

The Caregiver Toolkit

*Inadequate Support Systems &
Importance for Advocacy*

Meeting Objectives

1

Understand the definition of Long Term Supports and Services

2

Discuss barriers to receiving Long Term Supports and Services

3

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!

#DDAM2024

**Developmental
Disabilities
Awareness
Month 2024**
A World of Opportunities

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

- ❖ 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

**GIVING UP
WORK ALL
TOGETHER**

**HAVING TO
TAKE A LEAVE
OF ABSENCE**

**LOSING
BENEFITS**

**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. [National Association of Councils on Developmental Disabilities](#)
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

