

2023

Needs Assessment Report of Neurodiversity and Mental Health of Youth Transitioning to Adulthood



Thank you for building a stronger community in Passaic County and a better New Jersey!

Prepared for

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**Passaic County Needs Assessment of Neurodiversity and Mental Health for Youth
Transitioning to Adulthood Final Report**

Community Empowerment Research Group, William Paterson University of New Jersey

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Executive Summary

The **2023 Needs Assessment on Mental Health Support of Youth Transitioning to Adulthood** is a report to the Passaic County Department of Human Services (PCHS). It assesses needs, barriers to address the needs, and the services to fulfill the needs of individuals and families navigating issues of neurodiversity and mental health in Passaic County. It includes recommendations that could be implemented by PCHS in order address these needs.

We present this report knowing that we are both insiders and outsiders of the Paterson community and that working in any community requires a give and take, acts of humility, and a gracious spirit. We also acknowledge from the community the many individuals who have contributed in guiding this project, helping us to understand the valuable contributions that they make, and illustrating the challenges and frustrations that they have faced. Passaic County is an active and engaged community, with an incredibly diverse population that is rich in culture, community spirit, and a commitment to its future.

This needs assessment was completed within the limited duration allotted for data collection (summer 2023). Our distinctive approach to program evaluation and needs assessment is the foregrounding of a critical lens of social justice. The following key questions guide us: Whose needs are made visible in the community? Whose problems are registered? How do communities participate in the entire process of program development to address their needs and problems? How is feedback solicited, and partnerships forged with community members and leaders? How do programs contribute to strengthening community resilience, dignity, and empowerment)? We employed a mixed methods analytical approach integrating qualitative and quantitative techniques.

There exist several care providers and community groups in Passaic County who have been impactful in supporting success among youth with neurodiversity and mental health needs transitioning to adulthood. These organizations, community groups, care providers, and their services are laudable. Moreover, they have been critical in providing access to families struggling with questions about how best to support their own children undergoing this transition in services. Despite the work of many performing heroically to better the prospects of transitioning youth and their families in Passaic, our data clarified several challenges and barriers to access of much needed services. These challenges and potential remediations are parsed within this report to clarify how that pertains to neurodiversity and how that may be separable from other areas of mental health and psychopathology.

The findings in this report are that there exists a diversity of needs clustered around four domains—communication and accessibility to information, facilities, services and resources including social isolation and stigma. Each of these domains encompasses a set of barriers that parents and guardians of youth and adults with neurodiversity and mental health needs face in Passaic County.

Communication/Informational barriers include those of language, accessibility and the availability of reliable information for community members.

Parents, families, and service providers to **neurodiverse** individuals currently struggle to locate useful and valid clarifications about where and how to identify appropriate services (e.g., where to access people for early diagnosis, how this is covered, guidance on how to navigate the bureaucracy of accessing services). The linguistic issue of access reflects the large population of persons in Passaic County who predominantly rely on languages other than English. Many in Passaic County find a significant language barrier in accessing the range of resources.

Similar barriers to communication were found for mental health issues including **psychopathologies and trauma**. For these classifications and symptoms, there is less of an emphasis on early diagnosis. Rather individuals and their families need guidance for diagnoses and interventions during adolescence. Again, there are both barriers in identifying appropriate services and finding those services offered in appropriate languages.

Our recommendations to address these issues include improved dissemination, improved bilingual support, web optimization, and strengthening peer-parent networks. Our usability analysis also shows the barriers to digital access of validated information for those seeking services in Passaic County. Some of this could be directly addressed with optimization of the *Impact Passaic* website and better use of peer-partnerships to provide resource identification.

The domain of *Facilities* includes the barriers caused by a paucity of long-term residential homes and adequate special needs services at schools in Passaic County. Many services for the assessment, intervention, and community involvement of families with **neurodiverse** members are located outside of Passaic County. Most persons in the current report described a necessity to travel for services to neighboring counties, some with significant mobility issues, in order to address their needs. Recommendations to address this issue include the expansion of transportation options, and better support of the direct and indirect costs experienced by families.

The experience of *Services* and *Resources* include a slew of barriers that make that experience less than satisfactory for those seeking them. Members of the **neurodiverse** community and their families described barriers that include the paucity of available counseling and diagnostic and medical services, concerns in finding trained and empathetic staff at available homes, bureaucratic paperwork, multilingual cultural translators, good transportation, and lack of early diagnoses at schools.

Those who described accessing resources to address mental health issues relating to psychopathology and trauma also expressed concern about the limited availability of appropriate diagnostic and counseling options. Schools are likely to have some trained staff who will recognize the symptoms of a psychopathology, but often families will need to seek external services for diagnostics and interventions relating to these issues. Services are more

difficult to source in non-English languages for both assessment and treatment, and are likely to require options outside of Passaic County.

These barriers are related to the much broader ones of *Resources including Social Isolation and Stigma* faced by the families of youth and adults with neurodiversity and mental health needs. The barriers of isolation are rooted in the frustration felt by families seeking to support a member with neurodiversity or mental health concerns. They have voiced a sense of fighting for resources, feeling frustrated with an inability to identify effective allies, feeling a heavy burden in bureaucracy in accessing resources, frustration with a lack of dedicated spaces and forums to enable the strengthening of their sense of belonging in the community.

Recommendations in this report to address this are appropriate for both neurodiverse and mental health struggling families. An effective strategy would be to facilitate parent-to-parent support networks, improve the bilingual supports, and to support the creation of more regular forums for disseminating services, and dedicated spaces that can be used recreationally by those with neurodiversity and mental health concerns. The barriers of access relate to financial, transportation, and linguistic issues. Getting assessment and intervention can be a financial burden with upfront costs and the indirect costs from time away from work.

Passaic County is fortunate to have a community with a vibrant array of service providers and organizations, a network of parents who could be expanded to better help their peers, and the potential to make much broader use of its bilingual community. In addressing the needs of the community to support youth transitioning to adulthood with neurodiversity and mental health needs, this will further the visions of Passaic County for a brighter future.

1. Introduction

The **2023 Needs Assessment** is directed to the needs of neurodiversity and mental health youth transitioning to adulthood in Passaic County. We use the term “neurodiversity and mental health” instead of developmental disabilities to signal a need to view diversity as a foundational lens with which to identify needs within populations.¹ In describing the current state of this issue, it will be important to clarify the kinds of chronic and transient issues with respect to neurodiversity and mental health that would affect this population, stake holders involved in supporting this population, and clarifying the aims of the project undertaken to this end.

