



A Citizen's Jury Deliberative Method to Engage Stakeholder Groups in Developing Recommendations about Data Describing People on the Autism Spectrum



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INTRODUCTION

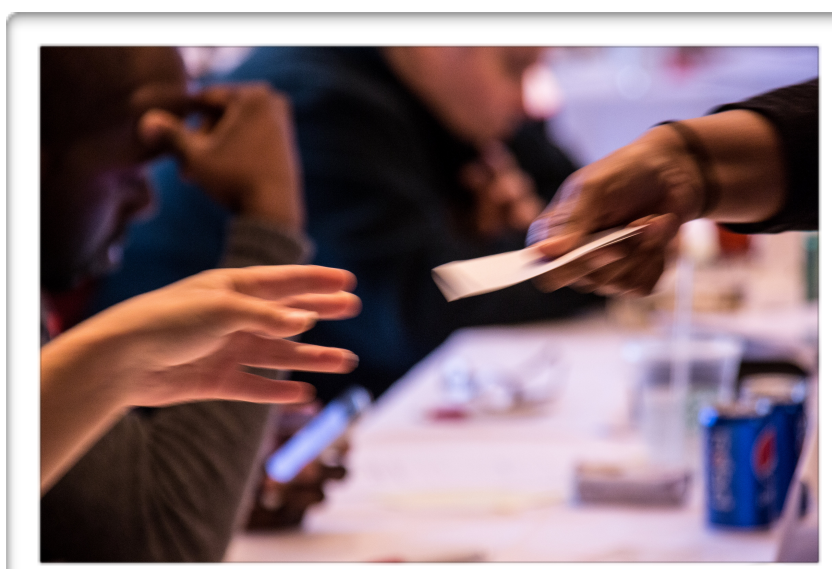
Massachusetts policymakers have been in the planning phases for an integrated data system to enhance policy decisions and supports available to people on the autism spectrum.

While the use of data to better understand the population and support needs was documented by the Massachusetts Governor's Special Commission relative to Autism in their 2013 report, individuals and stakeholder groups identified concerns regarding data security, individual privacy, and the proposed use of information that identifies people with autism or links their data.

Addressing this complex set of issues requires an examination of a broad range of issues and consideration of multiple perspectives.

The research project, funded by the Agency for Healthcare Research and Quality (AHRQ), explored the feasibility and use of a deliberative method, the Citizen's Jury, as it developed key principles for autism data collection in MA. As a community engaged project, it was developed and implemented in partnership with the Autistic Self Advocacy Network and the Jefferson Center, a national leader in Citizen Jury methodology.

This is the first demonstration of a Citizen's Jury approach to public deliberation that specifically incorporates people with disabilities.



METHODS

The project team used a multiphase project to gather public opinion and develop recommendations with significant stakeholder input in the early planning phases for an integrated statewide system that could describe demographics and services used by people on the autism spectrum.

The main questions reviewed by the 19-member Citizen's Jury included:

- **What are the key principles that should be followed for a data system that includes information about the population with autism receiving supports in Massachusetts?**
- **Should individuals be able to opt-out (partially or completely)?**
- **Should researchers have access to the information held by the state for analysis? What are acceptable reasons that the data should be shared with researchers?**

