

# HHS Report to Congress: Young Adults and Transitioning Youth with Autism Spectrum Disorder



Susan Daniels, Ph.D.  
Director, Office of Autism Research Coordination  
Executive Secretary, IACC  
National Institute of Mental Health

# Autism CARES Act Supports Federal Autism Activities



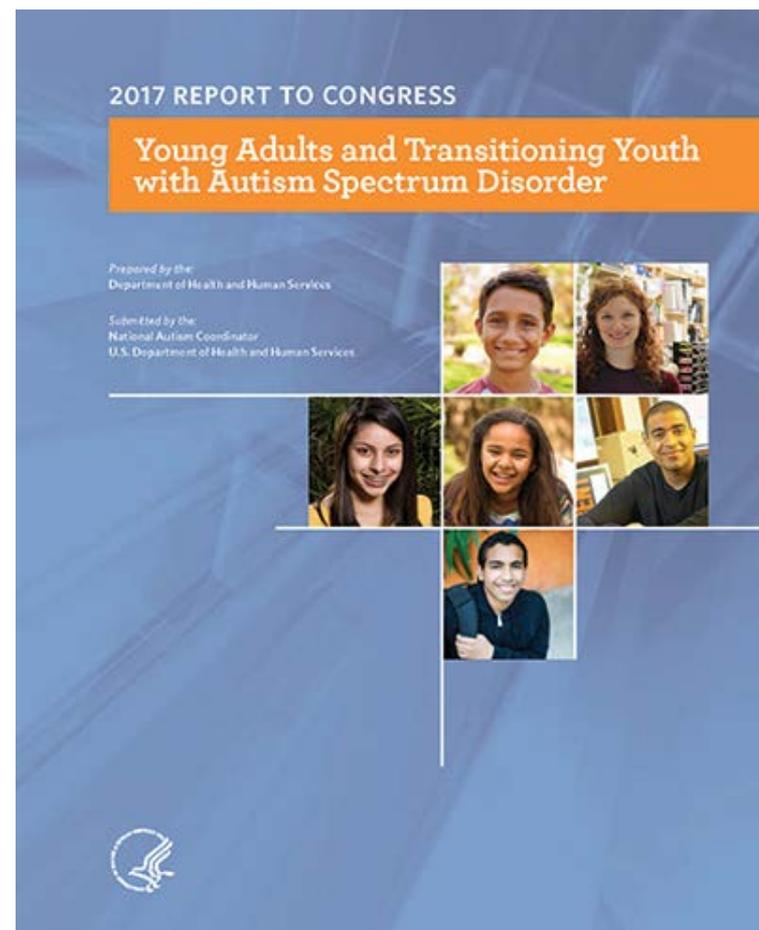
- Autism CARES Act signed into law on August 8, 2014
  - CARES = Collaboration, Accountability, Research, Education, and Support
  - Reauthorization of federal laws previously known as Combating Autism Act of 2006 and CARA of 2011
- Reauthorization of Interagency Autism Coordinating Committee (IACC)
- Requirement for a Report to Congress on Young Adults and Youth Transitioning to Adulthood on the autism spectrum
- Requirement for a report to Congress on all federal activities related to ASD
- Reauthorized support for autism-focused efforts from FY15-19

# Report to Congress Mandated by Autism CARES Act of 2014 (P.L. 113-157)



## Purpose

- Summarize existing Federal investments in transition research and services activities
- Identify gaps in Federal research, programs, and services that support youth with ASD during the transition to adulthood



# Process for Developing the Report



- The office of the HHS National Autism Coordinator convened a federal working group to develop the report
- The Steering Group for the report:
  - **Thomas E. Novotny**, M.D., M.P.H., HHS National Autism Coordinator
  - **Susan Daniels**, PhD, Director, Office of Autism Research Coordination National Institutes of Health
  - **Alicia Richmond Scott**, M.S.W., Office of the Assistant Secretary for Health
  - **Robin Harwood**, Ph.D. Health Scientist, Office of the Assistant Secretary for Health Office of the Secretary and Health Resources and Services Administration
  - **Julianna Rava**, M.P.H. Science Policy Analyst, Office of Autism Research Coordination National Institutes of Health U.S. Department of Health and Human Services
- Stakeholder Expert Panel and IACC Stakeholder Input
  - To provide input on gaps and opportunities

