Transition from Adolescence to Adulthood: A Public Health Perspective on Autism Spectrum Disorder

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Center for Health and Health Care in Schools
George Washington’s Milken Institute School of Public Health
Overview

- What do we know?: ASD and Transition from High School to Adulthood

- CDC’s ASD Data: Recent Findings, Implications, and Future Opportunities
ASD and Transition from High School to Adulthood
ASD and Transition to Adulthood: Multi-faceted, Complex Landscape
ASD and Transition to Adulthood: What Does Success Look Like?

“All people with ASD will have the opportunity to lead self-determined lives in the community of their choice through school, work, community participation, meaningful relationships, and access to necessary and individualized services and supports.”

--Interagency Autism Coordinating Committee’s Question 6 Aspirational Goal
ASD Transition Issues: Focus Areas: What do we know?

- Employment and vocational outcomes
- Post-secondary education
- Community living
- Social participation and quality of life
- Health care: medical/mental health
ASD Transition Issues: Employment & Vocational Outcomes

• Approximately ½ of young adults with ASD were ever employed since high school, significantly lower than other disability groups (Roux, 2013)
  • Fewer hours worked and earned lower wages

• Use of vocational rehab services has increased among young adults with ASD, but not met by gains in percent employed, number of hours worked or wages (Burgess & Cimera, 2014).

• Little evidence is available for which interventions are effective in supporting vocational skills among youth with ASD (Lounds Taylor et al., 2012)
Approximately 35% of youth with ASD had attended college (Shattuck et al., 2012)

- Lower than those in SLI or LD eligibilities, but higher than those with MR/ID.

- Highest risk for struggling first two years after high school

- Although college enrollment lower than general population, disproportionate STEM participation (Wei et al., 2012)
ASD Transition Issues: Community living

- Young adults with ASD more likely to live with a parent and less likely to ever have lived independently (Anderson et al., 2013)

- IQ was an important determinant of living arrangements among young adults with ASD (Gray et al, 2014)
  - More severe ID more likely living in care
  - Average IQ more likely to live independently
ASD Transition Issues: Social Participation and Quality of Life

- Young adults with ASD were more likely to than those with other disabilities to \cite{Ormond2013}:
  - Never see friends,
  - Never get called by friends,
  - Never be invited to activities,
  - To be socially isolated

- Quality of life is lower for people with ASD compared to people without ASD \cite{vanHeijstGeurts2012}
ASD Transition Issues: Healthcare and Support Services

- Approximately 36% of children had unmet need for specialty services (Check-Zamora, 2014)

- Promise of medical home model
  - Only 19-24% of children with ASD had medical home. (Check-Zamora, 2014, Farmer, 2014)

- Less than 25% of youth with ASD received healthcare transition services (Cheak-Zamora et al., 2012)

- Inadequate training for physicians in care of adults with ASD (Bruder, 2014).
ASD and Transition to Adulthood: Interagency Autism Coordinating Committee

• IACC Strategic Plan’s Question 6: Transitioning Youth and Adults

  • Total recommended budget for research on transition issues and adult diagnosis/interventions ~54 million

• Notable advances in research in this area over past 5 years

• However, rate of production of scientific knowledge about the experience of ASD in adulthood remains very low

Cumulative federal & private funding related to transition issues & adult diagnosis/interventions

<table>
<thead>
<tr>
<th>Year</th>
<th>Total Funding</th>
<th>Projects</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008</td>
<td>$9,796,491</td>
<td>9 projects</td>
</tr>
<tr>
<td>2009</td>
<td>$1,407,699</td>
<td>7 projects</td>
</tr>
<tr>
<td>2010</td>
<td>$6,643,124</td>
<td>34 projects</td>
</tr>
<tr>
<td>2011</td>
<td>$4,897,920</td>
<td>35 projects</td>
</tr>
<tr>
<td>2012</td>
<td>$3,859,177</td>
<td>34 projects</td>
</tr>
<tr>
<td>TOTAL</td>
<td>$19,746,603</td>
<td></td>
</tr>
</tbody>
</table>

Source: http://iacc.hhs.gov/strategic-plan/2013/future.shtml#q6
ASD and Transition to Adulthood: National Institute of Mental Health

- Recently funded 12 research grants to study models for ASD service delivery
  - 7.9 million in initial year funding
- 4 of the 12 projects focused on transition age (high school to adulthood)

“This research is aimed at testing care strategies, adaptable across communities, in which identification of need and engagement in optimal interventions and services will be standard for all ages”
- Thomas Insel, Director of NIMH (9/14)
ASD and Transition to Adulthood
CDC’s Surveillance of ASD: How Can We Help Reach This Goal?

