



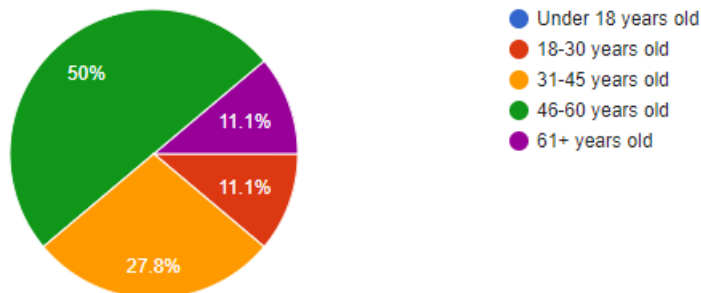
Survey: Understanding the Needs of South Carolinians with Disabilities

This report of the "Survey Responses as of 2.4.2024" underscores the urgent needs of South Carolinians with disabilities, spotlighting the critical gaps in accessibility and support services. It emphasizes the dire consequences of prolonged wait times for essential services on the well-being of individuals and their families. Key recommendations call for immediate legislative reforms, increased funding, and community-driven initiatives to forge a more inclusive, empathetic, and supportive environment. The report aims to galvanize policymakers, stakeholders, and the community at large towards actionable change, ensuring every voice is heard and valued in the quest for equity and dignity.

The survey data, titled "Understanding the Needs of South Carolinians with Disabilities," collected from 18 respondents as of February 4, 2024, reveals critical insights into the challenges and necessities of individuals with disabilities and their caregivers or family members in South Carolina. Here's a summary of the key findings from the responses:

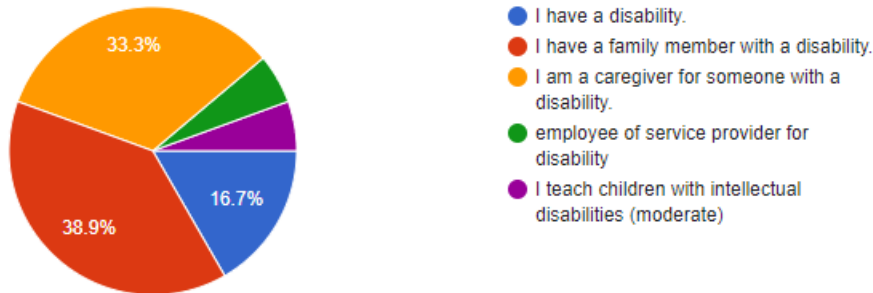
Age Range of Respondents

- Respondents span across various age groups, indicating the broad spectrum of individuals concerned with disabilities, including those who are 18-30 years old, 31-45 years old, and 46-60+ years old.



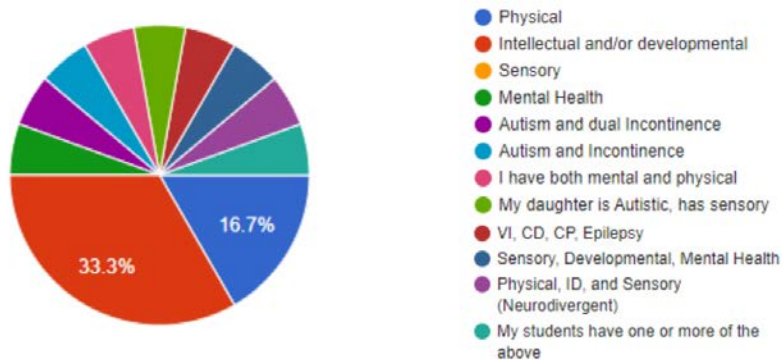
Relationship to Disability

- The survey captures diverse perspectives, including individuals who personally have a disability, caregivers for someone with a disability, and those with a family member with a disability.



Types of Disabilities Shared

- Respondents mentioned a range of disabilities, including autism, dual incontinence, intellectual and/or developmental disabilities, and physical disabilities. This diversity underscores the wide array of challenges faced by the community.



Essential Supports for Community Living

- Essential supports identified for living independently in the community include access to work opportunities, mental health services, adequate school opportunities, Medicaid coverage for supplies like adult diapers, Social Security Disability Insurance (SSDI) benefits, and in-home health and consumer-directed care.

