



Autism Info Matters: Data Collection, Participatory Action Research and the Autistic Community

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NOTHING ABOUT US WITHOUT US

Participatory Action Research and Gaining Perspectives

Participatory Action Research

- ◆ Engaging members of a community being studied in research projects
- ◆ People know their own communities best and may recognise particular needs that others may not
- ◆ ‘Nothing About Us Without Us’

Participatory Action Research

- ◆ HSRI and UMass Medical School teamed with ASAN to have self-advocate representation
- ◆ Autistic adult worked on the team to work on community engagement, drafting questions, advisory board, administrative tasks, writing the report
- ◆ Participants in Citizen's Jury project were included in the research through their suggestions/recommendations



Gaining Perspectives

- ◆ It's important to find out how people who may be affected feel about your research project
- ◆ One way to gain perspective is to use 'deliberative methods'
- ◆ Focussed discussion to consider multiple perspectives on a topic - more so than opinion polls and one-off focus groups

Gaining Perspectives

- ◆ Helps people feel more engaged and interested in participating
- ◆ Allows people to learn more about an issue
- ◆ Changing policy through community participation
- ◆ What we did for the Citizen's Jury

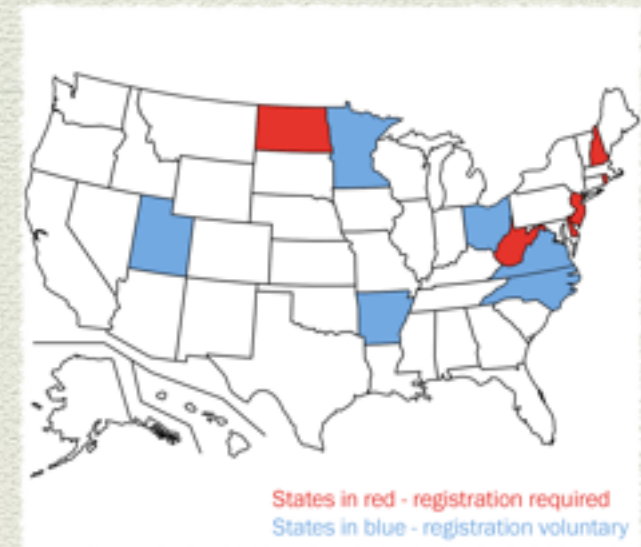
Data Collection and the Citizen's Jury Process

Why do data collection about autism anyway?

- ◆ How common is autism in a given area?
- ◆ What health disparities are people experiencing?
- ◆ What biological issues are connected with autism?
- ◆ Are services and supports working for people?

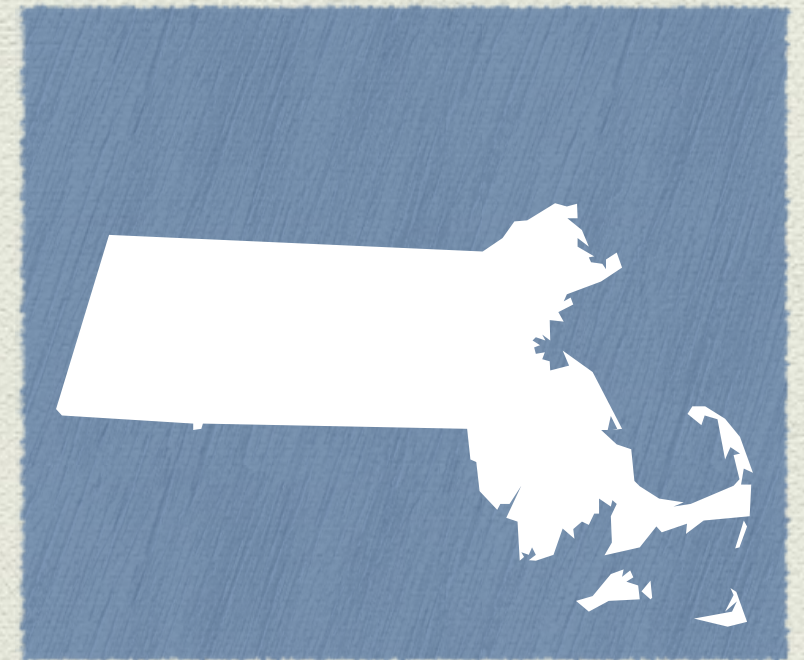
Other Autism Databases

- ◆ Autism registries in the following states – Arkansas, Minnesota, New Hampshire, New Jersey, North Carolina, North Dakota, Ohio, Utah, Virginia, West Virginia
- ◆ Canadian provinces
- ◆ Irish Autism and Neurodevelopmental Disorders Registry and Bio-Bank