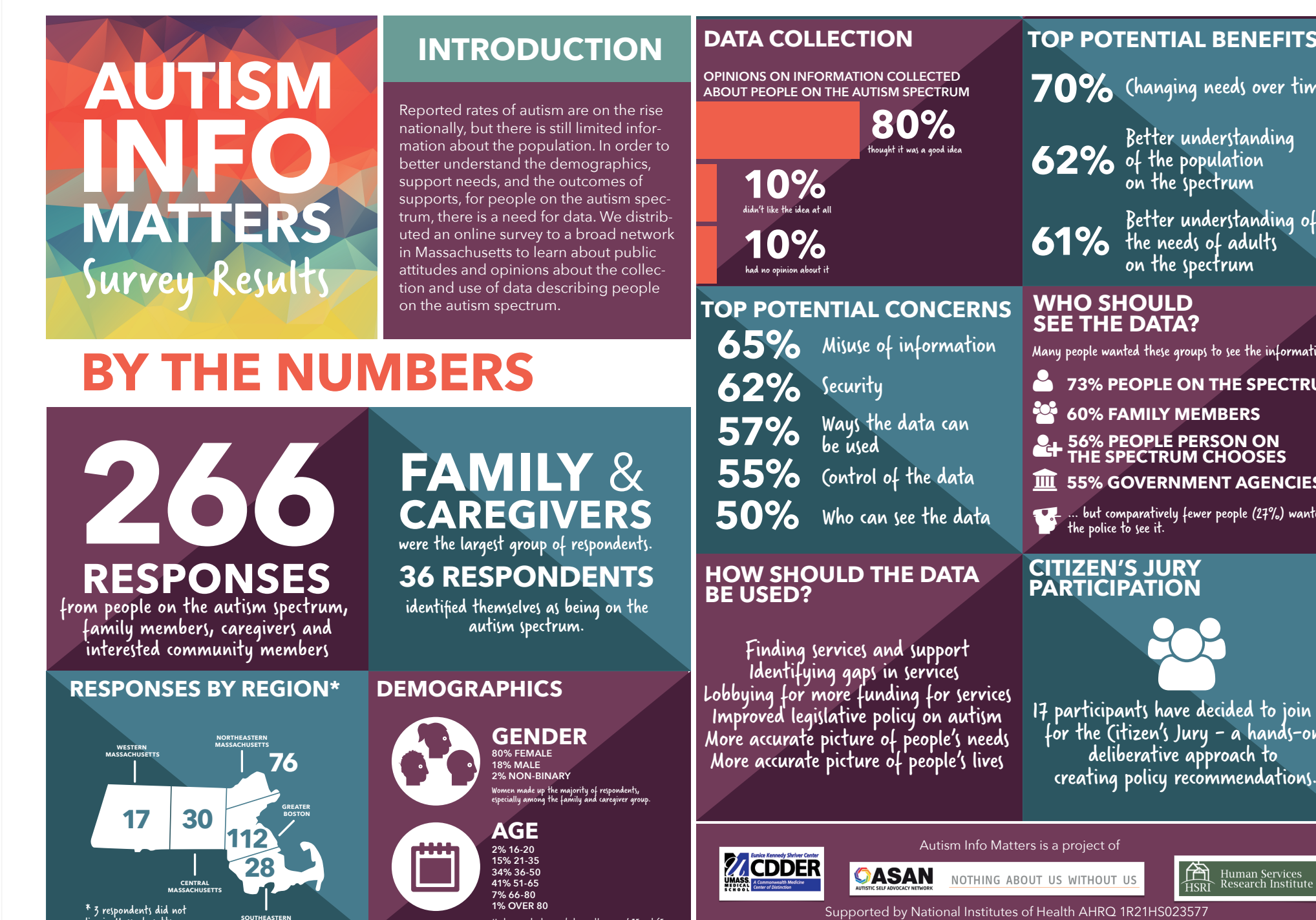
The Citizen's Jury met for three full days over two weekends, hearing presentations, or "testimony," from a range of expert witnesses. Expert witnesses provided content knowledge to the Citizen Jurors, however the power and outcome of the deliberation remained in the hands of the Citizen Jurors. The project team employed a multi-media approach to allow for a range of opportunities for input beyond direct face-to-face discussion. These included an on-line forum and the use of a wiki for the presentation of results of the deliberation.

Accommodations for face-to-face deliberation included availability of extra rooms to allow for time out, the provision of desk toys and other objects for participants to keep themselves occupied, provision of materials in multiple modes, and videotaping of all presentations to allow participants to review content if they choose.



RESULTS

Statewide Survey



Members of the Citizen's Jury

The Citizen's Jury recruitment project resulted in 19 Citizen Jurors, with 9 participants identifying on the autism spectrum. 7 identified as parents/ family members of people with disabilities, and 6 people identified as service providers or researchers.

