

Plain Language Version

**Beyond Coercion and
Institutionalization:
People with Intellectual and
Developmental Disabilities
and the Need for Improved
Behavior Support Services**

**Part 10:
Words to Know**

Words to Know in this Toolkit

988 Lifeline

A group of mental health crisis service providers people can reach by calling or texting 988. The 988 Lifeline will send the call or text to a local mental health crisis service who can help the person.

Abuse

Hurting someone or treating them badly as a way to control them.

Accommodations

Changes that help people with disabilities access the same services as everyone else.

Americans with Disabilities Act (ADA)

A law that applies to the whole United States. The ADA says that governments and most public places have to be accessible to people with disabilities.

Antipsychotics

A type of mental health medication that treat psychosis.

Appendix

An extra part of a toolkit that gives more information.

Applied behavior analysis (ABA)

A type of behavior support service that is mostly used on autistic children, but can be used on other people with IDD. ABA focuses on making people act “less autistic” by changing the way people behave.

Augmentative and alternative communication (AAC)

Ways of communicating other than speaking with your mouth or using a sign language. AAC includes things like writing, pointing to letters and words, or typing words on a computer.

Behavior

The different ways people act and respond to their feelings and the world around them.

Behavior support services

Services that help people deal with behavior that makes it hard for them to live the lives they want.

Behaviorism

A way of thinking about human behavior that says we should only think about the behavior we can see. Behaviorism focuses on changing a person's behavior but not on the person's thoughts or feelings. ABA is part of behaviorism.

Block treatment

When a group of people with disabilities all get the same services, even if they have different needs and wants.

Burnout

When someone feels really tired and like they cannot focus on their job because their job is so stressful.

Centers for Medicare and Medicaid Services (CMS)

The part of the U.S. government that runs Medicaid on the national level. CMS makes rules that all state Medicaid programs have to follow.

Challenging behavior

A term some people use to talk about behavior that makes it hard for a person to live the life they want.

Chronic illnesses

Illnesses that last a long time, like cancer or diabetes.

Coercion

Trying to change someone's behavior, even if that person does not want to change their behavior.

Communication

The different ways people tell each other information and ideas.

Community

A place where you can make choices about your own life.

Communities can be places like neighborhoods, towns, or cities.

Community living

When people with disabilities live in the same places as people without disabilities.

COVID-19

A bad disease that has spread around the world and made a lot of people very sick. COVID-19 has made it hard for people with disabilities to get good services.

Crisis respites

Houses or apartments where people can stay for a few days until a mental health crisis has passed. Crisis respites often have services like support workers or therapy groups.

Crisis support plan

A document that helps people know what to do when someone has a mental health crisis. A crisis support plan talks about:

- What the person does when they are calm and happy.
- What the person does when they start to get upset.
- What the person does when they are in a mental health crisis.
- What things a person might do that look like a mental health crisis but are really not.
- What service providers and support workers can do to make mental health crises less likely.
- What service providers and support workers can do to help the person when they get upset.
- What kinds of things cause the person to get upset.
- How service providers and support workers can help the person stay safe during a mental health crisis.
- What people or groups in the community can help the person during a crisis.

Dangerous behavior

Behavior that:

- Hurts the person doing the behavior badly.
- Hurts someone else around the person badly.
- Could really hurt the person doing the behavior or someone else if the behavior does not stop.
- Could get the person in trouble with the police if the behavior does not stop.

Data

Facts and information about something.

Deinstitutionalization

Moving people with disabilities out of institutions and into the community.

Diagnostic overshadowing

When doctors blame medical problems a person with IDD has on the person's disability.

Dignity of risk

The idea that people have the right to make choices, even if those choices might have risks or end badly.

Dual diagnosis

When someone has both an IDD and a mental health disability.

Environment

The different places a person lives, works, and plays in.

Food insecurity

When someone does not have enough food to eat and does not have money to buy more food.

Guardian

The person a court chooses to make choices for a person under guardianship.

Guardianship

When a court takes away a person with a disability's right to make choices for themselves. The court says another person can make choices for the person with a disability.

Hazard

Something that could hurt people. Common household and community hazards are household chemicals, furniture and large appliances, and wet or icy surfaces.

HCBS Settings Rule

A rule the U.S. government made. The HCBS Settings Rule says people getting HCBS have rights like the right to respect and privacy, the right to live in the community, and the right to make choices about services.

HCBS workforce crisis

A problem that is happening right now. The HCBS workforce crisis means that there are not enough support workers to help every person with IDD who needs support in their home or the community.

Health care passport

A document that lists out information about someone's health care, such as the medications they take or how to contact their doctors.