Situation in Massachusetts

- ◆ Governor's Special Commission Relative to Autism: instructed the Executive Office of Health and Human Services to *'establish and manage an integrated data system among state agencies and stakeholders to track diagnosis, treatment, services and outcomes...in order to improve coordination of care and disseminate information'*
- ◆ Pending legislation to create the database
- ◆ Needed input from people who would be affected ASAP – autistic people, parents and professionals

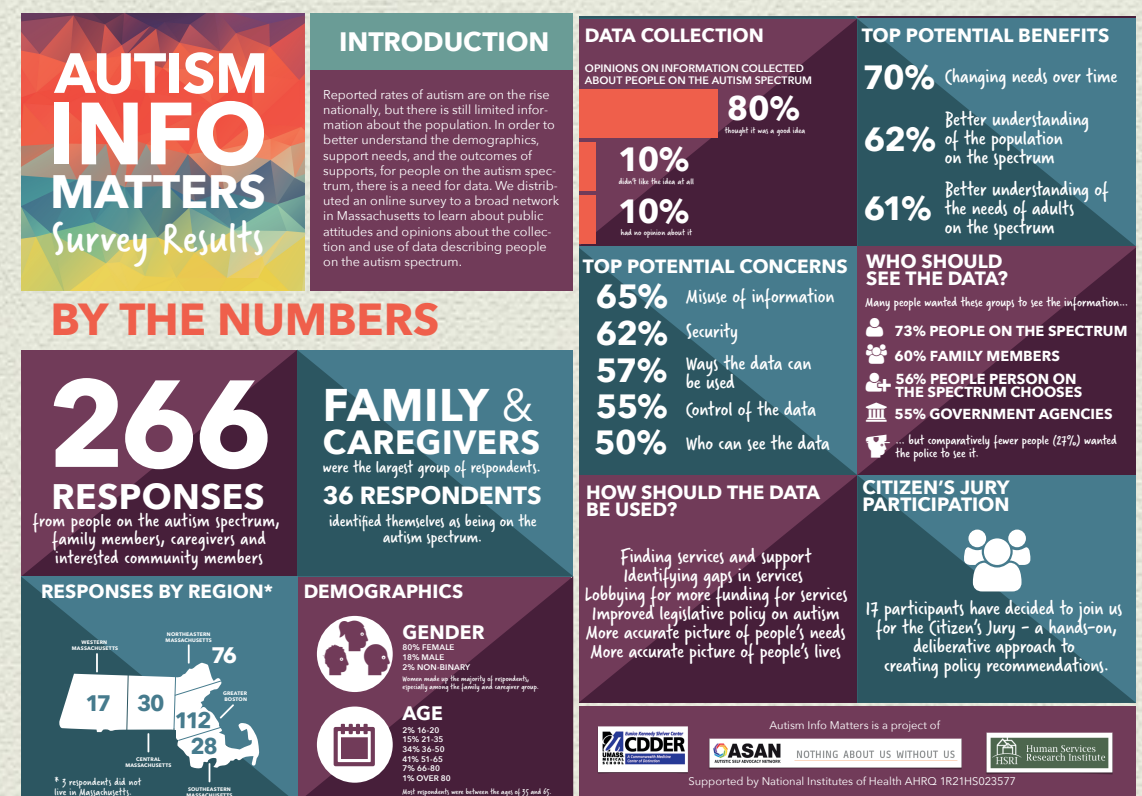


Concerns and Values about Autism Registries

- ◆ Privacy concerns
- ◆ Concerns about stigma
- ◆ Opt-in or opt-out?
- ◆ Incomplete data
- ◆ People may not have diagnoses
- ◆ ASAN's position: opt-in registry, no inaccurate or offensive language, written and informed consent for inclusion in a database

Citizen's Jury Project

- Used Participatory Action Research and Deliberative Methods principles
- Knowledge & Attitude Survey administered to autistic adults, parents and professionals – questions about the collection, use and sharing of info about autistic people by MA state agencies
- Survey used to recruit for the Citizen's Jury meetings



Citizen's Jury Project

- ◆ 19 Citizen Jurors (autistic people, parents and professionals; about half of participants were autistic)
- ◆ 7 Expert Witnesses
- ◆ Blended in-person and online experience
- ◆ Broad perspectives gained
- ◆ Intense debate

