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Symposium Articles

David Wasserman and Supported Decision-Making in Research

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Abstract

This memorial essay introduces the *Journal of Law, Medicine, and Ethics* special issue on supported decision-making in research by honoring David T. Wasserman (1953–2025), a major organizer of the NIH workshop from which the issue emerged and a coauthor of two papers in the volume. It situates supported decision-making in research as an emerging approach that aims to make participation by people with cognitive disabilities possible without displacing their agency through default reliance on legally authorized representatives. The essay highlights Wasserman's distinctive contribution to this developing area. He sought a position that is respectful while remaining clear eyed about exploitation risks and about well-intentioned practices that can undermine a participant's interests, especially in hard cases where meaningful authorization is fragile. Drawing on the two coauthored papers in the issue and on colleagues' recollections, the essay emphasizes Wasserman's commitment to conceptual clarity, workable institutional design, and mentorship through collaboration. It closes by reflecting on his intellectual virtues, humor, and lasting influence on disability bioethics and research ethics.

Keywords: David T. Wasserman; supported decision making; research ethics; cognitive disability; informed consent

This special issue is dedicated to David T. Wasserman, who died on December 28, 2025. David was a philosopher and bioethicist of extraordinary clarity and range. He was one of the main organizers of the NIH workshop from which this issue arose, and he coauthored two of its essays. Readers will encounter him here in a form he deeply valued, through careful argument.

There is a familiar tension in research ethics when prospective participants are people with cognitive disabilities. Abuse and exploitation have a painful history, which is part of why modern protections exist. Yet those protections can have exclusionary effects when researchers, IRBs, and institutions treat leaving such people out as the safe default. That default can limit access to trials as well as to the monitoring and follow-up they provide, distort the evidence base that informs clinical care, and send a demeaning message about who counts as a full participant in a shared scientific enterprise. David was acutely sensitive to the way appeals to protection can become a cover for paternalism. He took risk seriously, but he resisted treating it as a conversation stopper.

Supported decision-making in research is still in its early days, but it is increasingly presented as a promising middle ground. It aims to make the participation of people with cognitive disabilities possible without presupposing that every participant can navigate research concepts and decisions without assistance. It also aims to avoid replacing the agency of prospective participants with that of their legally authorized representatives. What unifies these approaches is a commitment that David affirmed throughout his work. Respect fundamentally involves treating people as having authority over the shape of their own lives, when that is ethically and practically possible. David cared deeply about where this discussion would go, and much of what follows reflects his effort to help shape it in a way that is both respectful and feasible.

David also had little patience for moral pieties and slogans when they make it too easy to feel righteous without thinking hard. He wanted careful distinctions and arguments that mattered in practice, especially for policy and institutional design. And he wanted our focus to remain on the people most affected by these practices, especially those often excluded "for their own good."

David's colleagues in the NIH Department of Bioethics saw these traits in action. David Wendler put it well when he wrote to me that David was one of those very special people "whose existence makes the world a better, more interesting place," and that his "insights, analytic abilities, and knowledge of the literature made all of our work better." Wendler also captured a revealing aspect of David's moral style. When Wendler found himself disagreeing with David, it was "almost invariably" because David was "too caring, too sympathetic."[1] David had a stubborn tendency to notice how neat theoretical devices can misrepresent the lives they are meant to address, and he never lost sight of what is at stake in bioethical debates for people who need support to be heard and understood.

David was central to the workshop that generated this issue because he insisted that we face difficult questions about supported decision-making in research directly, including what specific ethical challenges arise in the research context, what kinds of support are appropriate, and what limits must be respected if appeals to support are not to become ways of replacing the participant's own agency. David wanted supported decision-making in research to be respectful but also responsive to the significant risks of exploitation and of well-intentioned practices that can undermine a person's interests. He was impatient with default exclusion but also with

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views that treat participation as straightforwardly self-authorized in every case, without confronting the hard situations in which meaningful authorization is fragile. Wendler wrote that when he began planning the workshop, he knew David would be "an invaluable asset," especially in ensuring that recommendations were "appropriate and appropriately respectful of individuals with intellectual and cognitive impairments." The workshop was a success, and much of that success was due to David's insistence on conceptual and practical detail: Who is speaking to the participant, and how? What is the supporter permitted to do? What counts as understanding in this setting? What should we say about the hard cases where the participant's own contribution is minimal and the supporter must interpret or extrapolate?