1.1 Language and Terminology

Neurodiversity and Mental health at the level of public works encompasses a very broad range of topics, needs, and interventions. Essentially, mental health can be defined by an impairment in functioning due to psychological (moods, feelings), behavioral (actions) or neurocognitive (thoughts, decision-making) mechanisms. When a mental health concern is raised, the emphasis in diagnosis centers on the capacity of a person to fulfill daily life tasks without impairment, self-harm, or threat to others. Some aspects of mental health such as bipolar and depression disorders with suicidal ideations, eating disorders, and neurodevelopmental disorders like Fetal Alcohol Syndrome and Fragile X syndrome carry a high risk for mortality. Many neurodiversity and mental health issues including trauma disorders, Autism-Spectrum Disorder (ASD), and cognitive impairments may have pervasive symptoms that impair daily life functions but do not directly affect mortality – an individual with these diagnoses has a capacity for longevity even as they contend with the symptoms of that issue.

In defining a range of issues, from psychopathologies to traumatic brain injuries, what is evident is the complexity of needs, interventions, and expressions that might be associated under this umbrella of mental health. The major symptoms may be constant or transient for an individual, and their capacity for self-efficacy as they transition from early life to adulthood will also vary dramatically. These individual differences in diagnosed need will be further complicated in situations in which a person experience more than one disorder.

Comorbidity, defined as the co-occurrence of two or more diagnoses. It is estimated to have an occurrence of 40% among those diagnosed over the course of the lifespan (MHA, 2022). This finding about comorbidity is highlighted because of the structural distinctions in diagnosis, specialization, and treatment of mental health issues. The training and capacity for service in support of one diagnosis rarely would extend across into other mental health areas (e.g., comorbidity of depression, ASD, and substance use disorder – three distinct areas of

¹ “The word neurodiversity is often used in the context of such cognitive-neuro diagnoses as autism spectrum disorder (ASD), Attention-Deficit/Hyperactivity Disorder (ADHD), and other chronological atypicalities in neural and/or cognitive processing... It is primarily a social justice movement, neurodiversity research and education is increasingly important in how clinicians view and address certain disabilities and neurological conditions.” Available at <https://www.health.harvard.edu/blog/what-is-neurodiversity-202111232645>

assessment, care requirements, and symptom transience). Consequently, the support structures for mental health are separated by their targeted treatment demographics and by the intensity of care that they can support. These separations have a functional necessity to address the wide range of mental health needs, but also can pose barriers for individuals or families that contend with more than a single issue.

In defining neurodiversity and mental health for youth transitioning to adulthood, we also must consider how these disorders tend to emerge and the level impairment suffered by an individual.

- Many **neurodevelopmental diagnoses** (including ASD, Down Syndrome) are diagnosed early in life, typically during ages 0-5 years, and will receive persistent treatment for youth involved schools. The level of impairment varies with the neurodevelopmental diagnosis: from mild social disfunction and communication difficulty to severely reduced functioning and an inability for an individual to perform daily tasks. These tend to persist into adulthood, and consequently the needs for care must also transition from school and youth-based community organizations to adult-oriented community-based organizations. With more severe impairment, family members would be tasked to determine a strategy for guardianship into adulthood and to maintain a lifelong strategy with community-organizations for appropriate care.
- **Psychopathologies, eating disorders, personality disorders, substance use disorders, identity disorders** often emerge to create disfunction during mid-to-late adolescence (14-25 years). Individuals suffering these impairments may be higher functioning with a capacity for independence in function or may experience debilitating social and cognitive symptoms that require intensive care. Typically, these disorders will persist into adulthood and often school-based support is limited, with a greater reliance on community-based support if treatment is sought. Given the higher transience of the symptoms of a psychopathology, guardianship of a youth transitioning to adulthood may be controversial, and a lifetime maintenance of care is likely to be shared between the individual, their families, and community-support systems.
- **Trauma and Anxiety disorders** classify issues relating to emotional processes with respect to specific stressors or more broadly construed. Youth who undergo chaotic circumstances from abusive situations or as refugees from politically unstable regions may express trauma-related symptoms in the immediate aftermath and/or sporadically in the years to follow. The age range for diagnosis is broad and relates more directly to the timing of the events rather than developmental maturity. Similarly, anxiety disorders have a broad range of emergent ages, starting from symptoms such as mutism in early life to generalized anxiety disorders, phobias, and other specific anxieties during

adolescence and early adulthood. Trauma and anxiety disorders have been effectively treated with early interventions. When effective treatments are provided, there is a high rate of success that reduces chronic persistence over the lifespan.

In the archival research described below, a demographic representation is provided to clarify the occurrence rates of common mental health concerns for youth.

2. Passaic County Description

Archival analyses provide important context for a needs assessment. Several state and national agencies are tasked to develop comprehensive accounting of our region and have been included with this analysis. That included a reliance on the 2023 New Jersey Census and its targeted estimates for the Passaic County region and its residents. In addition, the National Health Interview Survey 2023 (sponsored by the CDC) provided estimates of insurance coverage and the epidemiology of neurodevelopmental disorders, psychopathologies, and related mental health needs of our region. The CDC also provides coverage of the health trends and data current as of 2021. The Substance Abuse and Mental Health Services Administration (SAMHSA) and its Center for Behavioral Health Statistics and Quality was used for its annual reporting in 2021, 2022 and 2023. These reports clarify predictive trends in mental health and it outlines epidemiological estimates for mental health concerns and the current estimates of comorbidity between substance abuse with other mental health concerns.

The New Jersey State Health Assessment Data was used to target specific mental health concerns as they pose behavioral risk in the most recent 30-day periods, in addition to estimates on current mortality rates as they correlate with mental health across age groups. The Mental Health America (MHA) archive (2017-2018) is generated in partnership with the American Psychological Association was used to clarify how the epidemiology of specific disorders and illnesses is distributed across demographic sub-groups. We were able to use the National Alliance on Mental Illness of New Jersey 2022 annual report for its accounting of current advocacy initiatives relating to mental health and regionally specific data sets.

The total population in New Jersey as estimated in the 2022 census is 9.262 million with 513,936 persons living in Passaic County. There are 23.4% minors or 120,261 minors living in Passaic County. There is very little reliable existing data on the size of the populations that are neurodiverse. The following is our attempt to assess and estimate this crucial data.

In assessing the neurodiversity and mental health needs of the county for minors transitioning to adulthood, the American Psychological Association and Mental Health America estimate that approximately 40% of people will experience a diagnosable mental health need during their lifespan. In applying those national estimates to Passaic County, our calculations are that the county will need to anticipate support for about 48,100 minors transitioning to adulthood during the next 18 years, and approximately 2800 persons each year. These estimates were

calculated as they might apply to each of the broad diagnostic subsets that are described above. It is helpful to emphasize that this is a very broad range of diagnoses and with varying levels of symptomatic intensity (e.g., transient and highly treatable anxiety disorders to more persistent behavioral/personality disorders to chronic neurodevelopmental disorders). Passaic County would need to anticipate the resources and support to transition about minors and their guardians/families with the tools for their livelihood.

