

Autism Policy & Advocacy



Ari Ne'eman
President

The Autistic Self Advocacy Network
2013 H St. 7th Floor • Washington, DC 20035
Voice: (202) 596-1056
www.autisticadvocacy.org

About the Autistic Self Advocacy Network



- Autistic people, cross-disability advocates, non-autistic family members, professionals, educators, and friends
- Advancing principles of disability rights movement for Autistic people
- Systems change and policy advocacy and leadership programming

Terminology Issue: Person-First vs. Identity-First Language

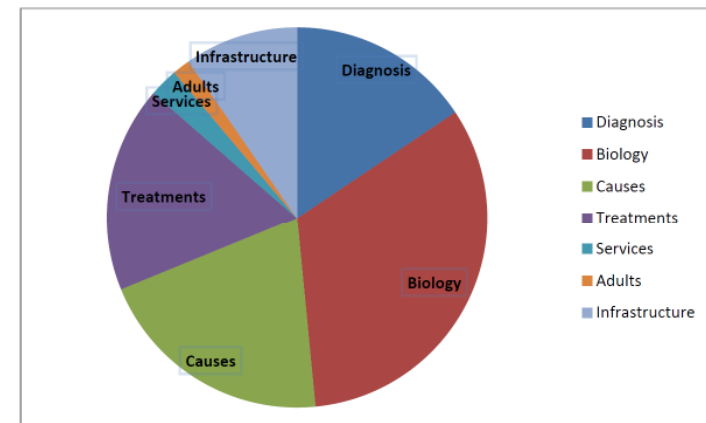
Recent Federal Policy Developments

- ✦ Passage of the Autism CARES Act of 2014
- ✦ July 2014 CMS EPSDT & Autism Guidance
- ✦ January 2014 CMS Home and Community Based Settings Regulation

Combating Autism Act of 2006

- ✦ Rhetorical emphasis on 'eliminating' autism through causation research and prevention
- ✦ Provided statutory authorization to a variety of existing autism and developmental disability programs (i.e: LEND, CDC Health Surveillance)
- ✦ Increased autism research funding

2010 NIH Autism Research Funding By Category Area



Source: IACC/OARC ASD Research Portfolio Analysis Web Tool, Office of Autism Research Coordination, National Institute for Mental Health

Autism CARES Act

- ✦ Changed rhetorical focus
- ✦ Slight increase in representation for self-advocates on the IACC
- ✦ Recognition of the need for greater emphasis on adult services

Schakowsky Letter

- ✦ Signed by Reps. Schakowsky, Speier, Castor, Duckworth & Tonko and sent to HHS in October 2014
- ✦ Called for greater self-advocate representation, shift in autism research funding patterns

Excerpt from Schakowsky Letter

- ✦ “Individuals with autism are not adequately represented in federally-run programs, such as the Leadership and Education in Neurodevelopmental Disabilities (LEND) programs, which train students interested in careers in disability services and supports.”
- ✦ “Very little autism funding is currently devoted to the daily needs of individuals with autism and their families. For example, according to the IACC’s Portfolio Analysis Web Tool, in 2010 only 2.4% of NIH’s autism research budget went towards research on improving the quality of services and only 1.5% went towards research on the needs of autistic adults.”

Autism is not going away - nor are Autistic people

July 2014 CMS EPSDT Guidance

- ✦ Requires states to shift “autism services” out of 1915(c) and into EPSDT benefit
- ✦ Explicitly states that this is not limited to – and may not even necessarily mean – Applied Behavioral Analysis
- ✦ Requiring states to “reboot” their behavioral health services to autistic children and youth

What do we mean when we say “autism services”?

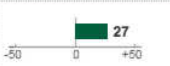
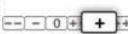
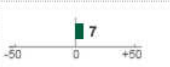
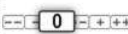
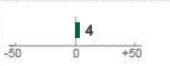
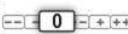
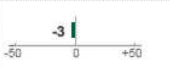
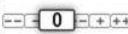
Behavioral vs. Developmental Approaches

Behavioral Interventions

- ✦ Strong emphasis on Applied Behavioral Analysis in much state advocacy
- ✦ Delivered by a BCBA or a para working under their direction
- ✦ Emphasis is on “indistinguishability from peers”, to quote Lovaas
- ✦ Many self-advocates & families are concerned that many ABA providers utilize aversives