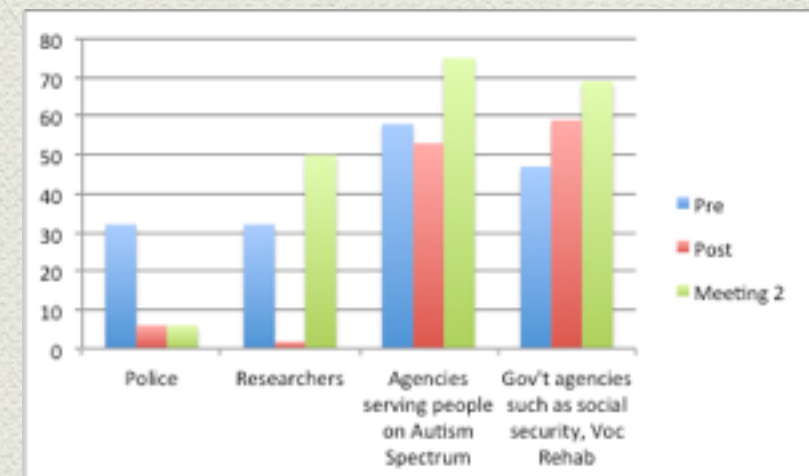
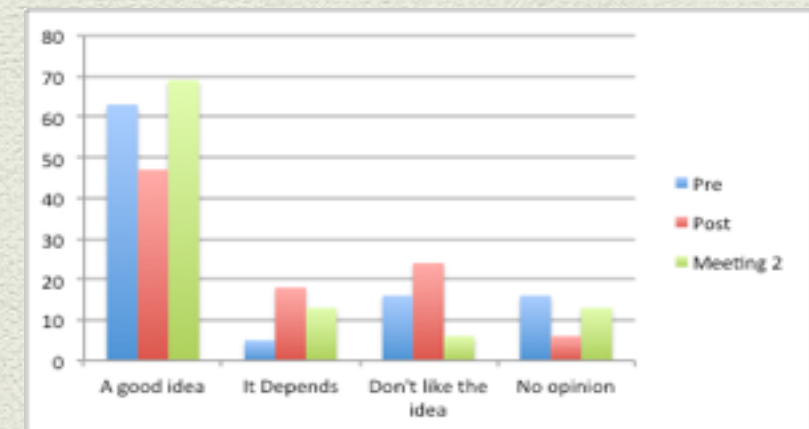


Questions for the Jury

- ◆ Guiding principles for a data system including information about autistic people receiving supports in MA?
- ◆ Should people 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 data should be shared with researchers?

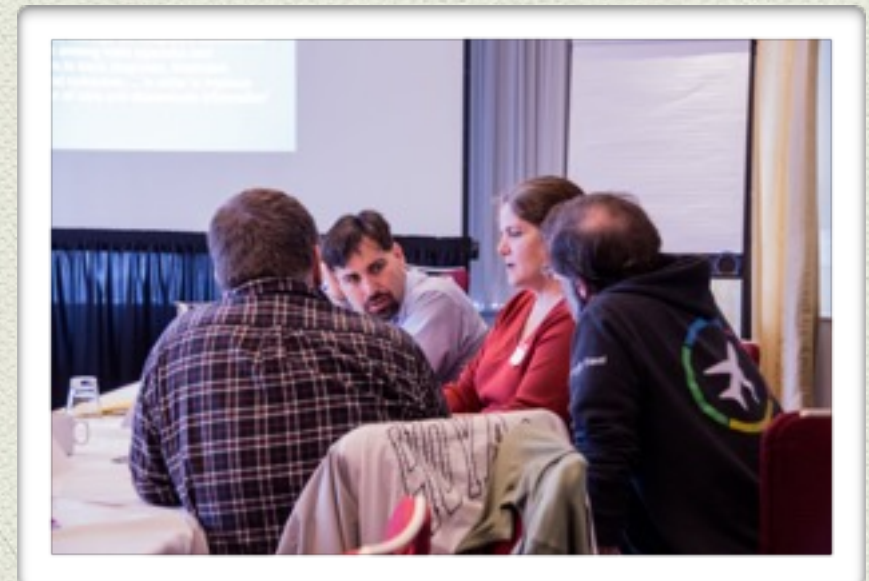
Findings

- Views about the creation of a database changed over the course of the project
- Opinions were more positive at the beginning and very end
- More supportive of researchers, autism non-profits and government agencies having the information than the police



Findings

- ◆ Participants established guiding principles
- ◆ Recognise gaps in available information about autistic people
- ◆ Information to develop and improve policy about autism
- ◆ Confidentiality is crucial – data security should be the same as other sensitive health information
- ◆ Autistic people should be part of continuing planning and administration of the database



Participants' Feedback

- ◆ ‘You go to a place and learn about a topic and talk with lots of people about it – it is confusing at first but gets easier over time. It’s hard but also rewarding. Everyone’s voice heard.’
- ◆ ‘Far more of a conceptual process than a focus group. Everyone’s voice heard.’
- ◆ Valued bringing diverse opinions together (autistic people and parents), being listened to, questioning the experts, coming to consensus required training and time



Conclusion

- ◆ Inclusion and PAR principles made this project effective because the voices of autistic people were incorporated throughout
- ◆ Rich perspectives from people with lived experience and potential allies
- ◆ Can be applied to other topics

Thank You!