

Autistic & Neurodivergent Needs in the Greater Lehigh Valley





# Good Shepherd (

Good Shepherd
Rehabilitation, an independent, not-for-profit rehabilitation network with more than 60 locations in Pennsylvania and New Jersey, is committed to transforming the lives of

people of all ages and abilities through curiosity, creativity, expertise and innovation. Headquartered in Allentown, Pennsylvania, Good Shepherd specializes in treatment of spinal cord injury, brain injury, stroke, major multi-trauma, pulmonary disease, respiratory failure, musculoskeletal/orthopedics and complex pediatric conditions. Good Shepherd also partners with Penn Medicine to provide rehabilitation and specialty services in the greater Philadelphia area and New Jersey through <u>GSPP Rehabilitation</u>. Info: www.goodshepherdrehab.org



Lehigh University's College of Health is dedicated to advancing the understanding of factors that contribute to healthier lives, with a mission to improve health outcomes for populations, communities, and individuals through research and education. It primarily

focuses on **determinants of health outside the healthcare system**, recognizing that health is profoundly shaped by environments where people live, work, and interact. Employing a **comprehensive**, **systems-level approach**, the College integrates this perspective with Lehigh's strengths in **innovation and technology** to foster a dynamic environment for transformative health advancements.

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# **Executive Summary**

One in every 31 children in the U.S. is estimated to have a diagnosis of Autism Spectrum Disorder (ASD, also referred to as Autism). It is perhaps the most well known—though not the most prevalent—of neurological impairments that comprise the category of "neurodivergence." The neurodivergent¹ make up a significant portion of the population but have received relatively little attention from healthcare and social service providers. As a result, there is a lack of comprehensive services and treatments for these individuals, many of whom suffer from poorer life outcomes than their peers due to intolerance and socially-created barriers.

Serving as the Community Health Needs Assessment (CHNA) for Good Shepherd Rehabilitation Network of Pennsylvania for 2025-2028, this document specifically investigates the needs and interests of the neurodivergent population. Through a combination of methods, this CHNA seeks to understand the needs and interests of the neurodiversity community that has been largely ignored in previous assessments. Specifically, the report triangulates between 4 methods to identify the community's strengths, needs, and interests:

- 1. scientific literature review.
- 2. analysis of secondary data, and
- 3. listening sessions, surveys, and focus groups with neurodivergent individuals, their parents and family members, and professionals with public and private organizations.

Based on our findings, this CHNA concludes that Good Shepherd should pursue more targeted service offerings for this population, with several qualifications. Principle among these is the need for further research to ensure that services provide a sufficient range of holistic services to respond to the diverse needs that neurodivergent individuals have across the lifespan. Services should not only target neurodivergent individuals but all stakeholder groups that play a role in the well-being of those with neurodiverse conditions: professionals, families, and the neurodivergent. By ensuring that services cover all three groups, Good Shepherd will have a chance to realize better outcomes for the neurodivergent and the communities in which they live.

Other recommendations respond to key factors relevant to autistic and neurodivergent individuals. These cover healthcare, person-centered services, education and transition, employment, and community living. They appear in each level of our analysis and serve as key thematic categories for analyzing the strengths, needs, and interests of neurodivergent individuals and those they depend on in their daily lives.

The study was planned, data was collected, findings were analyzed, and conclusions were drawn between late February and August 2025. Despite this limited time frame, because the findings, conclusions, and recommendations triangulate between four different sources of data across national, state, and local levels, they should be considered valid, reliable, and trustworthy. We recommend further study before planning and implementing any new programming or service options, but this CHNA amply demonstrates the need for them.

<sup>&</sup>lt;sup>1</sup> Owing to convention, as well as the wishes of many in the neurodivergent community, we switch between variations of "person with a disability" and "disabled person" language throughout this report, referring to the disabled/neurodivergent and those with disabilities/neurodivergent conditions equally.

### I. Introduction

# **Good Shepherd Rehabilitation**

Good Shepherd Rehabilitation is an independent, not-for-profit rehabilitation network with 30 locations throughout eight counties in eastern Pennsylvania. A nationally-recognized leader in rehabilitation, it first opened as Good Shepherd Home in Allentown, Pennsylvania in 1908. Over the next century, it would become established as the premier disability rehabilitation network in the region, opening one of the country's first rehabilitation hospitals in Allentown in 1967 that provided medical care, physical therapy, social work, and psychological services. It greatly expanded on the hospital and opened numerous other facilities serving specific disability types, providing intensive rehab and long-term housing for disabled, elderly, and other residents.

More recently, Good Shepherd Rehabilitation Hospital in Center Valley opened in 2023, offering "state of the art" services, technology, and care for stroke, brain injury, spinal cord, and complex medical rehabilitation.



Good Shepherd Rehabilitation Hospital in Center Valley, PA

## **2025-2028** Community Health Needs Assessment

This report serves as the 2025-2028 Community Health Needs Assessment (CHNA) for Good Shepherd, as required under the 2010 Patient Protection and Affordable Care Act (ACA). It is targeted towards a specific population, those with neurological disabilities referred to in the literature as *neurodivergent*. For that reason, the report does not at length discuss the needs, strengths, and interests of all disabled people Good Shepherd might serve. Instead, it works to define and identify the needs, strengths, and interests of autistic individuals, those living with Attention-Deficit Hyperactivity Disorder (ADHD), those who survived Traumatic Brain Injuries (TBIs), and the many other conditions highlighted by the term neurodiversity.

This CHNA focuses on the need in the community for treatments and services that Good Shepherd can introduce or strengthen in the Lehigh Valley. Because there is limited information on that population in the region, we combine analyses of existing data along with an extensive scientific literature review of neurodiverse populations, data gathered from the latest American Community Survey available (2023 1 and 5-year estimates), and primary data we collected from listening sessions, community surveys, and interviews we conducted over the course of 2025. We also draw on our own work with neurodiverse individuals and their families as well as the life experience of lead author, Dr. Austin W. Duncan, who is neurodivergent, himself.

### **Outline**

The report consists of five sections, each of which directly feed into a series of actionable recommendations for Good Shepherd and the surrounding community. The first of these is to assess the impact of the prior CHNA, to the extent possible. Following an analysis of this CHNA, which applies to the neurodivergent population equally as it applies to other disabled people for whom it was composed. It then presents an extensive discussion of the literature on neurodivergent conditions, needs, and barriers to care that served as a foundation for later data collection efforts. Next, as with most CHNAs, the community is presented and defined, comprising both the state of Pennsylvania and the counties of the eastern region Good Shepherd serves: Lehigh, Northampton, Monroe, Bucks, and Carbon counties. Then it presents findings from original data that were collected from April to July of 2025, including several community listening sessions, surveys, and interviews, as well as the strengths and limitations of each. Finally, it presents several actionable recommendations for both Good Shepherd and the community surrounding recommended programs and services for the neurodivergent.

# Strengths and Limitations

This report is the result of five months of data collection and analysis. It is further supported by extensive background research and academic studies the lead author has conducted over his entire academic career. As such, the conclusions contained in this report have been triangulated from multiple sources of data and should be considered strong, given the study's key limitations of time, resources, and community feedback.

Further efforts are clearly needed to account for these limitations, flesh out the study's conclusions, and evaluate their effectiveness. Future research should be as community-driven as possible, including neurodivergent individuals, their families, and professionals throughout the research process. While the current report, conducted and authored by neurodivergent and diverse scholars, was built on and presents community input, it could have done more within a larger time frame. Good research asks for significant resources, and planning any new interventions like those focusing on neurodiversity requires it. The present CHNA, comprehensive as it is, requires more of this research to be truly effective.

# II. Review of the 2022-2025 Community Health Needs Assessment

Data, findings, and recommendations from the previous CHNA are integral to this report. But because of both their limited scope, which focused only on the three counties of Lehigh, Northampton, and Monroe Counties instead of the five of this report (adding Bucks and Carbon Counties), and their general approach, analyzing the entire population of persons with disabilities in those counties, the current CHNA does not directly respond to them or address their implementation. Instead, the previous study serves as a foundation, both a partial baseline and a kind of archival data source, for the current analysis.

The earlier report's primary conclusion was that persons with disabilities in the three counties face negative outcomes based on Social Determinants of Health (SDOH) akin to race, gender, and other intersectional identity factors. Within months of its publication, the NIH designated persons with disabilities as a population facing unequal health outcomes specifically because of SDOH. This designation was the product of years of efforts by disabled persons' organizations, community organizations, and public health scholars (Reynolds 2024), however, and was not directly related to the CHNA. However, in our opinion as disability researchers, both the report and the designation responded to a clear empirical situation, as persons with disabilities exhibit significantly worse health outcomes than others in our society. As the 1990 ADA and 2008 ADA Amendments Act made clear, the population also faces significantly higher levels of discrimination, leading to worse rates of employment, poverty, and other well-known SDOH.

Data for the CHNA was collected and analyzed in 2020-2021. It consisted of secondary data analysis, 1,019 telephone surveys, and two community forums, all of which were conducted by Muhlenberg College in Allentown, PA. The CHNA report found three key themes in this data:

- 1. Disability is an Axis of Inequality
- 2. DEI Work Must Include Disability
- 3. Telehealth May Help Promote Health Access and Equity.

Good Shepherd has incorporated many of these recommendations into its strategy and programming. It was for this reason that it directed the current CHNA to focus on one unique and particularly marginalized population only partially served by the organization's services: the neurodivergent community. As such, the current study is unable to fully evaluate implementation of the prior CHNA's recommendations, but it can nevertheless offer partial appraisals of them.

# **Enhancing Inclusivity**

The prior CHNA remains pertinent today, as individuals with disabilities continue to experience negative health and life outcomes due to these SDOH. The needs and strengths of the disabled, as well as of those who support them and the wider communities of which they are a part, continue to depend on diverse factors. These may and often do include access to spaces, services, and supports—but those are often only a small part of their needs. Moreover, per the ADA, the disabled are already required to receive these supports in the US. Compliance with existing laws that pertain to health and well-being certainly should be considered in any CHNA, yet they should be considered a baseline for health and wellness and not a particular strength or specific category for analysis. True inclusion of all persons who have disabilities and those around them requires attention to the multiple factors that the prior CHNA identified as having an outsize

impact among them. While Good Shepherd cannot directly affect these diverse factors, it can respond to them in strategic ways that maximize inclusivity and the resulting benefits for disabled patients and the communities in which they live.

Moreover, as our review of the literature has clearly demonstrated, race, class, gender, and other identity-based concerns are still very important for the health and well-being of the disability community. Poor health outcomes among disabled people continue to be disproportionately distributed across these and other identity categories. Further, given the Lehigh Valley and surrounding areas' significant diversity in these areas, there is a clear need for Good Shepherd to continue programming that targets these and other social groups mentioned in the prior report. We only urge caution when it comes to naming specific programs, stressing their pragmatic and evidence-based rationales and maintaining a focus on realizing the largest benefits possible for all members of the disability community. Thus, while the current CHNA does not directly respond to or address the prior one, it should serve as a backdrop for all of our findings and recommendations.

### **III. Literature Review**

### **Defining Neurodiversity and Neurodivergence**

Neurodiversity is the idea that differences in how people think, learn, and process the world—such as autism, ADHD, and dyslexia—are natural parts of human diversity, not problems that need to be fixed. This concept was first introduced by sociologist Judy Singer in the 1990s and has since become a movement that focuses on rights, identity, and acceptance (McGee, 2012; University of St. Augustine for Health Sciences, 2024). Many scholars and advocates believe that instead of viewing neurodivergent people through a medical lens that focuses on their "deficits," we should focus more on inclusion and building environments that suit different ways of thinking (Botha et al., 2024; Armstrong, 2015). The goal isn't to "cure" neurodivergent individuals, but to recognize their strengths and support them by making adjustments in society (Armstrong, 2012; Goldberg, 2023). From both scientific and social views, neurodiversity is seen as something real and important because it's about respecting people's differences and giving them the autonomy and dignity they deserve (Goldberg, 2023; Sonuga-Barke & Thapar, 2021). Challenges often come not from the person themselves, but from how society fails to meet their needs (Sonuga-Barke & Thapar, 2021). Neurodiversity encourages more inclusive practices in areas like healthcare, education, and the workplace by valuing cognitive differences.

Neurodiversity itself is not a medical diagnosis, and it is also not the same as being neurodivergent. It describes the natural variety in how all human minds work, not just people with conditions like autism or ADHD (Shaw et al., 2024). Therefore, it is important not to treat neurodiversity like a list of symptoms or limit it to certain groups. Maynard (2024) points out that using neurodiversity as a simple label, such as dividing people into "neurotypical" and "neurodivergent," can ignore how complex and diverse people really are. At the same time, Baumer and Frueh (2021) remind us that supporting neurodiversity does not mean we ignore the real difficulties some people face. Medical care, support plans, and personalized help are still very important.

### **Autism**

The primary disability that is considered neurodivergent is Autism Spectrum Disorder (ASD), a developmental disability caused by differences in the brain that leads to significant social, communication, and behavioral challenges (CDC, 2025) According to the CDC, about 1 in 31 (3.2%) children aged 8 years in the U.S. has been identified with Autism Spectrum Disorder (also called Autism, as is heavily favored by members of the Autism Community), with diagnoses reported across all racial, ethnic, and socioeconomic groups (CDC, 2024). Autism is more than three times as common in boys than in girls. Furthermore, about 1 in 6 children aged 3–17 years have been diagnosed with a developmental disability, including autism, ADHD, and cerebral palsy, which is highlighting the importance of inclusive services across childhood.