This issue of *JLME* contains many perspectives on supported decision-making in research. David's own contribution is most visible in the two papers he coauthored for the issue. In both, we see his characteristic blend of moral seriousness, conceptual clarity, and humane concern.

The first paper, coauthored with Sawyer Lucas-Griffin and Wendler, is a kind of ethical stress test for supported decision-making in clinical research.[2] It begins from the familiar fact that protections for people with cognitive disabilities arose in response to significant research abuses, but in practice those protections are often paired with assumptions about cognitive disability that make exclusion seem like the safest institutional option. The paper's central thought is that, labels aside, what matters is whether a decision-making arrangement engages and centers the prospective participant in the decision.

A distinctive contribution of the paper, and the section that most bears David's stamp, concerns challenges of speculation and displacement. Supported decision-making is supposed to preserve the participant as the locus of authority, but it can slide toward substitution when the supporter is forced to speculate about what the participant wants, understands, or would endorse. The worry here is that the structure of the interaction may no longer count as the person's decision at all, even when everyone involved is acting conscientiously and with care.

The paper explores this problem through cases in which the participant's direct input is minimal or absent. It discusses the temptation to call such cases "supported decision-making" on the ground that those close to the person use a "best interpretation" of will and preferences, rather than a best interests standard. Yet it also notes that there is an important distinction between decisions that are supported and decisions that are merely made for someone under the guise of support. In the research context, the problem becomes even more pronounced. Research often involves unknown risks, unfamiliar procedures, and burdens that are taken on for the benefit of future patients. When a decision rests almost entirely on speculation, and the participant cannot understand or endorse what is being decided, the paper argues that we should be honest about what is going on. We are in surrogate decision-making territory, and the ethical justification for imposing risk must be correspondingly constrained.

When adults consent for themselves, risks can be justified in part by their consent. When someone else consents for them, risks must instead be justified by appeal to the participant's preferences and values as interpreted by the surrogate. The paper suggests that justified risk should track the degree to which the participant is making the decision with assistance rather than having the decision made for them. That is a distinctively David contribution. He wanted inclusion and support, but he also wanted to know what kind of authorization can justify what kind of risk.

Lucas-Griffin notes that the speculation and displacement section was David's idea, and that it initially seemed to introduce new knots that made a clean through line harder to maintain. But, as Lucas-Griffin put it, "that's why it was worth pursuing."[3] That nicely captures David's philosophical sensibility. He had a talent for finding the places where an attractive proposal is most likely to conceal the hardest cases, and for insisting that we face those cases directly.

The second paper, coauthored with Jasmine Gunkel and Leslie Pickering Francis, advances a constructive proposal that also shows David's way of thinking.[4] It begins from a premise David deeply affirmed, namely that when feasible, support in decision-making is morally preferable to surrogate decision-making, because it preserves the person whose life is at stake as the locus of control.

Against that background, the paper proposes a shift in how we think about enrollment in clinical research once a protocol involves more than minimal risk. Instead of treating support as a special accommodation for a small class of participants, the paper argues for support in decision-making for all above a risk threshold. The claim is not that every participant must enter a formal supported decision-making arrangement. It is that research should be designed with a presumption of support, and that IRBs should typically require research teams to recommend support and offer resources that make it feasible, especially as studies become riskier, more complex, or more unfamiliar.

What makes this proposal especially interesting is that it treats supported decision-making as a core feature of ethically serious research design. Drawing on the universal design movement, the paper suggests that instead of building a standard consent process and then patching it for those who cannot use it, we should build supportive structures into research from the start. One important reason is that misunderstanding of research is not confined to people who fall below standard capacity thresholds. Many participants misunderstand core features of clinical research, and that fact is partly a function of how research is structured and communicated. Support should thus be treated as a normal component of respectful research practice, not as an exception. This is a good example of David's instinct to build respect into workable institutions and practices rather than leaving it to good intentions and post hoc accommodations.

