



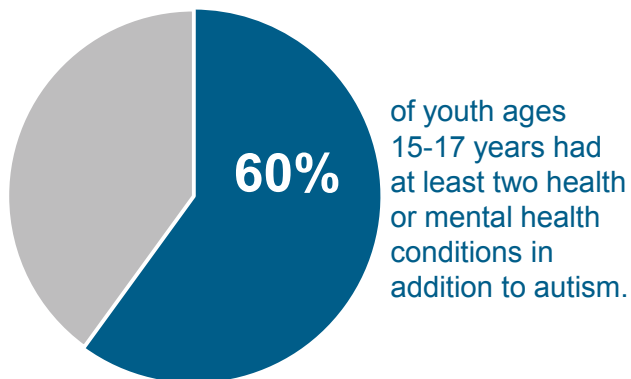
Key Findings from the National Autism Indicators Report: Transition into Young Adulthood

This fact sheet summarizes key findings from the National Autism Indicators Report which can be found here: drex.lu/autismindicators. The Autism Indicators report tracks statistics about issues facing individuals on the autism spectrum. These statistics set the stage to discover whether quality of life for those with autism and their families is improving over time.

The Life Course Outcomes Research Program is building a base of knowledge about the things other than clinical interventions that promote positive outcomes for people on the autism spectrum and their families and communities.



Youth with autism have complex health needs due to co-occurring conditions.



Health, Mental Health and Health Care Among Young Adults on the Autism Spectrum



It is rare to find youth on the autism spectrum who are only coping with the challenges of having an autism spectrum disorder. Dealing with more than one condition complicates health care needs and sometimes requires multiple medications, treatments, and service providers to address all of the youth's needs.

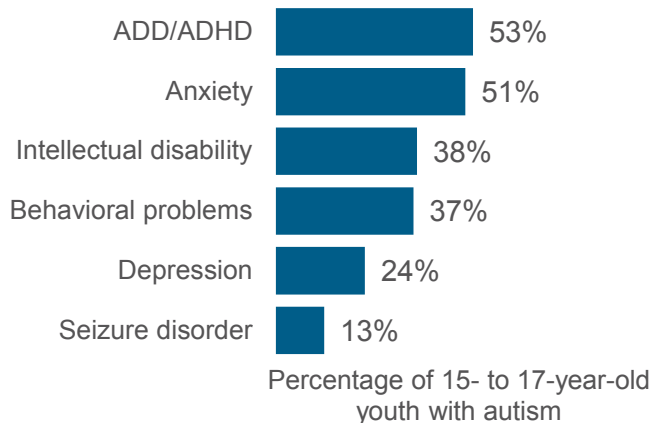
We have virtually no data on health, mental health and health care for young adults with autism. The richest source of nationally-representative data we currently have on these topics is surveys of the parents of teens.

In this report, we present the information we have about the health, mental health and health care of adolescents with autism. We used data from the 2011 Survey of Pathways to Diagnosis and Services, conducted in follow-up to the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN), for youth ages 15 to 17 years old.

Many had co-occurring conditions in adolescence.

The Pathways survey asked parents of youth on the autism spectrum whether the youth currently had other health, behavioral, and mental health conditions. Over half of parents reported that youth ages 15-17 years had Attention Deficit Disorder or Attention Deficit Hyperactivity Disorder (ADD/ADHD) and/or anxiety problems that co-occurred with the youth's autism diagnosis. Nearly 13% reported that the youth had a seizure disorder. It was possible for parents to report more than one co-occurring condition.

Over half of youth had ADD/ADHD and anxiety issues in addition to autism.



Good health care access, but gaps in treatment coverage.

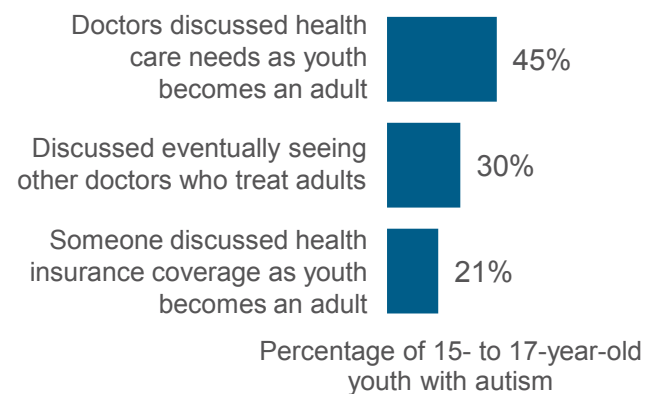
Nearly all (97%) parents reported in the Pathways survey that their adolescent had some type of health care coverage including health insurance, prepaid plans such as HMOs, or government plans such as Medicaid. Three-fourths (76%) said that the youth received all treatment and services needed to support development in the past year.

Less than half (45%) of families said their doctor discussed health care needs the youth might experience as an adult.

Little help to prepare for health care transition

It is not unusual to hear parents express problems with continuity of care during the transition to adult health care, and providers may have limited awareness of how to best prepare youth for health care transitions. Most youth (74%) received health care from providers who only treat children and adolescents, according to parents who took the Pathways survey (as indicated in their responses to the 2009-2010 NS-CSHCN survey). About 45% of parents reported that the youth's doctor talked with them about new health care needs the youth might experience as he entered adulthood, but few were told about changes in health care coverage at adulthood and ways to prevent gaps in coverage. One in three parents said their pediatrician discussed the need to eventually transition to an adult physician.

Few had early health care transition experiences.



Source: Survey of Pathways to Diagnosis and Services (parent responses to NS-CSHCN 2009-2010)

Health, Mental Health and Health Care Factors

We explored aspects of adolescent health, mental health and health care:

Co-occurring Conditions

Over 60% of youth had at least two health or mental health conditions in addition to autism spectrum disorder.

Medication Use

Many youth with autism took at least one type of medication for conditions that co-occurred with autism. Nearly one-quarter to one-third were currently taking stimulants, anti-depressants, and/or anti-anxiety or mood stabilizing medications.

Treatment Coverage

Psychological services (23%) were the most common service not covered by youths' insurance, followed by speech/language therapy (15%) and occupational therapy (13%).

Health Care Transition

Nearly 40% of health care providers always encouraged youth to take some level of responsibility for their own health care, while 12% usually encouraged youth, and 21% sometimes did.

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