Autism, a central part of the neurodiversity movement, highlights that differences in thinking and behavior are a natural part of human diversity and can bring unique strengths. Researchers note that autism exists in two dimensions which are social-adaptive traits and neurodevelopmental differences, shaped by both genetic and environmental factors (Chawner & Owen, 2022). Early support is critical, as caregivers can enhance participation and reduce behavioral challenges through sensory adjustments (Pfeiffer et al., 2017), while parents' beliefs, income, and education

influence openness to interventions (Mire et al., 2015). A positive autism identity, linked to higher self-esteem, develops when individuals feel connected to the autistic community (Cooper et al., 2020). However, many autistic individuals, despite strong academic abilities, may face loneliness, sensitivity, low self-esteem, and barriers such as poverty or cultural differences (Cierzniewska & Podgórska-Jachnik, 2021; First et al., 2018). Cultural background, ethnicity, and socioeconomic status also shape diagnosis and treatment, underscoring the need for culturally competent approaches like the R.E.S.P.E.C.T.F.U.L. model (Ennis-Cole et al., 2013). Beyond autism, the neurodiversity perspective encompasses ADHD, traumatic brain injury, Down syndrome, dyscalculia, dyspraxia, Tourette's syndrome, and intellectual and developmental disabilities, all of which deserve respect, individualized support, and care.

### **ADHD**

Attention Deficit Hyperactivity Disorder (ADHD) is one of the most common neurodivergent conditions. According to the CDC (2023), approximately 12% of children aged 3-17 in the US have been diagnosed with the condition. Yet it is often underdiagnosed, despite its widespread prevalence (Sayal et al., 2018)). Research highlights the importance of resilience and personal strengths in supporting those affected, aligning with the neurodiversity perspective (Sayal et al., 2018; Kessler et al., 2006; Schei et al., 2018).

# **Tourette's Syndrome**

Tourette's Syndrome is a neurodevelopmental disorder characterized by sudden, repetitive, involuntary movements or vocalizations known as tics (Robertson, 2015). Tourette's Syndrome, affecting about 0.3–0.7% of children, involves persistent motor or vocal tics, is linked to genetic and brain development factors, often co-occurs with ADHD or OCD, and may improve over time or require medical or therapeutic support (Greydanus & Tullio, 2020).

### TRI

Traumatic brain injury (TBI) is another common cause of neurodivergence, affecting over 2 million Americans annually (CDC 2019). Being an injury and not a congenital condition, it is often left out of the neurodiversity paradigm. But when a TBI occurs in early childhood, it can lead to long-term developmental changes, including risk for ADHD, autism, and other delays, clearly supporting its inclusion within the neurodiversity framework (Chang et al., 2018).

# **Intellectual and Developmental Disabilities**

Intellectual and Developmental Disabilities (I/DD) are impairments that affect individuals before the age of 21. They affect an estimated 7% of children in the United States. Not all I/DD are neurodivergent, but many of them are, including the most well known I/DD: Autism, Down Syndrome, and some instances of Cerebral Palsy.

- *Down syndrome:* Down syndrome (DS) is a genetic condition included in the neurodiversity framework, affecting about 1 in 640 births in the U.S. As life expectancy for children with DS increases, there is a growing need for culturally respectful lifelong support and equitable access to care (CDC, 2022; Shin et al., 2009; de Graaf et al., 2017).
- Other I/DD, such as cerebral palsy, Fragile X syndrome, Williams syndrome, and fetal alcohol spectrum disorders, affect how individuals think, learn, and function, with about 7% of U.S. children aged 3–17 diagnosed in 2016 (CDC, 2016), and research shows that professional training using methods like Functional Communication Training (FCT) and

Behavioral Skills Training (BST) can reduce problem behaviors and improve communication in adults with I/DD (Gregori et al., 2020).

# **Learning Disability**

Learning disabilities are neurologically-based processing disorders that disrupt one or more basic psychological processes, such as input, integration, memory, or output. This can interfere with academic skills like reading, writing, or math as well as higher-order abilities, such as organization, time management, or abstract reasoning (Chieffo & Dupaul, 2023). Learning disabilities that are discussed in the literature include:

- Dyscalculia, a math-related condition affecting 3–7% of children and adults for which early, personalized support from trained professionals has been shown to significantly improve outcomes (Haberstroh & Schulte-Körne, 2019).
- Dyspraxia, a commonly misunderstood developmental coordination disorder (DCD) that affects 5-6% of children despite it often going unrecognized in children due to overlapping symptoms with other disorders (Gibbs et al., 2007; Blank et al., 2019.)
- Dyslexia, also known as a reading disorder, primarily impairs reading and spelling abilities. It is the most frequently diagnosed specific learning disability, accounting for roughly 70% to 80% of all cases (Sahoo et al., 2015).
- Dysgraphia is recognized as both a specific learning disability and a transcription disorder, impairing the mechanics of writing such as handwriting fluency, the orthographic encoding of written language, and the sequential coordination of finger movements required for writing (McCloskey, 2017).

# **Increasing Prevalence of Neurodiversity**

Neurodiversity has over recent years become a frequent topic of disability care and research and is prominent in disability research today (McLennan, 2025). There are numerous journals, research centers, government offices, and public and private organizations established to provide research, service, and training for various educators and professionals (Smeltz et al., 2024). For example, the Autism and Developmental Disabilities Monitoring Network (ADDM), established in 2000, has been tracking and monitoring the prevalence of autism and other neurodivergent conditions for many years (Baio, 2012). ADDM has reported a consistent increase in these conditions, though the reasons for the increase are unclear (Maenner et al., 2023). Other organizations have also been following the increasing prevalence of neurodivergent conditions, sparking increased academic debate and discussion.

# **Barriers for Neurodivergent Individuals**

Despite growing awareness and diagnosis, neurodivergent individuals still face significant barriers in healthcare, education, and life transitions, as systems often lack the inclusive, coordinated support needed to meet their diverse needs (Srinivasan, 2025; Dwyer, 2023; de Paor, 2025). These gaps highlight the urgent need for culturally responsive, individualized services aligned with the neurodiversity framework (Shaw et al., 2023; Beaux et al., 2024), spread among the following categories:

Access to Care: Neurodivergent individuals have a difficult time accessing adequate and consistent healthcare. Many face significant healthcare barriers of high costs, long waitlists, limited provider training, and negative attitudes that vary across the lifespan, from inadequate childhood screening to poor adult services (Weitzman et al., 2024). The SAFE Consensus Statement calls for accessible, inclusive care throughout life, while the "triple empathy problem" highlights the unique communication and emotional challenges that contribute to healthcare avoidance among autistic adults (Weitzman et al., 2024; Shaw, Carravallah, & Doherty, 2023).

Person-Centered Services: Neurodivergent individuals, particularly autistic people, face multiple barriers to receiving appropriate person-centered care. including provider bias, lack of autism-specific training, inaccessible communication, and fragmented service systems (Mason et al., 2019). These challenges often result in care that does not align with patients, limiting autonomy, engagement, and equitable health outcomes (Babalola et al., 2024; Quinn, 2023)

*Employment*: Many neurodivergent individuals and their families face barriers such as stigma, unequal access to education, and fragmented support systems, with low-income and minority families often experiencing greater hardship and fewer resources (Anderson et al., 2020). Families relying on multiple public services, like child welfare or mental health systems, may encounter additional stress and regional disparities, making it even harder to secure and maintain meaningful employment (Goerge & Wiegand, 2019).

Social Marginalization and Discrimination: Many neurodivergent individuals experience lifelong social exclusion and discrimination rooted in stigma, negative portrayals, and systemic barriers, with contributing factors including professional attitudes, visible traits, disclosure, and cultural context (Turnock, Langley, & Jones, 2022). Such experiences often lead to camouflaging behaviors and "affiliate stigma" for caregivers. This can cause significant emotional harm, including anxiety, depression, and trauma (Cleary et al., 2023).

Mental Health and Wellness: Wellness for autistic individuals is deeply personal and shaped by autonomy, meaningful relationships, supportive environments, and opportunities to use personal strengths, rather than by neurotypical standards (Parenteau et al., 2024; Maddox et al., 2023). Studies show that social acceptance, stable routines, sensory-friendly spaces, and the ability to pursue personal interests contribute to happiness, while exclusion, lack of support, and unstable jobs can harm well-being (Datu et al., 2022; Viner et al., 2024). Using strengths such as creativity, honesty, and curiosity is linked to higher quality of life, better mental health, and greater satisfaction in relationships and work (Maddox et al., 2023).

Mental health care for neurodivergent individuals is often limited by stigma, inappropriate assessment tools, therapy models that do not fit diverse needs, and systemic barriers such as poverty and insurance gaps (Paynter, Sommer, & Cook, 2025). Research highlights the importance of respectful, identity-affirming, and individualized therapy that builds on strengths, involves clients in the process, and adapts to their unique situations (Paynter et al., 2025). A neurodivergence-informed approach centers on self-acceptance, advocacy, and community connection, shifting from "fixing" individuals to understanding and valuing their lived experiences, while calling for systemic change in training, practice, and policy (Chapman & Botha, 2023).

# Recommendations

The literature has numerous recommendations for how our society should address the increasing prevalence of neurodivergent conditions that we group into five significant categories:

Name	Description	Recommendations
Care	There is a growing need for neurodiversity-affirming care that moves away from deficit-based models, recognizing that neurodiversity is a natural part of human variation and only becomes disabling when systems fail to accommodate individual neurological differences.	- Provide accommodations and inclusive training to help neurodivergent individuals thrive; recognize strengths, adapt environments to support success in medical and professional settings (Johnson & Ahluwalia, 2025) Shift from masking to affirming identities and communication styles; foster peer acceptance and prioritize well-being over conformity (Wagland et al., 2025).
Person- Centered Services (PCC)	Research highlights the value of individualized, person-centered planning for autistic adults, focusing on personal goals, communication preferences, and identity to promote autonomy, inclusion, and meaningful relationships. Standardized services risk causing disengagement.	<ul> <li>Use individualized planning to foster self-advocacy, independence, and inclusion; avoid overly standardized approaches that may miss developmental opportunities (O'Neal, 2024).</li> <li>Promote autonomy by allowing individuals to define success on their own terms (O'Neal, 2024).</li> </ul>
School and Transition	Neurodivergent students often lack adequate support during key educational transitions due to limited preparatory resources, inconsistent planning, and experiences of bullying and stigma, especially in college settings.	<ul> <li>Ensure personalized, inclusive, and sustained postsecondary planning (Grigal et al., 2023).</li> <li>Provide emotionally supportive environments and anti-bullying policies during transitions (Sideropoulos et al., 2024).</li> <li>Improve campus awareness of autism to reduce stigma and promote inclusive practices (Tipton &amp; Blacher, 2014).</li> </ul>
Employment	Employment remains a major challenge for neurodivergent individuals due to early educational disparities, stigma, and limited systemic support. Those with learning disabilities face higher risks of unemployment and mental health issues, while families, especially in low-income or minority groups, often experience economic strain from fragmented services and limited caregiver job options.	<ul> <li>Provide early intervention and long-term career planning tailored to learning profiles (Aro et al., 2019).</li> <li>Increase access to services for low-income and minority families raising autistic children (Anderson et al., 2020).</li> <li>Address systemic issues affecting families who rely on multiple public services, which impact employment stability (Goerge &amp; Wiegand, 2019).</li> <li>Develop a comprehensive employment support system that includes educational access, workplace accommodations, mental health support, and career flexibility (Doyle, 2020).</li> </ul>
Home and Community- Based Services (HCBS)	Home and Community-Based Services (HCBS) offer flexible, person-centered support outside institutional settings. Research shows HCBS waivers reduce unmet healthcare needs, improve family stability, advance care equity, lessen racial disparities, and provide economic benefits.	- Expand HCBS access, increase per-child spending, and broaden enrollment to improve outcomes for children with autism (Leslie et al., 2017) Standardize and grow HCBS programs to reduce caregiver strain, improve care equity, and enhance employment retention; conduct more research on cross-state differences and long-term impacts to optimize program effectiveness (McLean et al., 2020).

# **IV. Community Profile**

CHNAs are fundamentally grounded in the communities they cover. The present CHNA covers a region of five counties located in eastern Pennsylvania.

# Pennsylvania

Pennsylvania is a large state in the U.S. northeast of just over 13 million residents. It consists of several distinct geographic regions, which have communities as diverse as the major cities of the state's eastern and western regions and much of the state's more sparsely populated and rural center. The CDC estimates that 1 in 4 individuals has a disability of some sort, resulting in a total population of over 3.25 million disabled people.

Pennsylvania has a diverse population. Though the 2018-2022 American Community Survey (ACS) estimates that the state has a largely white population (75%), it also has significant populations of Black or African American (11%) and Hispanic (10%) individuals.