Advocacy and Solutions

Respondents voiced their challenges and offered solutions:

- **Challenges:** Difficulties include finding employment, caring for a loved one without adequate support, managing life with disabilities, and navigating bureaucracies and waitlists for essential services.
- **Solutions:** Proposed solutions encompass ending the tax on diapers for all ages, expanding school offerings like summer camps and care during days off, increasing investments in support for individuals in need, enhancing access to therapies and essential supplies, more funding for people with disabilities, and funding Medicaid waivers to eliminate waitlists.

Additional Information Shared by Respondents

- Some respondents shared personal stories, highlighting feelings of shame and trauma due to societal attitudes toward disabilities, the need for expanded Applied Behavior Analysis (ABA) services, and frustration over discrepancies in available support and understanding within the community.

This summary encapsulates the critical needs, challenges, and proposed solutions by South Carolinians with disabilities or those caring for them. It underscores the urgency for comprehensive legislative actions and policies that address these concerns, emphasizing support for independent living, increased funding for essential services, and a call for empathy and understanding from elected officials and the broader community. These insights should be pivotal for South Carolina legislators when considering bills and laws impacting individuals with disabilities.

It's also important to mention that the following quotes vividly convey the frustrations, challenges, and aspirations of individuals with disabilities and their families, making a strong case for more compassionate policies and supportive actions.

1. **On the Urgency for Support:** "This waitlist is unacceptable. You want someone to be independent, but you are tying their hands."
2. **On Accessibility and Inclusion:** "I cannot understand why there is such discrepancy in support...everyone's needs should be met."
3. **On the Emotional Impact:** "Being on a disability list was very hard. I lost my job and income...it's a constant battle for dignity."
4. **On Advocacy for Change:** "We need more accountability for Special Education...our children deserve quality education tailored to their abilities."

Here are the responses regarding the supports deemed essential for independent living within the community, as shared by respondents in the "Community Living & Support" section:

1. Access to work opportunities, mental health services, and proper healthcare.

2. Adequate school opportunities.
3. Access to Medicaid covering supplies like adult diapers and catheters.
4. Home health, Occupational Therapy (OT), Physical Therapy (PT), and paid caregivers.
5. Family paid caregivers for home support services.
6. Support person, Personal Care Assistant (PCA).
7. Caregiver and security.
8. Financial, medical, and housing support.
9. Assistance with life skills.
10. Full-time help for living in the community.
11. Access to affordable daycare and housing.
12. Respite care, social events in the immediate area, and life skills training.
13. Transportation and housing.
14. Transportation services for clients.
15. Personal Care Assistant and in-home support.
16. Supervision throughout life for students with disabilities.
17. Respite/Aide, Education Services, Incontinence Supplies.

These responses highlight a diverse range of needs, including healthcare, educational opportunities, financial and housing assistance, transportation, personal care, and social inclusion services, emphasizing the comprehensive support system required for individuals with disabilities to live independently and thrive within their communities.

Access to Services: Waiting List Responses

- **Currently on a Waiting List for Any Services?**
 - Yes: A significant number of respondents are on a waiting list for services.
 - Yes, No: One response indicated a mixed situation.

Impact of Being on a Waiting List on Daily Life

- **Responses include:**
 - "Feels like my problems would not be important enough to be prioritized."

- "No resources in Orangeburg County."
- "Feeling like I'm just a number, and not valuable."
- "Makes me sad."
- "We have no services after having extensive support in the past."
- Being on a disability list was described as very hard, leading to a loss of job and income.
- "Covid set us back about a year with all services."
- "It hurts financially."
- "Doesn't help."
- "No daytime care or help and financially burdened."
- "It causes a lot of stress and frustration and affects our quality of life."
- "We are always nervous of the future."
- "No access or awareness of available services."
- For families not yet on services: "These families need assistance early in the child's life."

These responses shed light on the varied impacts of being on waiting lists for services, from emotional distress and financial hardship to concerns about the future and lack of access to needed services. The mixed experiences highlight both the challenges faced due to delays in receiving support and the resilience of some families navigating these circumstances.