# Interdepartmental Transition Workgroup



- U.S. Dept. of Health and Human Services: 15 agencies and HHS offices represented on the workgroup –
- NIH, HRSA, CDC, CMS, FDA, AHRQ, ACL, ACF, IHS, SAMHSA, HHS offices: OASP, ASPE, ASL, OGA, OASA
- U.S. Dept. of Labor
- U.S. Dept. of Education
- U.S. Dept. of Transportation
- U.S. Dept. of Housing and Urban Development
- U.S. Dept. of Justice
- U.S. Dept. of Defense
- U.S. Social Security Administration
- 34 members

# Stakeholder Expert Panel



- **Kristy Anderson**, M.S.W., A.J. Drexel Autism Institute Drexel University
- **Scott Badesch** President, Autism Society
- **Julia Bascom**, Autistic Self Advocacy Network
- **Shelby Crants**, Autism Speaks
- **Marc Ellison**, Ed.D., Marshall University
- **Angela Lello**, Autism Speaks
- **David Mandell**, Sc.D. University of Pennsylvania
- **Margaret (Peggy) McManus**, MHS Got Transition
- **Anne Roux**, M.P.H., M.A., A.J. Drexel Autism Institute Drexel University
- **Paul Shattuck**, Ph.D., A.J. Drexel Autism Institute Drexel University
- **Stuart Spielman**, Esq., Autism Speaks
- **Julie Lounds Taylor**, Ph.D. Vanderbilt University
- **Patience White**, M.D., M.A., Got Transition

# Structure of the Report



- Part 1: Background Information on ASD and the Transition to Adulthood
- Part 2: Overview of Relevant Federal Programs
- Part 3: Input from Key Stakeholders
- Part 4: Conclusions and Recommendations

# Background - Overview



- Transition period challenges:
  - Complexities caused by the heterogeneity of ASD and any co-occurring health and mental health conditions – represents a wide variety of needs
  - Magnified by complexities in transitioning from a set of supports coordinated around and through the educational system to a set of health and social service systems geared to adults that may be provided by many different agencies and services that are not necessarily coordinated



- **Population Characteristics**

- Estimated 50,000 youth with ASD turn 18 each year
  - Currently, about 450,000 youth with ASD aged 16-24 years old in U.S.

- **Health and Wellbeing: Secondary School**

- When compared to all youth with IEPs, youth with ASD who have IEPs are:
  - More likely to have a co-occurring chronic health or mental health condition
  - Less likely to be able to manage independently and develop friendships
  - Less likely to take steps to prepare for college and employment



- **Health and Wellbeing: Young Adults (20-25 years old)**
  - Young adults with ASD who had IEPs in high school:
    - Less than 1 in 5 had ever lived independently following high school
    - Nearly two-thirds received Supplemental Security Income (SSI) benefits
    - Only 58% had ever worked during their early 20s
    - Only 36% of youth with ASD had ever participated in postsecondary education or training of any kind between high school and their early 20s



- **Health and Wellbeing: Adulthood**

- Adults with ASD, compared to the general population:
  - Die an average of 16 years earlier than people not on the spectrum
  - Are 40 times more likely to die prematurely of a neurological condition (such as epilepsy) if they also have a learning disability
  - Are 9 times more likely to die from suicide
  - Are at heightened risk for co-occurring conditions such as depression and anxiety
  - Are at higher risk for other non-communicable diseases including diabetes and heart disease

# Stakeholder Input from IACC



## Topics that emerged through IACC Public Comment:

- Services and Supports Based on Individual Needs
- Postsecondary education and training;
- Employment opportunities
- Treatment for concurrent conditions, and access to occupational, speech, and language therapies
- Housing
- Transportation supports
- Community integration services and supports
- Coordinated, 'wraparound' services
- Relief from barriers to access, coordinate, and finance what are experienced as 'piecemeal' services on their own, or services they may not even be aware of
- Transition supports and information beginning in early adolescence

