

Plain Language Version

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

**Part 9: Appendix B:
Tools to Help People With IDD
and Our Supporters Know
What to Do in a Crisis**

Words to Know in Part 9

Appendix

An extra part of a toolkit that gives more information.

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.

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.

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.

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.

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 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.

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.

Appendix B: Tools to Help People With IDD and Our Supporters Know What to Do in a Crisis

A **mental health crisis** is when someone has thoughts or feelings that hurt them. They might not be able to control these thoughts or feelings, and may try to hurt themselves or others. It can be hard for someone to **communicate** what they want and need during a mental health crisis.

People need help during a mental health crisis. Having a plan helps people stay safer during a mental health crisis. It helps people know what to do to support someone through a crisis.

This **appendix** is about tools to help people with IDD and our supporters plan for a mental health crisis. We found tools to help people plan for a mental health crisis. We have listed them here, and split them into 5 categories:

- Psychiatric advance directives.
- Tools to help plan for a mental health crisis.
- More tools to help plan for a mental health crisis. These tools are just for people with IDD and our supporters.
- Health care passports.
- Other tools.

Some of these tools were made by people with IDD and/or mental health disabilities. We marked these tools with an asterisk (*).

Psychiatric Advance Directives

Psychiatric advance directives are a way to plan for a mental health crisis. They let someone write down what they want and need, before a mental health crisis happens. That way, other people know what to do if a mental health crisis happens.

Someone can write things down like:

- Where they want to go for help.
- Who they want to help them.
- What kind of medical care they want or don't want.
- When they want someone else to make choices for them.

Psychiatric advance directives are a legal document. That means, in most cases, doctors and mental health workers have to follow what a psychiatric advance directive says. Psychiatric advance directives make sure people listen when someone has a mental health crisis.

Here is a list of tools to help you make a psychiatric advance directive:

- Mental Health America: Creating a Psychiatric Advance Directive: <https://www.mhanational.org/creating-psychiatric-advance-directive>

This is a tool by Mental Health America. It uses a step-by-step process to help someone make a psychiatric advance directive.

- National Resource Center on Psychiatric Advance Directives: <https://nrc-pad.org/>

This website has information about making psychiatric advance directives in each state. You can click on your state to find out more information.

- SMI Advisor: My Mental Health Crisis Plan app: <https://smiadviser.org/getmyapp>

This is an app by SMI Advisor that helps people make a psychiatric advance directive on their smartphone. This makes it easier for someone to always have their psychiatric advance directive with them.

Tools to help plan for a mental health crisis

- * Fireweed Collective: Crisis Toolkit: <https://fireweedcollective.org/crisis-toolkit/>

This toolkit has links to many helpful pages that can help during a mental health crisis. The toolkit has information about:

- ◇ Planning for a mental health crisis.
- ◇ What to do if you feel like hurting yourself.
- ◇ Where to call for help if you have a mental health crisis.
- ◇ Different kinds of mental health medication.

- * Fireweed Collective: Madness & Oppression: Paths to Personal Transformation and Collective Liberation: <https://fireweedcollective.org/publication/madness-oppression-paths-to-personal-transformation-and-collective-liberation/>

Oppression is when a group of people gets treated unfairly by others because of who they are. Oppression makes it so some groups of people get treated better than other groups. Oppression happens because one group gets more power than others.

For example, people of color in the U.S. go through oppression because of their race. White people don't go through oppression because of their race. White people have most of the power in the U.S. That power gets used to oppress people of color.

This toolkit talks about how people with mental health disabilities get oppressed. It talks about how oppression makes people feel, and how to cope with feelings about being oppressed. The toolkit talks about fighting back against oppression.

- Mental Health Minnesota: Crisis Plan for Your Support System: <https://screening.mhanational.org/content/worksheet-crisis-plan-for-your-support-system/>

This short tool is easy to fill out, and can help you plan for a mental health crisis. You can give a copy to your family or friends so they know how to help you during a mental health crisis.

