, the proposed limitation is too restrictive. Individuals with Williams syndrome may have an interest in helping others that could be served by participation in research on other conditions. To think otherwise would be to identify individuals with their condition and assume that all their affinities trace to it. Individuals with Williams syndrome can identify with their family members, neighbors, or friends and want to help ameliorate the conditions that affect them. Or they might sympathize with people with medical conditions generally. By requiring that any risks to research participants are strictly necessary for the study's aims and that, for participants who cannot consent, participation is expected to further their overall interests, our proposal already forestalls concern that vulnerable, altruistic participants are being used as mere means.

The question may arise what would happen if a research project that, at the time of approval, appeared to meet these standards, ends up falling short. It might be thought that, in this event, vulnerable participants (or their surrogates) would not be in a strong position to raise objections. One way to address this concern might be to ensure that, where the purpose of the research permits it, altruistic individuals who cannot consent are recruited alongside similarly motivated members of the general population, who may be better placed to raise concerns. Such mixed recruitment may also help address the worry that risks to vulnerable research participants'

health are perceived by those carrying out or approving the research as having lesser significance.[48]

Conclusion

Enrolling altruistic individuals in research that offers no clinical benefit to them raises the specter that they are being used merely as a means and are not being treated as ends in themselves. This concern is especially acute when their autonomy is in question because they have cognitive limitations and their altruistic motivation is bound up with their medical condition.

For altruistic individuals who can consent, we have argued that this concern can be addressed by ensuring that (i) they autonomously consent; and (ii) the net health risks are outweighed by the combination of (ii-a) the extent to which the research promotes their considered, final aims and thereby contributes to their wellbeing and their ability to shape the world and (ii-b) the social value of the research.

For altruistic individuals who cannot consent, we have argued that it can be addressed by ensuring that (I) a surrogate consents for them and they assent, ideally for the reasons that make participation in their interest; and (II) the net health risks are outweighed by the extent to which participation furthers their steady, final aims.

For all individuals, these criteria take seriously the ways in which fulfillment of their altruistic ends can be of value, for their own sake. For individuals with cognitive impairment,

[48] Institute of Medicine, *Ethical Considerations for Research Involving Prisoners*, The National Academies Press, 2007, 125, https://doi.org/10.17226/11692

these criteria recognize the agency that they possess. For people with Williams syndrome, these include an ability to value and endorse their values, a capacity to set aims for themselves and judge the success of their lives by how well they achieve these aims, and the ability to determine their will. Treating them as ends in themselves requires that we aim to promote their ability to meet their considered, final aims and respect their will. Our criteria pair this recognition of the altruistic agency of individuals who cannot consent with special protection for their interests, since, in normal circumstances, only intrapersonal balancing of risks to their health against the satisfaction of their own aims is permitted.

While our analysis has focused on Williams syndrome, our conclusions are relevant for the permissibility of enrolling altruistic individuals who are not able to consent but possess similar agential capabilities. This includes others with mild to moderate cognitive impairments and minors, many of whom embrace the opportunity to participate in research to help others.[49]

[49] Jaworska, "Margins of agency"; David Wendler and Tammara Jenkins, "Children's and their parents' views on facing research risks for the benefit of others," *Archives of Pediatric Adolescent Medicine* 162, no. 1 (2008): 9–14, https://doi.org/10.1001/archpediatrics.2007.3; David Wendler, Emily Abdoler, Lori Wiener, and Christine Grady, "Views of adolescents and parents on pediatric research without the potential for clinical benefit," *Pediatrics* 130, no 4 (2012): 692-9, https://doi.org/10.1542/peds.2012-0068.

Our findings may therefore be relevant to other questions in bioethics, such as whether to expand the enrollment of people with Down syndrome in trials for novel treatments for Alzheimer's.[50]

It follows that, if participation substantively furthers the ends of a strongly altruistic person (say, because the research is especially promising), then it may be permissible to enroll them in research with more than minimal net health risks. Keeping other things constant, altruistic individuals may be enrolled in riskier research than would be permissible for non-altruistic individuals. This is true for both people in the general population and people with vulnerabilities of the kind reviewed here.

These proposals recognize the ways in which authentic, altruistic agency can be of value to members of the general population and to those with cognitive impairments. They stem from the idea that all are entitled to exercise this agency and should be supported in doing so, out of respect for their abilities and because it is good for them, and for others.

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[50] Economist, 2025, "Volunteers with Down's syndrome could help find Alzheimer's drugs," https://www.economist.com/science-and-technology/2025/01/15/volunteers-with-downs-syndrome-could-help-find-alzheimers-drugs

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