Here are the challenges and issues facing families as shared by the survey respondents:

1. Lack of access to financial assistance with managing disability needs.
2. No behavioral support available for access.
3. Lack of necessary coverage for dental needs and not enough support for autism and incontinence.
4. Mental health concerns for a new quadriplegic over 21 years old.
5. Waitlists prevent hiring in-home help.
6. Need for a Personal Care Assistant (PCA).

7. Challenges faced in November of 2023, including loss of job and income due to being on a disability list.
8. Financial struggles, lack of resources, and missing school to make therapy sessions.
9. Concerns about care for a son after the parent is gone and keeping him busy now.
10. Difficulty accessing services for blindness in the community.
11. Military family struggling to access consistent services due to relocations.
12. Inability for family members to attend school or work.
13. Challenges with transportation while working.
14. Clients' feedback on the need for awareness and education on available services.
15. Uncertainty about what to do when a child with disabilities graduates from high school.
16. Lack of support groups that bring families together to share experiences and solutions.
17. Challenges with education services or the lack thereof, and finding work for young adults with disabilities.

These responses highlight a broad range of concerns, from healthcare and education to financial and emotional support needs, underscoring the complex challenges faced by families dealing with disabilities.

Advocacy & Solutions: Issues Highlighted by Respondents

1. Skills and willingness to contribute are overshadowed by disabilities.
2. The necessity to care for a son with severe disabilities prevents employment.
3. Challenges of living with autism and dual incontinence require more understanding and support.
4. The difficulties of navigating life with disabilities and dealing with bureaucracies.
5. Unacceptable waitlists for services that are essential for quality of life.
6. The scarcity of PCA care and insufficient care hours available.
7. The importance of recognizing the efforts of state-certified notaries public who have disabilities.
8. A general call for more funding.

9. Uncertainty about how to address the issues.
10. The need for a better system to help children with autism.
11. Vision services should be more inclusive and affordable.
12. The excessive length of waitlists for essential services.
13. The necessity for additional funding in schools for special education.
14. The need for more affordable healthcare for everyone.
15. The importance of elected officials learning about disabilities firsthand.
16. The need for affordable options for assistance.
17. Better services are needed to build a strong foundation for individuals with disabilities.
18. A call for more accountability in Special Education services.

Proposed Solutions

1. Ending the tax on diapers for all ages.
2. Offering summer camps and care during school days off through schools.
3. More investments in support for individuals in need and better access to necessary supplies.
4. Increased funding for people with disabilities.
5. Funding Medicaid waivers to eliminate waitlists.
6. Offering better pay for caregivers.
7. Making state electors and community leaders aware of the challenges faced by individuals with disabilities.
8. Emphasizing that funding is crucial for addressing these challenges.
9. Establishing a centralized information center for service access.
10. Increasing staffing and always providing more funding where needed.
11. More funding for personnel to improve service delivery.
12. Community education, funding, and incentives for qualified personnel.
13. Implementing a better insurance system.
14. Improving policies and conducting audits to ensure effective service delivery.

15. Developing residential community options that are safe and affordable.
16. Adopting a more realistic approach to serving families with special needs.
17. Urging lawmakers to listen to families/parents and provide needed supports.

These responses reveal a comprehensive view of the challenges faced by individuals with disabilities and their families, alongside a range of proposed solutions focusing on financial support, accessibility to services, policy improvements, and the crucial role of funding in enhancing the lives of those with disabilities.

Here are the additional comments or information shared by the respondents:

1. Experiences of shame and trauma from wanting to be independent but facing societal and logistical barriers.
2. A call for the expansion of Applied Behavior Analysis (ABA) services.
3. (No additional information provided for several responses.)
4. Confusion and frustration over the discrepancies in available support and understanding within the community.
5. The isolating nature of disability.
6. The need for assistance is emphasized without further details.
7. Vocational Rehabilitation (Voc Rehab) described as a demeaning experience for an individual's son.
8. The challenges of having multiple family members with disabilities.
9. A respondent with a master's degree in policy expresses willingness to assist in making meaningful changes.
10. Highlighting the importance of support for teachers of children with special needs and the need for community understanding.

In conclusion, the most important and powerful message gleaned from these survey responses is the urgent need for comprehensive support and understanding for individuals with disabilities and their families. Across various sections of the survey, respondents highlight significant challenges such as the lack of accessible and affordable services, the long waitlists for essential supports, the financial and emotional strain on families, and the societal barriers that exacerbate these difficulties.