# Stakeholder Input from Expert Panel



## Gaps in Research

- Descriptive data
- Existing programs available to study
- Outcomes research
- Research on access and barriers to service

## Gaps in Services and Programming

- Individualized planning
- Coordinated, comprehensive care responsive to individual needs
- Transition planning
- High-quality services and programming that challenge
- Better coordination of services
- Strengthened workforce
- Increased access

# Background Information

## *Challenges and Barriers to Service*



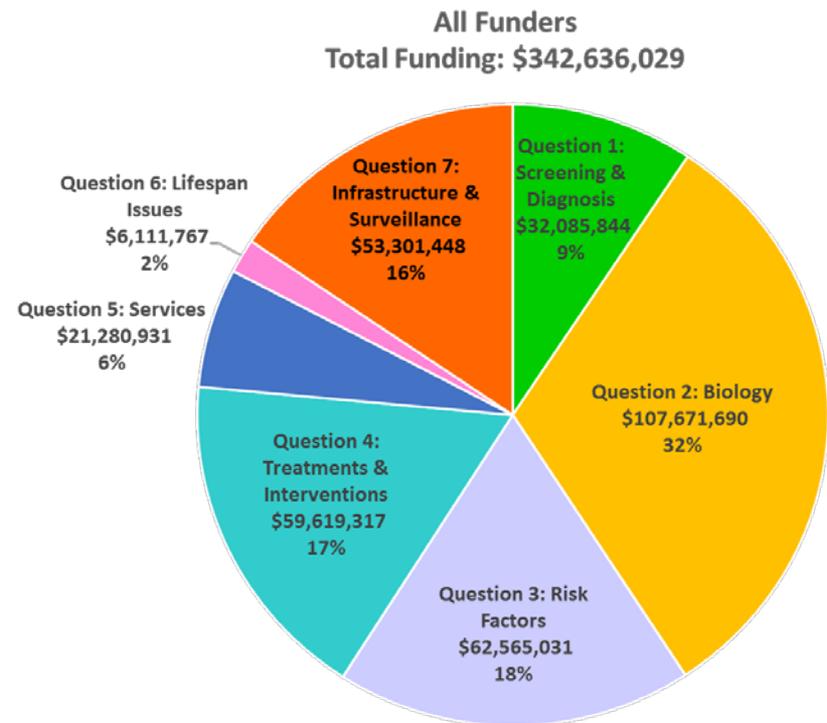
- Coordination of complex service and support needs across multiple systems
- Access to needed resources, which may be limited in availability
- Access to services and supports to facilitate managing a complex condition and co-occurring health conditions
- Achievement and management of independent living
- Development of meaningful relationships and broader social networks as the individual desires
- Lack of availability of and consistency in ASD-specific training
- Communication challenges faced by adults with ASD in accessing and interacting with health service providers
- Need to build greater community understanding and acceptance of neurodiversity that ASD represents

# Overview of Relevant Federal Programs



## Research

- NIH, HRSA, ED, and DOD funded 18 projects devoted to transitioning youth with ASD funded between FY13 and FY16
- IACC Portfolio Analysis: Lifespan issues (including transition) received 2 percent (\$6.1 million) of overall combined federal and private ASD funding in 2015



# Overview of Relevant Federal Programs



## Programs that Provide Services and Supports

- Mainstream Programs available to all U.S. citizens meeting eligibility requirements
  - Do not usually track ASD
- Cross-Disability Services and Supports
  - Most do not track utilized services and goals according to specific diagnoses such as ASD
  - Eligibility requirements vary
- Autism CARES Act Programs
  - Population surveillance and risk factor research at CDC
  - Capacity building through training and intervention research at HRSA

# Overview of Relevant Federal Programs

## *Summary*



- ASD-related research and programming conducted under and administered through multiple agencies
- Most provide broadly targeted programs that individuals with ASD may be eligible for if they meet program criteria
  - In most cases, these programs do not track specific diagnoses such as ASD due to cost and overall program goals to serve based on need rather than diagnosis
  - This presents a challenge in collecting data

