

Autism in the Context of Ableism

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My Background

- Ran the Autistic Self Advocacy Network from 2006 to 2016;
- Served for five years as one of President Obama's appointees to the National Council on Disability;
- Autistic;
- Actively involved in both the disability rights and the neurodiversity movements
- Currently runs MySupport.com and is completing a book on the history of the American disability experience from the Civil War to the present day.

Today's webinar

1. What is the History of Autism?
2. How should we think about autism?
3. Who gets to decide what matters in autism research and services?
4. The path forward: including autistic adults in research and service-provision
5. Forming genuine partnerships
6. Including self-advocates with CARES programs

A Note on Language

“Autism isn't something a person has, or a "shell" that a person is trapped inside. There's no normal child hidden behind the autism. Autism is a way of being. It is pervasive; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person--and if it were possible, the person you'd have left would not be the same person you started with” (Sinclair, 1999)

→ We use identity-first language (i.e., 'autistic person') to reflect this perspective (see Gernsbacher, 2017, Kenny et al., 2016).

What is ableism?

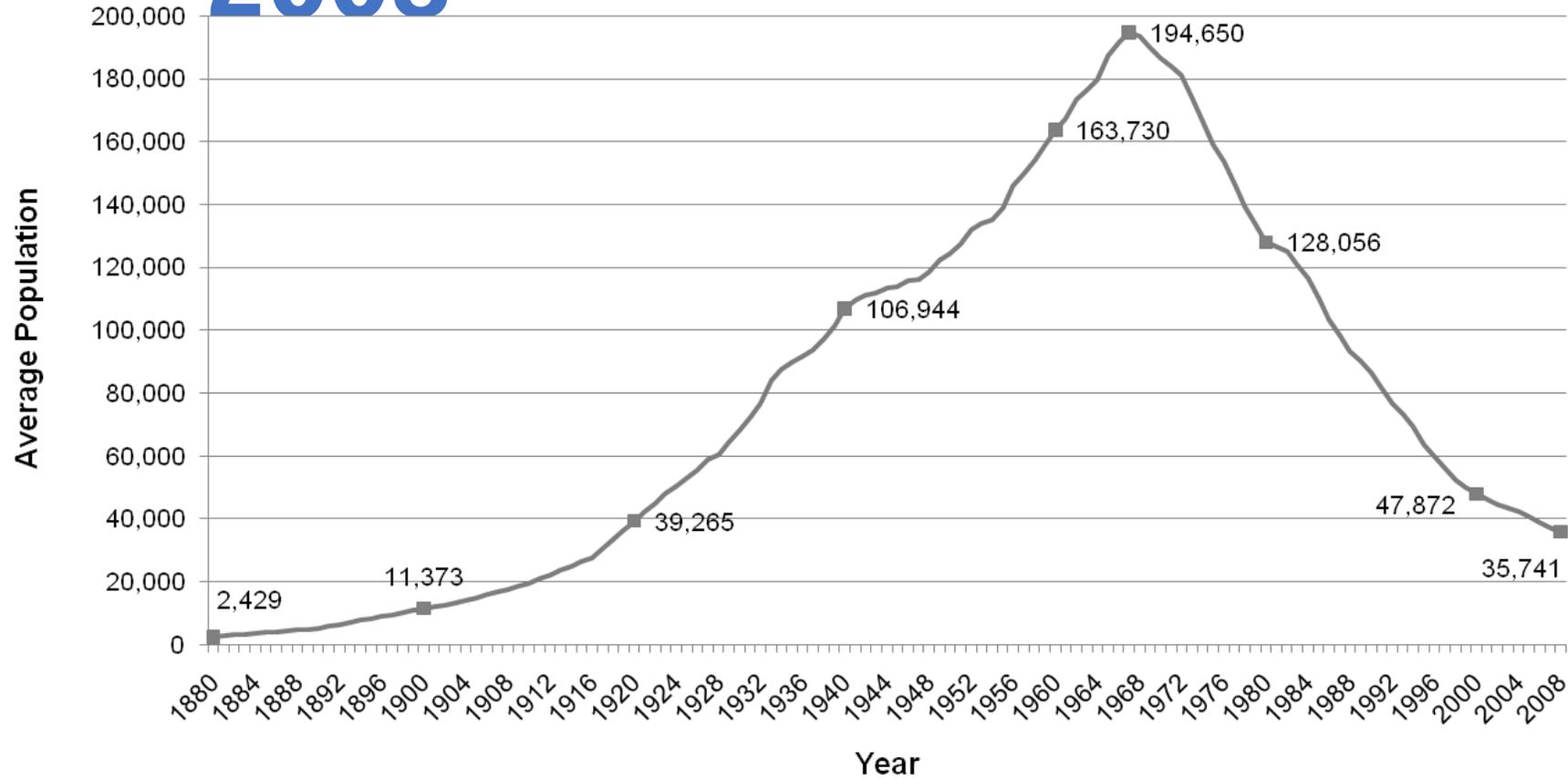
Ableism is discrimination against, prejudice against or disregard for the needs of people with disabilities.

It can be:

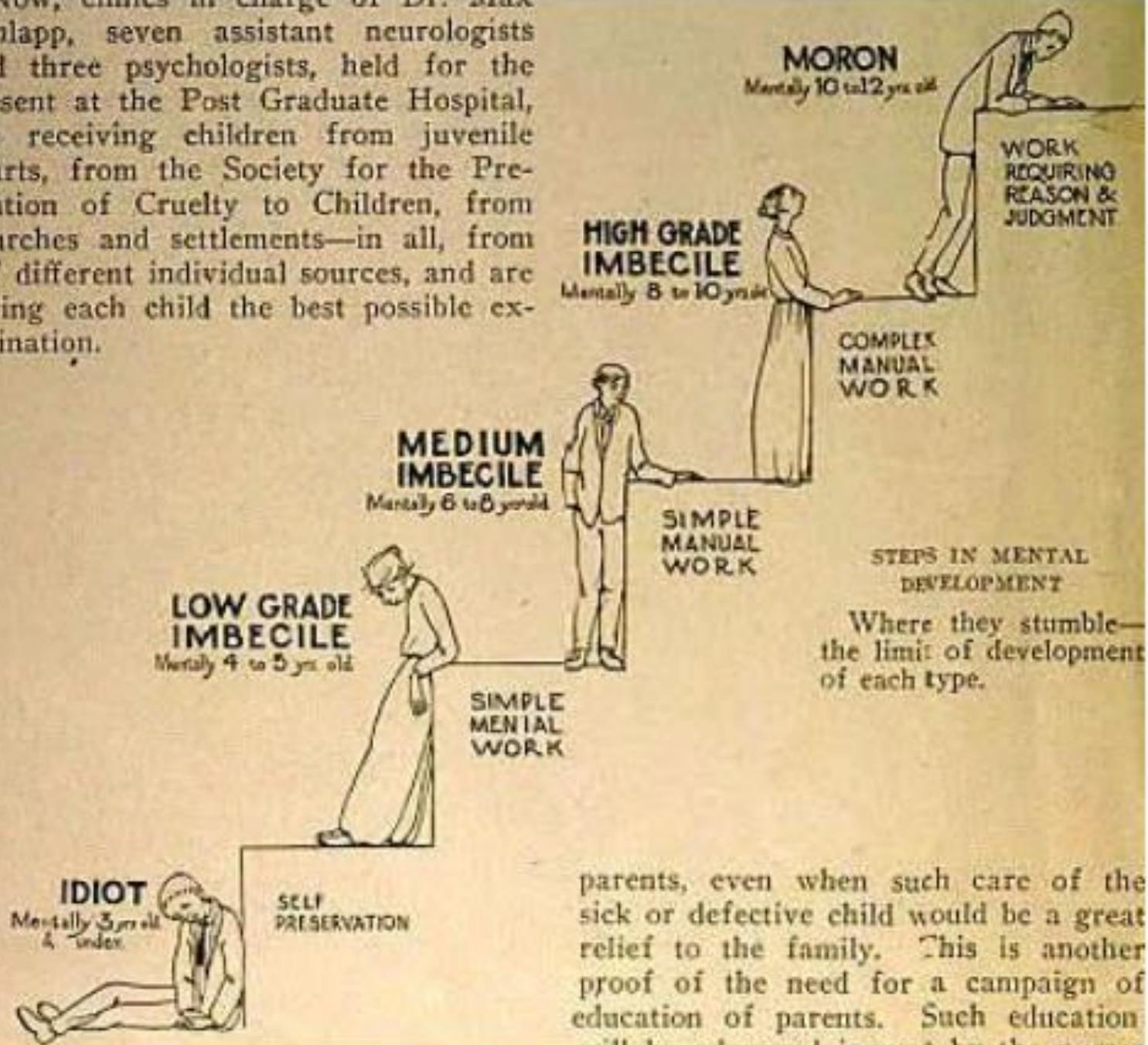
- About attitudes;
- About structures or systems;
- Expressed implicitly or explicitly;
- Intentional or accidental;
- Something that impacts different kinds of disabled people differently