Key themes that emerge include:

- **The Necessity for Immediate Action:** Respondents express a clear call for more immediate and direct support from elected officials and policymakers to address the pressing issues they face daily. This includes funding for essential services, reducing waitlists for support, and improving access to healthcare, education, and employment opportunities.
- **The Importance of Understanding and Empathy:** There's a profound need for greater societal understanding and empathy towards individuals with disabilities. Personal stories shared in the survey responses reveal feelings of isolation, frustration, and the desire for dignity and independence, underscoring the importance of community awareness and sensitivity.
- **The Call for Inclusive Solutions:** Solutions proposed by respondents emphasize not just financial support but also structural changes to make communities more inclusive. These include tax relief on necessary supplies like diapers, better pay for caregivers, expanded educational and vocational opportunities, and more robust support systems for families navigating disability services.
- **Empowerment Through Advocacy:** The survey responses collectively underscore the importance of empowering individuals with disabilities and their families to advocate for their needs and rights. This empowerment comes through in calls for policy changes, more significant involvement in decision-making processes, and the creation of platforms for their voices to be heard.

The overarching message is a call to action for legislators, community leaders, and society at large to recognize and address the multifaceted challenges faced by individuals with disabilities and their families. It's a plea for policies and practices that not only provide necessary supports but also foster a more inclusive and empathetic society that values the contributions and dignity of all its members, regardless of their abilities.

Actionable Appeal

Empower, Include, Act: A Call to Action for Individuals with Disabilities and Allies

In the heart of our community lies the strength of diversity, the power of inclusion, and the undeniable right to dignity and opportunity for every individual, including those living with disabilities. The voices from the "Understanding the Needs of South Carolinians with Disabilities" survey resonate with a clear, powerful message: It's time for change, understanding, and action.

To Individuals with Disabilities: Your experiences, challenges, and triumphs illuminate the path toward a more inclusive world. You possess unique talents, perspectives, and the resilience that inspire progress. We urge you to raise your voices, share your stories, and assert your rights. Your involvement in advocacy and policy-making can transform

societal views and legislative landscapes. Remember, your voice is not just heard; it echoes, bringing about change and empowering others.

To Families and Caregivers: You are the unsung heroes, providing support, love, and advocacy. We recognize your dedication and the challenges you face. Together, we can create a network of support, sharing resources, and experiences to lighten each other's loads. Your advocacy is crucial in shaping a world that understands and accommodates the needs of your loved ones.

To Allies and Advocates: Stand with us, armed with empathy and commitment. Your support amplifies our call for change, breaking down barriers and paving the way for equality. Educate, advocate, and push for policies that ensure accessibility, inclusion, and fairness in every aspect of society.

Our Collective Call to Action:

1. **Empower Through Education:** Knowledge is power. Educate yourself and others about the rights, needs, and potential of people with disabilities. Schools, workplaces, and communities must become platforms for learning and understanding, eradicating ignorance and prejudice.
2. **Demand Inclusive Policies:** Advocate for laws and policies that recognize and address the diverse needs of people with disabilities. From healthcare to employment, accessibility to social services, our policies must reflect the values of equity and inclusion.
3. **Foster Community Support:** Build and participate in networks that offer support, resources, and advocacy. Whether through local groups, online communities, or national organizations, there's strength in numbers.
4. **Celebrate Diversity:** Recognize and honor the contributions of individuals with disabilities. From art and science to advocacy and leadership, the achievements of people with disabilities enrich our world.
5. **Challenge Inequality:** Stand up against discrimination, exclusion, and injustice. From the classroom to the boardroom, ensure that environments are not just accessible but also welcoming and inclusive.

Our journey toward a more inclusive society requires every one of us to act with courage, compassion, and conviction. Let's unite in our efforts to create a world where every individual, regardless of their abilities, has the opportunity to thrive, contribute, and live a fulfilling life. Together, we can turn challenges into opportunities, barriers into pathways, and dreams into realities. Let's empower, include, and act—today, tomorrow, and always. Email us at scpdoinfo@gmail.com or visit www.scpdo.org to learn more about this report and how you can get involved!