Table 1 shows the projective estimates derived for this report with respect to the neural diversity and mental health needs of Passaic county with respect to youths transitioning to adulthood:

Table 1. Projective Estimate of Transitioning Minors to Adulthood with Neurodiversity and Mental Health Needs Per Year

<i>Diagnosis</i>	<i>Projected Number of Transitioning Cases</i>
<i>Mild Neuro: ADHD</i>	600 per year
<i>Neuro: ASD</i>	120 per year
<i>Neuro: Down Syndrome</i>	10 per year
<i>Neuro: Cerebral Palsy</i>	130 per year
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<i>Psychopathologies & mood disorders</i>	50 per year
<i>Trauma and anxiety disorders</i>	900 per year

In Passaic County, 2022 Census data further shows that 49.8% of people speak a language other than English at home, and more than 60% of the county is bilingual/multilingual. The majority non-English language used is Spanish (53%) but there are sizable representations of Arabic, Begali, Gujarati, Tagalog, Polish, Russian, Italian and Hindi speakers. The county demographics are estimated to include 61.6% traditionally under-represented minority populations, see Table 2.

Table 2. New Jersey 2022 Census Estimates of Racial/Ethnic Demographics in Passaic County

Ethnicity	Percentage
African-American/Black	15.1%
Asian/Hawaiian/Pacific Islander	6.1%
Caucasian/Non-Latin or Hispanic	38.8%
Indigenous/Native American/Aleutian	1.7%
Latino/Hispanic	44.3%
Two or more	2.8%

This is critical as families advocate for services to minors and transition those minors to adulthood. With half of the Passaic County residents more comfortable in a language other than English, and most predominantly Spanish. This would necessitate resource centers, help lines, neurocognitive assessments, and the range of diagnosticians and therapists be prepared to provide meaningful support in at least two languages. The range of needs and services can be unclear, and this language barrier can mean that families may be unsure how to request forms for guardianship of a child aging into adulthood nor how to determine the legal standing to request greater intervention and support for a minor or disabled adult with unmet needs.

In terms of mental health, the Substance Abuse and Mental Health Services Administration (SAMHSA, 2021) finds that of individuals aged 13-17 years, 14% experience mood disorders, 32% experience anxiety disorders, and 19% experience behavior disorders. Notably, 7.5% of New Jersey youth – a total of 48,000 minors experienced a Major Depressive Episode in 2022, putting them at risk for suicide and comorbidity for a range of physical health problems such as chronic pain disorders, diabetes, obesity, COPD, cancer, and heart disease (MHA 2023; Zahorodny et al., 2023).

These estimates partially correlate with the Children’s InterAgency Coordinating Council (CIACC) reports of services requested/rendered. The CIACC dashboards provide a monthly summary of requests for service, referrals, and activities provided for a range of mental health needs, including neurodiverse populations. The CIACC reports provide a raw indicator of active requests for service during a given period. Notably from January 2022 to August 2023 there has been an increase by about 4% in I/DD eligible cases. This rise in cases was accompanied by an increase in the number of requested and the number of approved special needs cases (all increases were statistically reliable at the $p < 0.05$). While the cases increased, CIACC reporting also shows that there were consistent and unchanged levels of service provided. After school respite services, agency respite services, overnight respite services, and self-hired respite services remained relatively constant with no statistical change during this period. There were also no statistical increases in the requests for weekend recreation opportunities and educational advocacy. There was a marginal increase in the requests for assistive technologies to be used in support of I/DD eligible persons. *These findings seem to indicate that while developmental diversity needs are increasing in the population both locally and nationally, families of those in need are either not seeking support or are seeking support services independent from I/DD.*

These are mental health needs that tend to emerge in late adolescence and early adulthood, and as described above, may not be detected for minors while still in school. However, these disorders tend to become persistent and pervasive in adulthood. And, just as with cognitive-neurodevelopmental diversity like ASD, early intervention tends to be more effective and improve the outcomes for these individuals. The state prevalence of adult mental illness is estimated to be 16.37% or about 1,122,000 adults in New Jersey (MHA, 2022). In terms of

insurance coverage, New Jersey is ranked 22 of 50 states for individuals and an estimated 54.1% do not have coverage for mental or emotional difficulties (MHA, 2022).

Figure 1 shows the estimated number of cases of minors with neurodiversity and mental health needs in Passaic County. These estimates are produced using the 2022 Census data and calculated with the MHA (2022) frequencies for particular diagnoses. The MHA estimates are determined using population norms with inclusion of diagnosed and undiagnosed/untreated cases in North America. For the current analysis, the total number of minors in Passaic County and their distribution by age were compared with the national norms for diagnoses as they tend to emerge across the lifespan (focusing on early life/adolescence). Because of this method, these estimates include both diagnosed and undiagnosed cases. For ASD which has very specific regional differentiation in diagnosis, the northern New Jersey estimates are used. Other disorders are based on national estimates and do not capture any specific regional variability. Importantly, we estimate from the population statistics that of the minors who receive a diagnosis, 85% will have a single diagnosis and an estimated 15% will have comorbidities.

Figure 1. Estimated Cases of Youth (0-17 yrs) with Neurodiversity and Mental Health Concerns in Passaic County