**History Shapes The
Current Day**

Institutional Census, 1880-2008



NOW, CLINICS IN CHARGE OF DR. MAX Schlapp, seven assistant neurologists and three psychologists, held for the present at the Post Graduate Hospital, are receiving children from juvenile courts, from the Society for the Prevention of Cruelty to Children, from churches and settlements—in all, from 47 different individual sources, and are giving each child the best possible examination.

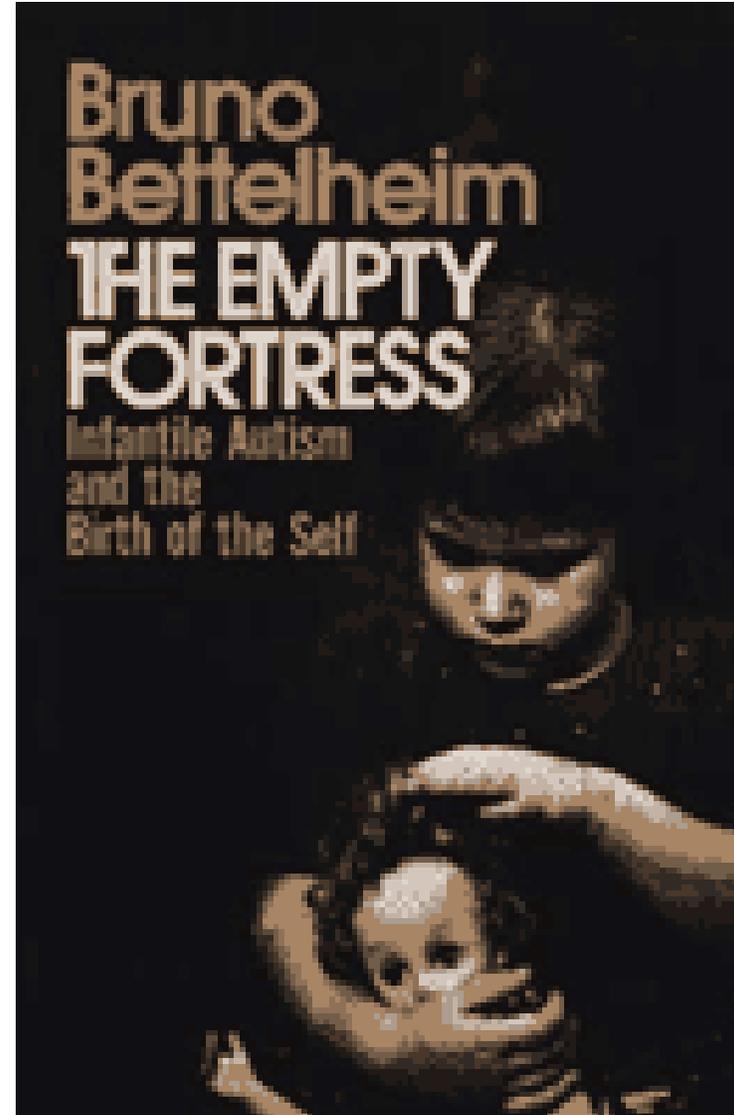


parents, even when such care of the sick or defective child would be a great relief to the family. This is another proof of the need for a campaign of education of parents. Such education will be advanced in part by the nurses

**Where were Autistic
adults in prior
generations?**

**Often in institutions
or under other
diagnoses**

Bruno Bettelheim and “Refrigerator Mother” Theory



Bernie Rimland



- Founder of Autism Research Institute and helped to found Autism Society
- Helped to de-bunk “refrigerator mother” theory
- Popularized “vaccines cause autism” idea and many pseudo-scientific treatments
- Opposed de-institutionalization & supported aversive interventions

Rimland on De-Institutionalization

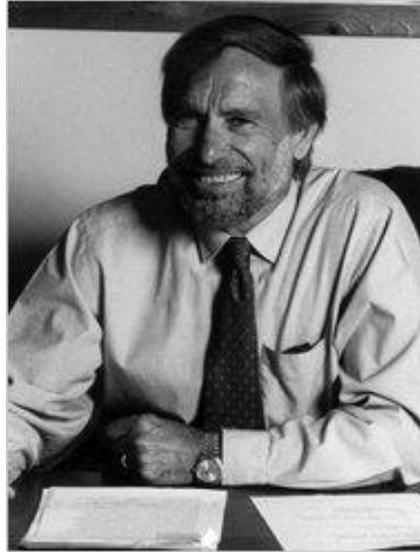
“Community living—with no other options—is an ideology pushed with religious fervor by the sanctimonious but misguided Association for Persons with Severe Handicaps (TASH). I read with grim amusement the complaint in their most recent newsletter: “Although persons with severe disabilities have been living in the community physically for some time, they have not generally been participating in the shared life of those communities.” What shared life? Community, my foot!”

-“Community, My Foot!” Bernie Rimland, *Autism Research Review International*, 1991, Vol. 5, No. 3

Rimland on De-Institutionalization

- **BEWARE THE ADVOZEALOTS: Mindless Good Intentions Injure the Handicapped**
 - *Autism Research Review International*, 1993, Vol. 7, No. 4, page 3
- **Reopen the Institutions? Advocates Reverse Stand as "Community" Tragedy Unfolds**
 - *Autism Research Review International*, 1997, Vol. 11, No. 1, page 3

O. Ivar Lovaas



- Developed Applied Behavioral Analysis as an autism treatment;
- Title of 1965 Life Magazine profile: *"Screams, Slaps & Love: A surprising, shocking treatment helps far-gone mental cripples"*
- Sought to make autistic children "indistinguishable from peers", pioneered the idea of "recovery" from autism as the goal of autism intervention, utilized aversives in experiments
- ABA has evolved – but the emphasis on "indistinguishability" remains. Autistic people have severe concerns to this day.

Jim Sinclair – “Don’t Mourn For Us” (1993)

“Autism isn't something a person *has*, or a "shell" that a person is trapped inside. There's no normal child hidden behind the autism. Autism is a way of being. It is *pervasive*; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person--and if it were possible, the person you'd have left would not be the same person you started with.

This is important, so take a moment to consider it: Autism is a way of being. It is not possible to separate the person from the autism.

Therefore, when parents say,

I wish my child did not have autism,

what they're really saying is,

I wish the autistic child I have did not exist, and I had a different (non-autistic) child instead.”