Figure 1: Race Demographics for Pennsylvania

., , , ,	Percentage	Population
White	74.9	% 9,750,687
Black or African American	10.9	% 1,423,169
Asian	3.9	% 510,501
Hispanic or Latino	8.9	% 1,151,76
American Indian and Alaska Native	0.2	% 31,052
Native Hawaiian and Other Pacific Islander	0.03	% 3,276
Some other race	3.9	% 508,531
Two or more races	5.9	% 774,484

*Source*: U.S. Census, 2023 American Community Survey, 1-Year Estimates; \*2023 American Community Survey, 5-Year Estimates

Its population is aging, now with an estimated 20% being 65 years and older, which is slightly greater than the national average.

Figure 2: Age Demographics for Pennsylvania

	Percentage
	20.25%
Under 18 years	(2,624,629)
	9.00%
18 to 24 years	(1,166,048)
	12.74%
25 to 34 years	(1,651,405)
	12.82%
35 to 44 years	(1,660,159)
	11.76%
45 to 54 years	(1,524,092)
	13.40%
55 to 64 years	(1,737,396)
	20.04%
65years and older	(2,597,954)

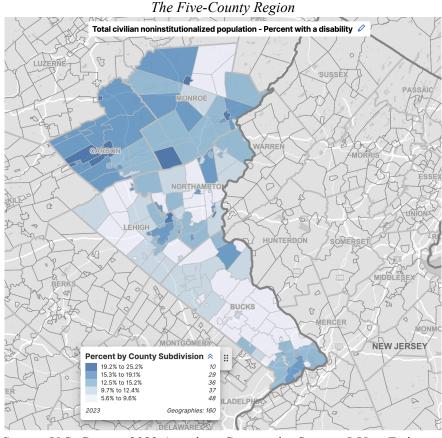
Source: U.S. Census Bureau, U.S. Department of Commerce. "Population by Age." American Community Survey, ACS 1-Year Supplemental Estimates

This population is spread throughout 67 counties and 1,546 distinct townships. Many of these have existed for hundreds of years. Most are primarily rural, though the state has a few large urban centers, primarily clustered around the cities of Philadelphia and Pittsburgh. Numerous smaller cities also exist outside of these, however, including the cities of the Lehigh Valley.

As one of the former centers of U.S. steel and manufacturing, Pennsylvania is known as one of the "rustbelt" states. Much of its economy was devastated when these industries fled the state and country in the 20th century. While many areas have since recovered, this recovery is not distributed equally across all regions, especially in the Lehigh Valley. Consequently, the health and well-being of neurodivergent individuals and their families largely depends upon the community within which they live.

The state is generally considered a "purple" state—that is, containing a mix of conservative, liberal, and independent voters that regularly switch support between Republican, Democratic, and other political parties. More liberal areas are primarily centered in cities, while conservative ones are more rural, but there are pockets of both ideologies in every community. The cultural background of the state varies widely, with large impacts on the needs and interests of neurodivergent persons and their families. The state includes large influences from German, Caribbean, and African-American cultures, along with significant and growing Hispanic populations arriving from all across the Americas. These are more predominant in urban areas than in the state's rural counties, but even rural communities are increasingly diversifying.

# **Geographic Focus**



Source: U.S. Census, 2023 American Community Survey, 5-Year Estimates

Good Shepherd is headquartered in the Greater Lehigh Valley area. For that reason, this report is primarily focused on the counties that comprise the region, specifically Lehigh, Northampton, Monroe, Carbon, and Bucks counties. This area is considered the state's third largest population center in the state, with around 1,572,555 residents, centered around the cities of Allentown (125,094), Bethlehem (77,617), and Easton (30,341).

The region's economy has changed significantly in the last century, with its once prosperous steel and manufacturing industry winding down and ending by the early 2000s. Today, the economy has significantly diversified, and is based in services such as healthcare, finance, and education, some manufacturing, and some retail and other trade. Politically, the area appears much like the state overall, with pockets of progressive and conservative populations surrounded by so-called "swing districts" that contain a wide range of policy initiatives. The area is also very diverse. It is home to larger Black and African-American, Hispanic, and Asian populations. They are dispersed throughout the five counties but most prominent in the urban core surrounding Allentown, Bethlehem, and Easton. Residents of the five counties have a wide range of incomes, including 7.9% of the population who live at or below the Federal Poverty Line (2023 American Community Survey, 5 year estimates).

# V. CHNA Methodology

Building on this literature review and our prior research as neurodivergent scholars and neurodiversity researchers, we developed several methods for the kind of rapid data collection this targeted CHNA requires. Each of these methods built on earlier ones, creating a scaffolding and triangulated study that diminishes the challenges raised by the time and budgetary-limited nature of the study.

# **Identification of Neurodiversity-Serving Organizations**

We compiled a list of neurodiversity-serving organizations in the state and the five-county region, using publicly-available internet sources, input from Good Shepherd, and answers to each of our data sources.

# **Secondary Data Analysis**

We collected secondary data that was available for both the state and the five-county region from the most recent American Community Survey (ACS). These data were compiled and summarized separately from other data collection activities, so that more community-based data could also be community-driven (see below).

# Primary Data Collection: Listening Sessions, Surveys, and Interviews

To begin, we summarized the research and developed open-ended questions to encourage debate and discussion. These questions were specifically targeted for representatives from neurodiversity-serving organizations, as well as families members of neurodivergent individuals, and neurodivergent individuals themselves. Two such listening sessions were conducted via Zoom in the months of April and May. Transcripts from these meetings were coded and thematically analyzed, guiding later modalities of data collection.

Branching surveys were developed according to themes that had emerged in the listening sessions. Neurodivergent individuals, family members, and professionals each had different though related questions. Surveys were distributed by Good Shepherd to staff, local organizations, and other stakeholders throughout the months of June and July. A total of 141 surveys were submitted. Most were completed by family members (88, 62%), while smaller numbers were completed by neurodivergent individuals (18, 13%) and professionals (15, 11%).

A small convenience sampling of local individuals who work in the neurodiversity sector were arranged throughout data collection for the CHNA. These interviews were only meant to fill in small details unaddressed by other data collection activities and constitute a small portion of data collection.

### **Report Preparation**

The present report was analyzed and conducted independently by Austin W. Duncan, Rebecca (Xinyueng) Chang, and Cheyenne B. Desmond. The report was drafted and then edited by Katherine Jones. Finally, it was sent to Good Shepherd and reviewed by its board before an implementation plan could be authored and the two could be published online.

# VI. Neurodiversity-Serving Organizations

# **Support Services**

These services assist individuals and families with managing daily life, offering help with case management, coordination, social and emotional support, and building life skills. These services are vital for community integration and independence.

- (1) The Arc of Lehigh Valley (2289 Avenue A, Bethlehem, PA 18017, <a href="https://arcoflehighnorthampton.org/">https://arcoflehighnorthampton.org/</a>)
- (2) Lehigh Valley Center for Independent Living (713 N. 13th Street, Allentown, PA 18102, <a href="https://lvcil.org/">https://lvcil.org/</a>)
- (3) Via of the Lehigh Valley (Lehigh, Northampton, Monroe, Carbon, Bucks, Berks Counties) (336 W. Spruce Street, Bethlehem, PA 18018, <a href="https://www.vianet.org/">https://www.vianet.org/</a>)

### **Education and Vocational Training**

Education-focused organizations provide special education services, inclusive instruction, and neurodiversity-affirming teaching. They support both academic learning and social-emotional development for neurodivergent students.

- (4) ESU Autism Education Center (60 W. Broad Street, Bethlehem, PA 18018, www.esu.edu/autism-education-center)
- (5) The Lehigh Valley Office of Vocational Rehabilitation (45 N. 4th Street, Allentown, PA 18102,
  - https://www.lehighcounty.org/Departments/Human-Services/Mental-Health/Adult-Mental-Health/Vocational-Programs/)
- (6) Developmental Education Services (400 Powerhouse Lane, Stroudsburg, PA 18360, 2336 US-209, Brodheadsville, PA 18322, <a href="https://devedmc.org/">https://devedmc.org/</a>)

### **Transition Services**

Transition support helps youth and young adults move from school to adulthood. These statewide services often include independent living skills, housing support, and adult system navigation (e.g., Medicaid waivers).

- PA Secondary Transition (<a href="https://www.pasecondarytransition.com/">https://www.pasecondarytransition.com/</a>)
- The Neurodiversity Employment Network (<a href="https://neurodiversityemploymentnetwork.org/">https://neurodiversityemploymentnetwork.org/</a>)

### Rehabilitation

These include therapies and interventions that aim to improve daily functioning, behavior regulation, communication, and physical abilities in neurodivergent individuals. Rehabilitation can be medical, behavioral, or developmental.

- (7) Good Shepherd Rehabilitation (3200 Center Valley Parkway, Center Valley, PA 18034, <a href="https://www.goodshepherdrehab.org/">https://www.goodshepherdrehab.org/</a>)
- (8) Lehigh Valley Health Network (3900 Sierra Circle, Center Valley, PA 18034,

https://www.lvhn.org/)

• (9) St. Luke's Lehigh Valley Headquarters (801 Ostrum Street, Bethlehem, PA 18015, <a href="https://www.slhn.org/">https://www.slhn.org/</a>)

# **Therapy and Counseling**

These providers offer direct mental health or behavioral services. Many specialize in neuro-affirming, trauma-informed, or autism-specific care. This category includes individual therapists, clinics, and counseling centers offering support for neurodivergent individuals, their families, and groups. Comprehensive listings for these providers can be found online at Psychology Today (<a href="https://www.psychologytoday.com/us/therapists/pennsylvania">https://www.psychologytoday.com/us/therapists/pennsylvania</a>).

# **Advocacy and Support Groups**

These organizations offer advocacy, education, and support groups to empower neurodivergent individuals and their families. They help reduce stigma, connect families, and advocate for equitable access and inclusion.

- PA Family Network (<a href="https://www.visionforequality.org/programs/pa-family-network/">https://www.visionforequality.org/programs/pa-family-network/</a>)
- Disability Rights Pennsylvania (301 Chestnut Street # 300, Harrisburg, PA 17101, https://www.disabilityrightspa.org/) 10
- Arc of Pennsylvania (1007 Mumma Road #100, Lemoyne, PA 17043, https://thearcpa.org/)

  Northampton

  Lehigh 37 34 Bucks

# VII. Secondary Data Analysis

### **Disability Prevalence**

The five counties of the greater Lehigh Valley Region are home to a large number of disabled persons. In the 2023 ACS 5-year estimates, the most recent federal data available, there were 211,586 people, approximately 13.45% of the total population, who identified as a person with a disability. In our research, we found that a significant number of residents who have disabilities in one major Lehigh Valley city, Bethlehem, did not identify themselves as disabled. Additionally, older people are more likely to have disabilities than younger people. Thus as the population continues to age, the number of persons with disabilities is likely to grow. While we cannot estimate the exact number, it is likely closer to the CDC's predicted 25%.

# Geography

This population does not live predominantly in any one area. The relatively small area of Lehigh Valley cities implies that major hospitals within the Lehigh Valley metropolitan area are not located within the region's three major cities. Indeed, Good Shepherd's main rehabilitation hospital is today located in Center Valley, several minutes south of Bethlehem and Allentown. While none of our participants complained that this was too far away for them to drive, many professionals we spoke to did mention trouble with transportation as a key challenge in the region. Consequently, it stands to reason that our data did not include the large number of disabled persons who do not have access to their own transportation and instead must rely on public transportation.

# **Disability Categories**

ACS data uses six categories to describe disabled people. These were found throughout the five county area at rates that were similar to the state as a whole:

Figure 3:	Proportion	of Disabled	<i>Individuals</i>	by County

Individuals with:	Bucks	Carbon	Lehigh	Monroe	Northampton
	3.00%	5.20%	2.90%	3.80%	2.90%
Hearing difficulty	(19,252)	(3,359)	(10,911)	(6,420)	(9,146)
	1.50%	2.50%	2.20%	2.50%	2.00%
Vision difficulty	(9,509)	(1,582)	(8,342)	(4,214)	(6,338)
	4.60%	7.20%	6.30%	6.40%	5.10%
Cognitive difficulty	(27,770)	(4,411)	(22,098)	(10,196)	(15,284)
	5.70%	8.30%	6.10%	7.50%	6.20%
Ambulatory difficulty	(34,636)	5,120)	(21,387)	(11,908)	(18,530)
	2.20%	2.70%	2.30%	3.40%	2.40%
Self-care difficulties	(13,299)	(1,628)	(7,934)	(5,402)	(7,103)
	5.40%	5.70%	5.60%	6.90%	5.70%
Independent-living difficulties	(27,772)	(2,986)	(16,101)	(9,281)	(14,418)

### Age

The data indicates that a large portion of the disabled in the five counties are older. This is corroborated by research, indicating that more and more people are becoming disabled through injury, impairment of one or more bodily function, or chronic illness as they age. As several Disability Studies scholars have noted, "We all will become disabled if we are lucky to live long enough" (Garland-Thomson 2002).