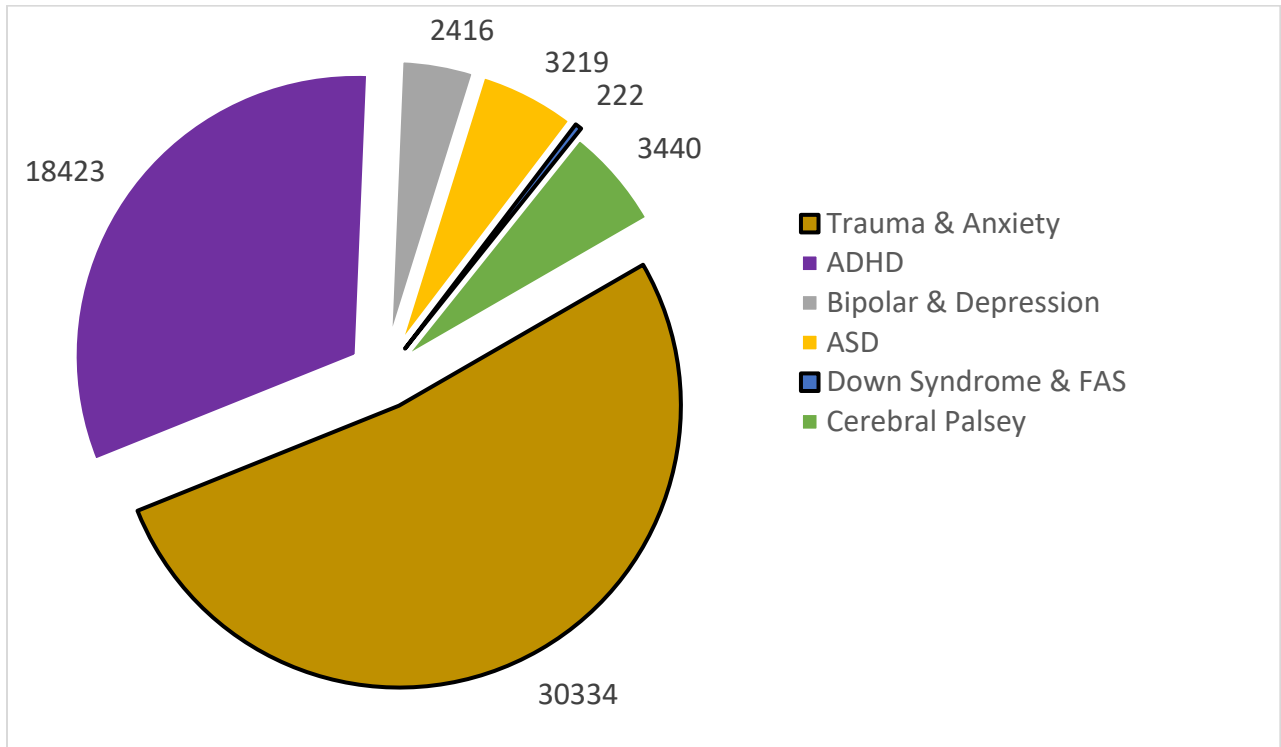


Figure notes. Estimated total cases of minors (0-17 years) who meet the criteria for neurodiversity and mental health diagnoses in Passaic County (both diagnosed and undiagnosed). This figure was calculated for this report using the SAMHSA (2023) regional estimates for ASD, MHA (2023) national estimations for all other diagnoses with these age groups, and 2022 New Jersey census data for Passaic County.

3. Research Methodology

This needs assessment was completed within the limited duration allotted for data collection (summer 2023). To complete this needs assessment of neurodiversity and mental health resources and support for minors transitioning into adulthood we employed a variety of research methods.

- A. Archival Sources: A broad overview description of Passaic County and its constituents was analyzed from existing archival sources, including recent census reporting by the state of New Jersey, CIACC dashboards from 2022-2023, national data from the Centers for Disease Control (CDC) and several well-established mental health organizations (e.g., Substance Abuse and Mental Health Services). See Section 2 on County Description for how this method was used and our findings.

- B. User-Experience: An assessment of user-experience of internet and community-outreach materials, including user journeys with the *Impact Passaic* website and related tools for connecting Passaic County residents with appropriate resources.
- C. Semi-Structured Interviews and Focus Groups, Participant Observation and Surveys: Empirical data collection using a series of stakeholder interviews, focus groups, site visits, and a broad-based survey and analyzed using a mixed qualitative-quantitative approach.

3.1. User Experience Analyses

Usability studies are critical to enabling users to access and function with the resources intended for them. The usability analysis focused specifically on resources for parents/guardians who care for youths with neurodiversity and mental health needs transitioning to adulthood. Given the reported services provided by Passaic County parents in the semi-structured interviews and in learning about the primary marketing tools used by mental health practitioners, this analysis was directed towards internet sites and social media groups which targeted these needs. Our team and a set of 17 naïve users conducted a series of general web searches from the perspective of a parent seeking support and guidance for a youth transitioning to adulthood with neurodiversity and mental health needs. In addition, we examined Facebook groups and specific usage of the *Impact Passaic* website.

Those searches and the outcomes were analyzed to determine the ease of use, the specificity of the findings, and the access enabled by those findings to initiate gaining mental health resources. Competitive analyses were conducted to clarify search durations on the site to reach outcomes, the number of outcomes for a particular search, and relevance of those findings. In addition, the search functions were compared to user interface best practices in hierarchical design, contrast, and clarity.

3.2. Semi-Structured Interviews and Focus Groups, and Participant Observation

To directly engage voices from the community, a primary method we used were in-depth semi-structured interviews with stakeholders regarding neurodiversity and mental health support and the transition of youths to adult services. Site visits were conducted to three service providers in Passaic County, New Jersey, followed up with interviews of key leaders and office bearers to learn about the programs and services provided by their organization. We also conducted a series of interviews with parents and guardians of children with neurodiversity and mental health needs. The parents included those with younger children, adolescents, and in adulthood.

The semi-structured interviews focused on several questions that covered a range of issues: the kinds of problems experienced by the child, the kinds of services needed; the kinds of services that a service provider designed to address those issues; the options for services available for

those children both within and outside of Passaic County; whether the services provided were sufficient to the needs of the child; and what the barriers were to gaining access to those services. We also asked about how parents and guardians came to be aware of which services to access and to understand the experience of seeking and engaging those services.

A focus group was conducted with the leading community-based network in this domain, and allowed for a broad and open discussion of critical issues with which parents and guardians of children and youth with neurodiversity and mental health needs contended. The focus group included 11 parents of children aged from adolescence to adulthood and with ASD, Down Syndrome, ADHD, and other cognitive impairments. Our team members also attended three events organized by a parent-based community group committed to neurodiversity during the period of this study in order to gain a better and more first-hand understanding of the needs.

3.3. Survey

An online survey was constructed using Passaic community specific questions about needs and access. These questions were in addition to established lines of inquiry that have been in use by the *CDC's Special Needs Survey*, the *National Health Insurance Survey*, the *US Department of Health and Human Services National Survey of Children's Health*, the *New Jersey Department of Children and Families Children's System of Care Survey* and using guidelines from the *American Psychological Association*. The survey was available in English and Spanish language versions and distributed to community organizations and through parent associations and the *Impact Passaic* website.

The survey was targeted to those who are caretakers to youth and/or adults with neurodiversity and mental health needs. The survey selected for those residing in Passaic County. Several lines of inquiry were addressed in the survey:

- Demographic information including gender, race/ethnicity, age, zip code, education level, living arrangements
- Specific mental health consideration for the person under care, including primary diagnosis and secondary physiological and psychological health concerns
- Barriers to gaining services including financial considerations, transportation, linguistic inaccessibility, wait times, and uncertainty about resources
- Impacts of person under care on the guardian, including needs to change jobs, locations, and experienced anxiety
- Community support questions, including issues of community safety, food resources, and housing stability

The survey was distributed to a large number of individuals and collaborating organizations during its distribution. A total of 71 people responded to the survey and a subset of 11 respondents who were Passaic residents with care responsibilities for person with mental health needs. In that this sample size is small, the results were analyzed as case studies.