**How did parents and
professionals talk
about autism?**

“Autism is worse than cancer in many ways, because the person with autism has a normal lifespan.”

-David Vardy of the Autism Society of Canada, in testimony to the Canadian Parliament’s Standing Senate Committee on Social Affairs, Science and Technology

We have your son.

We will make sure he will
not be able to care for
himself or interact socially
as long as he lives.

*This is only the beginning.

Autism

Don't let a psychiatric disorder take your child.
The NYU Child Study Center is dedicated to giving children
back their childhood by preventing, identifying, and treating
psychiatric and learning disorders.
To learn more, call (888)7-NYU-MED or visit AboutOurKids.org.



NEW YORK UNIVERSITY
CHILD STUDY CENTER

WE HAVE YOUR SON. WE ARE DESTROYING HIS
ABILITY FOR SOCIAL INTERACTION AND DRIVING HIM
INTO A LIFE OF COMPLETE ISOLATION.

IT'S UP TO YOU NOW.

ASPERGER
SYNDROME

Don't let a psychiatric disorder take your child.
To learn more, call 1-800-9-NUM-NEED or visit AboutOurKids.org.



NATIONAL INSTITUTE OF MENTAL HEALTH
DEPARTMENT OF HEALTH AND HUMAN SERVICES



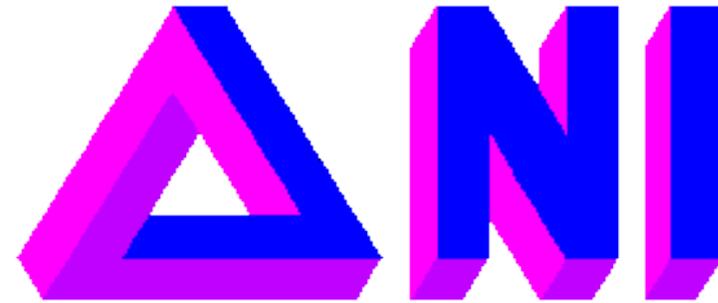
12 **MILLION** kids **ARE** **HELD**
HOSTAGE **by** **A** **PSYCH**iatric **disORDER**.