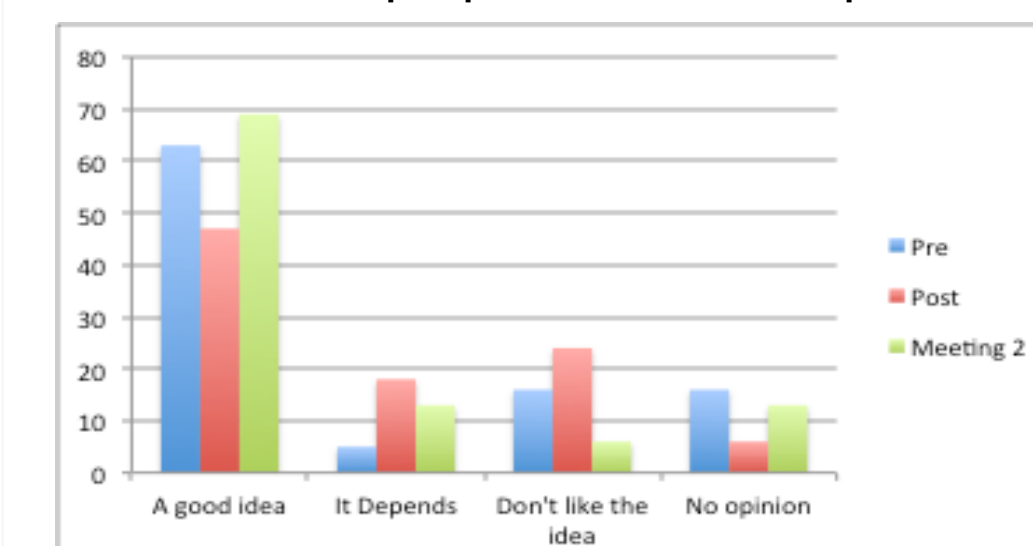
Recommendations from the Citizen's Jury

- Stakeholders recognize gaps in available information about autistic people, and need for information to help develop and improve policy
- Confidentiality is critical, with specific recommendations regarding data security – along the lines of most sensitive health information.
- Opting out must be an option for people.
- Stakeholders' inclusion of people on the autism spectrum should be part of ongoing planning and administration.

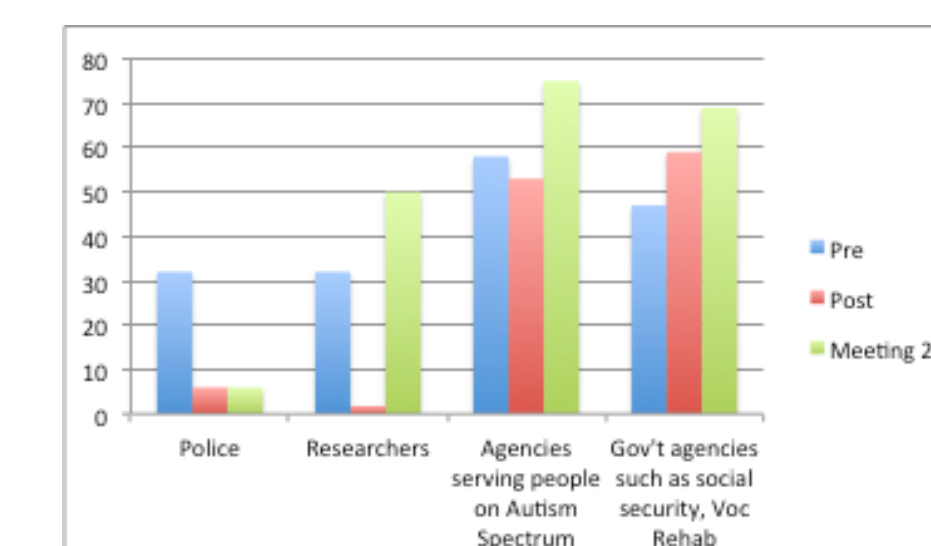
Evaluation Results

Jurors completed an attitude survey before the first meeting, after the second day, and at the completion of the deliberation, two weeks later.

What do you think about the idea of information collected about people on the autism spectrum?



Who should be able to see the information the state collects?



CONCLUSIONS

This project has demonstrated success of the first Citizen's Jury method specifically with people on the autism spectrum.

In addition to the results/recommendations, the process of deliberation, both in person and on-line, was significant and was reported to change how people thought about a broad range of issues beyond the deliberation topic.

This model can be used successfully to bring the voice of people with disabilities, in particular on the autism spectrum into public deliberation.

Accommodations to encourage participation for people who do not communicate verbally should be explored for further deliberations.

RESOURCES

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