4. Key Findings: A Diversity of Needs

The needs of adults and minors transitioning to adulthood with mental health needs and neurodiversity are wide ranging due to the diversity of this demographic on the following two axes:

- *Symptom Severity and Diagnosis:* Our data collection included families and caregivers for individuals with severe learning disabilities, Down Syndrome, Autism-Spectrum Disorder, and traumatic brain injury as well as those with psychopathologies, mood, and trauma disorders. This range requires many different kinds of assessments for diagnosis and a range of specialized training for effective treatment. The diversity also extends functional abilities (verbal or non-verbal, high/low functioning), and their persistence (transient, cyclic or chronic). Importantly, individuals with a transient issue may require only short-term support, while another individual with chronic and persistent symptoms will tend to require lifetime care. This makes for a diversity of needs and appropriate interventions, and these will have large differences in the projected cost and level of support.
- *Social Identities:* There is ethnic/linguistic, racial, and class diversity within the populations of this target demographic. This, too, translates into a diversity of needs especially with respect to modes of diagnosis, communication with the individual and their family, and access to services.

Consequently, interventions should target *specific* mental health needs to maximize the effectiveness of the interventions. Services for persistent and neurological disorders serve a smaller population. They require greater resource intensiveness to be effective in comparison to services for more transient and less severe diagnoses.

4.1. Key Service Needs

Based on our data analysis of parents/guardians of youth with neurodiversity and mental health needs who are seeking services in Passaic County, we find the following four major domains to cluster the wide range of service needs:

1. *Communication and Accessible Information:* There is a persistent need for better quality information available from the Passaic County governmental offices, better access to appropriate divisions, offices or departments within the county bureaucracy for special needs, and multilingual personnel and informational materials. Communication would be appropriately targeted to the major subdivisions in each of the neurodiversity and mental health domains:
 - a. *ASD*

- b. *ADHD*
 - c. *Cerebral Palsey*
 - d. *Down Syndrome*
 - e. *Learning disabilities (non-specific)*
 - f. *Mood disorders including depression and bipolar*
 - g. *Anxiety disorders*
 - h. *Trauma disorders*
 - i. *Substance use disorders*
2. *Facilities*: There is a large and growing need for facilities such as special needs support in schools, full-time residential homes, part-time care and dedicated recreational spaces in Passaic County. The need for facilities is most prevalent for the **neurodiverse community**. Families that caretake for youth and young adult individuals with Down Syndrome, TBI, Cerebral Palsey, FAS and similar impairments have few opportunities for recreation and engagement in Passaic. They seek a space to allow consistent, weekly activities such as sports leagues, gaming spaces, and other forms of engagement. CIACC data show that about 8 requests are made each month for weekend recreation for children. As these children age to adulthood, they will no longer have reareational opportunities during weekdays within the schools and would no longer be appropriate for recreational engagement with minors. Devoted space and support for recreation would benefit the minors and the growing population of adults with neurodiversity.
3. *Services*: There is a persistent need in Passaic County for more doctors including psychiatrists, psychologists, and counsellors for early diagnosis and continuing evaluation, legal advocacy and representation, and special-access transportation from home to school or caregiving spaces. This recommendation applies to the range of mental health needs. However, the specific need for legal repretation and support is particularly critical for **neurodiverse individuals** who may suffer symptoms that are chronic and severe, and would prevent self-representation as adults. Families of minors with neurodiverse needs struggle to determine what resources are appropriate and available to them, how to ensure that those needs are being met, and how to remediate issues when the service is not sufficient for a particular child. As these minors age to adulthood, the families may need to retain legal guardianship and determine once again the appropriate services, which organizations are involved, and how to retain and maintain those services during the child's adult life.
4. *Resources including social isolation and stigma*: There is a need to attend to the facts of social isolation and stigma faced by the families, the need therefore for better parental

support systems in the form of per-networks, and the need for child-care, accommodations at work, and economic relief in Passaic County that would enable better caregiving. Individuals with **psychopathology**, including mood, personality, and trauma disorders, will tend to experience the emergence of those symptoms in late adolescence and early adulthood. Those psychopathologies are atypical and often serve to cause social withdrawal by the individuals. Consequently, the behaviors associated with psychopathology are often hidden by individuals for fear of stigma and exclusion (an irony of these disorders). With respect to **neurodiversity**, there are some cultural traditions in which these impairments have been stigmatized (e.g., Down Syndrome has been historically linked to a family curse in some southeast Asian cultures). Support to family members, including caregivers, to address the concerns with stigma is important to enable them to seek and use support services.

4.1.1. Barriers to Service Needs

There are numerous barriers to each of the above needs for services. We have found it useful to align the barriers to the identified domains above.

1. *Communication / Accessible Information*

- a. Lack of easily accessible and clear information from the county about available facilities, services for parents and guardians of youth with **developmental disabilities**
- b. Persistence of ignorance, lack of knowledge of **neurodiversity symptoms** and effective supports, or lack of empathy among public officials (e.g., police, schools, town and county boards and offices) which leads to misdiagnosis of behaviors, punitive actions or misdirection for services
- c. Difficulty of access for parents in need due to immigration status, and/or being non-English first language speakers affects families of those with **neurodiversity needs and psychopathologies**

2. *Facilities*

- a. Distance from home to residential facilities and dedicated spaces for **neurodiverse** individuals
- b. Distance and availability of schools that exclusively service special needs with more intensive **developmental disabilities and neurodiverse needs**

3. *Services*

- a. Lack of easily and clearly available help in county for the children's needs for each of the domains of neurodiverse and mental health needs

- b. Lack of appropriately fluent bilingual speaking employees at relevant county offices for each of the domains of **neurodiverse and other mental health needs**
 - c. Lack of early diagnosis at schools with appropriate intervention particularly for **neurodiverse** and children who **experienced trauma**
 - d. Lack of quality staff at available residential homes or day-care facilities (low quality training or professionalism results in problems of bad practices, seclusion, bullying, and even abuse)
 - e. Cutting of special needs programs in schools
 - f. Bureaucratic paperwork within I/DD that leads to frustrated parents and guardians seeking help
 - g. Paucity of accessible transportation (home to school for minors with special needs)
 - h. Long wait period for doctor appointments or for space at available facilities that serve **neurodiverse individuals**
 - i. Incomplete capture of all parental issues and concerns for each of the domains of **neurodiverse and mental health needs**
 - j. Lack of Spanish-speaking parent support for each of the domains of neurodiverse and mental health needs
4. *Resources including social isolation and stigma*
- a. Social isolation and stigmatization (by peers, neighbors, and other parents) is very common in the lives of children and adults with developmental disabilities and their parents/guardians
 - b. Lack of time for parents to take away from work in order to care for their child

4.1.2. Corroborations: Quotes from Parents / Guardians

To give some more context to our findings above, we include some exemplary quotes from parents of children with neurodiverse and mental health needs in Passaic County.