Institute for Education Sciences: What Works Clearinghouse

Intervention Effectiveness Rating

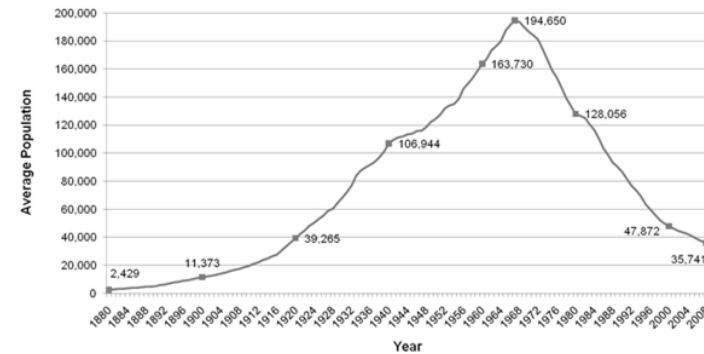
| Student Outcome | Improvement Index (percentile gain for average student) | Effectiveness Rating | Extent Of Evidence |
|------------------------------|--|---|--------------------|
| Cognition |  27 |  | Small |
| Social-emotional development |  7 |  | Small |
| Functional abilities |  4 |  | Small |
| Language competencies |  -3 |  | Small |

Developmental Approaches

- ✦ Typically delivered by an OT, SLP or sometimes Psychologist
- ✦ Often play based and/or parent-mediated interventions
- ✦ Broad range of options: DIR/Floortime, SCERTS, TEACCH, etc.

What is the goal of autism service-provision?

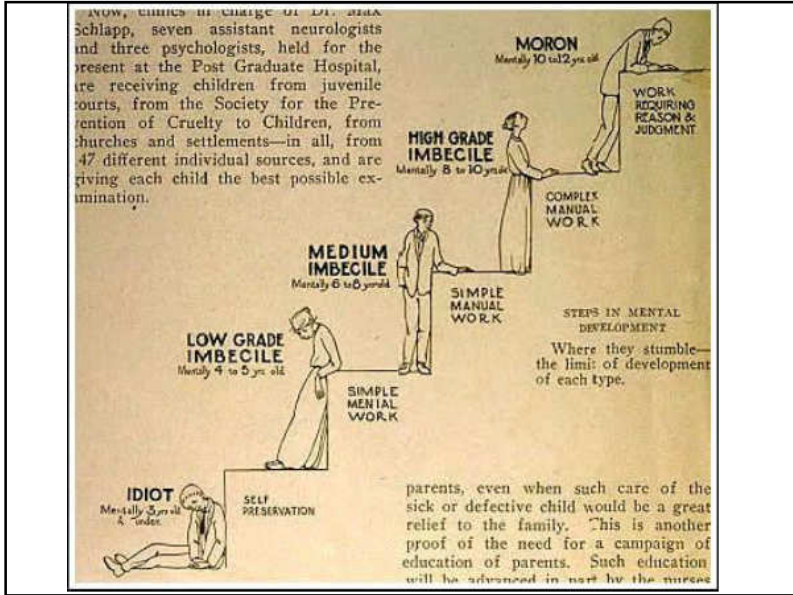
Institutional Census, 1880-present



Who Went Into Institutions in the Early 20th Century?