Figure 4: Age of Disabled Individuals by County

Age Group	Bucks	Carbon	Lehigh	Monroe	Northampton
	0.2%	0.0%	0.2%	3.0%	0.1%
Under 5 years	(64)	(0)	(49)	(235)	(19)
	5.4%	6.6%	9.0%	6.8%	6.4%
5 to 17 years	(5,346)	(624)	(5,631)	(1,674)	(2,972)
	7.7%	12.4%	8.8%	9.4%	7.7%
18 to 34 years	(9,213)	(1432)	(7,141)	(3,248)	(5,345)
	8.3%	15.4%	12.2%	13.2%	10.2%
35 to 64 years	(22,019)	(4,088)	(17,437)	(9,023)	(12,308)
	16.7%	27.3%	19.6%	24.6%	19.4%
65 to 74 years	(12,570)	(2,342)	(7,304)	(4,885)	(6,839)
	41.5%	42.3%	44.3%	46.0%	41.8%
75 years and older	(20,861)	(2,236)	(11,133)	(5,240)	(10,672)

Source: U.S. Census, 2023 American Community Survey, 5-Year Estimates

### Race

State data indicates that, similar to literature, disabled individuals exhibit far higher rates of SDOH than other populations. For example, persons facing any disability were more likely to identify with non-white races, as well as to be older and have significantly higher rates of poverty than the non-disabled.

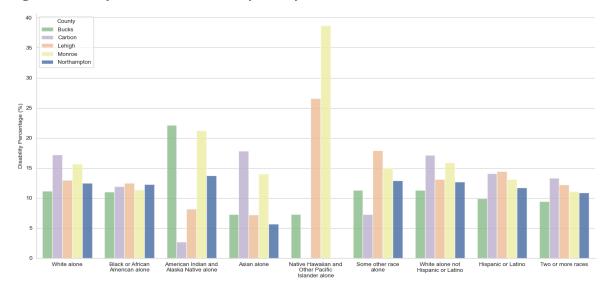


Figure 5: Race of Disabled Individuals by County

Source: U.S. Census, 2023 American Community Survey, 5-Year Estimates

# **Education**

Educational status of the general population shows stark differences between the counties, but we could not find education by disability or neurodivergent status.

Figure 6: Educational Status by County

Educational Attainment	Bucks	Carbon	Lehigh	Monroe	Northampton
Less than 9th grade	1.5%	1.7%	4.1%	3.1%	1.9%
9th to 12th grade, no diploma	2.8%	6.9%	5.9%	6.7%	3.8%
High school graduate/equivalent	28.2%	47.9%	32.1%	36.2%	33.4%
Some college, no degree	14.8%	16.6%	16%	18.7%	17.1%
Associate's degree	8.5%	8.5%	7.7%	8.5%	9.4%
Bachelor's degree	26.3%	10.3%	21.4%	17.8%	20.4%
Graduate or professional degree	17.9%	8.0%	12.7%	9.0%	14.0%
High school graduate or					
higher	95.7%	91.3%	89.9%	90.2%	94.3%
Bachelor's degree or higher	44.2%	18.3%	34.1%	26.8%	34.3%

Source: U.S. Census, 2023 American Community Survey, 5-Year Estimates

# **Poverty**

A significantly greater portion of disabled than non-disabled individuals live in poverty in the five-county region. Reliable data could not be obtained for these counties regarding neurodivergence, but it is likely to be similar to overall poverty rates for other disabled.

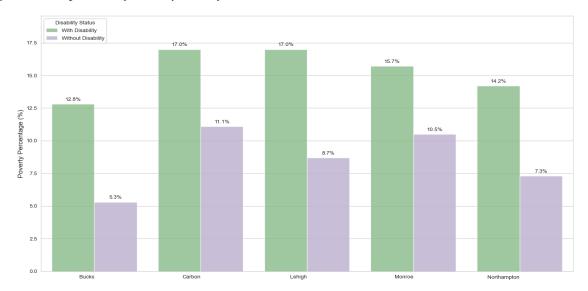


Figure 7: Comparison of Poverty Rates for Disabled and Non-Disabled Individuals

Source: U.S. Census, 2023 American Community Survey, 5-Year Estimates

# **Employment**

Additionally, most disabled individuals in the state remain unemployed, though the rates vary widely by county.

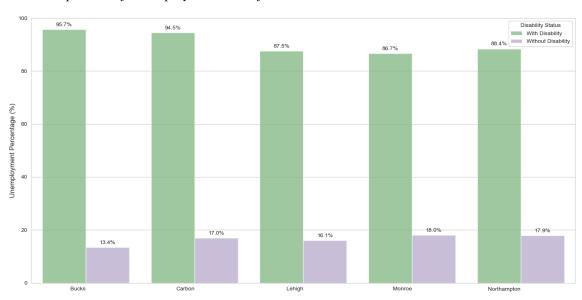


Figure 8: Comparison of Unemployment Rates for Disabled and Non-Disabled Individuals

Source: U.S. Census, 2023 American Community Survey, 5-Year Estimates

### **Limitations to the Data**

These secondary data are based on sound sampling techniques and should be considered reliable. However, the correlation between neurodivergence and "disability" is not always recognized. Some individuals with neurodivergent conditions may not consider themselves or be considered disabled at all, and hence would be left out of these statistics. Moreover, prevalence reported in state and national health statistics for many neurodivergent conditions indicates it is growing faster than the population nationwide. The exact reasons for this growth are unclear (Maenner, et al., 2023), but it calls the long-term reliability of any prevalence estimate into question. The ACS data do act as reasonable proxies for neurodivergent conditions in the short term, however, as long as these limitations are taken into account. For that reason and to gain the community's perspective, any conclusions to be drawn from this data are triangulated with intensive though time-limited primary data collection with the community itself.

# **VIII. Primary Data Collection**

CHNAs are required to have extensive community input in identifying the needs, strengths, and interests of the populations that healthcare centers serve. For the neurodivergent community, this includes professionals and families alongside neurodivergent individuals, as the neurodivergent often hold unique relationships to those they interact most frequently with. We therefore worked with the neurodivergent along with their families and, to a lesser extent, professionals they work with on a regular basis in collecting data for this CHNA.

Generally, findings from our primary data reflected existing research, with some notable suggestions. This is not surprising, as neurodiversity is increasingly studied, given the enormous increase in prevalence of neurodivergent conditions in recent years. Below, we discuss these findings based on broad themes that emerged from data collected from each group.

### **Professionals**

During preliminary listening sessions and subsequent interviews, we asked professionals about the autistic and neurodiverse individuals they worked with. Key themes that emerged were:

- 1. **Professionals (including front-line staff) can provide good insight** into the needs, strengths, and interests of neurodivergent individuals. As one participant said, who was both a parent and administrator, "Don't underestimate the perspective of the staff...I think that for us to continue to create and strengthen this community of supporting each other, those voices (should) have an impact, also."
- 2. **Families of neurodivergent individuals are important** voices for a Needs Assessment. Participants all relayed how vital the perspectives of family members were for understanding the strengths, needs, and interests of the neurodivergent, especially those with limited or no speech.
- 3. **Parents need to be more connected** to each other. The ones that were had built wonderful communities of support, but these did not extend to all parents.
- 4. **Parents need help navigating** the complex legal and policy systems in place, including education, employment, and healthcare. For younger parents with their first neurodivergent child, navigating these systems can be an especially large challenge. Moreover, parents need support to discover the rights that they have in the system.
- 5. **Young children** were clearly a priority for service provision in the community. For many, this was essential, given the importance of early diagnosis for so many. Those with less complex needs, including children with autism, ADHD, or other neurodiverse conditions who did *not* have co-occurring intellectual disabilities, have less access to services.
- 6. **Teens and adults** had few services available in the region. Needs that were mentioned include access to psychological services, "safe spaces" where they could work together on community-building activities, and the importance of more and stronger employment services, including transition programs for teens, soft skills training for all older employees, and other employment services—especially for neurodivergent adults.
- 7. **Tailored services** are required to meet patients' needs. Everyone who is neurodiverse has specific needs, strengths, and interests that depend on a host of other factors in their lives, including their age, their specific diagnosis, their family lives, etc.
- 8. Additionally, they referenced several **key societal needs**, specifically: affordable housing, improved transportation, and organizational staffing.

### **Individuals**

Not many neurodivergent individuals completed surveys, participated in listening sessions, or contributed to the academic literature referenced earlier in this report. A majority of our participants with disabilities come from Northampton County, which does not reflect the population distribution of the five-county region. However, the 18 that did respond offered several suggestions that complement our other data sources. As such, while the survey sample is not large enough to be considered significant, our results do offer reliable suggestions when considered in relation to our other findings.

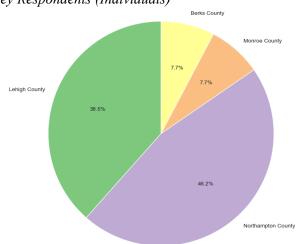


Figure 9: Location of Survey Respondents (Individuals)

They were mostly women between age 30 and 64, but men, children, young adults, and the elderly also participated. Over half of all respondents were white, and their disabilities varied. Most reported having ADHD (38.7%) and autism (25.8%), in line with national prevalence.

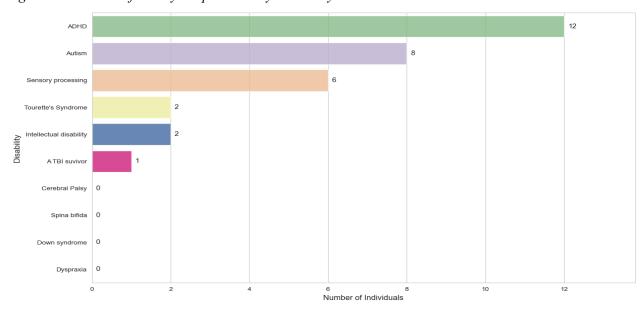


Figure 10: Number of Survey Respondents by Disability

Neither finding is as we would expect from the literature or secondary data analysis, but they are both what we would expect given that individuals with ADHD may be more accepted and consequently have more resources, energy, and independent time to complete our surveys than those with other neurodivergent conditions.

### Care

Neurodivergent respondents in our research were similar in terms of satisfaction with medical care, including mental health care. This is similar to what parents report but not to findings reported by professionals or in the literature. Given that our surveys were distributed through existing care and community service organizations, it is likely that individuals completing the surveys were already receiving care when they were given a link to the survey. Additionally, while many reported needing mental health care, reliable and trained counselors were hard to come by:

I wish it was easier to find a psychiatrist who specializes in neurodivergent conditions in adults, and more specifically how these conditions may manifest differently across demographics...In my experience, psychiatrists have consistently been the most dismissive and underinformed [of] my condition.

### **Person-Centered Services**

The large majority of respondents did *not* feel well understood by their colleagues or providers, nor did they have the services and supports they wanted in their daily lives. When asked what they would like more of, most responses were tailored to social supports for neurodivergent adults like support groups, peer mentoring, and coaching. As one said:

I feel lost, I feel like I have no identity since getting diagnosed. I don't know who I am, I struggled with that before getting diagnosed and it just got 10 times worse after. I don't really know what I need or want.

While this was the most extreme of the responses, others also mentioned the need for personally-relevant mental health and other care that respected neurodiversity. Several desired that their clinical and emotional healthcare providers would learn more about autism, neurodivergence, and the co-occurring health conditions that often go along with them.

# **School and Transition / Employment**

Most respondents were adults, and most of those reported that they did not have the supports they needed to succeed in their employment. The children largely reported that they *did* have enough supports to succeed in school. Neither group responded to questions about what supports they received or would like to receive, and clearly more research is needed to fully address these key sectors of neurodivergent services.

### **Community Living**

Most respondents reported living with others and having others nearby that they could rely on. Some lived with parents, while others reported living with spouses, other family members, or roommates. Most suggested that they needed these others around them for emotional support,

accountability, and help with transportation. The large majority of respondents (91%) said that they had people they could rely on in their lives. This contradicts what research says, suggesting that those that were able to complete surveys had enough supports in their lives to do so. Further research is needed to explain this discrepancy. Only one answered our question about who they would *like* to be able to rely on, answering only "Family."

Most notably, individuals with disabilities were asked if they felt that those they encountered in their communities understood them and treated them with respect. While it is certainly not necessary for disabled individuals living independently in the community to feel understood or respected, it is much more important for those who are integrated into their communities. Curiously, most of our neurodivergent respondents reported that their communities treated them with respect (58%), while a larger number reported that people around them did not understand them (67%). They did not comment on how they were treated or would like to be treated. Neither of these figures are what we would have expected from the literature, our listening sessions, and our interviews. More research is necessary to determine the true level of respect that neurodivergent individuals feel in their communities.

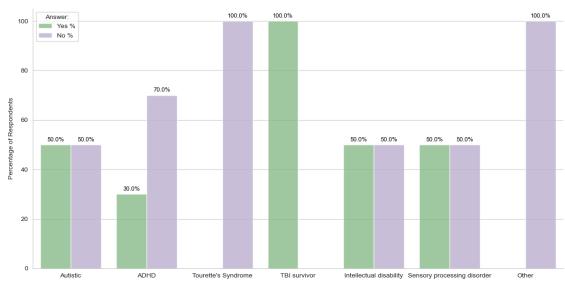


Figure 11: Individual Perception of Respect by Disability

# **Families**

Family members expressed several needs that corroborated our findings. As expected per population, the majority of those we surveyed lived in Lehigh County, with smaller amounts in other counties.

	Percentage
Bucks	1.2%
Carbon	0.0%
Lehigh	55.3%
Monroe	7.1%
Northampton	34.1%
Other	8.3%

The large majority surveyed were women (83.5%), mostly with neurodivergent boys (61%) who are relatively young. This suggests that respondents were mostly mothers who were young and healthy enough to care for their neurodiverse children.