Help a child at aboutourkids.org



NEW YORK UNIVERSITY
CHILD STUDY CENTER

Autistic Self-Advocacy Organizations



Autism Network International



MOURN FOR THE DEAD ...AND FIGHT LIKE HELL FOR THE LIVING

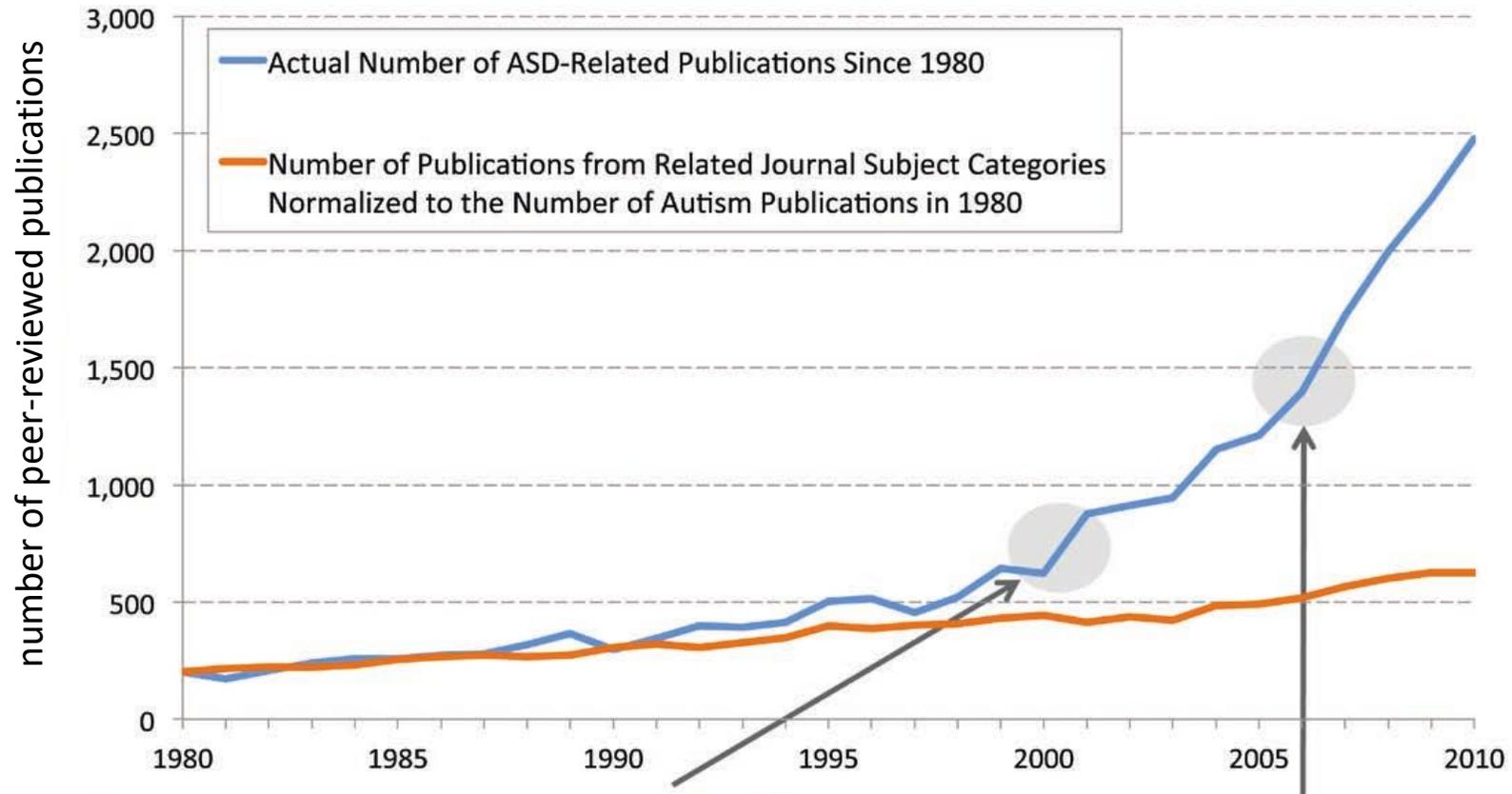
– Mary Harris “Mother” Jones

TRACY LATIMER, 12 years old, gassed by her father, 1993 • **SCARLETT CHEN**, 4 years old, drowned by her mother, July 2004 • **KATIE MCCARRON**, 3 years old, suffocated by her mother, May 2006 • **FRANCECCA HARDWICK**, 18, locked in a burning car with her mother, October 2007 • **NAOMI HILL**, 4, drowned by her mother, November 2007 • **TOM INGLIS**, 22, died after his mother administered an overdose of heroin to him, November 2008 • **JEREMY FRASER**, 9 years old, died of recurrent leukemia after his mother withheld the medication that would have saved his life. March 2009 • **PETER EITZEN**, 16, stabbed by his mother, July 2009 • **JEREMY BOSTICK**, 11, gassed by his father. September 2009 • **TONY KHOR**, 15, strangled by his mother, October 2009 • **BETTY ANNE GAGNON**, 48, tortured to death by her sister and brother-in-law, November 2009 • **WALTER KNOX HILDEBRAND JR.**, 20 years old, died of a seizure induced by his brother’s physical abuse. November 2009 • **LAURA CUMMINGS**, 23, tortured to death by her mother and brother, January 2010 • **AJIT SINGH**, 12, forced to drink bleach by his mother. February 2010 • **GERREN ISGRIGG**, 6 years old, died of exposure after his grandmother abandoned him in a remote area. April 2010 • **LEOSHA BARNETT**, 17, starved to death by her mother and sister, May 2010 • **GLEN FREANEY**, 11, strangled by his mother. May 2010 • **PAYTON ETTINGER**, 4, starved by his mother, May 2010 • **CHRISTOPHER MELTON**, 18, gassed by his mother, June 2010 • **RYLAN ROCHESTER**, 6 months old, suffocated by his mother because she believed him to be autistic. June 2010 • **KENNETH HOLMES**, 12, shot by his mother, July 2010 • **ZAIN AKHTER**, 5, and **FARYAAL AKHTER**, 2. Strangled by their mother, July 2010 • **ROHIT SINGH**, 7, beaten to death by his father, September 2010 • **ZAHRA BAKER**, 10, murdered and dismembered by her stepmother and perhaps her father. October 2010 • **CHASE OGDEN**, 13, shot by his mother along with his sister Olivia. October 2010 • **KYLE SNYDER**, 9, shot by grandmother. October 2010 • **KARANDEEP ARORA**, 18, suffocated by his parents, October 2010 • **JULIE CIRELLA**, 8, poisoned by her mother, July 2011 • **NOE MEDINA JR.**, 7 months, thrown 4 stories by his mother, August 2011 • **BENJAMIN BARNHARD**, 13, shot by his mother. August 2011 • **JORI LIRETTE**, 7, decapitated by his father, August 2011 • **GEORGE HODGINS**, 22, shot by his mother. March 2012 • **TIFFANY PINCKNEY**, 23, starved by her sister. 2005 • **CALISTA SPRINGER**, 16, smoke inhalation-chained to her bed by her father & stepmother, February 2008 • **CHRISTOPHER DEGROOT**, 19, locked in apartment set on fire by his parents, May 2006

REMEMBERING PEOPLE WITH DISABILITIES KILLED BY THEIR PARENTS OR CAREGIVERS

**What's Happening
Now?**

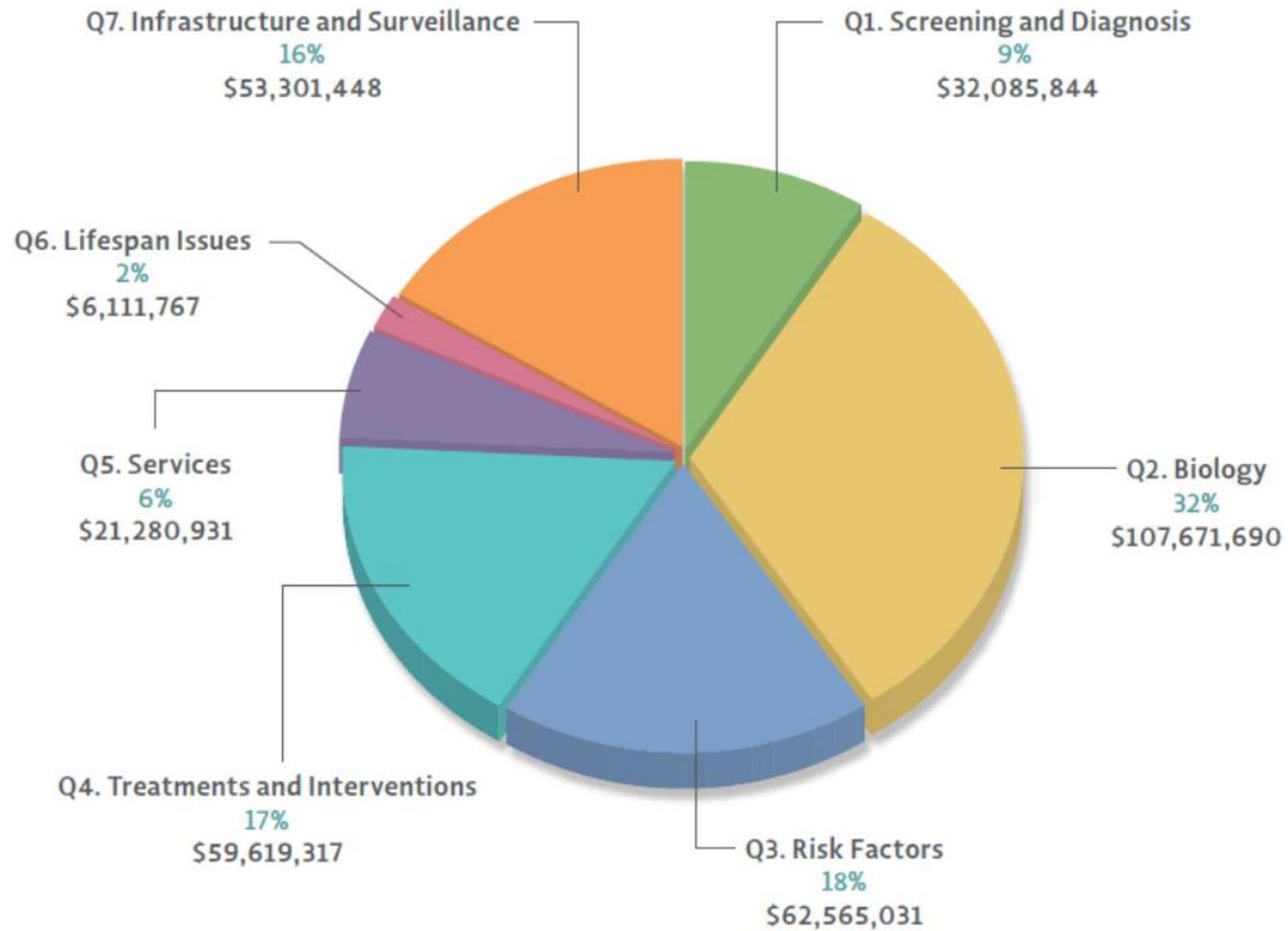
An Explosion in Autism Research



but where does the money actually go?

2015

ASD Research Funding by IACC Strategic Plan Question
Total Funding: \$342,636,029