Home and community based services (HCBS)

LTSS someone gets in their home or in the community.

Homeless

When someone does not have a long-term place to live.

Institution

A place where a lot of people with disabilities live. People in institutions usually did not decide to live there. They were put there by someone else. Institutions are not run by the people who live in them. Institutions are run by the people who work in them

Interviewing

Talking to people about a specific topic they know a lot about to learn more about the topic.

Literature review

A way to gather information about a topic. During a literature review, you look at different materials people have written about your topic and take notes on the materials.

Long-term services and supports (LTSS)

Services that help people with disabilities live our everyday lives, such as support workers, transportation, or job coaches.

Medicaid

A health care program run by state governments. Medicaid helps people get health care if they have a disability or don't have a lot of money.

Medically underserved population

A group of people who do not have enough access to health care.

Mental health crisis

When a person is having thoughts or feelings that hurt them that they cannot control. During a mental health crisis, a person might try to hurt themselves or others.

Mental health crisis services

Services that are supposed to help people who are dealing with emotions or behavior that hurt them that they cannot control.

Mental health disabilities

Disabilities that change how people think and feel. Mental health disabilities can make it hard for people to feel in control of their emotions.

Mental health services

Services that help people with mental health disabilities deal with their emotions and live in the community.

Mental health therapy

Talking to a mental health doctor about your emotions and thoughts.

Occupational therapy

A service that helps people learn and practice skills they need in their everyday lives.

Olmstead v L.C.

A Supreme Court case that said people with disabilities in the United States have the right to live and get services in the community.

Operant conditioning

Changing someone's behavior using rewards and punishments.

Peer support

A service where people with IDD or mental health disabilities can talk to a peer worker.

Peer worker

A person with IDD or mental health disabilities who gets special training in helping other people with IDD or mental health disabilities.

Person-centered planning

A way of figuring out what services might help a person live the life they want to live. Person-centered planning asks about a person's needs, wants, hopes, and goals. Then, the person-centered planning team figures out services might help the person get those things.

Physical therapy

A service that helps people move their bodies in ways that do not cause pain or injury.

Positive behavior supports (PBS)

A newer kind of behavior support service that is based in ABA. PBS focuses more on community living and a person's own goals than ABA does. PBS also uses some ideas from other kinds of psychology.

Prevent

When you prevent something, you stop it from happening in the first place.

Preventive health care

Health care that can prevent, or stop, medical problems from happening or getting worse.

Primary care doctor

A doctor you see for regular, general health care, like getting shots or when you have the flu.

Provider-owned settings

When the HCBS provider owns the place people get HCBS in.

Providers

People or places that give people with disabilities health care or services, like doctors or in-home services.

Psychiatric advance directives

A way to plan for a mental health crisis that lets someone write down what they would or would not like to happen if they were in a mental health crisis.

Psychology

The study of how people think, feel, and act. Psychology includes behaviorism, but psychology is also bigger than behaviorism.

Psychosis

A symptom of some mental health disabilities that causes people to think and experience things most people do not, like hearing or seeing things nobody else can.

Punishment

Something a person gets for having “bad behavior.”

Research

A way people learn new things about the world. When people do research, they collect information about a topic, use that information to answer questions on the topic, and share what they learned with others.

Researchers

People who do research as their jobs.

Restraint

Stopping someone from moving by holding them down, tying them up, or making them take medication to make them tired.

Reward

Something a person gets for having “good behavior.”

Seclusion

Locking someone in an empty room.

Secondary trauma

When someone has trauma from seeing someone else go through a really stressful experience

Self-direction

An option that some people who get HCBS through a waiver use. Self-direction lets a person design and run the HCBS they get.

Speech therapy

A service that helps people learn and practice ways of communicating that work for them.

Support workers

People whose job it is to help people with IDD in our homes and in the community. Support workers are sometimes called direct support professionals.

Survey

When scientists ask people about a specific topic and write down what the people say.

Symptoms

Signs that a person has an illness or disability.

Themes

Big ideas that many different people talked about in their interviews.

Trauma

Changes in how a person thinks, feels, and behaves because of a scary situation they went through.

Trauma-informed care

A way to provide services to people with trauma. Trauma-informed care focuses on not making people's trauma worse. Trauma-informed care helps people work through their trauma.

Turnover

When someone gets a job but leaves it within a few months

Vacancy

When a job is hiring but nobody is applying to the job.

Voluntary

When the person getting services chooses to get the services. If the person is forced or coerced into getting services, the services are not voluntary.

Waiting list

A list of people who the state or a provider says qualify for services but cannot get services yet.

Waivers

Medicaid programs that let someone get HCBS instead of getting services in an institution.

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