Figure 12: Disabled Dependents' Age

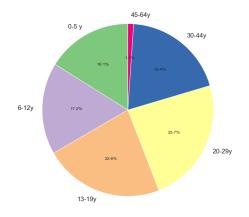
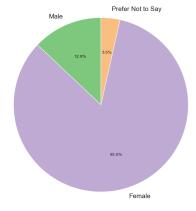


Figure 13: Family Member Respondents' Gender



### Healthcare

The large majority felt that their children have the healthcare services that they need in their lives. These included traditional therapies, as well as employment services from Vocational Rehabilitation and others, Disability Transportation, and direct support from family members. Additionally, family members felt that neurodiverse individuals had the services and supports they needed to succeed at school, in their work, and in the community at large.

Does your child or family member have the services and supports they need at work or school?

Yes

Does your child or family member have the services and supports they need in their daily lives?

Does your child or family member have access to the healthcare they need?

No

Yes

Does your child or family member have access to the healthcare they need?

No

Yes

Figure 14: Perceived Activeness and Accessibility for Healthcare and Social Environments

This is clearly at odds with the literature and other data sources included in this CHNA. It seems likely, given our research, that the age or respondents' children (school-based and young enough to have benefitted from recent developments in school-based transition education for teens and young adults) biased this data.

# **Person-Centered Services and Supports**

Parents also expressed the need for more person-centered services that were tailored specifically for their child. This is unsurprising, considering the wide variety of neurodivergent conditions that parents reported (see appendix). The supports that they desired for their children rarely

included increased traditional therapies and services, instead focusing on social support, recreational activities, and more holistic treatments like music and arts-based creative therapies.

### **School and Transition**

The majority of parents reported that their children received the services they needed in school. They also requested more socialization help for their children, along with increased transition classes, programs for them after school ends, on weekends, and during summer months, and programs and holistic educational services that are tailored for their child's particular needs and interests inside and outside of school.

# **Employment**

Along with increased transition services, parents requested job coachings for their children, and help with advocacy, both for themselves and self-advocacy training for their children.

# **Community Living**

Many parents reported that they supported their children living at home and that they did not receive HCBS. Some were concerned for what would happen to their child when they passed away or if their child wanted to live on their own in the community. Several requested help with life skills training along with employment training to help their children live independently, suggesting that there is limited information about what kinds of supports would help their children live independently and become independently integrated in the community.

Surprisingly, over 80% of parents largely felt that people treated their neurodivergent children with respect. This is not only different from the literature and our interviews with professionals, but it differs significantly from neurodivergent individuals expressed sentiments (see above) and differs from the number who they think understands their neurodivergent children. We suspect that this is in part because most of the parents who responded to our survey felt their children had adequate medical coverage and that their medical providers understood them. It is possible that their answers to this question largely reflected that, but clearly more research is necessary to understand this seemingly contradictory response.

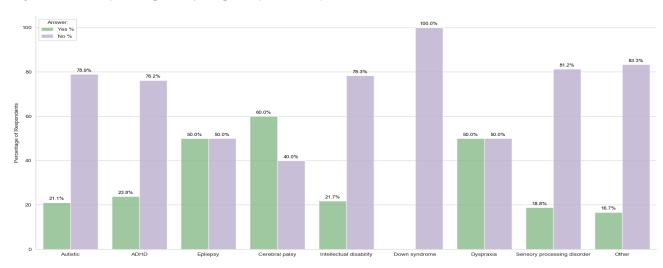


Figure 15: Family Perception of Respect by Disability

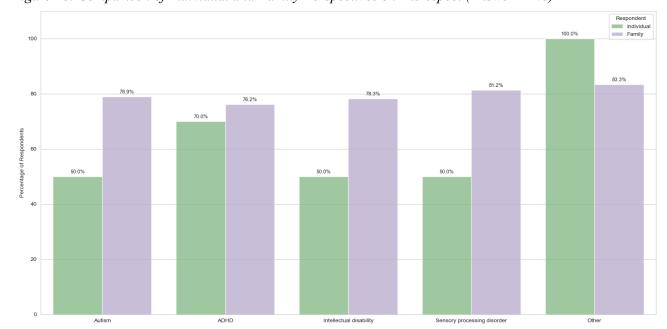


Figure 16: Comparison of Individual and Family Perspectives on Disrespect (Answer = No)

# Limitations with the Survey Data

The above data, when assessed independently of each other, are not robust. However, when examined together and against existing secondary data and research findings, several key conclusions can be drawn, with the following key limitations and considerations:

### Healthcare

According to survey data, many individuals with disabilities in the Greater Lehigh Valley have access to the healthcare services they need. However, access to healthcare services is largely dependent upon healthcare coverage, just as it is for residents who do not have disabilities, suggesting that those who completed our surveys had sufficient personal or family resources to afford adequate healthcare coverage. Therefore, it is reasonable to assume that respondents who were able to complete our surveys had the resources to afford good healthcare coverage, which is at odds with data stating high poverty rates for disabled persons in the five-county area. Clearly more research must be done with diverse methodologies that can reach poorer residents who do not have the resources to afford adequate healthcare.

### **Person-Centered Services**

Person-centered services are extremely broad. Given the relatively small number of survey respondents, the ideal scope of these services could not be assessed. For that reason, Good Shepherd must seek to clearly identify what person-centered services and care should look like in its patient population.

### **Schooling and Transition**

Children, especially children with significant I/DD, may not be able to complete surveys. In other research, these surveys have often been complicated by parents or aids completing the

surveys in children's places. There is very little data that we could get from them to contribute to this report. Additionally, because transition services overlap with the education system, further study and strategizing on how to positively impact them is clearly required.

### **Employment**

Most of our individual respondents were employed. Individuals who are either unemployed and looking for work or are unemployed and unable to work may not have had the time or resources to respond to our surveys. Additionally, reaching them might require more outreach to local communities than was possible with this study.

# **Community Living**

Like person-centered services, the details of community living are very specific to each person. More importantly, there is a significant amount of academic and professional research conducted about HCBS and other services that allow those with neurodivergent conditions to thrive in the community. While our results do allow us to draw some conclusions and make a few recommendations about community living, the matter is far beyond the scope of this CHNA.

### IX. Recommendations

Responding to these findings, we have developed several recommendations for Good Shepherd regarding new programs and services for neurodiversity in the region.

### 1. General Recommendations

- a. **Neurodiversity Center:** From the above findings, a Center for Neurodiversity could greatly benefit the Greater Lehigh Valley. This center should attempt to serve a range of neurodivergent conditions across age ranges, not solely children with autism, ADHD, and other commonly known neurodivergent conditions.
- b. **Future Research**: The present CHNA suggests some outlines for programming and services offered in this center, because of its limitations, could not fully explore them. Further research will benefit such a center enormously.
- c. **Diverse Perspectives:** Incorporate individual, families, and professional perspectives, as each of these groups has need for support and plays an important role in helping neurodivergent individuals to succeed.

### 2. Healthcare

- a. **Diverse Approach**: The well-being and success of neurodivergent individuals requires more than traditional healthcare and rehabilitation. Services should be far-ranging, innovative, and cover more than bodily health.
- b. **Mental Health**: Counseling and other mental health services must be a key part of any treatment for neurodivergent conditions. These services should be offered for neurodivergent individuals, their families, and caregivers.
- c. **Coordination**: Any program for neurodivergent individuals and their families need to ensure coordination and cooperation between the diverse services and treatments they receive in the community.

### 3. Person-Centered Services

- a. **All Ages**: Neurodivergent needs vary by age. Treatments and services for neurodivergent individuals must be tailored for their specific age in life.
- b. **Focus on Strengths**: Services should boost the particular strengths of neurodivergent individuals, along with their families and communities.
- c. **Holism**: Services must be far-reaching for each patient, treating their well-being beyond their physical functioning and health.

### 4. Education and Transition

- a. Work with Schools: Good Shepherd should conduct outreach with local schools and employers of neurodivergent individuals, raising awareness and promoting inclusive practices.
- b. **Emotional Services**: These must include awareness of and services for neurodivergent individuals' psychological and emotional health.
- c. **Postsecondary Outreach**: Increasing numbers of neurodivergent students are enrolling in colleges and universities. Outreach should include these institutions and seek to bolster their neurodiversity services.

# 5. Employment

- a. **Career Planning**: Neurodivergent individuals and their families should begin planning for employment at a young age and develop the plan as they grow.
- b. **Low-income and Minority Populations**: Services should be extended to low-income and other underserved minority populations.
- c. **Workplace Accommodation**: Good shepherd should develop strategies to conduct outreach with patients' employers, raising awareness and advising on neurodivergent-specific services.

# 6. Community Inclusion

- a. **Community Advocacy**: Much of the community lacks awareness about and knowledge of neurodiversity. Outreach and advocacy should be key activities of any programming.
- b. **Socialization**: Neurodivergent individuals have challenges with socialization. Diverse services should be tailored for all age ranges.
- c. **Caregiver Support**: Caregivers and family members need support in providing informal and personal care to neurodivergent individuals. They should be given respite and other support.

### 7. Short-Term Goals

- a. **Community Stakeholders**: Good Shepherd should seek to convene a community stakeholder board with representatives from each category.
- b. **Further Research Initiatives**: Good Shepherd should seek to conduct a larger and more time-intensive study of the specific needs, strengths, and interests of the neurodivergent communities they will serve with their programs and services.
- c. **Public Outreach**: Good Shepherd should launch a sustained public awareness-raising and outreach campaign about their neurodivergence.

# 8. Long-Term Goals

- a. **Work with Local Researchers**: Good Shepherd should partner with local disability researchers and community partners to study the long-term effects of their services on health and life outcomes.
- b. **Public Outreach**: Good Shepherd should seek to have a sustained program of public outreach that focuses on awareness raising of neurodiversity.
- c. **Satellite Services**: Many neurodivergent individuals live in remote areas that are far from available services. Good Shepherd should seek to have established satellite campuses and other arms of its neurodivergence services.

### 9. Community Goals

- a. **Support Neurodiversity**: The community of the Lehigh Valley should support neurodiversity in its schools and public services.
- b. **Build Awareness**: The community should seek to raise awareness and increase acceptance of the neurodivergent through the Lehigh Valley.
- c. **Key Issues** (Housing, Transportation, Staffing): The communities of the Lehigh Valley should seek to address key issues facing the neurodivergent community: housing, transportation, and staffing of neurodiversity-serving organizations.

# X. Appendices

1. Su	rvey Questions
Welc	ome!
anony are o	k you for participating in this survey. Your insights are very valuable. This survey is ymous, and your responses will not be linked to your identity. Please know that all questions ptional. If at any point you feel uncomfortable answering a question, you are free to skip it. may stop the survey at any time without consequence.
Are y	you a(n):
	☐ Individual with a neurodiverse condition (Autism, ADHD, brain injury, etc.)
	$\Box$ Family member of an individual with a neurodiverse condition (Autism, ADHD, brain injury, etc.)
	☐ Professional who treats, works with, or serves individuals with neurodiverse conditions (Autism, ADHD, brain injury, etc.) and their families
Indiv	idual Section
1.	. I identify as:
	☐ Autistic
	☐ A person with ADHD
	$\square$ A person with Tourette's Syndrome or other tic disorder
	☐ A TBI survivor
	☐ A person with Cerebral palsy
	☐ A person with Spina bifida
	☐ A person with Intellectual disability
	☐ A person with Down syndrome
	☐ A person with Dyspraxia
	☐ A person with sensory processing disorder

	☐ Other (please specify)
2.	Do you experience any of the challenges listed (check all those you experience):
	☐ Depression
	☐ Anxiety
	☐ Prefer not to say
	☐ Other Mental Health or Emotional Challenges
3.	What is your age?
	□ under 18
	□ 19-29
	□ 30-64
	$\square$ 65 and older
4.	What is your gender?
	□ Male
	☐ Female
	□ Non-binary / third gender
	☐ Prefer not to say
	☐ Prefer to self-describe
5.	What is your race or ethnicity?
	□ White
	☐ Black or African American
	☐ American Indian or Alaska Native
	□ Asian
	☐ Native Hawaiian or Pacific Islander
	☐ Hispanic or Latino
	☐ Prefer not to say

	□ Other
6.	Where do you live?
	☐ Lehigh County
	☐ Northampton County
	☐ Monroe County
	☐ Berks County
	☐ Montgomery County
	☐ Carbon County
	☐ Schuylkill County
	☐ Bucks County
	☐ Other (please specify)
7.	I have enough to do during the day.
	□ Yes
	8. (If Yes) What activities do you like to do?
	□ No
	9. (If No) What activities would you like to do more of?
10	. I have the services and supports I need to succeed at my school or job.
	□ Yes
	11. (If Yes) What services and supports do you receive?
	□ No
	12. (If No) What would you like to help you succeed?
13.	. I have the services and support I want in my daily life.
	□ Yes
	14. (If Yes) What services and supports do you receive?
	$\sqcap$ No

15. (If No) What do you want more of?
16. The people I usually interact with understand me.
□ Yes
17. (If Yes) What about other people?
□ Yes
□ No
□ No
18. (If No) What do you want them to know about you?
19. The people around me treat me with respect and as I want to be treated
□ Yes
20. (If Yes) How about other people in your community?
□ Yes
□ No
□ No
21. (If No) How do they treat you?
22. I am satisfied with the medical care I receive.
□ Yes
23. (If Yes) How often do you see your medical providers?
□ No
24. (If No) What would you like?
25. I am satisfied with the mental health care I receive.
□ Yes
26. (If Yes) What care do you receive?
□ No
27. (If No) What changes would you make to the care you receive?

