



---

Nothing about us without us!

November 19, 2021

Science of Engagement Funding Initiative  
Patient-Centered Outcomes Research Institute (PCORI)  
Via Electronic Mail: SoE-RFI@pcori.org  
1828 L Street, NW, Suite 900  
Washington, DC 20036

**Re: Science of Engagement Initiative REQUEST FOR INFORMATION RFI#  
SoE-2021**

The Autistic Self Advocacy Network<sup>1</sup> appreciates the opportunity to submit these comments in response to PCORI's request for information for its Science of Engagement initiative<sup>2</sup>.

ASAN is a national, 501(c)(3) nonprofit, run by and for autistic people ourselves, focused on advocating for the rights of people with intellectual and developmental disabilities. It is critically important to us that research concerning people with intellectual and developmental disabilities meaningfully includes people with intellectual and developmental disabilities. ASAN would like to take this opportunity to share our thoughts on engagement research priorities that are most significant for ensuring the full and equitable engagement of our community by researchers.

In the most recent reauthorization of funding for PCORI<sup>3</sup>, Congress identified individuals with intellectual and developmental disabilities as a priority community

---

<sup>1</sup> Autistic Self Advocacy Network, <https://autisticadvocacy.org/>.

<sup>2</sup> Request for Information: Science of Engagement Funding Initiative, <https://www.pcori.org/engagement/value-engagement/request-information-science-engagement-funding-initiative/>.

<sup>3</sup> Further Consolidated Appropriations Act of 2020, Pub L No. 116-94 (2020) <https://www.govinfo.gov/content/pkg/CPRT-116HPRT38679/html/CPRT-116HPRT38679.htm>

for research. However, substantial barriers to research participation continue to exist for this community, especially for those with intellectual disabilities. We know that it is possible to overcome these barriers and include people with intellectual disabilities in research, although this possibility is rarely fully realized; therefore, we recommend that PCORI prioritize research into the most important accessibility tools to support full participation, and research to improve our understanding and definitions around meaningful participation in research.

In recent years, there has been investigation into the state of participatory research including individuals with intellectual and developmental disabilities. Several qualitative studies have investigated the experience of co-researchers within participatory models, and there has been at least one systematic review of literature on participation of individuals with intellectual disabilities<sup>4</sup>. One notable observation is that few studies provide an explicit definition of participation<sup>5</sup>, and those that assess participation seldom explore participation beyond issues of accessibility and inclusion, failing to develop a picture of participation that includes personal impact factors such as meaning and choice for participants. While participatory research approaches focusing on people with developmental disabilities broadly continue to develop, we are also concerned that individuals with intellectual disabilities continue to be excluded from this research, either through explicit exclusions or inaccessible research approaches.

As a result, the IDD community has a much greater need for basic research on effective ways to support engagement, relative to other communities. For people with intellectual disabilities in particular, the field is much further behind than what we see in other disability communities. Many researchers do want to partner with people with intellectual disabilities and conduct the kinds of research PCORI prioritizes; they need deep investments in the fundamentals of engagement research in order to do so. Researchers need the best tools available to support engagement; engagement research should focus on identifying and refining these tools and building the body of knowledge around when and how they are best implemented.

---

<sup>4</sup> Dean, E. E., Fisher, K. W., Shogren, K. A., & Wehmeyer, M. L. (2016). Participation and Intellectual Disability: A Review of the Literature. *Intellectual and developmental disabilities*, 54(6), 427–439. <https://doi.org/10.1352/1934-9556-54.6.427>

<sup>5</sup> Ibid.

For many people with intellectual and developmental disabilities, the primary barrier to engagement is the manner in which information is presented, which means that identifying the best practices around research communications is an essential part of engagement for the IDD community. Several organizations, including ASAN, as well as other organizations such as Self Advocates Becoming Empowered, the Association of University Centers on Disabilities, and the Coleman Institute for Cognitive Disabilities, have been heavily engaged in work focusing on ways to assess and improve the cognitive accessibility of information that is presented to individuals with IDD; however, gaps in existing knowledge leave us with some very important unanswered questions about the best way to develop these tools. We hope that many of these questions can be answered through research conducted with the assistance of the Science of Engagement initiative.

## Topics of Inquiry to Understand the Science of Engagement

One essential aspect of engaging the IDD community is to ensure information is communicated in a cognitively accessible manner. However, existing research into the best practices to ensure cognitive accessibility of communications has been limited. This means that our understanding of how best to approach engagement in a way that fits the accessibility needs of the IDD community and satisfies the aims of that engagement is similarly limited by a lack of evidence.

