



Nothing About Us Without Us: Autistic People Shaping Policy About Our Lives

JULIA BASCOM

Executive Director, Autistic Self Advocacy Network (ASAN)



DREXEL UNIVERSITY

A.J. Drexel

Autism Institute



Run by and for autistic people

Civil rights framework to disability policy issues

Work focuses on policy advocacy and systems change



The Developmental Disabilities Act





Neurodiversity



Embracing a social model over a medical model



Looking at a disabled person as a whole person who interacts with the whole world



Identifying and removing barriers



Policy Advocacy

Public Policy:

The process of making decisions about how public dollars should be spent.

Policy Advocacy:

A big focus of ASAN, analyzing the history and what the community needs now to put forward proposals to change things for the better.



Participatory Policymaking

Making sure that the people impacted by a policy have a hand in shaping it.





Polycymaking and Research

**Need research
to craft
effective policy**

**Need research
to know how
much different
policy options
might cost**

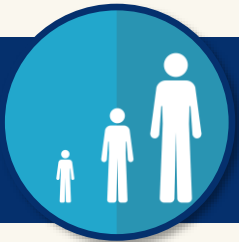
**Need research
to predict how
well they can
be expected to
work**

**Need research
to maximize
different
outcomes**

**Need research
to balance
competing
priorities**



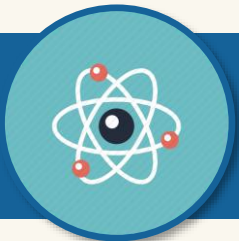
Issues with Autism Research



Only 2% of research spending on autism looks at autistic people across the lifespan--adolescents, adults, and elders.



48% of autism research funding looked at basic biology and what causes autism



Autism research dollars are concentrated at NIH, focus on traditional basic science



Participatory Research

Members of the community being studied share power with researchers

Work together to pick the research topic, form research questions, design the study, analyze data, and discuss the results

Must take autistic people seriously as part of the research process



Changing the Policy Process

Proxy Caller System

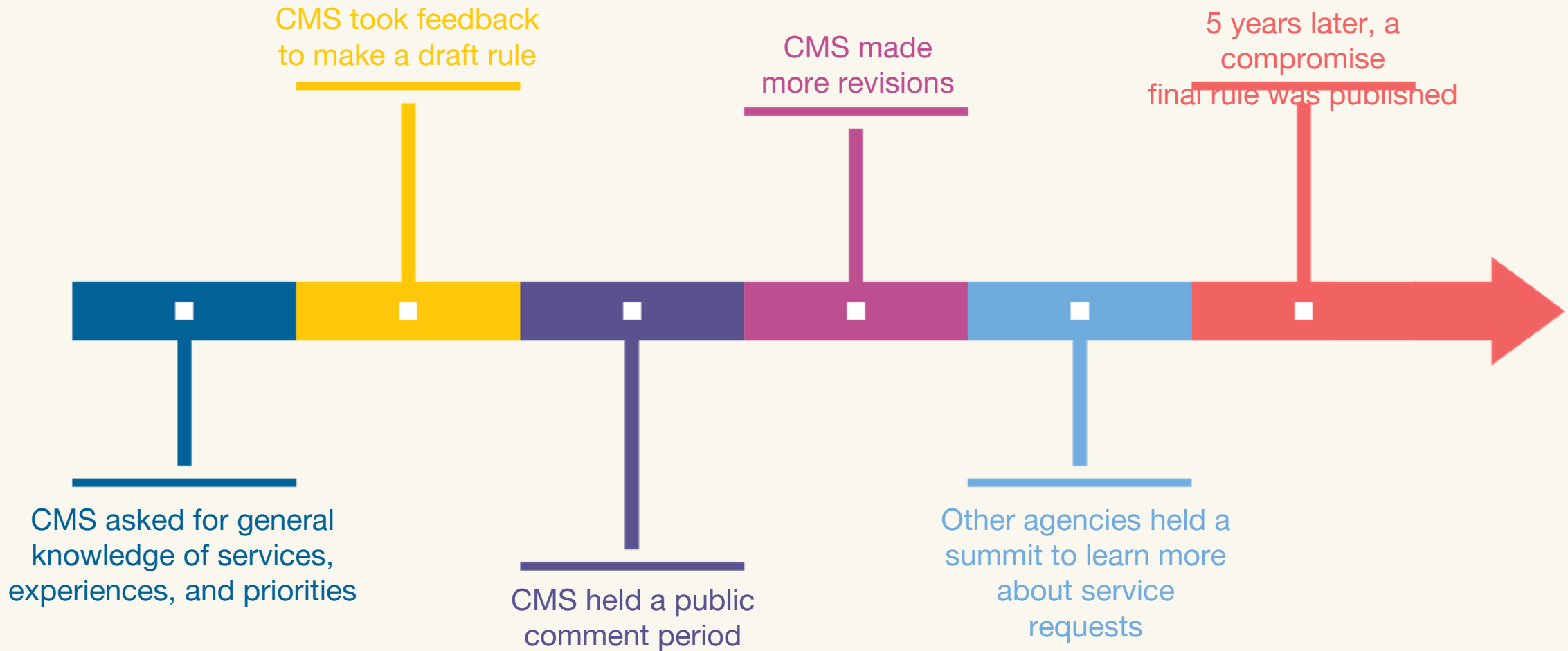
Encouraging people with disabilities to run for office

Equipping self-advocates to participate in the public comment process

Participation of self-advocates in every level of government and policy



Participatory Policymaking in Action: The HCBS Settings Rule





Small freedoms





Self-Advocates MUST be Involved





ASAN is fighting for everyone's right to speak for themselves. We all have a voice, no matter how we express it, and we are all going to be heard.





THANK YOU!