# Report Conclusions



## A Need For:

- Coordinated, comprehensive approach to services and supports
- Support coordination across service systems
- Family and Caregiver Support
- Data and Research on Transition-age youth and Young Adults with ASD



## **Epidemiological Data Collection and Monitoring**

- Assess and monitor experiences, needs, and life goals of transitioning youth with ASD
- National survey assessing full range of service and support needs, barriers, and facilitators
- More complete surveillance system to provide data on full spectrum of transition-age youth and young adults with ASD
- Longitudinal data to follow up on transition outcomes for individuals with ASD

# Recommendations



## Research needs:

- Targeted outcome research to assess efficacy of transition-oriented programs
- Program model development and testing
- Meaningful outcome measures
- Implementation and service delivery research
- Encouragement of more research specifically on transitioning youth and young adults with ASD and their caregivers



## Program Services and Delivery

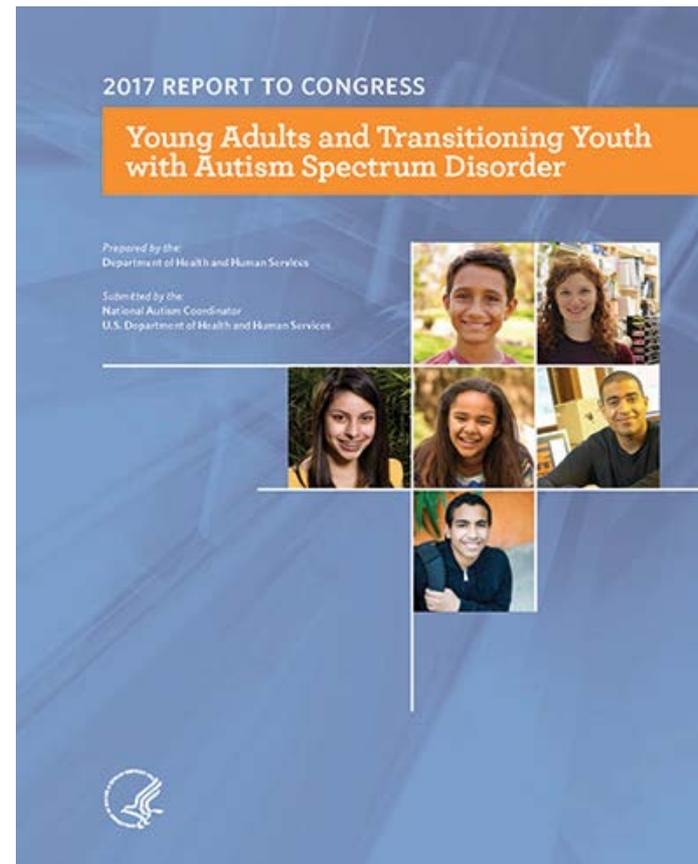
- Coordination is necessary across federal agencies, and across service systems at state and community levels
- Programs must be designed for broad access, but with individual flexibility
- Trained personnel are vital to help families navigate multiple, complex service systems
- Better preparation of all relevant adult service and support providers is essential
- Increased coordination is needed between youth and adult services and supports
- Federal policies that encourage blending and braiding of funds across agencies are critical
- Concerted communications efforts are crucial to dispel stigma and encourage acceptance

# Follow Up



- The HHS Office of the National Autism Coordinator was leading efforts to follow up on this report
- Seeking opportunities to collaborate with the Federal Partners for Transition (FPT) working group
- FPT is a workgroup with representatives of several **federal** agencies, including the Departments of Education, Health and Human Services, and Labor, and the Social Security Administration, was formed in 2005 to support all youth, including youth with disabilities, in successfully.
- 2020 Federal Youth Transition Plan: A Federal Interagency Strategy
- Future opportunities to collaborate with IACC?

# Report Available Online



<https://iacc.hhs.gov/publications/report-to-congress/2017/>