“All people with ASD will have the opportunity to lead self-determined lives in the community of their choice through school, work, community participation, meaningful relationships, and access to necessary and individualized services and supports.”

--Interagency Autism Coordinating Committee’s Question 6 Aspirational Goal
Monitoring the Prevalence and Characteristics of ASD: Ongoing Efforts at CDC
What role does public health surveillance play in understanding ASD transition issues?

- Public health surveillance: the ongoing, systematic collection, analysis, and interpretation of data

- Public health model:
What role does public health surveillance play in understanding ASD transition issues?

- Public health surveillance: the ongoing, systematic collection, analysis, and interpretation of data

- Public health model:
Autism and Developmental Disabilities Monitoring (ADDM) Network

Current ADDM Network Sites, Surveillance Years 2010 and 2012

Only collaborative network to monitor ASD and other developmental disabilities in multiple communities across the United States
CDC’s Method for Conducting ASD Surveillance

Multisite, multisource, records-based
## ADDM Network Autism Prevalence Results

Combining Data from All Sites

<table>
<thead>
<tr>
<th>Surveillance Year</th>
<th>Birth Year</th>
<th>Number of ADDM Sites Reporting</th>
<th>Estimated Prevalence (per 1,000 Children)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>1992</td>
<td>6</td>
<td>6.7</td>
</tr>
<tr>
<td>2002</td>
<td>1994</td>
<td>14</td>
<td>6.6</td>
</tr>
<tr>
<td>2004</td>
<td>1996</td>
<td>8</td>
<td>8.0</td>
</tr>
<tr>
<td>2006</td>
<td>1998</td>
<td>11</td>
<td>9.0</td>
</tr>
<tr>
<td>2008</td>
<td>2000</td>
<td>14</td>
<td>11.3</td>
</tr>
<tr>
<td><strong>2010</strong></td>
<td><strong>2002</strong></td>
<td><strong>11</strong></td>
<td><strong>14.7</strong></td>
</tr>
</tbody>
</table>

About 1 in 68 children (or 14.7 per 1,000 8 year olds) were identified with ASD in 2010.

MMWR Surveillance Summaries: February 9, 2007 / 56(SS-1); December 18, 2009 / 58(SS-10); March 30, 2012 / 61(3); March 28, 2014 / 63(SS-02).
Variation in ASD prevalence among 8 year olds
ADDM Network, 2010

Sites relying primarily on data from health-care sources
Sites with increased access to children's education records

Prevalence for All Sites Combined

MMWR Surveillance Summaries March 28, 2014 / 63(SS02);1-21
Variation in ASD prevalence among 8 year olds
ADDM Network, 2010

Prevalence Per 1,000

Sites relying primarily on data from health-care sources
Sites with increased access to children's education records

Prevalence for All Sites Combined

Alabama, Wisconsin, Colorado, Missouri, Georgia, Arkansas, Arizona, N. Carolina, Utah, New Jersey
ASD prevalence among 8 year olds by sex
ADDM Network, 2010
ASD prevalence among 8 year olds by race/ethnicity
ADDM Network, 2010

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Prevalence Per 1,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>1 in 68</td>
</tr>
<tr>
<td>White</td>
<td>1 in 63</td>
</tr>
<tr>
<td>Black</td>
<td>1 in 81</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1 in 93</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>1 in 81</td>
</tr>
</tbody>
</table>
ASD prevalence by most recent IQ score, sex & race/ethnicity
ADDM Network, seven sites*, 2010

Prevalence Per 1,000

- IQ unknown
- IQ>70
- IQ<=70

Male:
- IQ unknown: 3.6
- IQ>70: 16.8
- IQ<=70: 7.3

Female:
- IQ unknown: 0.8
- IQ>70: 3.4
- IQ<=70: 1.9

White:
- IQ unknown: 2.3
- IQ>70: 12.4
- IQ<=70: 4.1

Black:
- IQ unknown: 1.8
- IQ>70: 6.7
- IQ<=70: 6.1

Hispanic:
- IQ unknown: 1.8
- IQ>70: 5.2
- IQ<=70: 4.2
Most children identified with ASD were not diagnosed until after age 4, even though children can be diagnosed as early as age 2.