28	. I have people that I can rely on in my life.
	□ Yes
	29. (If Yes) How do you rely on them?
	□ No
	30. (If No) Who would you like to be able to rely on?
Family	y Section
1.	I am a parent or family member of an:
	☐ Autistic Individual
	☐ A person with ADHD
	☐ A person with epilepsy
	☐ A TBI survivor
	☐ A person with Cerebral palsy
	☐ A person with Spina bifida
	☐ A person with Intellectual disability
	☐ A person with Down syndrome
	☐ A person with Dyspraxia
	☐ A person with Sensory Processing Disorder
	☐ Other (please specify)
2.	What is your gender?
	☐ Male
	☐ Female
	□ Non-binary / transgender
	☐ Prefer not to say
3.	What is your race or ethnicity?

	☐ White
	☐ Black or African American
	☐ American Indian or Alaska Native
	☐ Asian
	☐ Native Hawaiian or Pacific Islander
	☐ Hispanic or Latino
	☐ Prefer not to say
	□ Other
4.	Where do you live?
	☐ Lehigh County
	☐ Northampton County
	☐ Monroe County
	☐ Berks County
	☐ Montgomery County
	☐ Carbon County
	☐ Schuylkill County
	☐ Bucks County
	☐ Other (please specify)
5.	What is the age of your child or family member with a neurodiverse condition?
	□ 0-5 years
	□ 6-12 years
	☐ 13-19 years
	☐ 20-29 years
	☐ 30-44 years
	☐ 45-64 years

	$\Box$ 65 or more years
6.	What is the gender of your child or family member with a neurodiverse condition?
	□ Male
	☐ Female
	□ Non-binary / transgender
	☐ Prefer not to say
7.	What is the race or ethnicity of your child or family member with a neurodiverse condition?
	□ White
	☐ Black or African American
	☐ American Indian or Alaska Native
	☐ Asian
	☐ Native Hawaiian or Pacific Islander
	☐ Hispanic or Latino
	☐ Prefer not to say
	□ Other
8.	Where does your child or family member with a neurodiverse condition live?
	☐ Lehigh County
	□ Northampton County
	☐ Monroe County
	☐ Other (please specify)
9.	Does your child or family member have a diagnosis of a neurodiverse condition?
	□ Yes
	10. (If Yes) What Diagnosis does your child or family member have?
	11. (If Yes) How long did it take to receive this diagnosis?
	☐ Within 6 months

☐ 6 months to 1 year
☐ More than 1 year
☐ Still seeking a diagnosis
□ Not sure
□ No
12. (If No) Are you currently in the process of obtaining a diagnosis for your child or family member, or have you tried to obtain one in the past?
$\square$ Yes, I am currently in the process of obtaining a diagnosis
$\square$ Yes, I have tried to obtain a diagnosis in the past
☐ No, I have not tried to obtain a diagnosis
☐ Prefer not to say
13. Do you feel that your neurodiverse child or family member has enough to do during the day?
□ Yes
14. (If Yes) What kinds of activities, programs, or support do they currently have
during the day?
□ No
15. (If No) What would you like them to be able to do during the day?
16. Does your child or family member have the services and supports they need at work or school?
□ Yes
17. (If Yes) What services and supports do they currently receive at work or school?
□ No
18. (If No) What services and supports do you think they should have or have more of?
19. Does your child or family member have the services and supports they need in their daily lives?

□ Yes
20. (If Yes) What services and supports do they receive?
21. (If Yes) How far away do you need to travel to receive the treatment?
□ No
22. (If No) What should they have more of?
23. Do you have the services and supports in your community that you need to help your child or family member succeed?
□ Yes
24. (If Yes) What services and supports do you receive?
□ No
25. (If No) What do you want more of?
26. What kinds of social opportunities do you wish existed for your child?
27. Do you feel like most people treat your child or family member with respect?
□ Yes
28. (If Yes) How about other people in your community?
$\square$ No
29. (If No) How do they treat your child?
30. Does your child or family member have access to the healthcare they need?
□ Yes
31. (If Yes) What do they receive?
□ No
32. (If No) What would you like to see for them?
33. Does your child or family member's clinical providers understand their neurodiverse condition?
□ Yes
34. (If Yes) How do they show it?

$\square$ No	
35. (If No) What do you think they should learn?	
36. Does your child or family member receive the mental and behavioral health care that the need?	ey
□ Yes	
37. (If Yes) What care do they receive?	
$\square$ No	
38. (If No) Why do they not receive the care they need?	
39. Does your child or family member have adequate healthcare insurance?	
□ Yes	
40. (If Yes) What services does it cover?	
□ No	
41. (If No) What services does it not cover that your child needs?	
42. Do you feel like the public has enough understanding of your child or family member at other neurodiverse conditions?	nc
□ Yes	
43. (If Yes) How do they show it?	
□ No	
44. (If No) What more should they learn?	
45. Are you connected to other parents or family members of neurodiverse individuals?	
□ Yes	
46. (If Yes) How are you connected to them?	
□ No	
47. (If No) What sorts of connections would you like to have?	
48. Do you feel that your child or family member is prepared for success in their future?	
□ Ves	

	49. (If Yes) What supports or services would help them in their success?
	$\square$ No
	50. (If No) What supports or services would help them to be successful?
	51. What benefits does living in the Lehigh Valley have for your child or family member?
	52. What is not available for your child or family member that they need or want in the Lehigh Valley?
	53. What opportunities or possibilities exist for your child or family member here in your community?
	54. What challenges or barriers does your child or family member face?
	55. Do you have any suggestions for how we could improve services and supports for your child or family member and others like them in the Lehigh Valley?
Pr	ofessionals Section
	1. What organization do you work for?
	2. What is your professional role?
	☐ Administrator
	□ Staff
	3. What is your or your organization's medical or other specialty?
	4. What is the age range of patients or clients that you serve? (select all that apply)
	☐ Pediatric
	☐ Young adult
	☐ Adult
	5. What programs, treatments, or services does your organization provide for neurodiverse individuals and/or their family members?

- 6. What interactions do you have with neurodiverse individuals and/or their family members? If possible, please describe their typical age, gender, race, and location as well.
- 7. What neurodiverse populations do you feel are being prioritized in the Lehigh Valley?
- 8. Are there any neurodiverse populations that you feel are being underserved in the Lehigh Valley?
- 9. What barriers does your organization face in serving neurodiverse individuals?
- 10. What type of additional training or resources would help you or your team better serve neurodiverse clients?
- 11. What strengths does the Lehigh Valley have for individuals who are neurodiverse and their families?
- 12. What gaps does the Lehigh Valley have in serving or caring for individuals who are neurodiverse and their families?
- 13. What possibilities exist for improving care and services for individuals who are neurodiverse and their families in the Lehigh Valley?
- 14. What barriers exist for individuals who are neurodiverse and their families in the Lehigh Valley?
- 15. What are the most common reasons for appointments being cancelled or missed among your patients?
- 16. Is there anything else that you would like to say about the needs and interests of individuals who are neurodiverse and their families in the Lehigh Valley?

**End of Survey** 

# 2. List of Neurodivergent Conditions

Many conditions may be considered neurodivergent. Some of the most common include:

- Autism Spectrum Disorder (ASD), also called Autism: A developmental condition
  affecting communication, social interaction, and behavior, with a wide range of
  presentations and abilities.
- Attention-deficit hyperactivity disorder (ADHD): A neurodevelopmental disorder marked by inattention, impulsivity, and hyperactivity that interferes with daily functioning.
- DiGeorge syndrome: A genetic disorder caused by a deletion on chromosome 22, which leads to heart defects, immune system problems, and developmental delays.
- Down syndrome: A genetic condition caused by an extra chromosome 21, associated with intellectual disability, distinct facial features, and developmental delays.
- Dyscalculia: A learning disability that makes it difficult to understand numbers and mathematical concepts
- Dysgraphia: A learning disorder that affects writing abilities, including spelling, handwriting, and organizing thoughts on paper.
- Dyslexia: A specific learning disability that impairs a person's ability to read, spell, and decode words.
- Dyspraxia: A developmental disorder affecting motor coordination and physical movement planning.
- Intellectual disabilities: Conditions characterized by limitations in intellectual functioning and adaptive behaviors, often noticeable before age 18.
- Mental health conditions: Disorders like bipolar disorder or OCD that affect mood, thinking, or behavior and impact daily life and functioning.
- Prader-Willi syndrome: A rare genetic disorder causing low muscle tone, constant hunger, intellectual disability, and hormonal issues.
- Sensory processing disorders: Conditions where the brain has trouble receiving and responding to sensory information, leading to over- or under-sensitivity.
- Social anxiety disorder: An intense fear of social situations where one might be judged, leading to avoidance or severe distress.
- Tourette syndrome: A neurological disorder characterized by repetitive, involuntary movements and vocalizations called tics.
- Williams syndrome, also called Williams-Beuren Syndrome: A rare genetic condition causing developmental delays, strong verbal abilities, a friendly personality, and cardiovascular problems.

# **3. List of Neurodiversity Organizations and Contact Information (By Category)** Support Services

- Access Services (3975 Township Line Road, Bethlehem, PA 18020)
   <a href="https://www.accessservices.org/">https://www.accessservices.org/</a>
- Autism Society Lehigh Valley (PO Box 3523 Allentown, PA 18106) https://asalehighvalley.org/
- Bucks County Intellectual Disabilities/Autism Services (via Bucks County ODP) (Bucks County Administration Building 55 East Court Street, Doylestown, PA 18901)
   https://www.buckscounty.gov/962/Intellectual-DisabilitiesAutism-Services)
- Carbon Lehigh Intermediate Unit (CLIU #21) (4210 Independence Drive, Schnecksville, PA 18078)

http://www.cliu.org/

- Carbon-Monroe-Pike Mental Health and Developmental Services (MH/DS) Program (10 Buist Road #404, Milford, PA 18337)
  - https://www.cmpmhds.org/
- Centers for Independent Living of the Lehigh Valley (713 N. 13th Street, Allentown, PA 18102)

https://lvcil.org/

- Bucks County Center for Independent Living (3466 Progress Drive Suite 111, Bensalem, PA 19020)
  - http://buckscil.org/
- Developmental Education Services (400 Powerhouse Lane, Stroudsburg, PA 18360)
   <a href="https://devedmc.org/">https://devedmc.org/</a>
- Devereux Pocono Center (1547 Millcreek Road, Newfoundland, PA 18445) <a href="https://www.devereux.org/site/SPageServer/?pagename=pa\_pocono\_center">https://www.devereux.org/site/SPageServer/?pagename=pa\_pocono\_center</a>
- Lehigh County Intellectual Disabilities Program https://www.lehighcounty.org/Departments/Human-Services/Intellectual-Disabilities
- Pocono Autism Society <u>http://www.poconoautism.org/</u>
- Supports Coordination Services

https://www.buckscounty.gov/1011/Supports-Coordination

- o Lenape Valley Foundation (621 N. Shady Retreat Road, Doylestown, PA 18901)
- o St. Luke's Penn Foundation (64 N. County Line Road, Souderton, PA 18964)
- Penndel Mental Health Center (2005 Cabot Blvd West, Suite 100, Langhorne, PA 19047)
- The Arc of Lehigh and Northampton Counties (2289 Avenue A, Bethlehem, PA 18017) https://arcoflehighnorthampton.org/
- Via of the Lehigh Valley (336 W Spruce Street, Bethlehem, PA 18018)
   <a href="https://www.vianet.org/">https://www.vianet.org/</a>

# Therapy and Counseling

- Acorn Health ABA Therapy (6990 A Snowdrift Road Suite 200, Allentown, PA 18106)
   https://www.acornhealth.com/
- Neurodiverse Counseling Associates, LLC (1011 Brookside Road Suite 122F, Allentown, PA 18106)

https://www.neurodiversecounselingassociatesllc.com/

• Dustan Barabas, PsyD. (1801 W. Main Street, Stroudsburg, PA 18360, telehealth available)

http://poconopsychologist.com/

- Center For Integrated Behavioral Health (1 E. Broad Street STE 510, Bethlehem, PA 18018) https://www.centerforibh.com/
- Helping Hands Family ABA Therapy (3790 West Drive, Center Valley, PA 18034; and 1510 Valley Center Parkway, Bethlehem, PA 18017)
   <a href="https://hhfamily.com/locations/lehigh-valley-pa">https://hhfamily.com/locations/lehigh-valley-pa</a>
- Lehigh University Autism Services (111 Research Drive, Bethlehem, PA 18015) https://ed.lehigh.edu/research/lehigh-university-autism-services
- Lehigh Valley Center for Child and Family Development (1005 Brookside Road #105, Allentown, PA 18106)

https://www.lvccfd.com/

 Lotus Behavioral Health Services (Casa Guadalupe Center, 218 N 2nd Street, Allentown, PA 18102, telehealth available)

https://lotusbhs.com/

 NeurAbilities Healthcare (2760 Emrick Blvd, Bethlehem, PA 18020; 1405 N. Cedar Crest Boulevard Suite 109, Allentown, PA 18104)

https://neurabilities.com/

• Pine Laurel Wellness (1513 Evergreen Road, Pocono Pines, PA 18350, telehealth available)

http://pinelaurelwellness.com/

- Positive Intentions, LLC (811 Monroe Street, Stroudsburg, PA 18360)
   http://www.positiveintentionsllc.com/
- Pro Neuro Counseling
   https://propourceounseling
  - https://proneurocounseling.com/
- Spectrum of Solutions (546 Hamilton Street #100, Allentown, PA 18101) <a href="http://spectrumss.com/">http://spectrumss.com/</a>
- The ReDCo Group (110 S 1st Street, Lehighton, PA 18235; 564 Main St, Stroudsburg, PA 18360)

http://www.redcogrp.com/

 Thriveworks Counseling & Psychiatry Allentown (1320 Hausman Road Suite 100, Allentown, PA 18104, telehealth available)
 https://thriveworks.com/allentown-counseling/ • ZimZum Consulting (20 S. Fourth St, Emmaus, PA 18049, telehealth available) http://www.zimzumcc.com/