Gunkel's recollection of working with David helps explain the moral spirit of this proposal. As she notes, David repeatedly pressed for greater clarity about what counts as support and understanding, how risk thresholds and capacity assessments should be handled, and how proposals could plausibly be implemented. She describes his criticisms as "incisive and project shaping," but delivered "gently and encouragingly," and she emphasizes his distinctive ability "to find the worthwhile pieces of your ideas and help you to better appreciate them too."[5] That is both a personal and philosophical virtue of David's, and it is on display in this essay.

Stepping back, the concerns that animate supported decision-making in research were present throughout David's work. He worried about institutional practices that assign second-class status under the guise of neutrality. He resisted categorical judgments about competence that treat diagnosis as destiny. And he consistently distinguished between assistance that enables agency and substitution that merely acts in a person's name. David often returned to these themes, pressing against both exclusionary protectionism and simplistic accounts of consent and agency.[6]

His earlier writings help explain why David approached supported decision-making in research as he did. He wanted to preserve the moral significance of consent without being exclusionary.

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He wanted institutions to take responsibility for creating conditions under which understanding and meaningful authorization are possible. And he wanted us to reflect on difficult boundary conditions, especially when support for decision-making can easily co-opt agency.

These commitments are expressed not only in what David argued for, but in how he did philosophy with other people. Both of his papers here exemplify his approach to mentorship through coauthoring. Lucas-Griffin describes how David's seriousness in conversation gave her confidence to pursue nuance and complexity, and Gunkel describes his mentorship as careful criticism delivered in a way that makes you want to do better philosophy. Gunkel also brings out David's gift for seeing where important values collide and for finding ways to proceed that are practical, humane, and sensitive to detail. David was thoroughly egalitarian. In a note to Gunkel he wrote, "you've long seemed more of a colleague than a mentee."[7] He treated junior colleagues as fellow thinkers, bringing them into high level work by doing that work with them.

Lucas-Griffin's recollection brings this out vividly. She wrote to me that she would come to David expecting a clarifying answer and instead receive "an enthusiastic ramble" about similar questions, what they meant, and where the inquiry could go. Gunkel's recollection highlights a complementary side of David's mentoring. She describes him as "truly an exemplary mentor," kind, generous, and insightful, with a good humor that made talking philosophy fun. I saw the same thing when David asked me, early in my career, to co-edit the *Oxford Handbook of Philosophy and Disability* with him, which allowed me to see his breadth, his feel for good philosophy and good philosophers, and his determination to expand the field while supporting those already in it. This way of mentoring through collaboration reflects, in its own way, the aspiration behind supported decision-making, to make room for a person's agency under conditions that might otherwise invite substitution.

In addition to being an excellent philosopher, David was also one of my best friends, and it is hard to write about him without mentioning that. He was extremely funny and opinionated in a way that kept conversations lively. He had a knack for deflating pretension without making anyone feel inferior, along with a bemused appreciation for the minor dramas of his friends and communities. He had a way of making serious disagreement feel like part of a shared search for what is worth thinking, and worth doing. He liked to joke that his work at NIH put him "in the neighborhood of the nonidentity problem," and that his job was to make it harder for the rest of us to ignore it or think about it carelessly. That joke captures something significant about him. He wanted us to see where the hard problems are but also to keep our sense of humor while facing them.

It is fitting that this issue honors David. Supported decision-making in research is, at bottom, an attempt to design our practices around respect, not convenience or fear. David's work in this area reflects his long-standing commitments and his characteristic virtues. It also reflects his belief that philosophy can matter, not only by changing minds, but by changing how institutions treat people. Those of us who knew him will miss him badly. Those who did not know him can still meet him here, in the arguments, distinctions, and humanity he brought to these discussions.

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