

Life Course Outcomes Program Fact Sheet Series

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Life Course Outcomes
Research Program



Qualitative Research

What is qualitative research?

Qualitative research focuses on the way people interpret and make sense of their experiences. Often this involves talking to people to understand their perspective. This approach is useful in research about the transition to adulthood because we know very little about what this important phase of life is like for people on the autism spectrum.

Qualitative research is different from quantitative research, such as surveys; lab-based research, like research on genetics; or clinical research, such as observing the behavior of children in treatment. These types of research are more

common for studying autism, but qualitative research gathers information that these other approaches do not. For example, we know from survey data that transition age youth on the spectrum have much lower rates of employment than their peers. However, we don't have explanations for why that is the case. If a researcher interviewed a young adult about employment, he or she might talk about the challenges of interviewing for a job if they have difficulties communicating with people. Hearing a lot of these stories can tell researchers about challenges

that many people on the spectrum face and this information could be used to design services, such as a program to teach job seeking skills.

Qualitative methods can also complement other research approaches. Using the example above, we could use information from 20 interviews to design a national survey about what are the biggest obstacles to employment for young adults with autism and what services they would find helpful. If researchers simply designed a survey without asking people what is important to them, we might not ask questions that best capture their experiences and concerns.

What kind of questions can researchers answer about the transition to young adulthood using qualitative research?

- What is life like for transition age youth with autism and their families?
- What are their goals?
- What are they doing to try to achieve them?
- What kinds of challenges are making it harder for them?
- What kind of support do young adults with autism need and what are they currently getting?



DREXEL UNIVERSITY
A.J. Drexel

Autism Institute

What should researchers be studying?

The answer to that question depends on who you ask: researchers and people with autism and their families may have different ideas about which research topics are top priority. Current autism research often focuses on biological causes and risk factors for autism in children or on clinical treatments. However, research also needs to focus on the growing population of adolescents and adults with autism - half a million youth with autism will turn 18 in the next decade. Researchers at the Centre for Research in Autism and Education in London asked a group of adults with autism, their families, practitioners, and researchers about current and future priorities for autism research. They found that adults with autism and their families wanted services and supports to teach life skills for managing daily living. They also wanted more research about a broader range of the autism population because there is currently little research that studies the experiences of people with moderate to severe autism. [Pellicano et al. (2014)]

What have researchers already found using qualitative studies about transition?

A few examples illustrate what qualitative research has told us so far about transition for youth with autism:



Transition planning: Researchers at Drexel University interviewed young adults on the autism spectrum, parents, teachers, and employers about the transition to life after high school. Young adults emphasized the importance of planning for new situations faced in adulthood, identifying a reliable person as a source of guidance and support, and working toward a self-identified goal. Parents saw their role as encouraging the young adult to take risks. Teachers observed that youth felt anxiety about securing future employment. And employers discussed the need for the young adult to structure the employment setting in a way that meets their needs. [Giarelli & Fisher (2013)]



Health care transition: Young adults often have to leave their pediatric health care providers and switch to adult doctors. Not only is this transition hard for some families, there are not many health care providers who have experience working with patients with autism. Researchers at the University of Missouri talked to parents and youth and found that parents were concerned about losing a relationship with their child's doctors, felt they didn't receive support when transitioning from pediatric to adult care, felt that new providers did not know much about autism, and were concerned about losing guardianship when their child turned 18. Youth emphasized their confusion and anxiety about the role of doctors during the transition and managing their health care independently. [Cheak-Zamora & Teti (2014)]



School to work: Preparing for a job after college is a concern for all students, but many young adults with autism struggle with finding and keeping a job and services are very important. One study by researchers at Virginia Commonwealth University interviewed 17 college students and found that college career centers were the *least* likely source for information and support. Students with autism felt that their limitations with social communication added to the challenges of finding and keeping work. They felt that more hands-on learning opportunities and understanding of what accommodations they could ask for would be helpful. [Briel & Getzel (2014)]

Summary

Qualitative research gives participants the opportunity to describe their experiences in their own words, which can tell us both what is most important to them and point out topics that are not currently being researched. As the field of autism research grows, so do opportunities to hear young adults with autism tell us about their lives and to develop research focused on their concerns.

Measuring What Matters

Dr. Collette Sosnowy leads the *Measuring What Matters* qualitative research study at the Life Course Outcomes program. Most autism research is currently focused on children, yet every year more and more people on the autism spectrum leave high school and age into adulthood. There are a lot of challenges for young adults with autism with things like getting a job, continuing on with school, and establishing their independence. However, we don't have a thorough enough understanding of these complex "outcomes" to improve them.

This study relies on in-depth interviews to gain a better understanding of what young adults on the spectrum, family members, service providers, advocates and others think are "good outcomes." The information gathered will help to craft better measurement tools for agencies and programs that are specific to the unique issues facing those on the autism spectrum.

Sources:

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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.