**Limitations:**

1) Diagnostic information obtained from evaluation records may not capture the exact age of each child’s earliest diagnosis
2) Instability of diagnostic subtypes over time

<table>
<thead>
<tr>
<th>Diagnostic Subtype</th>
<th>Autistic Disorder</th>
<th>ASD/PDD</th>
<th>Asperger Disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median Age</td>
<td>4 years</td>
<td>4 years, 2 months</td>
<td>6 years, 2 months</td>
</tr>
</tbody>
</table>

*Age at earliest documented diagnosis*  
ADDM Network, 2010
Receipt of Special Education Services for Autism
ADDM Network, 2010

Percentage of ASD case children

ADDM Site
- % of ASD cases with special education records
- % of ASD cases with a primary special education eligibility of autism
Receipt of Special Education Services for Autism
ADDM Network, 2010

Percentage of ASD case children

% of ASD cases with special education records
% of ASD cases with a primary special education eligibility of autism

ADDM Site

Arizona, Arkansas, Colorado, Georgia, Maryland, New Jersey, North Carolina, Utah
Change in Autism Prevalence Among ADDM Sites

ASD Prevalence per 1,000 8-year-old Children

Source

Alabama | Arizona | Arkansas | Colorado | Georgia | Maryland | Missouri | New Jersey | N. Carolina | Utah | Wisconsin


2000

2002

2004

2006

2008

2010
Change in Autism Prevalence Among ADDM Sites

ASD Prevalence per 1,000 8-year-old Children

Source

Maryland

Challenges: Understanding Autism Prevalence

- Wide variation in prevalence estimates across time and space
  - Increased awareness in communities
  - Increased symptoms in population vs. documentation of symptoms
  - Geographic differences in diagnostic practices, program eligibility
  - Changes in policy affecting availability of services
  - No single explanation - multiple factors at play

- Changing criteria used to diagnose autism (DSM-IV, DSM-5)

- Limited data on severity of autism symptoms

- Questions about prevalence among older children and adults
Implications of CDC’s Surveillance Data
Implications of CDC’s ASD Data

- Use prevalence data to plan for varied resource needs
- More children are being recognized with ASD, particularly those with average to above average intellectual ability
- Continued disparities in prevalence across sites and minority race/ethnicities
- Some children are still not recognized as early as they could be
Implications of CDC’s ASD Data

“CDC data highlight the need for similar data on autistic adults to understand more about autism across the lifespan.”

-Ari Ne’eman
President, Autistic Self Advocacy Network

“[CDC] data provide critical insight into how we can best meet the real needs of real people.”

-Alison Singer
Co-Founder and President, Autism Science Foundation

“CDC’s data give Easter Seals and the individuals and families that we serve the information that is essential to our efforts to close service gaps so that children and adults with ASD can live, work, and play in their communities.”

-Mary Andrus
Assistant Vice President, Easter Seals
Implications of CDC’s ASD Data for Young Adults

• Children with ASD become adolescents and adults with ASD....

• If there are 4 million children born each year:
  – In 2020, there will be an estimated **294,000** youth with ASD (18-22 years old) in transition
Future Opportunities:

Building Upon CDC’s ASD Surveillance Data
Longitudinal Follow-Up of ADDM cohorts

<table>
<thead>
<tr>
<th>Surveillance Years</th>
<th>Birth Year(s)</th>
<th># Cases</th>
<th>Ages at follow-up by calendar year</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>2015</td>
<td>2016</td>
</tr>
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</table>

- Significant potential for longitudinal follow-up using ADDM’s population of over 16,200 adolescents and young adults identified with ASD ages 13-26
Metropolitan Atlanta Developmental Disabilities Follow-Up Study of Young Adults

- Examined transition issues among young adults identified at age 10 with a developmental disability.
Metropolitan Atlanta Developmental Disabilities Follow-Up Study of Young Adults

- **Sample:**
  - n = 635
  - Population-based cohort of young adults, aged 21-25 (1997-2000) identified at age 10 with childhood impairment:
    - Intellectual disability, cerebral palsy, hearing loss, vision impairment, epilepsy
    - Contemporaneous group of children not in special education
    - 5 counties of metropolitan Atlanta

- **Methods**
  - Structured questionnaire
Acquisition of Adult Social Roles by Type and Severity of Developmental Disability, MADDS Follow-Up Study

Van Naarden Braun K et al, *Disability and Rehabilitation*, 2006
Autism CARES Act

- On August 8, 2014, President Obama signed the new Autism CARES Act
- Continuation of Combatting Autism Act (2006)
- Calls for $260 million annually through 2019 for autism surveillance, research, screening, training, and other initiatives.
- Mandates a new report on the needs of youth during transition period
- Specifies that CDC collect and report epidemiological data on both children and adults with ASD.
Conclusions

• Individuals with an ASD have unique patterns of strengths and difficulties, further study needed to understand the pairing of strengths with opportunities.

“This journey of a thousand miles begins with a single step”

-Lao Tzu
Thank You!

Want more information about CDC’s ASD data and its implications for ASD transition issues? Please contact me at kbn5@cdc.gov

For more information please contact Centers for Disease Control and Prevention
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Telephone, 1-800-CDC-INFO (232-4636)/TTY: 1-888-232-6348
E-mail: cdcinfo@cdc.gov Web: www.cdc.gov