### Education and Vocational Training

 ACHIEVE Program at Bucks County Community College (275 Swamp Road, Newtown, PA 18940)

https://www.bucks.edu/

- Associated Production Services (APS): A community-based work setting ideal for adults with employment challenges.
- Bethlehem Area Vocational-Technical School (3300 Chester Avenue, Bethlehem, PA 18020)

http://www.bethlehemavts.org/

- Bucks County Intermediate Unit (705 N. Shady Retreat Road, Doylestown, PA 18901)
   http://www.bucksiu.org/
- Carbon Lehigh Intermediate Unit (4210 Independence Drive, Schnecksville, PA 18078)
   <a href="http://www.cliu.org/">http://www.cliu.org/</a>
- Colonial Intermediate Unit (6 Danforth Drive, Easton, PA 18045)
   <a href="http://www.ciu20.org/">http://www.ciu20.org/</a>
- Developmental Education Services (400 Powerhouse Lane, Stroudsburg, PA 18360)
   <a href="https://devedmc.org/">https://devedmc.org/</a>
- ESU Autism Education Center (200 Prospect Street, East Stroudsburg, PA 18301) www.esu.edu/autism-education-center
- Goodwill Keystone Area & Clubhouse (1901 Lehigh Street, Allentown, PA 18103)
   <a href="https://www.yourgoodwill.org/services/employment-services">https://www.yourgoodwill.org/services/employment-services</a>
- Lehigh County Adult Mental Health Vocational Programs
  <a href="https://www.lehighcounty.org/Departments/Human-Services/Mental-Health/Adult-Mental-Health/Vocational-Programs">https://www.lehighcounty.org/Departments/Human-Services/Mental-Health/Adult-Mental-Health/Vocational-Programs</a>
- Northampton Community College (3835 Green Pond Road, Bethlehem, PA 18020) <a href="https://www.northampton.edu">https://www.northampton.edu</a>
- Office of Vocational Rehabilitation (45 N. 4th Street, Allentown, PA 18102) https://www.lehighcounty.org/Departments/Human-Services/Mental-Health/Adult-Mental-Health/Vocational-Programs

Application at:

https://www.pa.gov/services/dli/apply-for-vocational-rehabilitation-services

- PA Inclusive (22 East Street Suite 3, Pittston, PA 18640)
   <a href="https://www.painclusive.org/">https://www.painclusive.org/</a>
- Pennsylvania CareerLink (555 Union Boulevard, Allentown, PA 18109)
   <a href="http://www.careerlinklehighvalley.org/">http://www.careerlinklehighvalley.org/</a>
- The Next Step Programs (TNS) (204 N. West Street STE 102, Doylestown, PA 18901) <a href="http://tnsprograms.org/">http://tnsprograms.org/</a>

#### Transition Services

- Fitzmaurice Community Services (2115 N. 5th Street, Stroudsburg, PA 18360) <a href="http://www.fitzmaurice.org/">http://www.fitzmaurice.org/</a>
- Indian Creek Foundation (420 Cowpath Road, Souderton, PA 18964) http://indcreek.org/
- PA Secondary Transition
   https://www.pasecondarytransition.com/
- The National Technical Assistance Center on Transition https://transitionta.org/
- The Neurodiversity Employment Network https://neurodiversityemploymentnetwork.org/about/
- Transition Consults, LLC http://www.transitionconsults.com/

#### Rehabilitation

- Clarvida Behavioral Health Monroe County (564 Main Street, Stroudsburg, PA 18360) https://www.clarvida.com/
- Easton Neuropsychology and Behavioral Services, LLC (299 Industrial Drive, Nazareth, PA 18064)
  - http://eastonneuropsychology.com/
- Good Shepherd Rehabilitation Network (3200 Center Valley Parkway, Center Valley, PA 18034
  - https://www.goodshepherdrehab.org/
- Lehigh Valley Health Network (3900 Sierra Circle, Center Valley, PA 18034)
   <a href="https://www.lvhn.org/">https://www.lvhn.org/</a>
  - Rehabilitation Services (1148 W. Main Street, Stroudsburg, PA 18360)
     <a href="https://www.lvhn.org/locations/rehabilitation-services-stroudsburg">https://www.lvhn.org/locations/rehabilitation-services-stroudsburg</a>
- St. Luke's (locations statewide) https://www.slhn.org/

## Advocacy and Support Groups

- The Arc of Pennsylvania (1007 Mumma Road # 100, Lemoyne, PA 17043) <a href="https://thearcpa.org/">https://thearcpa.org/</a>
- Disability Rights Pennsylvania (301 Chestnut Street # 300, Harrisburg, PA 17101)
   <a href="https://www.disabilityrightspa.org/">https://www.disabilityrightspa.org/</a>
- NAMI Keystone Pennsylvania (105 Braunlich Drive # 200, Pittsburgh, PA 15237) https://www.namikeystonepa.org/
- PA Family Network
   https://www.visionforequality.org/programs/pa-family-network/

#### 4. References

Anderson, K., Rast, J., Roux, A., Garfield, T., & Shattuck, P. (2020). National autism indicators report: Children on the autism spectrum and family financial hardship. Life Course Outcomes Program, A.J. Drexel Autism Institute, Drexel University.

Armstrong, T. (2012). Neurodiversity in the classroom: Strength-based strategies to help students with special needs succeed in school and life. ASCD.

Armstrong, T. (2015). The myth of the normal brain: Embracing neurodiversity. AMA Journal of Ethics, 17(4), 348–352. <a href="https://doi.org/10.1001/journalofethics.2015.17.4.msoc1-1504">https://doi.org/10.1001/journalofethics.2015.17.4.msoc1-1504</a>

Aro, T., Eklund, K., Eloranta, A.-K., Närhi, V., Korhonen, E., & Ahonen, T. (2019). Associations between childhood learning disabilities and adult-age mental health problems, lack of education, and unemployment. Journal of Learning Disabilities, 52(1), 71–83. https://doi.org/10.1177/0022219418775118

Babalola, T., Sanguedolce, G., Dipper, L., et al. (2024). Barriers and facilitators of healthcare access for autistic children in the UK: A systematic review. *Review Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s40489-023-00420-3

Baumer, N., & Frueh, J. (2021, November 23). What is neurodiversity? Harvard Health Blog. <a href="https://www.health.harvard.edu/blog/what-is-neurodiversity-202111232645">https://www.health.harvard.edu/blog/what-is-neurodiversity-202111232645</a>

Baio, J. (2012). *Prevalence of autism spectrum disorders—Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008.* Morbidity and Mortality Weekly Report: Surveillance Summaries, 61(SS03), 1–19. https://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm

Botha, M., Chapman, R., Onaiwu, M. G., Kapp, S. K., Ashley, A. S., & Walker, N. (2024). *The neurodiversity concept was developed collectively: An overdue correction on the origins of neurodiversity theory. Autism, 28(6), 1591–1594.* <u>https://doi.org/10.1177/13623613241237871</u>

Butti, M., Diano, M., Amadeo, M. B., Calabrò, A., Villani, D., & Benso, F. (2024). *Social perception and neuropsychological profile in adolescents and adults with Williams syndrome: A virtual reality study*. Scientific Reports, 14, Article 1334. https://doi.org/10.1038/s41598-024-79289-z

U.S. Centers for Disease Control and Prevention (CDC). (2019). CDC. Surveillance report of traumatic brain injury-related emergency department visits, hospitalizations, and deaths—United States, 2014. Atlanta, GA: Department of Health and Human Services.

- Chang, H.-K., Hsu, J.-W., Wu, J.-C., Huang, K.-L., Chang, H.-C., Bai, Y.-M., Chen, T.-J., & Chen, M.-H. (2018). Traumatic brain injury in early childhood and risk of attention-deficit/hyperactivity disorder and autism spectrum disorder: A nationwide longitudinal study. *The Journal of Clinical Psychiatry*, 79(6), 17m11857. https://doi.org/10.4088/JCP.17m11857
- Chapman, R., & Botha, M. (2023). Neurodivergence-informed therapy. *Developmental Medicine and Child Neurology*, 65(3), 310–317. <a href="https://doi.org/10.1111/dmcn.15384">https://doi.org/10.1111/dmcn.15384</a>
- Chawner, S. J. R. A., & Owen, M. J. (2022). Autism: A model of neurodevelopmental diversity informed by genomics. Frontiers in Psychiatry, 13, 981691. https://doi.org/10.3389/fpsyt.2022.981691
- Chieffo, D. P. R., Arcangeli, V., Moriconi, F., Marfoli, A., Lino, F., Vannuccini, S., Marconi, E., Turrini, I., Brogna, C., Veredice, C., Antonietti, A., Sani, G., & Mercuri, E. M. (2023). Specific Learning Disorders (SLD) and Behavior Impairment: Comorbidity or Specific Profile?. *Children (Basel, Switzerland)*, 10(8), 1356. https://doi.org/10.3390/children10081356
- Cierzniewska, R., & Podgórska-Jachnik, D. (2021). Neurodiversity and (semantic) space for the academic inclusion of people on the autism spectrum. *Multidisciplinary Journal of School Education*, 10(20), 71–88. <a href="https://doi.org/10.35765//mjse.2021.1020.04">https://doi.org/10.35765//mjse.2021.1020.04</a>
- Cleary, M., West, S., Kornhaber, R. A., & Hungerford, C. (2023). Autism, discrimination and masking: Disrupting a recipe for trauma. *Issues in Mental Health Nursing*, *44*(8), 1–10. https://doi.org/10.1080/01612840.2023.2239916
- Cooper, R., Cooper, K., Russell, A. J., & Smith, L. G. E. (2020). "I'm proud to be a little bit different": The effects of autistic individuals' perceptions of autism and autism social identity on their collective self-esteem. *Journal of Autism and Developmental Disorders*, *51*, 704–714. <a href="https://doi.org/10.1007/s10803-020-04575-4">https://doi.org/10.1007/s10803-020-04575-4</a>
- Datu, J. A. D., Andres, R. A. A., & Diaz, M. P. C. (2022). Positive psychology and well-being of children with autism spectrum disorder: A systematic literature review. *Child Indicators Research*, *15*, 93–119. <a href="https://doi.org/10.1007/s12187-021-09861-2">https://doi.org/10.1007/s12187-021-09861-2</a>
- de Graaf, G., Buckley, F., & Skotko, B. G. (2017). Estimation of the number of people with Down syndrome in the United States. Genetics in Medicine, 19(4), 439–447. https://doi.org/10.1038/gim.2016.127
- de Paor, E., King, E., McGuinness, S., & Guerin, S. (2025). Transition from School to Adult Life: Scoping Review of Perspectives of Young Adults with Intellectual Disabilities and Families. *Disability & Society*, 1–30. https://doi.org/10.1080/09687599.2025.2470740

Doyle N. (2020). Neurodiversity at work: a biopsychosocial model and the impact on working adults. *British medical bulletin*, *135*(1), 108–125. https://doi.org/10.1093/bmb/ldaa021

Dwyer, P., Cox, D. J., & Rich, J. J. (2023). Adherence to person-centered language in autism research: Trends and implications. *Intellectual and Developmental Disabilities*, *61*(5), 366–375. https://doi.org/10.1352/1934-9556-61.5.366

Ennis-Cole, D., Durodoye, B. A., & Harris, H. L. (2013). The impact of culture on Autism diagnosis and treatment: Considerations for counselors and other professionals. *The Family Journal*, 21(3), 279–287. <a href="https://doi.org/10.1177/1066480713476834">https://doi.org/10.1177/1066480713476834</a>

First, J. M., Cheak-Zamora, N. C., Teti, M., Maurer-Batjer, A., & First, N. L. (2018). Youth perceptions of stress and coping when transitioning to adulthood with autism: A photovoice study. *Qualitative Social Work, 18*(4). <a href="https://doi.org/10.1177/1473325018757078">https://doi.org/10.1177/1473325018757078</a>

Garland-Thomson, R. (2002). Integrating Disability, Transforming Feminist Theory. *NWSA Journal*, *14*(3): 1–32.