1. "That's the problem. **We have to fight** for everything"
2. "It's all about the **money**. The first thing they cut in districts is the special needs program"
3. "They're just going to keep leading you around with more redundant paperwork"
4. "We as parents are very vulnerable, especially when we first find out and get the diagnosis. If it's your first time or you don't know enough about it...if somebody were to tell me, oh, drink that. Have him drink this bottle of water cost you \$5000. He will be

cured. You don't think I'm going to do it?...The **money we've I've spent**, we've spent between hiring attorneys, hiring attorneys, yeah, therapies...”

5. “At a very broad. Level **we need guidance**, right if they. Can give us, you know, have a person. Here that will ask us what do you. Mental health go talk to her. What do you need? You know, after school after high. You know, programs go over there. What do you need therapy for? My 9-year old go? Over there. They. Can tell us where to go locally?”
6. “For local resources, right? Don't tell me there's a doctor all the way in, Ramsey. Can go to. You know I want? Someone **local in Passaic County**, right, waiting for two years, right?...There's not enough physicians. There's not enough help. Not ABA therapists. No psychologists, no social groups.” (composite quote)
7. “In general, the resources are not there. The guidance are not, are not there. The empathy is not there. **The inclusion is not there.**”
8. “It's a language thing...[they] feel that they're **shunned because of the language**. The language barrier.” (bilingual speaker translating Spanish speaker)
9. “...there's somebody that she know that it's been trying to do activities like soccer programs and things for the kids and he never get the help, the proper help to do the implementation of these services.”
10. “You have to remember how you're going to create friends and **you don't have a friend**, your daughter, your son, don't make friends at school. Those friends come growing up with you in elementary [school]. They didn't invite you to birthday party. They didn't invite you to different outings...Let's go here. Let's go to the movie. Let's have pizza. You have a son or a daughter with special need. You don't get invitations. It's very rare.”
11. “You have to understand the two basics. They **[parents] don't have time**, but if you find somebody like me, who's a fighter, who have a big mouth who has to stay still, if something's wrong with this picture, we need to do something. We need to advocate for this community. That's what I did.”
12. “And the fact that my child was costing the town or the Board of Education about \$\$...a year didn't bode well with anybody. Everybody hated me. OK, so you have to have a very thick skin. Because most of the board of Education will fight you.”
13. “When push comes to shove, **this is inequity**. This is inequity. Why [are] our kids, on top of being disabled, the parents being poor,...have to be in ***** [shitty] places or [with] no services at all. When all the other kids have, you know, the plush life? Because you don't consider us equal, directly.”

4.1.3 Corroborations: Case Studies of Parents / Guardians

Our findings about service needs above are corroborated by eleven (11) cases that we have constructed from our surveys and interviews. Outlined in Table are the six (6) of those respondents who described great difficulty obtaining care or an inability to obtain care. An additional five respondents were analyzed as cases and were able to find appropriate easily or

very easily for a person in their lives with a mood or anxiety disorder. All names are anonymized to protect the respondents.

Table 3. Specific Cases that Produced Difficulty for Gaining Services and Support

CASE DESCRIPTION	BARRIERS TO ACCESS
<p>Elijah (48) is the father of a 17-year-old, White son who experiences Social-<u>Cognitive Impairment due to a stroke</u>. Elijah stated that his son has been very lonely and depressed since experiencing the stroke that changed his life. His son’s school has been difficult to work with as the teachers and school counselors did not always understand how to best support his son and were not always following through with providing the resources his son needed. Elijah also told us that he was not always able to make appointments for his son in a timely manner due to the unavailability of the medical provider. These services were also not available in Passaic County so Elijah had to travel out of the county to find doctors who could work with his son. Elijah also stated that these services were rarely covered by his insurance, which resulted in significant financial difficulty for their family.</p>	<ul style="list-style-type: none"> • Transportation to service outside of Passaic • Financial burden for service; Insufficient services
<p>Maddie (61) is the mother of a 22-year-old, White son who has <u>Autism Spectrum Disorder (ASD)</u>. Maddie told us that she has sought a variety of different services for her son’s care, including mental health care and educational support but that it was impossible for her to find these services in Passaic County. Maddie explained that in addition to her son’s ASD diagnosis, he is minimally verbal, experiences significant anxiety, and has ADHD and Tourette syndrome, which increases the amount of services that she is seeking for her son. Maddie also faces significant barriers as she experiences mobility issues herself, which makes it very difficult to get her son to appointments even when she is able to find someone to work with him. They were not able to obtain care.</p>	<ul style="list-style-type: none"> • Mobility impairment for caregiver (services outside of Passaic County) • Limited verbal expression ability for child
<p>Gordon (63) is the close family member of a 51-year-old Black woman who experiences significant <u>depression</u> in addition to <u>anxiety and trauma</u> symptomatology. Gordon stated that he has watched this family member continue to face barriers to finding care for her mental health due to the limitations of services in Passaic County as well as the stigma associated with receiving mental health care. They were not able to obtain care.</p>	<ul style="list-style-type: none"> • Transportation to service outside of Passaic • Stigma of mental health needs
<p>Maria (38) is the mother of a 13-year-old son with a mixed ethnic background. Maria completed high school and her son is currently attending middle school. The son is experiencing <u>neurological impairment</u> and has behavioral dysfunctions. Maria described finding health care for her son to be very difficult and has had to take a leave of absence from work to support him. They are currently working with NJ Care Management Organizations.</p>	<ul style="list-style-type: none"> • Finding appropriate care • Financial burden for service
<p>Sonja (48) is the mother of a 17-year-old son with an <u>anxiety disorder and ADHD</u>. Sonja completed a college degree and her son is currently a high school student. They described that finding services has been very difficult, expensive, and that many organizations did not work with their insurance provider. Her son is currently receiving treatment but this has remained a</p>	<ul style="list-style-type: none"> • Finding appropriate care • Financial burden for service; • Insufficient services

<p>source of dissatisfaction because all of the counseling services they could locate are virtual-only, without availability for in-person services.</p>	
<p>Georgie (48) is the mother of a 16-year-old, bi-racial daughter who struggles with a substance use disorder (SUD). Georgie told us that it has been exceedingly difficult for her daughter to get treatment for this condition while she is still enrolled in high school. A large part of this difficulty comes from the fact that there are not many clinicians in Passaic County who will work with adolescents or have the availability in their caseload. In addition to this SUD, Georgie’s daughter also manages anxiety, a mood disorder, an eating disorder, and suicidal ideations, which means that she needs a higher level of care than she can easily access. Georgie told us that she does not always know who she can go to for assistance in their community, but that she has found some support from her place of worship.</p>	<ul style="list-style-type: none"> • Finding appropriate care • Insufficient services

4.2. Key User Needs

We supplemented our analysis of experiences of parents / guardians of youth with neurodiversity and mental health needs for particular kinds services in Passaic County, with an analysis of how users (such as parents / guardians) experienced website and internet accessibility to service providers (see Research Methodology above with more details). The search goal was iteratively explored with the following criteria: a caregiver seeking mental health resources for a young person transitioning to adulthood. Searches were targeted to assessment and diagnostic services, support groups for parents/caregivers, interventions and therapies, and legal guidance.