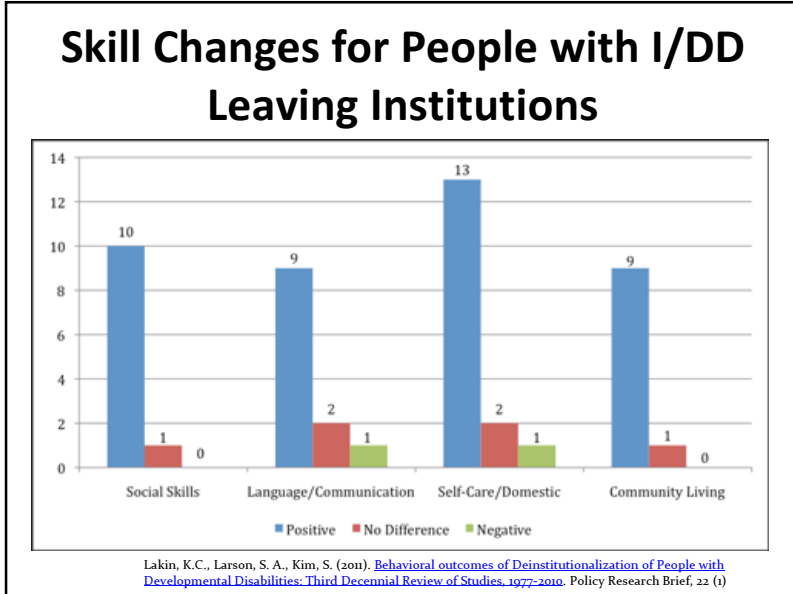
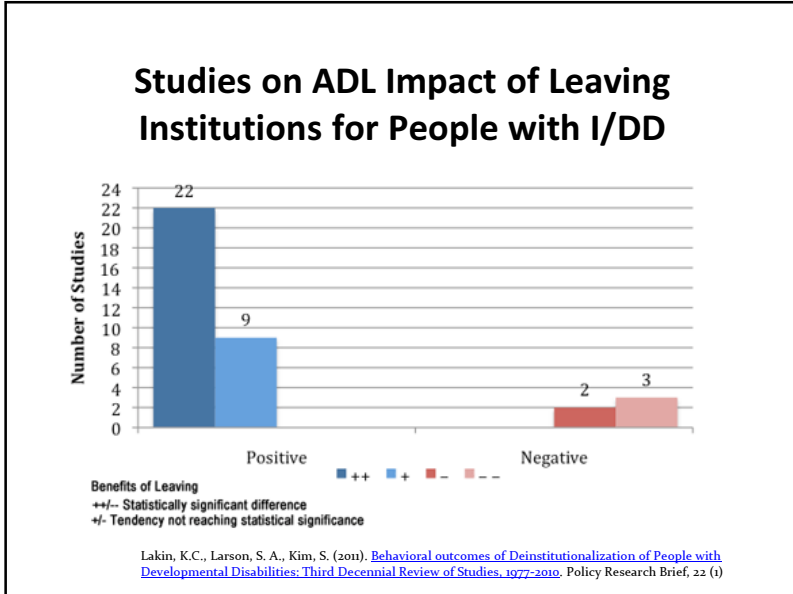
Early 20th Century Institutional Population

- Mostly not the severely disabled!
 - Orphaned or homeless children
 - Sexually promiscuous teens
 - Unwanted babies
 - Juvenile Delinquents
- Had schools, bands - some even had a football team playing the local high school
- “Feeble-mindedness” was a popular label
- “Morons”, “Imbeciles” and “Idiots” were technical terms
- “High Grade” and “Low Grade” Residents
- 3 in every 1,000 Americans was in an institution



Missouri Medical Association Presidential Address, May 1918

Feeble-mindedness is rapidly and dangerously on the increase, and nothing, or practically nothing, is being done by the state or municipality to control it. Provision should be made by the state to give institutional care, throughout life, to every feeble-minded person, in order that the propagation of their kind may be prevented. Such a policy would reduce our criminal class about 75 per cent.; reduce the number of prostitutes to an even greater extent, and to a considerable degree relieve society of the annoyance and unsocial acts of the hoboos, the I. W. W.'s and others of their kind.



HCBS Settings Regulation

HCBS Settings Requirements:

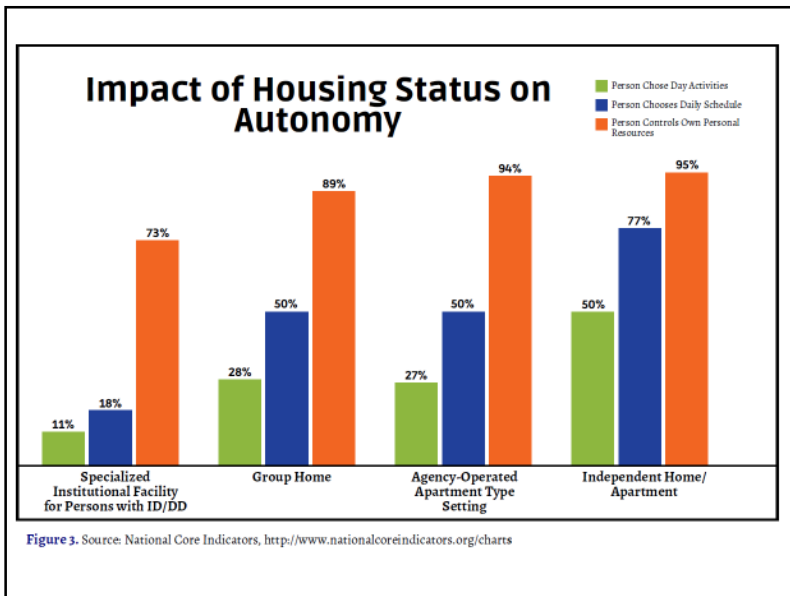
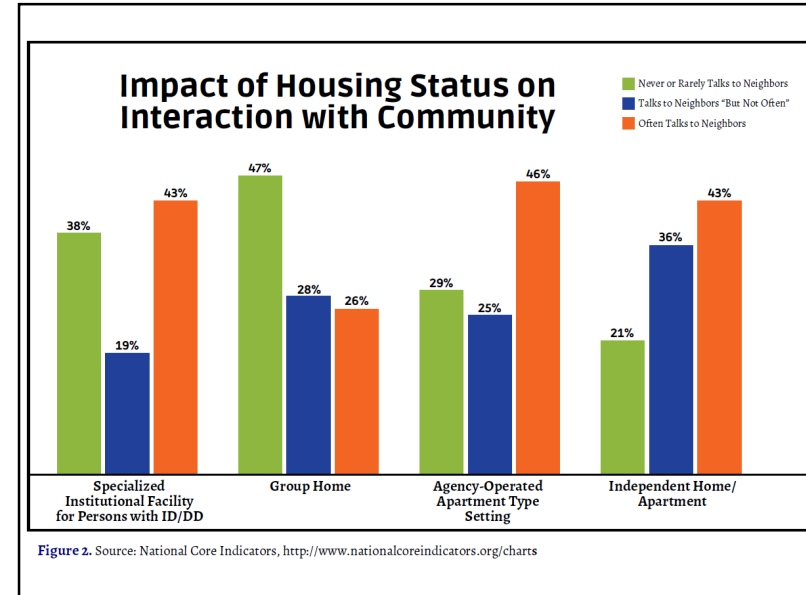
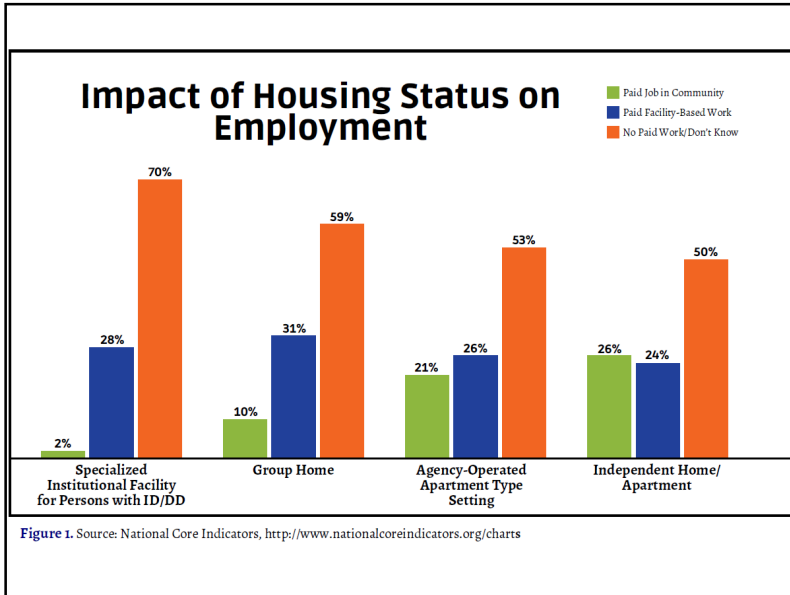
- *The setting is integrated in and supports full access to the greater community;*
- *Is selected by the individual from among setting options;*
- *Ensures individual rights of privacy, dignity and respect, and freedom from coercion and restraint;*
- *Optimizes autonomy and independence in making life choices; and*
- *Facilitates choice regarding services and who provides them.*

Provider Owned Settings Requirements

- *The individual has a lease or other legally enforceable agreement providing similar protections;*
- *The individual has privacy in their unit including lockable doors, choice of roommates and*
- *freedom to furnish or decorate the unit;*
- *The individual controls his/her own schedule including access to food at any time;*
- *The individual can have visitors at any time; and*
- *The setting is physically accessible.*

Settings Presumed to Have Institutional Qualities

- *those in a publicly or privately-owned facility that provides inpatient treatment;*
- *on the grounds of, or immediately adjacent to, a public institution*
- *that have the effect of isolating individuals receiving Medicaid-funded HCBS from the broader community of individuals not receiving Medicaid-funded HCBS*
 - *Gated communities*
 - *Farmsteads*
 - *Settings that “co-locate” multiple services*



What do we mean when we talk about “the community”?



Questions?