- * Oakland Power Projects of Critical Resistance: SAGE Response to a Psychosocial Crisis: <https://docs.google.com/document/d/1DFE6KTf6EZkURIGyBo30jLvpu2hAiM4BLSdggkG7Tdso/edit>

This is a guide for people who want to support someone else having a mental health crisis. The guide has information to help someone through a mental health crisis. It has tips to help stay calm and figure out the best way to handle an emergency.

- * Project LETS: Anti-Carceral Crisis Plan: https://drive.google.com/file/d/1cXgw_a30JMkuhN3KUiu_H5B_PKVzTE0c/view

This tool helps keep people from going to jail or an institution because of a mental health crisis. It helps people plan so that police don't need to step in during a mental health crisis. This tool helps people stay in the community while getting mental health support. This tool can help people make better choices during a mental health crisis.

- Wellness Recovery Action Plan: <https://www.wellnessrecoveryactionplan.com/what-is-wrap/>

This is a longer tool to plan for a mental health crisis. It helps people make plans to stay well and have less mental health problems. It can help people plan out their day and figure out what things hurt their mental health. This tool can also help people figure out when a mental health crisis is coming, and how to get through it faster.

Tools to help plan for a mental health crisis. These tools are specifically for people with IDD and our supporters.

- Missouri Department of Mental Health: Crisis Safety Plan Assessment and Template for Plan: <https://dmh.mo.gov/media/pdf/crisis-safety-plan-assessment-and-template-plan>

A safety plan is another tool to plan for a mental health crisis. They get made to fit each person who needs one. Safety plans lists things like:

- ◇ What can cause a mental health crisis.
- ◇ How to tell if someone is having a mental health crisis.
- ◇ What to do to help with the mental health crisis.

This tool lists what kinds of things should go in a safety plan. It also has empty safety plans to fill out. You can make your own safety plan.

- North Carolina Department of Health and Human Services: Crisis Prevention and Intervention Plan Training: <https://www.trilliumhealthresources.org/sites/default/files/docs/Provider-documents/Crisis-Prevention-intervention-plan-training.pdf>

This is a tool for people that work with people with disabilities. It may be hard for people with disabilities to understand. This tool trains people on how to:

- ◊ Know what to do if a mental health crisis happens.
 - ◊ Write a good crisis plan.
 - ◊ Help people with disabilities be a part of their crisis plan.
- Surrey Place Center: A Guide to Understanding Behavioural Problems and Emotional Concerns in Adults with Developmental Disabilities (DD) for Primary Care Providers and Caregivers: https://ddprimarycare.surreyplace.ca/wp-content/uploads/2018/04/Guide_to_Understand_Bx_Probs-2.pdf

This is a tool for doctors who help people with disabilities. It is also for family and friends who care for people with disabilities. The tool has checklists and flowcharts to go through. They can help people plan for a mental health crisis. Checklists make sure nobody misses anything important. Using flowcharts can help people know what to do next.

- Elspeth Bradley and Yona Lunsky/Surrey Place Center: Risk Assessment Tool for Adults with DD in Behavioural Crisis: https://ddprimarycare.surreyplace.ca/wp-content/uploads/2018/03/Risk_Assessment_Tool.pdf

This is a tool for people who care for people with IDD. It can help them figure out if someone they care for might have a mental health crisis. It helps plan out ways to keep people from hurting themselves or others.

- * Ambitious about Autism: What's Your 'Normal'? Toolkit: <https://www.ambitiousaboutautism.org.uk/sites/default/files/youth-participation/toolkit/Ambitious-about-Autism-know-your-normal-toolkit.pdf>

This toolkit is for autistic people. But it can also help other people with IDD. Every autistic person is different. What is "normal" for one person might be different for someone else. This toolkit lets you list out what is "normal" for your life. You can list things like:

- ◇ Your day-to-day routine.
- ◇ Who you are closest with.
- ◇ Your interests.
- ◇ How you take care of yourself.
- ◇ What your mood is usually like.

This helps others know more about you. You could give a copy to your doctor. You could also give one to family or friends.