In general, we believe there needs to be significant research into the nature and use of cognitively accessible materials and whether their use improves understanding, participation, effective communication, and meaningful decision making for individuals with intellectual disabilities engaged in research. Without a deep body of evidence around whether and how the use of cognitive accessibility improvements assist the engagement of people with IDD, we have a very limited evidence base around the specifics of *what* types of cognitive accessibility improvements work, and for whom. Without that evidence, researchers are often unable to move forward with effective engagement. Relevant research questions here include:

- Whether different subpopulations of individuals with intellectual disabilities-- such as populations with and without co-occurring language processing disabilities, or with different literacy levels-- benefit from different cognitive accessibility modifications.
- How best to modify existing materials such as survey instruments, consent materials, or research findings to make them cognitively accessible the widest range of people with intellectual disabilities
- Whether picture-assisted materials --presenting graphical icons alongside plain language text-- improve comprehension and retention of materials over plain text alone. If so, are these effects consistent across all IDD populations, or do they vary between subpopulations?
- The efficacy of different approaches to visual supports for cognitive accessibility-- what kinds of icons are most effective for communicating ideas of differing abstractness or complexity? Are there different graphical approaches that are more effective in assisting comprehension for percentages or probability, or expressing a contingent or negated concept? We do know that presentation can have a substantial impact on data accessibility<sup>6</sup>; additional investigation can provide additional insight into best practices for presenting information of varying complexities for people with IDD.
- Whether video approaches are more effective than written or picture assisted resources for effective engagement, either across ID populations or for identified subpopulations.
- If conversational facilitation of a written, pictographic, or video resource improves accessibility, or if there are circumstances or types of resource for which self-directed access is more accessible
- The impacts of document length on accessibility, and what methods of engagement can be effective at improving accessibility and comprehension of lengthy materials--for example, whether breaking material across multiple sessions is an effective method.

In order to ensure that individuals with IDD--particularly those with low literacy, language disabilities, or the most complex needs--can meaningfully participate in research, it is imperative that they have access to information they can understand about the many components of any research study. Without

---

<sup>6</sup> Wu, K., Petersen, E., Ahmad, T., Burlinson, D., Tanis, S., & Szafir, D. A. (2021, May). Understanding data accessibility for people with intellectual and developmental disabilities. In Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems (pp. 1-16).

accessible information, participation falls apart at the start. While these questions may seem tangential to PCORI's work, we hear over and over again from researchers that without a firm evidence base for best practices in cognitive accessibility, further work in more traditional areas is challenging.

We also believe that additional investigation must be done into the best ways to promote and assess participation for individuals with IDD in research. This requires identifying standards for assessing meaningful participation in research. Too often, studies with low expectations and minimal participation are considered adequate levels of engagement when it comes to the IDD community, when this level of participation would not be accepted for other communities. Similarly, many studies rely heavily or exclusively on the participation of proxies, such as family members, rather than the direct participation of people with IDD. While family members are stakeholders with valuable insights, as they are in other disability communities, this overreliance on proxies is again out of step with the standards we see used for other communities, and should not be considered any more acceptable than it would be for other communities. This often leaves IDD individuals excluded from true participatory research relevant to community concerns. IDD individuals should be fully included in all levels of research, including study design and leadership, and measures of participation that include personal-level experiences should be incorporated into existing standards for assessing participation. Priority should be given to participatory research which includes comprehensive measures of participation within the study framework itself.

Improving participation also means identifying existing barriers and facilitators for research participation for IDD populations. We are already aware of some barriers to participation, and recommend additional investigation that would address some of these barriers. One such barrier to participation centers around accessibility. As discussed above, ensuring that research materials and communications are accessible to IDD populations is an essential part of ensuring our engagement with research. To that end, it is paramount to ensure that research information is produced and disseminated in an accessible fashion.

Another barrier is driven by mistaken beliefs about the capacity of people with intellectual and developmental disabilities to provide fully informed consent and participate fully in research. In a misguided effort to avoid concerns about informed consent, researchers often avoid engaging directly with individuals with

IDD and instead engage with caregivers or other proxies for IDD individuals themselves. Sometimes these approaches are driven by ethics review board considerations which erroneously identify disabled individuals as lacking the capacity to provide consent for research, even reaching well beyond any concerns about safeguards for people with IDD as a potential vulnerable population. Frequently, this has the net effect of limiting IDD participation in research, and excluding methodologies that would rely on more extensive participation from IDD participants. This reinforces existing research gaps by discouraging research into issues impacting IDD individuals that includes participation from people with IDD. As an alternative, we propose research into consideration of approaches that support informed consent in people with intellectual disabilities who wish to participate in research, such as supported decision making frameworks. Supported decision-making approaches can permit fuller participation by IDD individuals with appropriate safeguarding while still respecting the ability of people with IDD to be informed and make choices about participation in an accessible manner.