Gibbs, J., Appleton, J., & Appleton, R. (2007). Dyspraxia or developmental coordination disorder? Unravelling the enigma. Archives of Disease in Childhood, 92(6), 534–539. https://doi.org/10.1136/adc.2005.088054

Goerge, R. M., & Wiegand, E. R. (2019). Understanding vulnerable families in multiple service systems understanding vulnerable families. RSF: The Russell Sage Foundation Journal of the Social Sciences, 5(2). https://doi.org/10.7758/rsf.2019.5.2.05

Goldberg, H. (2023). Unraveling neurodiversity: Insights from neuroscientific perspectives. Encyclopedia, 3(3), 972–980. https://doi.org/10.3390/encyclopedia3030070

Gregori, E., Rispoli, M., Neely, L., Lory, C., Kim, S. Y., & David, M. (2020). Training direct service personnel in functional communication training with adults with disabilities. *Journal of Developmental and Physical Disabilities*, 33(4), 669–692. https://doi.org/10.1007/s10882-020-09766-6

Greydanus, D. E., & Tullio, J. (2020). Tourette's disorder in children and adolescents. *Translational Pediatrics*, 9(Suppl 1), S94–S103. https://doi.org/10.21037/tp.2019.09.11

Grigal, M., Papay, C., Migliore, A., Choiseul-Praslin, B., & Chen, J. (2023). Preparation for postsecondary education of transition aged youth with intellectual disability and autism spectrum disorder in the United States: An Analysis of data from the national longitudinal transition study 2012. *Journal of Intellectual Disabilities*, 17446295231220093. <a href="https://doi.org/10.1177/17446295231220093">https://doi.org/10.1177/17446295231220093</a>

Haberstroh, S., & Schulte-Körne, G. (2019). The diagnosis and treatment of dyscalculia. Deutsches Arzteblatt international, 116(7), 107–114. https://www.aerzteblatt.de/int/archive/article/205469

Johnson, J.-A., & Ahluwalia, S. (2025). Neurodiversity in the healthcare profession. *Postgraduate Medical Journal*, 101(1192), 167–171. https://doi.org/10.1093/postmi/ggae108

Kessler, R., Adler, L., Barkley, R., Biederman, J., Conners, C., Demler, O., Faraone, S., Greenhill, L., Howes, M., Secnik, K., Spencer, T., Ustun, T., Walters, E., Zaslavsky, A. (2006) The prevalence and correlates of adult ADHD in the United States: results from the national comorbidity survey replication. The American Journal of Psychiatry, 163(4), 716-723. <a href="https://pubmed.ncbi.nlm.nih.gov/16585449/">https://pubmed.ncbi.nlm.nih.gov/16585449/</a>

Kleberg, J. L., Bölte, S., & Falck-Ytter, T. (2023). *Social feedback enhances learning in Williams syndrome*. Scientific Reports, 13, Article 290. https://doi.org/10.1038/s41598-022-26055-8

Maddox, L., Grindle, C., Bailey, T., Chaplin, H., Hepplestone, E., & Hastings, R. P. (2023). Psychological strengths and well-being: Strengths use predicts quality of life, well-being and mental health in autism. *Autism*, 27(5), 1314–1326. https://doi.org/10.1177/13623613221148928

Maenner, M. J., Warren, Z., Williams, A. R., Amoakohene, E., Bakian, A. V., Bilder, D. A., Durkin, M. S., Fitzgerald, R. T., Furnier, S. M., Hughes, M. M., Ladd-Acosta, C. M., McArthur, D., Pas, E. T., Salinas, A., Vehorn, A., Williams, S., Esler, A., Grzybowski, A., Hall-Lande, J., Nguyen, R. H. N., ... Shaw, K. A. (2023). Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. *Morbidity and mortality weekly report*. Surveillance summaries (Washington, D.C.: 2002), 72(2), 1–14. <a href="https://doi.org/10.15585/mmwr.ss7202a1">https://doi.org/10.15585/mmwr.ss7202a1</a>

Martens, M. A., Wilson, S. J., & Reutens, D. C. (2008). *Research review: Williams syndrome: A critical review of the cognitive, behavioral, and neuroanatomical phenotype*. Journal of Child Psychology and Psychiatry, 49(6), 576–608. https://doi.org/10.1111/j.1469-7610.2008.01887.x

Mason, D., Ingham, B., Urbanowicz, A., Michael, C., Birtles, H., Woodbury-Smith, M., & Parr, J. R. (2019). A systematic review of what barriers and facilitators prevent and enable physical healthcare services access for autistic adults. *Journal of Autism and Developmental Disorders*, 49(8), 3490–3513. https://doi.org/10.1007/s10803-019-04049-2

Maynard, D. W. (2024). The human spectrum: A critique of "neurodiversity." *Symbolic Interaction*, 48(1), 91–122. <a href="https://doi.org/10.1002/symb.691">https://doi.org/10.1002/symb.691</a>

McCloskey, M. (2017). *Developmental dysgraphia: An overview and framework for research. Cognitive Neuropsychology*. <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6238209/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6238209/</a>

McGee, M. (2012). Neurodiversity. Contexts, 11(3), 12–13. https://doi.org/10.1177/1536504212456175

McLean, K. J., Hoekstra, A. M., & Bishop, L. (2020). United States Medicaid home and community-based services for people with intellectual and developmental disabilities: A scoping review. *Journal of Applied Research in Intellectual Disabilities*, *34*(3), 684–694. <a href="https://doi.org/10.1111/jar.12837">https://doi.org/10.1111/jar.12837</a>

McLennan, D. (2025). *How has "neurodiversity" been defined and conceptualised in empirical academic literature? A scoping review.* Discover Psychology, 5(1), Article 8. https://doi.org/10.1007/s40489-025-00493-2

Menezes, M., Pappagianopoulos, J., & Mazurek, M. O. (2025). Prevalence of discrimination experienced by autistic youth as compared to neurotypical youth and youth with other neurodevelopmental diagnoses. *Autism*, *29*(7). https://doi.org/10.1177/13623613241312445

Mire, S. S., Gealy, W., Kubiszyn, T., Burridge, A. B., & Goin-Kochel, R. P. (2015). Parent perceptions about autism spectrum disorder influence treatment choices. *Focus on Autism and Other Developmental Disabilities*, 32(4), 305–318. https://doi.org/10.1177/1088357615610547

Morris-Rosendahl, D. J., & Crocq, M.-A. (2020). Neurodevelopmental disorders—the history and future of a diagnostic concept. *Dialogues in Clinical Neuroscience*, *22*(1), 65–72. <a href="https://doi.org/10.31887/DCNS.2020.22.1/macrocq">https://doi.org/10.31887/DCNS.2020.22.1/macrocq</a>

National Center for Health Statistics (CDC). FastStats - Attention Deficit Hyperactivity Disorder. Hyattsville, MD. 2023.

O'Neal, N. (2024, October 4). The power of person-centered planning in supporting autistic adults. *Bancroft*.

https://autismspectrumnews.org/the-power-of-person-centered-planning-in-supporting-autistic-adults/

Parenteau, C. I., Lampinen, L. A., Ghods, S. S., Taylor, J. L., Adams, R. E., Bishop, S. L., & Zheng, S. (2024). Self-reported everyday sources of happiness and unhappiness in autistic adults. *Journal of Autism and Developmental Disorders*, *54*(4), 1538–1548. https://doi.org/10.1007/s10803-023-05892-0

- Paynter, J., Sommer, K., & Cook, A. (2025). How can we make therapy better for autistic adults? Autistic adults' ratings of helpfulness of adaptations to therapy. Autism, 29(6), 1540–1553. https://doi.org/10.1177/13623613251313569
- Pfeiffer, B., Coster, W., Snethen, G., Derstine, M., Piller, A., & Tucker, C. (2017). Caregivers' perspectives on the sensory environment and participation in daily activities of children with autism spectrum disorder. *The American Journal of Occupational Therapy, 71*(4). <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5490458/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5490458/</a>
- Pritchard-Rowe, E., de Lemos, C., Howard, K., & Gibson, J. (2025). Autistic adults' perspectives and experiences of diagnostic assessments that include play across the lifespan. *Autism*, *29*(1), 64–75. <a href="https://doi.org/10.1177/13623613241257601">https://doi.org/10.1177/13623613241257601</a>
- Quinn, A. (2023). Listening to the experts: Person-centred approaches to supporting autistic people and people with an intellectual disability in the mental health system. *BJPsych Advances*, 29(5), 308–317. https://doi.org/10.1192/bja.2023.29
- Reynolds J. M. (2024). National Institutes of Health Designates Disabled People a Health Disparity Population. *JAMA Health Forum*, *5*(6):e241185.
- Robertson, M. M. (2015). A personal 35-year perspective on Gilles de la Tourette syndrome: Assessment, investigations, and management. *The Lancet Psychiatry*, *2*(1), 88–104. https://doi.org/10.1016/S2215-0366(14)00132-1
- Russell, G. (2019). Critiques of the neurodiversity movement. In S. K. Kapp (Ed.), Autistic community and the neurodiversity movement: Stories from the frontline (pp. 287–303). *Palgrave Macmillan*.
- Sahoo, S., Biswas, H., & Padhy, S. K. (2015). Psychological co-morbidity in children with specific learning disorders. *Journal of Family Medicine and Primary Care*, 4(1), 21–25.
- Sayal, K., Prasad, V., Daley, D., Ford, T., & Coghill, D. (2018). ADHD in children and young people: Prevalence, care pathways, and service provision. The Lancet. Psychiatry, 5(2), 175–186. https://doi.org/10.1016/S2215-0366(17)30167-0
- Schei, J., Nøvik, T. S., Thomsen, P. H., Lydersen, S., Indredavik, M. S., & Jozefiak, T. (2018). What predicts a good adolescent to adult transition in ADHD? The role of self-reported resilience. Journal of Attention Disorders, 22(6), 547-560. doi: 10.1177/1087054715604362
- Shaw, S. C. K., Brown, M. E. L., Jain, N. R., George, R. E., Bernard, S., Godfrey-Harris, M., & Doherty, M. (2024). *When I say ... neurodiversity paradigm. Medical Education. Advance online publication*. https://doi.org/10.1111/medu.15565

Shaw, S. C. K., Carravallah, L., & Doherty, M. (2023). Barriers to healthcare and a 'triple empathy problem' may lead to adverse outcomes for autistic adults: A qualitative study. *Autism*, *28*(7). https://doi.org/10.1177/13623613231205629

Shin, M., Besser, L. M., Kucik, J. E., Lu, C., Siffel, C., Correa, A., & Congenital Anomaly Multistate Prevalence And Survival (CAMPS) Collaborative. (2009). Prevalence of Down syndrome among children and adolescents in 10 regions of the United States. Pediatrics (Evanston), 124(6), 1565–1571. <a href="https://Doi.Org/10.1542/Peds.2009-0745">https://Doi.Org/10.1542/Peds.2009-0745</a>

Smeltz, L., Havercamp, S. M., & Meeks, L. (2024). Aspiring to disability consciousness in health professions training. *AMA Journal of Ethics*, *26*(1), E54–E61. https://doi.org/10.1001/amajethics.2024.54

Sideropoulos, V., Palikara, O., Burchell, E., Ashworth, M., & Van Herwegen, J. (2024). Anxiety during transition from primary to secondary schools in neurodivergent children. *JCPP Advances*, *5*(2), e12262. https://doi.org/10.1002/jcv2.12262

Sonuga-Barke, E., & Thapar, A. (2021). The neurodiversity concept: Is it helpful for clinicians and scientists? The Lancet Psychiatry, 8(7), 559–561. https://doi.org/10.1016/S2215-0366(21)00167-X

Srinivasan, H. (2025). Neurodiversity 2.0-Harnessing cross-disciplinary disability insights. *Research in Autism*, 127, 202652.

Tipton, L. A., & Blacher, J. (2014). Brief report: Autism awareness: Views from a campus community. Journal of Autism and Developmental Disorders, 44(2), 477–483. https://doi.org/10.1007/s10803-013-1893-9

Turnock, A., Langley, K., & Jones, C. R. G. (2022). Understanding stigma in autism: A narrative review and theoretical model. *Autism Adulthood*, *4*(1), 76–91. https://doi.org/10.1089/aut.2021.0005

University of St. Augustine for Health Sciences. (2024, December 9). What is neurodiversity? Understanding neurodiversity.

https://www.usa.edu/blog/what-is-neurodiversity-understanding-neurodiversity/

Viner, H. E., Yuill, N., Costa, A. P., Radford, H., & Kornadt, A. E. (2024). A qualitative interview study on quality of life and ageing experiences of autistic adults. *Communications Psychology*, *2*(99). <a href="https://doi.org/10.1038/s44271-024-00142-0">https://doi.org/10.1038/s44271-024-00142-0</a>

Wagland, Z., Sterman, J., & Njelesani, J. (2025). Promoting neurodiversity–affirming care for autistic children: A scoping review. *Neurodiversity*. <a href="https://doi.org/10.1177/27546330251357479">https://doi.org/10.1177/27546330251357479</a>

Weitzman, C., Nadler, C., Blum, N. J., Augustyn, M., & Supporting Access for Everyone Consensus Panel. (2024). Health care for youth with neurodevelopmental disabilities: A consensus statement. *Pediatrics*, *153*(5), e2023063809. <a href="https://doi.org/10.1542/peds.2023-063809">https://doi.org/10.1542/peds.2023-063809</a>