- * Ren Koloni, The Link Center: What To Do When I Don't Feel Okay: Big Ideas Guide: <https://www.nasddds.org/wp-content/uploads/2023/11/What-To-Do-When-I-Dont-Feel-Okay.pdf>

This is a guide made by and for people with IDD. It is written in plain language. This helps more people understand the guide. This toolkit answers questions like:

- ◇ What is a crisis?
- ◇ Why does a crisis happen?
- ◇ What is a crisis plan?
- ◇ What should I think about when I make my crisis plan?
- ◇ Who can help me?
- ◇ What do I do if I do not know anyone who can help me?

Health Care Passports

It can be hard to remember all the information about your health, especially during a mental health crisis. Health care passports can make this easier. A **health care passport** is a paper or electronic document that lists out all the information about someone's health care.

A health care passport lists things like:

- Your name, birthday, and address.
- What medications you take.
- Your allergies.
- Your doctors and their contact information.
- What surgeries you have gotten.
- What helps you during a mental health crisis.
- And more!

Listing out this information can help your family, friends, and doctors. They will know where to look if they need to help you stay healthy.

Here are some tools to make your own health care passport:

- Melhas et al./Surrey Place Center: About My Health: Learning about the healthcare and communication needs of adults with intellectual and developmental disabilities: <https://ddprimarycare.surreyplace.ca/wp-content/uploads/2021/03/5.1-About-My-Health-new.pdf>

This is a tool for people with disabilities. Doctors and family members can also use this tool. It lists out medical information about a person. It lists things the person wants others to know about them. It also says what doctors can do to make medical visits easier.

- Elizabeth Perkins/Florida Center for Inclusive Communities: My Health Passport: http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf

This health care passport is called My Health Passport. It is one kind of healthcare passport that lets you list lots of different information. You can list things like:

- ◇ Your name and birthday.
- ◇ Your doctor's name and phone number, and an emergency contact.
- ◇ How you communicate best.
- ◇ Your medical history, what medications you take, and your allergies.
- ◇ What it looks like when you're in pain or upset.
- ◇ What kind of help you need in your day-to-day life.
- ◇ Your favorite things and things you dislike.

- Virginia Department of Behavioral Health and Developmental Services: My Care Passport: <https://dbhds.virginia.gov/wp-content/uploads/2022/09/DBHDS-My-Care-Passport-9.25.22.pdf>

This healthcare passport is called My Care Passport. It lets you list many of the same things as My Health Passport, but it also adds some other things like:

- ◇ The people who know the most about you
- ◇ The kind of home you live in
- ◇ How others can help keep you safe
- ◇ Who helps you make medical decisions
- ◇ How you usually act on a normal day

My Health Passport also lets other people help fill it out. Doctors or other health care workers can add to it. That helps you and other people keep track of your health.

Other tools

- * Mia Mingus/Bay Area Transformative Justice Collective: Pods and Pod Mapping Worksheet: <https://batjc.wordpress.com/resources/pods-and-pod-mapping-worksheet/>

Pods are groups of people who share a community. Or, that share the same ideas about how the world should work. People in pods can help each other. They can build their communities. Pods are a way to work together to make a better world.

This tool can help you figure out who your pod is. Or, who could be in your pod. You can use the pod “map”. That way, you can see what your pod looks like. It can help you think more about what you want your pod to become.

- * Autism Society of Minnesota: What is Pod Mapping?: <https://ausm.org/wp-content/uploads/2021/11/Pod-Mapping.pdf>

This is an adapted version of the pod mapping resource we just talked about. This resource has more information to help people with IDD do pod mapping. This resource uses simpler language than the first pod mapping resource.

- Oregon ISP: One Page Profiles: <https://oregonisp.org/1ppa/>

One page profiles are a little like health care passports. But they are shorter than health care passports. And they talk less about health. One-page profiles have information like:

- ◇ What people like about you.
- ◇ The things that are important to you.
- ◇ Ways other people can help you.

This website lists out the parts of a one-page profile. It also has examples of one-page profiles. And it has empty profiles you can fill out yourself.

- Parents Helping Parents: Introduction to One-Page Descriptions: <https://www.php.com/elearning/introduction-to-one-page-profiles/>

One-Page descriptions are another kind of one- page profile. This website has lots of different profile templates. You can use them to make your own one-page description.

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