Per usability best practices, an ideal search outcome would be contact information for no more than three service providers who are locally accessible, and have indications of validity (i.e., appear to be trustworthy and effective sources). While larger pools of outcome options can be helpful, usability research has found that an abundance of choices can be overwhelming and tends to make users feel less confident in their choices and less satisfied by the outcome. In addition, a very large pool of search results can create frustration for a user due to the burden of time and effort needed to sort and follow-up on the options.

Search results were assessed with respect to whether the top choices matched the search goals, whether users deemed those top options to be valid/accessible sources, and whether users were able to connect successfully with their top options. Results of the usability were as follows.

4.2.1. Key Usability Findings

1. *Overwhelming options:* Users using these search parameters tended to return 12.6 sources per *Impact Passaic* search; thousands of outcomes for a standard Google search; 10.3 outcomes per a *Facebook* search. As noted above, an ideal outcome would be *3 or fewer valid sources* instead of a large list of possible, low-validity sources. Users reported frustration with the number of options and uncertain about which they might feel comfortable selecting to proceed.
2. *Challenges of accessibility:* Users targeted their searches to Passaic County or specific cities within Passaic (i.e., Wayne, Paterson, West Milford, and Pompton Lakes). Users reported that of the top 3 items in a search, the services for diagnoses were all found outside of Passaic and most choices tended to be greater than 10 miles from their location. Services with closer localities were available for support groups, interventions, and legal advocacy and most were identified in Bergen and Hudson counties. Passaic-based services did not appear in their top options. Importantly, while there are Passaic-based services, the search outputs identified by our users did not produce these as options within the top-3 selections for their search outcome lists.
3. *Low source validity:* Legal services tended to have user reviews and comments to clarify the past experiences of others in the community. Validity measures and indicators of good service were not available for diagnoses, support groups, and most care providing organizations. Search users described their uncertainty about whether sources were appropriate and would justify the investment of time, effort, and money to follow-through for service.

Users reported greater confidence about recommendations that came from Facebook groups associated with friends or family in their social network. They also reported that a recommendation from a school or primary care provider would have given them confidence in the validity of a source.

4.2.2. Key Usability Needs

1. *Expansion of Parent-to-Parent Networks.* The community-based parent-to-parent networks offer immediate source validity and confidence by virtue of being peers. Organizations like PACOPAD and *Yo Soy Así* have been successful with families of **neurodiverse** individuals because of the trust and confidence that they instill with their membership and affiliated families. To make this accessible would require expanding the infrastructure and capabilities of these organizations to become recognized partners to schools and community organizations, and connecting parents to them as they start IEP and 504 processes for their children. This would

require growth of the organizations, and enable longer term planning with these organizations, oriented towards support of those children as adults.

2. *Optimizing Impact Passaic Search Results.* This could be accomplished using two important adjustments. (a) Network feedback for iterative search refinement. This could be accomplished by allowing users to see the top-3 match percentage options for a given selection and then asking whether these are outcomes that meet their needs. If yes, then the search algorithm could be strengthened for the association of those search terms to those outputs in the future. If no, then a follow-up question would allow user to refine or alter their search to identify a more appropriate match (or to be put in contact with an appropriate county/city representative to help direct them). In addition, the association of those search terms to the outcome could be weakened. (b) Improving the search filter options to **clarify the types of neurodiversity and mental health categories more discretely** to better match the institutional divisions in the supports for substance use, psychopathologies, and cognitive-neuro kinds of diagnoses, in addition to stress/self-care resources. Specifically, a person seeking resources for a depressive episode should not be directed to care options for a substance use disorder. *A parent seeking care for an adolescent with ASD should not receive options relating to a psychopathology or substance use disorder.* In the search algorithms all of these kinds of diagnoses are part of mental health and support, but in terms of access and service, they are addressed by different groups. It would benefit the site in usefulness and better direct users to instantiate those divisions into the practical options for a mental health search.

One final note, the multilingual options of the *Impact Passaic* search site were lauded by users, although some overlooked this feature. Making this language selection one of the options in the top tool bar instead of below the fold at the bottom of the page would increase the accessibility of this feature.

3. *Greater Partnership in Support Resource Identification.* In the usability search and other investigations for this report, people voiced concerns about barriers in the resource requirements to engage with this process. Accessing diagnostic services and engagement with an intervention for a **child with a neurodiversity need** typically requires transportation, time away from employment (many users noted the potential loss of wages for persons who are employed with hourly positions) compounded with the cost of that service, and for low-use/non-English speakers translation support – often another child or sibling who might require temporary absence from school. Data from the case studies and interviews revealed that people tended to feel isolated with little or no support in seeking these services. These issues could be more effectively addressed by a follow-up email to *Impact*

Passaic users that provided a helpline or guide for effective use of diagnostic services (if appropriate to the accessed outcomes), or support services that could enable transportation, provide translation, or remediate wage-losses (if appropriate to their search).

Figure 2. Collage of Usability Search Results Conducted in English and Spanish.

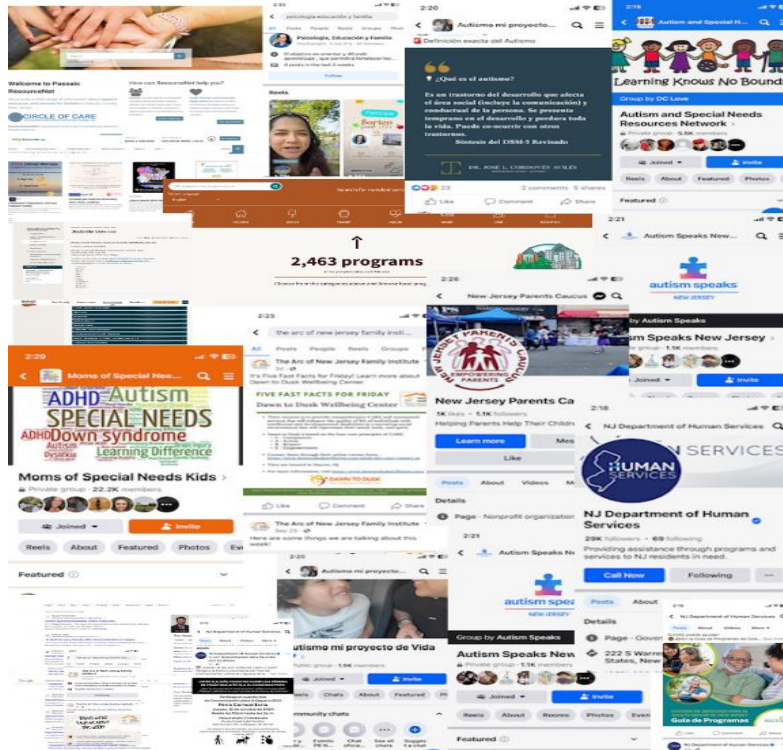


Figure 2 shows the outcomes for users who searched *Impact Passaic*, Facebook, and more generally across the internet for outcomes to support a caregiver seeking mental health resources for a young person transitioning to adulthood in Passaic County. Notable in the figure are the wide-ranging options that come up during these searches. Users reported feeling overwhelmed and uncertain how best to proceed to support their goals.