**What assumptions
are reflected within
this research
agenda?**

Frequent assumptions in autism research and services

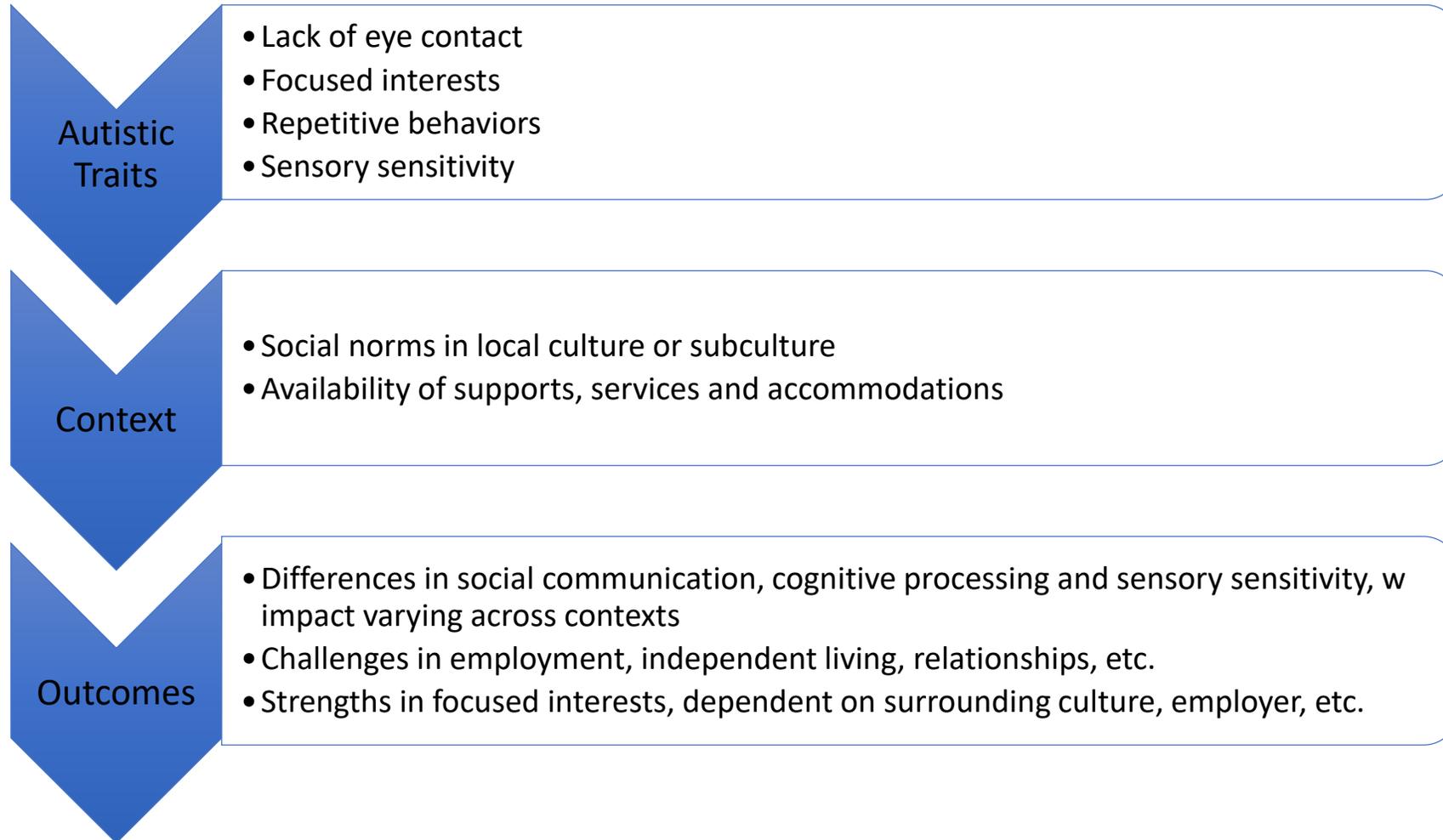
- Autism as a recent phenomena or 'epidemic'
- Goal of autism intervention/treatment a return to 'normalcy'
- Biomedical interventions most effective means of improving quality of life (as opposed to services)
- Comparatively limited opportunities for quality of life improvements in adults as compared to children

Medical Model of Autism



- The medical model presumes that autistic traits are themselves the inevitable source of challenges faced by autistic people.
- As a result, that which is identified for diagnostic purposes also serves as the focus of 'treatment' – and as a measure of treatment effectiveness
- Focus of intervention effectiveness is on removal of autistic traits, 'indistinguishability from peers'

Social Model of Autism



Social Model of Autism

- Associated with the “neurodiversity” movement
- The social model says that outcomes, including challenges, from autistic traits are mediated by social and policy contexts.
- As a result, that which is identified for diagnostic purposes may not serve as an appropriate goal for intervention.
- Focus of intervention effectiveness is on improving quality of life, skills, goals as defined by individual & community preferences and larger cultural context.
- Where should common co-occurring conditions (i.e., ID, SIB, epilepsy) fit in this model?

Implications of models

- Political divides exist between research and self-advocate groups on the direction of autism research funds and goal of autism service-provision
- Early research suggests that autistic identity & awareness of neurodiversity increase likelihood of:
 - Positive identity around autism
 - Opposition to search for “cure”
 - Preference for identity-first language (Kapp, 2012)
- Crucially, these do not reduce support for efforts to teach adaptive skills, suggesting nuanced distinctions not always acknowledged by researchers (Kapp et al., 2012).

Service Implications of models

- Shift in the goal of service-provision and intervention – from encouraging “indistinguishability” to promoting person-centered goals
 - i.e: eye contact, reduction of stimming are indistinguishability-oriented;
 - i.e: communication skills, independent living are person-centered goals
- Goal is a healthy and happy autistic adult, not a non-autistic person.
- Need to adjust to viewing autism through a diversity lens and as a backdrop for co-occurring MH issues that autistic people may actively want treatment for (i.e: anxiety, depression, etc.)

**What kinds of policy
implications emerge
from these models?**

Policy Implications of models

- How do we design a behavioral health benefit?
 - Need for options other than just Applied Behavioral Analysis;
 - Reinforced in CMS and ED guidances;
- Need for statutory requirements for Autistic participation in task forces, councils & committees;
- Policy must emphasize both direct service needs and addressing attitudinal and social barriers through investing in services that support natural relationships and independence;
- If autism is not new, the DD Act framework is still our best path forward.

July 7, 2014 CMS Guidance on Medicaid EPSDT

“While much of the current national discussion focuses on one particular treatment modality called Applied Behavioral Analysis (ABA), there are other recognized and emerging treatment modalities for children with ASD....”

July 6, 2015 ED Guidance

- “OSEP has received reports that a growing number of children with ASD may not be receiving needed speech and language services, and that speech-language pathologists and other appropriate professionals may not be included in evaluation and eligibility determinations.”
- “Some IDEA programs may be including applied behavior analysis (ABA) therapists exclusively without including, or considering input from, speech language pathologists and other professionals.”
- “We recognize that ABA therapy is just one methodology used to address the needs of children with ASD and remind States and local programs to ensure that decisions regarding services are made based on the unique needs of each individual child.”

**Autism Isn't THAT
Special!**

**Use the Values of the
DD Act and the ADA**

**Are we REALLY
talking about
different
populations here?**

Addressing the Roots of Autism Communal Divisions

- Parents are pushed to prioritize “indistinguishability from peers”, “cure/recovery” over other, more person-centered goals;
- Parental priorities heavily influenced by their interactions with clinicians, researchers;
- We need researchers, providers, parents to be exposed to Autistic voices early and often – introduced to neurodiversity, social model of autism, etc.;
- Need more acknowledgment that Autistic people can ALSO be researchers, providers and parents.
- Parents and Autistic people NOT the same constituency, have to be approached differently.