## Methods and study designs appropriate for producing evidence on Potential Topics of Inquiry.

The basic research needs of this topic make it clear that even the optimal methods and study design are themselves subjects that require additional research. We strongly believe that research involving people with intellectual disabilities should be as maximally participatory as possible, and involve people with intellectual disability not simply in an advisory role, but actively involved in project leadership, study design, instrument development, publication, and dissemination. Participatory research focused on intellectual and developmental disabilities frequently exclude individuals with the most significant intellectual disability or with co-occurring communication disabilities-- in the interest of both generalizability of research findings and of the principle of equity, it is important to ensure that participatory research extends to broad and diverse members of the IDD community. This will require some common extant methodological approaches to be modified to ensure accessibility to IDD participants.

Many of the topics of inquiry we identify above, such as those investigating the relative efficacy of accessibility tools, call for stand-alone research approaches, while others, such as research into defining meaningful participation, are more

amenable to a study-within-a-study framework. Study designs would be highly contingent on the specific topic being investigated, but we strongly support the use of qualitative methods such as focus groups, guided interviews, and thematic elicitation, as stand-alone qualitative research or as part of a mixed-methods approach, as appropriate to the research question. Qualitative research approaches are particularly appropriate to the research questions outlined above, as they include assessment of participant experiences with meaningful participation, and identifying barriers and facilitators for IDD engagement.

## Important and appropriate outcome measures for engagement research

We firmly believe that one of the most important ultimate goals of engagement research is to enhance the meaningful participation and leadership of people with intellectual disabilities in research involving people with intellectual disabilities. To this end, we believe that engagement research should focus on outcome measures that focus on the participatory experiences of people with intellectual disabilities. One important foundation for this research is developing and validating measures of meaningful participation. We know that many measures of participation to date exclude important measures of personal impact for participation, such as measures evaluating experiences of meaning and choice for participants<sup>7</sup>, and developing measures that incorporate the full dimension of participant experience is important for establishing a definition of meaningful participation that accurately reflects the desired outcomes of participatory and engagement work<sup>8</sup>.

## Things to keep in mind for inclusive, accessible research

We think one of the most important aspects of ensuring that research is inclusive is to ensure depth of participation from people with disabilities in the research

---

<sup>7</sup> Dean, et al., 2016

<sup>8</sup> Schwartz, A. E., Kramer, J. M., Cohn, E. S., & McDonald, K. E. (2020). "That Felt Like Real Engagement": Fostering and Maintaining Inclusive Research Collaborations With Individuals With Intellectual Disability. *Qualitative health research*, 30(2), 236–249. <https://doi.org/10.1177/1049732319869620>

process. Even beyond typically-defined standards for participatory research, this means involving people with intellectual and developmental disabilities, especially those with intellectual disabilities and co-occurring disabilities, in all stages of the research process and in leadership roles for the research itself. PCORI should seek out research teams with extensive experience in working with intellectually disabled populations and with providing deep accessibility in these contexts. As part of this it is also important to ensure that all materials related to research, be provided in a cognitively accessible manner. This includes research materials such as consent, research instruments, and information about research. PCORI can provide guidance on the best practices for ensuring that research materials are cognitively accessible, while also ensuring the accessibility of its own materials and communications. In order to encourage deep participation, this should extend to materials related to research partners and planning, materials related to stakeholder meetings and engagement, and information about research and funding opportunities.

The Autistic Self Advocacy Network is grateful for the opportunity to share our views on the critical topic of engaging the intellectually and developmentally disabled community in a productive, comprehensive and inclusive manner. We believe that this approach and focus in research are critically important for addressing the needs of our chronically underserved community. We look forward to seeing PCORI's action on these issues, and stand ready to provide any assistance we can in crafting and evaluating accessibility tools to support IDD participants and co-researchers in the future. For more information on ASAN's engagement research priorities, please contact our policy analyst, Gregory Robinson at [\*\*grobinson@autisticadvocacy.org\*\*](mailto:grobinson@autisticadvocacy.org)