The Caregiver Toolkit

Inadequate Support Systems & Importance for Advocacy

Meeting Objectives

- Understand the definition of Long Term Supports and Services
- Discuss barriers to receiving Long Term Supports and Services
- Review the negative effects of barriers to receiving Long Term Supports and Services
- 4 Review supports that caregivers request
- 5 Discuss the importance of advocacy



Happy Developmental Disabilities Awareness Month!

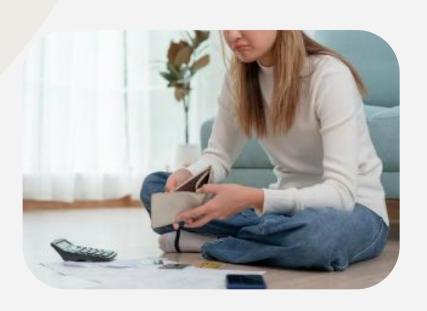
Long Term Supports & Services

"Health-related services and supports needed by individuals who lack the capacity for self-care due to a physical, cognitive, or mental disability"



- Issue: complex, uncoordinated, limited, difficult to access, and offer no clear path to assistance
- Barriers to receiving LSS:
 - Insufficient Medicaid funding
 - Institutional bias in the Medicaid program
 - Continued and worsening crisis of unmet needs
 - Persistent and worsening workforce crisis

Insufficient Medicaid Funding



- Medicaid Funding:
 - > Means-tested
 - Is not portable across state lines
 - > Differs from state to state
 - Does not meet the demand for community-based LTSS
 - > Has decreased since 2017
- Common Funding Sources:
 - > Family income (80%)
 - ➤ Family savings (70%)
 - > Social Security income (63%)

Institutional Bias of Medicaid

- **\Delta** Lack of autonomy:
 - > Lack of opportunities to make decisions
 - > Choices being ignored
- Lack of client-centered support:
 - Decisions based on availability and cost, not on the person's choices
- Increase in bias:
 - Institutional services are mandatory under federal law
 - Community-based supports and services are optional

Crisis of Unmet Needs

- Lack of accessibility:
 - Accept services that are available but inappropriate/inadequate, or receive no supports at all
- Long waiting lists:
 - ➤ Waiting for a Medicaid Home and Community-Based Services waiver (42%)
 - > On a waiting list for more than 5 years (33%)
- Low satisfaction:
 - Less than half of caregivers are satisfied with the quantity and quality
 - > Issues with communication and coordination

Workforce Crisis



- Decreased availability of DSPs:
 - Loss of DSPs during the COVID-19 pandemic
 - Continued shortage
- Quality of DSPs:
 - Depends on the skills and training of the providers
- Insufficient funding:
 - > Impacts recruitment
 - ➤ Impacts DSPs wages
 - > Impacts DSPs training
 - > Impacts retention

"I got into caregiving because I've always loved people. I have respect for people and all they've been through in life. We need to invest more in this profession. I have two jobs, working six to seven days a week to make ends meet. And I have to do that to live comfortably and pay my rent. Caregiving needs to be valued in our society in a way that it is not now."

 Aryana, a direct support professional in Washington, DC and Maryland

81%

of caregivers provided more supports due to decreased available supports

73%

of caregivers paid more out-of-pocket, and 37% report difficulty paying for supports and services

68%

of caregivers reported that the direct support workforce crisis had negatively affected supports

DECREASED HEALTH

INCREASED STRESS

ATTENDED WORK LATE OR LEFT EARLY

RECEIVING WARNINGS ABOUT ATTENDANCE

Effects

HAVING TO TAKE A LEAVE OF ABSENCE

LOSING BENEFITS GIVING UP WORK ALL TOGETHER BEING PAID FOR PROVIDING SUPPORTS

RESPITE

Requested Supports

HAVING PAID LEAVE

SYSTEM NAVIGATION ASSISTANCE

EMPLOYEE ASSISTANCE PROGRAMS

Importance of Advocacy



- Stay Informed
 - On legal rights, resources, policy changes and/or issues
- Network
 - > With other families/caregivers
 - With policy makers and local legislators
- Advocate
 - > For laws that promote funding
 - For improvements to the quality and quantity of supports and services
 - ➤ Vote!

Advocacy Resources

- 1. The Arc
- 2. AAIDD
- 3. <u>National Association of Councils on Developmental</u>
 <u>Disabilities</u>
- 4. North Carolina Council on Developmental Disabilities NCCDD
- 5. NADSP
- 6. NADD

Questions?

Activity Time!

- 1. Please provide a list of supports and services that you need as a caregiver.
- 2. Please provide a list of support and services needed by the individual under your care.

Satisfaction Survey

Please scan the QR code to fill out



References

Scan the QR below