**What are community
priorities for autism
research?**

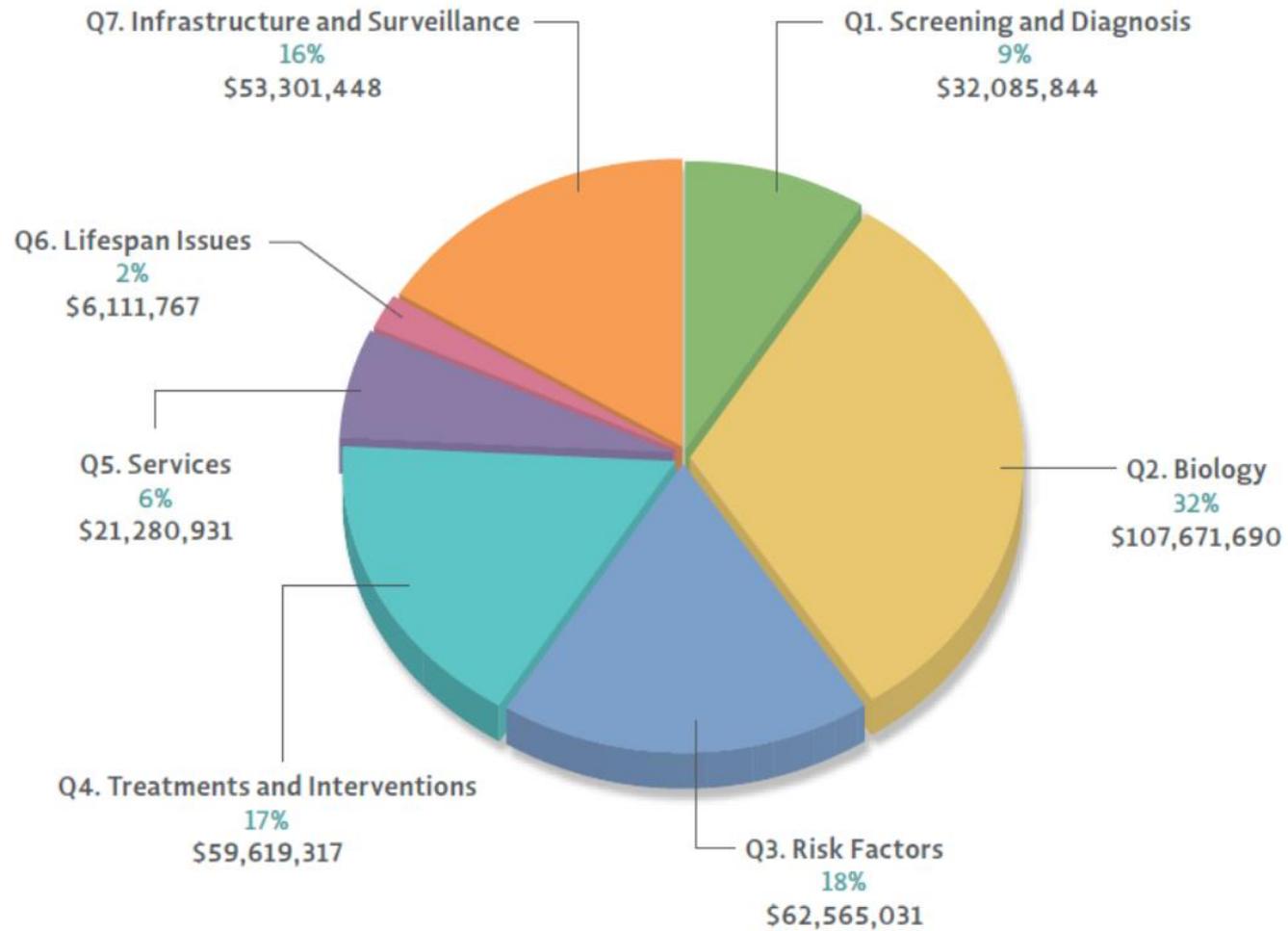
Identifying people's priorities (UK)

- >1,600 people responded to an online survey
- They rated the relative importance of 13 research questions on a 5-point scale
- From: Pellicano, Dinsmore, Charman, 2014

Questions	Mean rating
1. How can we better recognise the signs and symptoms of autism?	4.2
2. Are there different types of autism?	3.7
3. How common is autism?	3.4
4. How do autistic people think and learn?	4.5
5. How are autistic people's brains different from the brains of non-autistic people?	4.0
6. To what extent is autism caused by environmental factors?	3.5
7. To what extent is autism caused by genetic factors?	3.6
8. What are the best ways to treat the core symptoms of autism?	4.2
9. How can public services best meet the needs of autistic people?	4.6
10. What is the place of autistic people in society today?	4.0
11. What are the best ways to improve the life skills of autistic people?	4.6
12. What does the future hold for autistic adults?	4.4
13. Why do autistic people appear to be more at risk from some medical conditions than non-autistic people?	4.0

2015

ASD Research Funding by IACC Strategic Plan Question
Total Funding: \$342,636,029



→ huge mismatch between what is researched and what people want to be researched

Addressing the mismatch

- Need for comparable research on autistic and family priorities in autism research in the US;
- Need a better mechanism for considering stakeholder input in the research funding agenda;
- Some progress on this in publicly funded research – relatively little in privately funded research;
- What are the moral and ethical obligations of research funders?

the path forward:
participatory autism research

Community Participation in Autism Research

- in other health-related fields of research, such gaps have been narrowed by involving community members in the research process, beyond passive participants
- if we get people involved, we should get research that is:
 - more thoroughly **relevant** to people with disabilities and communities,
 - sufficiently **tailored** to the realities of their everyday lives, and
 - **consistent with their values**

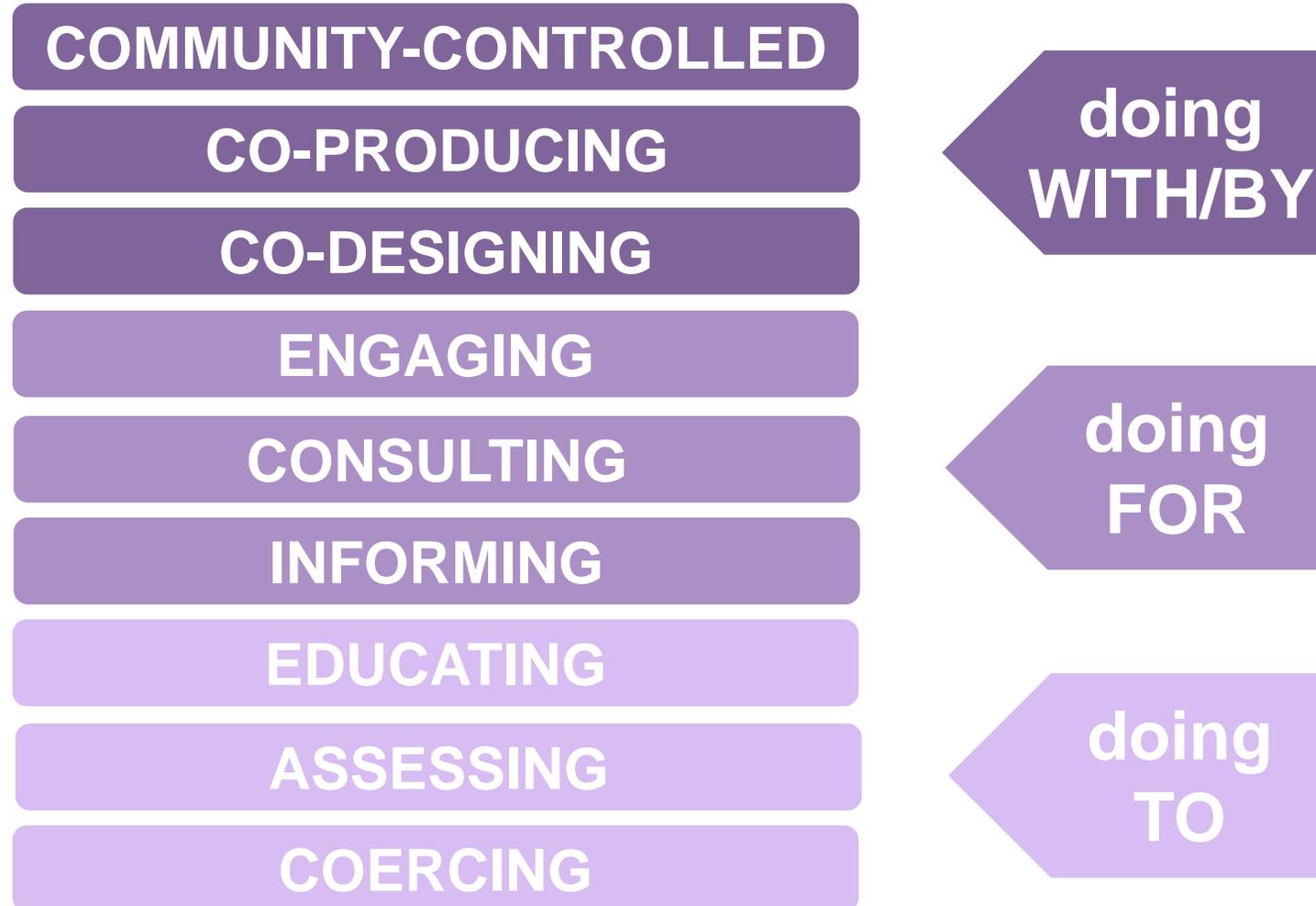
Forming Genuine Partnerships

- Community Based Participatory Research (CBPR)
 - Collaborative research in which members of a community are asked to be – and treated as – co-researchers throughout the entire research process
- CBPR goal: to create (shared) knowledge ... AND to use that knowledge for action/social change within that community
- Developing meaningful partnerships in training the next generation of providers by including Autistic people as LEND trainees and faculty & in other CARES programs