Given the breadth of mental health services and associated organizations, searching within those categories for support produces a similar breadth of outcomes for a user. The challenge is that users are not able to easily distill the specific outcomes they need, nor to identify appropriate and effective follow-up steps to make the best use of that resource. In addition, a user must contend with sorting through questions of source validity and trust: is this an organization I can trust with intimate details of my life and my family? Will this organization require documentation that I have available? What are the burdens in time and finances if I connect with them? Will this service be sufficient to address the issues of my loved one? A little

follow-up after the search or the option to work with a trusted, independent representative from a peer-network of parents would reduce the isolating feeling of these processes.

5. Recommendations

Drawing on the data and clearly voiced concerns of this needs assessment, we recommend the following interventions be made in Passaic County. These interventions would effectively improve the support of families contending with neurodiversity and mental health concerns, and reduce the frustration that they have experienced by the barriers that have been described in Passaic County. We have again found it useful to align the interventions to the barriers and needs identified above in Table 4.

1. *Communication / Accessible Information*

- a. A County-wide Informational wiki and booklet that targets **each of the mental health and neurodiversity areas** made available as a guidance for parents / guardians (support functions of I/DD, what facilities exist, where and for what specific need)
- b. Better professional development programs for state officials to increase awareness of adults with **neurodiversity**
- c. Better professional development programs for state officials to have awareness of **psychopathologies and mental health needs**

2. *Facilities Enhancement*

- a. Increase in full-time residential Group homes in Passaic County for **neurodiverse, low independence individuals**
- b. Increase in availability of trained psychiatrists and doctors in Passaic County to address **psychopathologies**

Specifically for Neurodiverse populations:

- c. Increase in availability of trained psychiatrists and doctors in Passaic County to address **neurodiverse** individuals across domains
- d. Increase in case managers, better IEPs, and transition programs at schools in Passaic County for service to **neurodiverse** individuals in the primary grades
- e. Increase in recreational spaces and inclusion for **neurodiverse** individuals at both youth and adult ages
- f. Increase in speech clinics with speech therapy programs to service **neurodiverse** individuals
- g. Increase in availability of special education teachers for **neurodiverse** individuals

- h. Increase in part-time / volunteer opportunities with local businesses as part of vocational rehabilitation for **neurodiverse** individuals

3. *Services Improvement*

- a. Better early intervention and diagnosis for special needs within schools to ease transitions for all **mental health areas, including neurodiversity and psychopathology**
- b. Increase county sponsored Transition Fairs (distributed across Passaic County) to serve as a forum for all service providers in the county and beyond for all **mental health areas, including neurodiversity and psychopathology**

Specifically for Neurodiverse populations:

- c. Strengthen accountability (including better surveillance cameras in spaces where adults with special needs are given care) at existing facilities
- d. Strengthen SPAN (Special needs Parents Advocacy Network)
- e. Strengthen advocacy network through ombudsperson and framework of Disability Rights
- f. Improve coordination between PCHS and already existing parent-networks to expand inclusion and forums for voices to be heard
- g. Streamline processes for seeking assistance with I/DD
- h. Hire bilingual counselors to assist parents seeking special needs resources
- i. Increase transportation from home to school
- j. Hire additional bilingual speaking employees at County offices
- k. Hire bilingual Spanish parent coordinators to act as liaisons between providers and parents

For better usability of readers of this report, we reproduce the same in tabular form below (Table 4).

Table 4. Key Needs, Barriers, and Recommendations

KEY NEED	BARRIER TO NEED	RECOMMENDATION
Communications / Accessible Information	Lack of easy and clear information about available facilities, services for parents and guardians of youth with neurodiversity and mental health needs	A County-wide Informational wiki and booklet (what is DD, what facilities exist, where and for what specific need) made available as a guidance for parents / guardians

	Persistence of ignorance, lack of knowledge of ASD, or lack of empathy among public officials	Better professional development programs for state officials to increase awareness about neurodiversity and mental health
	Difficulty of access for parents in need due to Immigration status, and/or being non-English first language speakers	Hire additional bilingual speaking employees at county offices
		Hire counselors to assist parents
Facilities: Special needs schools, full-time residential homes, part-time care and recreational spaces	Distance of Home from Parents	Increase in full-time residential group homes in Passaic County
	Distance and Availability of schools with special needs	Increase in case managers, better IEPs, and transition programs at schools in Passaic County
		Increase in availability of special education teachers
		Increase in recreational spaces and inclusion for special needs individuals
Services: More doctors including psychiatrists and counsellors and special-access transportation from home to school or caregiving spaces	Lack of easily and clearly available help in county for the children’s needs	A County-wide Informational wiki that clarifies the services of DD, extant facilities, where and for what specific need and is made available as a guidance for parents / guardians
		Increase county sponsored Transition Fairs (distributed across Passaic County) to serve as a forum for all service providers in the county and beyond
	Lack of appropriately fluent bilingual speaking employees at relevant County offices	Hire additional bilingual speaking employees at County offices
	Lack of early diagnosis at schools	Better early intervention and diagnosis for special needs at schools to ease transitions
	Lack of quality staff at available residential homes or day-care facilities	Strengthen accountability (including better surveillance cameras in spaces where adults with special needs are given care) at existing facilities
	Cutting of special needs programs in schools	Strengthen advocacy network through ombudsperson and framework of Disability Rights
	Application process with DDD for service has left frustrated parents / guardians	Streamline processes for seeking assistance
		Hire counselors to assist parents
	Paucity of accessible transportation (home to school for youth with special needs)	Increase transportation from home to school
	Long wait period for doctor appointments or for space at available facilities	Increase in availability of trained psychiatrists and doctors in Passaic county
Incomplete capture of all parental issues and concerns	Strengthen SPAN (Special needs Parents Advocacy Network)	

		Better coordination between PCHS and already existing parent-networks to expand inclusion and forums for voices to be heard
	Lack of Spanish-speaking parent support	Hire bilingual Spanish parent coordinators who act as liaisons between providers and parents
Resources: parental support systems.	Lack of time for parents to take away from work to care for their child	Provide supplemental financial support
	Social isolation and stigmatization (by peers, neighbors, and other parents)	Increase in part-time / volunteer opportunities with local businesses as part of vocational rehabilitation

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