

Panelist Questions from Harvest Full of Hope

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ArtsQuest at SteelStacks
Bethlehem, PA

Question #1: How can the neurodiversity perspective be reconciled with its concerns of its opponents?

Answer:

If we want to see the positive change we need in the world, it is important for us to recognize our differences as strengths. Too commonly, adults that describe themselves as neurodivergent are socially rejected.

Australian sociologist Judy Singer, in 1998, developed the term *neurodiversity* and published it within her undergraduate thesis. Singer self-identifies as neurodiverse; she writes about her lived experience, including experiences raising a neurodiverse child and being parented by a neurodiverse mother. Singer's term neurodiversity is offered as "a new paradigm and language set apart from the Medical Model" and as a "social movement for people who were misdiagnosed, misunderstood and marginalized."

Neurodiversity is not a medical term. It is a description of the diverse nature of humans. According to Singer, "Neurodiversity refers to the virtually infinite neuro-cognitive variability within Earth's human population. It points to the fact that every human has a unique nervous system with a unique combination of abilities and needs."

By focusing on individual strengths and unique abilities, this approach helps individuals to recognize their positive attributes and work towards meeting life goals. It has broad implications in medicine, education, therapy, and the workplace. You can read more about Singer's work and her personal connection to the topic [in her blog](#).

Question #2: In addition to Autism, do neurodiverse populations include individuals with OCD, Downs, etc...?

Answer:

Yes, Singers original idea sparked a movement which aims to integrate medical, educational, and therapeutic services for children and adults with potential neurodiverse diagnoses including, but not limited to: ADHD, Autism, Dyslexia, Intellectual Disability, and other Developmental Disorders.

Question #3: 'Double Empathy Problem' comes from the journal article by Damian E.M. Milton. Simply put, Milton presents the perspective that challenges are due to different communication styles employed by ASD and 'neurotypical' social interactions. How can other aspects of neurodivergent experiences be interpreted in a similar fashion?

Answer:

According to Milton and his colleagues,

"For a long time, research has shown that autistic people can have trouble figuring out what non-autistic people are thinking and feeling, and this can make it difficult for them to make friends or to fit in. But recently, studies have shown that the problem goes both ways: people who are not autistic also have trouble figuring out what autistic people are thinking and feeling! It is not just autistic people who struggle."

This is what is known as the double empathy problem.

If we took that definition of "double empathy" one step further, it is, in essence, the entire definition of neurodiversity. The sole end goal of communication is, in any form, to bring awareness into one's thoughts, feelings, and perspectives. Given that we all think, act, and perceive the world differently and unique to our own being, it is important to recognize each experience should be treated as such. Milton largely studied teens and adults. Milton acknowledges not much is known about the extent this is learned behavior in early childhood.

A promising practice exists in our Lehigh Valley -- one that seeks to educate elementary school children to be mindful of human diversity, inclusion, and acceptance -- while providing them with inclusive actions and welcoming social skills that they can apply in their classrooms, at home, and throughout their lives. The Arc of Lehigh and Northampton County [Infusion of Inclusion 2.0 Program](#) helps ensure inclusivity in classes and activities with neurotypical children.

Question #4: Are there any actions being taken to support adults with ASD? Autistic children become autistic adults and an increasing number of individuals are being diagnosed later in life, with the challenges many face, and the diagnosis is already isolating. Are there any actions being taken to create social and supportive programs to help adults get help and get connected with each other? Also, learning does not end after formal education. How can someone get involved with neurodivergent assistance after high school is over?

Answer:

While not as plentiful as desired, programs do exist that assist those with autism and other intellectual and developmental disabilities in creating social connections and continued learning. Reaching out to The Arc of Lehigh & Northampton Counties' Advocacy Department (<https://arcoflehighnorthampton.org/advocacy/>) and/or [The Autism Society of Lehigh Valley](#) is a great start for getting the most current information on the programs available at any given time.

A new navigation guide for services and supports for youth and young adults with autism spectrum disorder has been produced by The Autism Action Committee of Lehigh and Northampton Counties. It teaches how to request services and accommodations. The guide is written for young people. The Autism Action Committee includes families of people diagnosed with autism spectrum disorder, County Departments of Human Services, and Magellan Behavioral Health of Pennsylvania (Magellan). For additional information, please see:

- [Online resource guide](#) and
- [2023 Transition Age Navigation Guide for Lehigh and Northampton Counties](#)

Individuals should consider discussing behavioral health services with their doctor. Behavioral health services promote mental well-being; the treatment of mental health and substance use concerns occurs at any age. Mental wellbeing can vary over the course of a lifetime. The continuum of behavioral health care services involves a wide variety of specialty providers.

People with behavioral health conditions are at greater risk of developing chronic diseases such as heart disease or diabetes and more likely to have unstable employment, insecure housing, or involvement with the criminal justice system.

For behavioral health services available to neurodiverse children, youth, young adults, and adults, and to learn more about how to access these services, please see Magellan's Autism Resources webpage. <https://www.magellanofpa.com/for-providers/services-programs/autism-resources/>

Question #5: I work in an adult medical office, and I see young adults who have 'graduated' and seem to lose supports they have had. Is it a goal to have neurodiverse/special needs connect to Office of Developmental Services to help individuals get service coordinators?

Answer:

Pennsylvania Office of Developmental Program (ODP) Waivers are administered by County offices. The 48 County Administrative Entities (AEs), through an Operating Agreement with ODP, carry out administrative functions that enable individuals to enroll in services and ensure that services are available and meet quality standards, including service coordinators. The County AE is your first stop in the services system.

In the Lehigh Valley area, the Northampton County Office of Developmental Programs and Lehigh County Office of Intellectual Disabilities are the Administrative Entities and should be contacted directly.

- **For Northampton County residents:**
<https://www.northamptoncounty.org/HS/DP/Pages/About-Us.aspx>
- **For Lehigh County residents:**
<https://www.lehighcounty.org/Departments/Human-Services/Intellectual-Disabilities>
- **To learn more about waivers and what they provide:**
<https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/Intellectual-Disabilities-Services.aspx>
- **The PA Family Network has educational presentations on ODP Waivers:**
<https://www.visionforequality.org/programs/pa-family-network/>
- **Lehigh Valley Supporting Families Collaborative (for information specific to the Lehigh Valley):**
<https://m.facebook.com/p/Lehigh-Valley-Supporting-Families-Collaborative-100070637372167/>

For those individuals that may not qualify for these waivers and support coordinator services, there are programs through Medical Assistance for neurodiverse individuals with Dual Diagnosis. Please see the answer to Question 4 for additional guidance.

Question #6: Why do you think camouflaging happens? Why is it important to appear normal?

Answer:

Camouflaging involves hiding aspects of autism and trying to fit in with others. Because neurodevelopmental conditions are lifelong many have learned strategies to work around or camouflage autism. Overall, camouflaging might help some people to make friends, for example, but it can be very exhausting and might even cause people stress and harm.

This is because neurodiversity is, unfortunately, not widely understood and/or accepted. The standard societal "norm" we are conditioned to is not wholly inclusive and still contains stigmas surrounding those identifying as neurodiverse and differently-abled individuals.

Question #7: How does being neurodiverse relate to diversity?

Answer:

Neurodivergence is a mostly overlooked dimension of diversity. Promoting inclusion and equity at all levels can make it easier for all people to reach their potential. Employers, for example, might consider adding a neurodiversity program with the goal being to reduce barriers to employment for neurodiverse workers.

Ultimately the choice of when to disclose a disability or neurodiversity is personal and will depend on many factors. Factors such as, where you are in your life, your previous experiences, and what you're trying to achieve.