Forming Genuine Partnerships

- Prioritized within the NIH National Institute on Minority Health and Health Disparities
- CBPR has a strong track record in work to reduce health disparities among racial and ethnic minority groups
- Participatory Action Research, a different partnership model from CBPR, has been prioritized by the ACA's Patient Centered Outcome Research Institute, including for the disability community
- Who counts as “the community”? Parents and self-advocates aren't the same.

Participation Can Take Many Forms



Case Study: AASPIRE

- Academic Autistic Spectrum Partnership in Research and Education (AASPIRE)
- Involves traditional researchers partnering with Autistic community-based organizations.
- Has both an Autistic and NT Co-Director (Dora Raymaker and Christina Nicolaidis)
- Includes Steering Committee, Community Council and Academic Council for shared governance.
- <https://aaspire.org/>

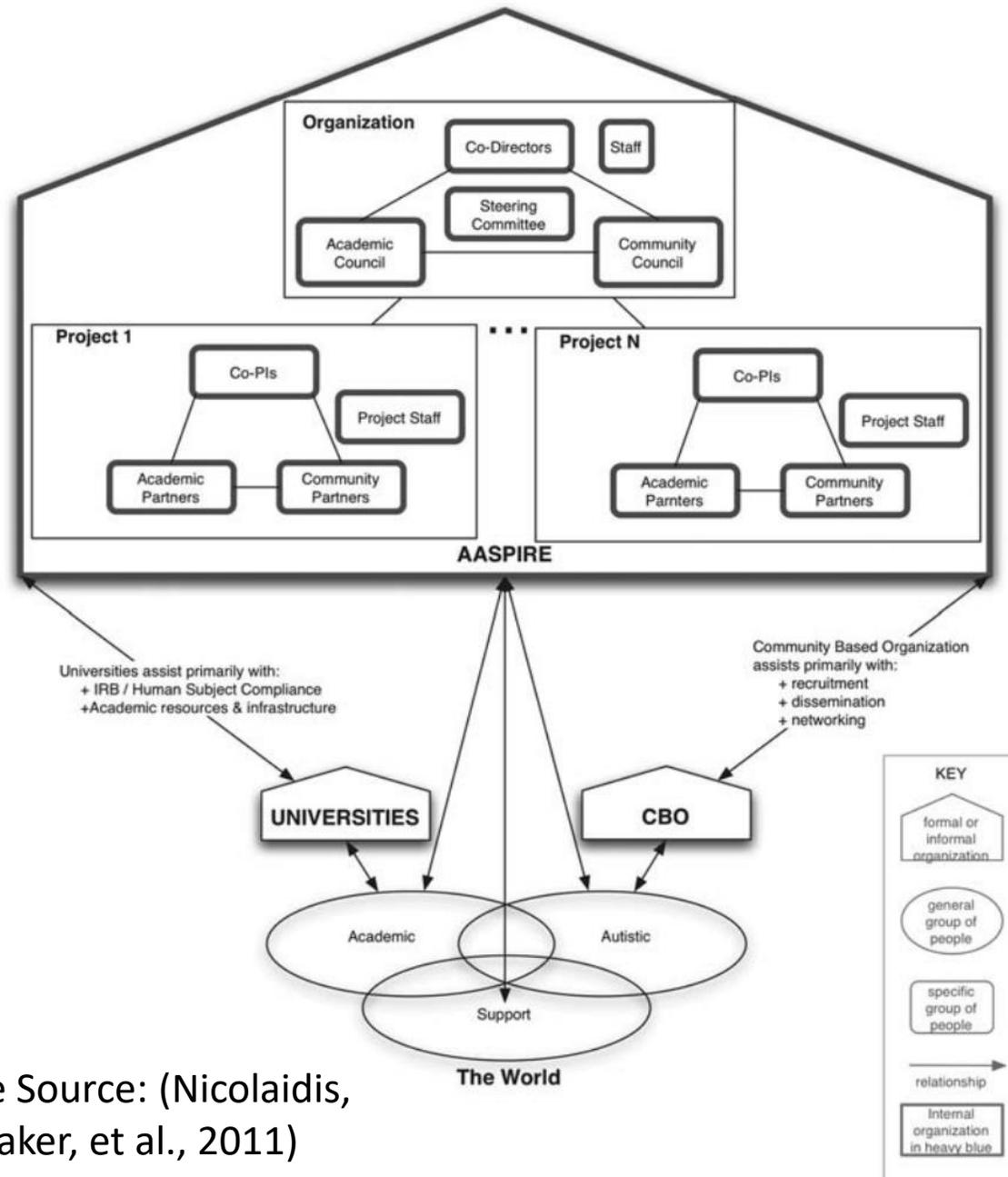


Image Source: (Nicolaidis, Raymaker, et al., 2011)

Figure 1. AASPIRE's Infrastructure

AASPIRE Healthcare Toolkit

- Funded by NIH to develop a toolkit of primary care resources for Autistic adults and primary care providers
- Available at autismandhealth.org
- Includes both resources and a Personalized Accommodation Report tool to assist in communications w physicians
- Recently funded by NIH to integrate into three healthcare systems

Personalized Accommodations Report

1 of 2

What can your healthcare provider's staff do before the visit to make it more successful?

- If possible, give me a way to make appointments without using the telephone.
- Schedule longer appointments if possible.
- Schedule appointments at a time when the provider is less likely to be late (for example, the first appointment).
- Let me or my supporters know what is likely to happen during an office visit (for example, what can I expect when checking in, during and after the visit, who I will be seeing, and how long things usually take).
- Notify me as soon as possible if there is an unexpected change (for example, I need to see a different provider).
- Let me or my supporters fill out paperwork at home.
- Give me pictures, or let me or my supporter take pictures, of the office and/or staff.
- Give me detailed information about how to communicate with your office staff between visits (for example, how to make appointments, contact my regular provider, or contact the clinic in an emergency).
- I **don't need** accommodations ahead of time.
- I need accommodations ahead of time, but they are **not listed** here.



Lessons Learned

- Collaboration must include all stages of the research process, from topic selection to data collection & analysis to conclusions and publication;
- Power imbalances exist between researcher and self-advocate partners that must be addressed to allow for equality;
- Important to accommodate different communication needs, even if it increases time necessary to implement research.

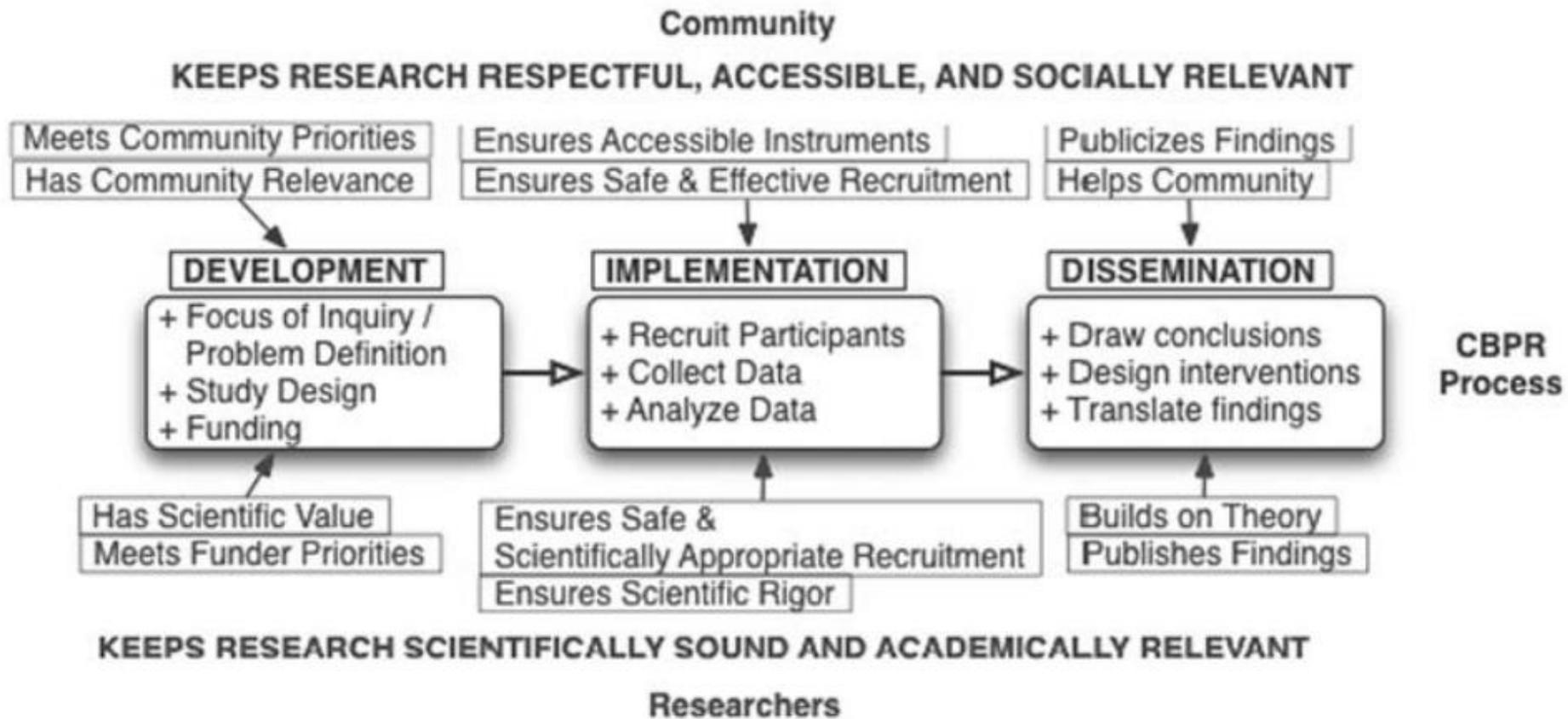


Image Source: (Nicolaidis, Raymaker, et al., 2011)

Including Autistic People as Full Partners

- Consider ways to equalize the power dynamic between researcher/clinician perspectives and non-researcher/clinician Autistic perspectives;
- Recognize that Autistic people may also be researchers/clinicians and seek to recruit us to “both sides of the table”
- Don't make anyone the “token” Autistic – invite and include many Autistic voices from diverse backgrounds and experiences.

One Finger -- Yay, I approve! Do it!

Two Fingers -- Meh, I'm not thrilled, but I'll approve.

Three Fingers -- I am not sure, I need more information or discussion.

Four Fingers -- I don't like it, I won't approve it, but I can live with it.

Five Fingers -- I hate this so much that I can't live with having my name associated with it.

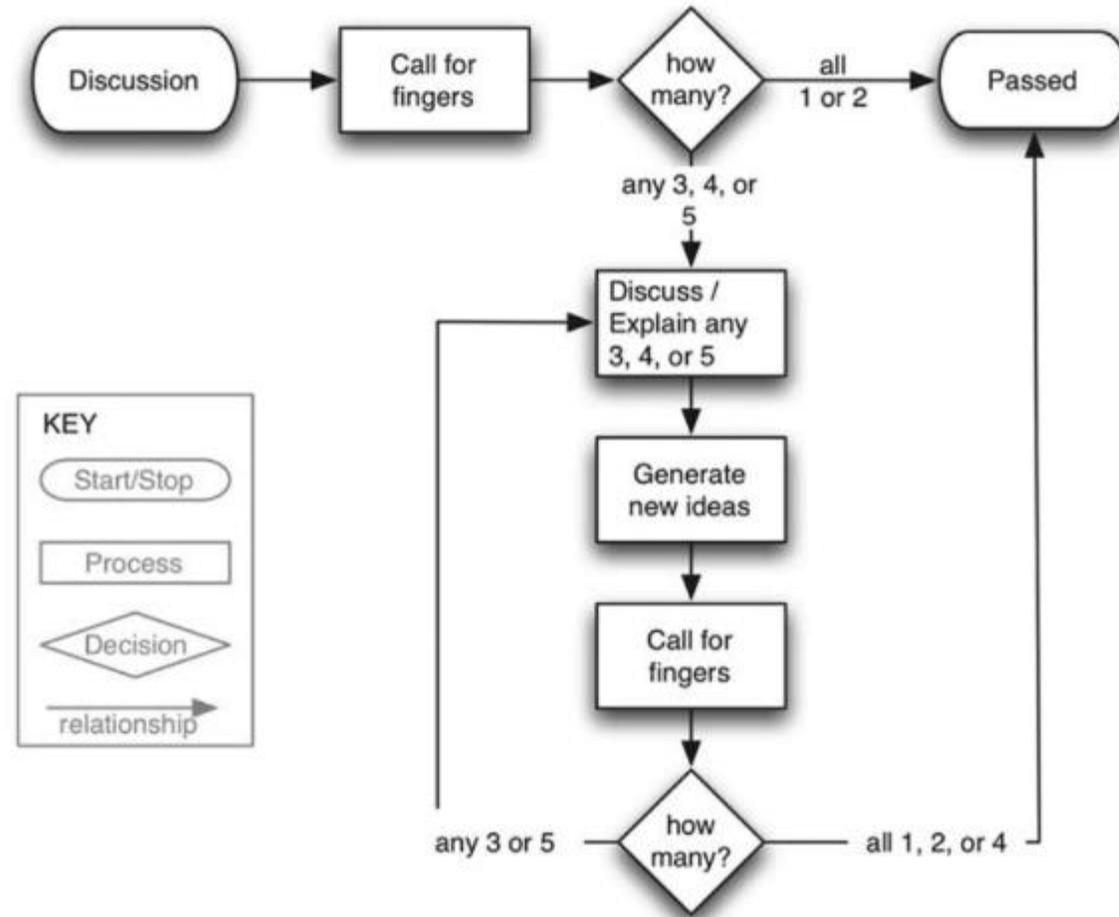


Figure 3. The Five-Finger Discussion/Decision Method

Key Takeaways re: Including Self-Advocates as Trainees and Faculty in LEND & other CARES Programs

- Adds value for both disabled and non-disabled participants
- Avoid tokenism – trainees come to learn, not just to “educate peers”
- Provide a meaningful career pathway
- Don't fall prey to “very special” thinking

Key Takeaways from this Webinar

- Neurodiversity and the social model of autism offer professionals a chance to treat Autistic people as real partners;
- Autism research and services rests on assumptions we need to challenge and change;
- The key to change is involving Autistic people as real partners in research, service-provision, education and training.

Questions?