

THE NATIONAL ALLIANCE
TO ADVANCE ADOLESCENT HEALTH



Emergency Preparedness Toolkit

for Young Adults with Intellectual and Developmental Disabilities and their Primary Care Team

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This project is supported by the WITH Foundation.

About The National Alliance to Advance Adolescent Health

The National Alliance is a nonprofit organization whose mission is to achieve long-term, systemic improvements in comprehensive health care and insurance coverage for adolescents, with focused attention on those from low-income families, racially and ethnically diverse groups, and with special health care needs. Through policy analysis, technical assistance, quality improvement, and advocacy, The National Alliance works to promote effective transitions from pediatric to adult health care as part of its Got Transition program. In collaboration with others, The National Alliance also works to expand the availability of adolescent-centered care, access to mental and behavioral health services, and improvements in health insurance coverage for adolescents and young adults. For more information about The National Alliance, please visit TheNationalAlliance.org.

About the WITH Foundation

Established in 2002, the WITH Foundation is a private foundation whose mission is to promote the establishment of comprehensive health care for adults with developmental disabilities that is designed to address their unique and fundamental needs. The Foundation's initial grantmaking benefited the disability community. In 2011, the Foundation began to focus its support on organizations and projects that promote the establishment of comprehensive and accessible health care for adults with intellectual and developmental disabilities. For more information about the WITH Foundation, please visit WITHFoundation.org.

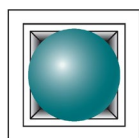
Introduction

Young adults with intellectual and developmental disabilities (ID/DD) and their parents and/or support persons have unique needs during disasters and emergencies. The COVID-19 pandemic brought to light that there are many emergency issues that require additional planning. Equally important, many young adults with ID/DD and their parents and/or support persons look to their primary care team to assist them in this planning and during such stressful times.

With support from the WITH Foundation, The National Alliance to Advance Adolescent Health worked with young adults with ID/DD and their parents, a group of advocates for young adults with ID/DD, and representatives from the major primary care professional organizations to create two tip sheets to assist primary care teams and their young adult patients with ID/DD to plan for disasters and emergencies. Allysa Ware, MSW, Associate Director of Programs & Strategy at Family Voices, conducted key informant interviews with self-advocates and their parents to learn about key topic areas that should be covered in the tip sheets.

Tip Sheet #1: Emergency Preparedness for Young Adults With Intellectual and Developmental Disabilities: Considerations for Primary Care Team. The first tip sheet in this toolkit (page 4) is for primary care teams to use in assisting young adults with ID/DD, their parents and/or support persons to develop a disaster emergency care plan, which consists of a set of steps to consider with them.

Tip Sheet #2: Emergency Preparedness for Young Adults with Intellectual and Developmental Disabilities and Their Families: Areas to Consider and Discuss With Your Doctor. The second tip sheet (page 7) is written for young adults with ID/DD and their parents and/or support persons and contains questions for them to consider as they are completing their personalized disaster emergency care plan, which can be done together with their primary care team.



Emergency Preparedness for Young Adults with Intellectual and Developmental Disabilities: Considerations for Primary Care Team

This tip sheet lays out the initial steps a primary care team could consider in order to assist their young adult patients with intellectual and developmental disabilities (ID/DD) and their parents and/or support persons to prepare for a disaster or an emergency. Creating this disaster emergency care plan is likely to take many shared decision-making discussions over several in-person or telehealth appointments.

STEP 1. Choose a Disaster Emergency Care Plan for Use in Your Practice

Become familiar with some of the templates available for young adults with ID/DD, and decide which one is best for your practice. Some samples are below.

1. The Arc Emergency Preparedness Workbook for People with Disabilities (click [here](#) for English and [here](#) for Spanish)
2. CDC Complete Care Plan (click [here](#) for English and [here](#) for Spanish)
3. American Red Cross Family Disaster Plan (click [here](#) for English and [here](#) for Spanish)
4. FEMA Family Emergency Plan (click [here](#) for English and [here](#) for Spanish)
5. American Academy of Pediatrics Policy Statement – Emergency Information Forms and Emergency Preparedness for Children With Special Health Care Needs. *Pediatrics*; 125(4):2010. (click [here](#))
6. American Academy of Pediatrics Committee on Pediatric Emergency Medicine. Emergency Preparedness for Children With Special Health Care Needs. *Pediatrics*;104(4):1999. (click [here](#))

STEP 2. Create a Medical Summary

Create/update a medical summary and share it with your young adults with ID/DD and add it to their disaster emergency care plan and electronic health record (EHR) portal, if available.

STEP 3. Review Key Areas to Include in a Disaster Emergency Care Plan

During a routine visit ask the young adult and/or parent or other support person, “Do you have a disaster emergency care plan?”

If yes: Ask them to bring it in to the next appointment so you can: 1) have a copy added to their chart and 2) be sure the key areas outlined below are covered. Offer the young adult with ID/DD and their parent and/or support person the tip sheet (starting on page 7 of this toolkit) and ask them to review the questions in the tip sheet and add the additional information to their disaster emergency care plan. Once completed, add the disaster emergency care plan to their EHR portal so they have access when they need it.

If no: Offer a disaster emergency care plan template (see Step 1) and ask the young adult and their parent and/or support person to begin to fill it out. At future appointments consider discussing the key areas below:

KEY AREAS

Medical Information

- Does the young adult have a current medical summary and does their disaster emergency care plan include their current medical summary?
- Does the young adult, parent, and/or support person understand their medical summary, and can they explain it to others?
- Does the young adult have their emergency contact information on a medical alert bracelet or their phone? For a description of how to add medical information and emergency contact information into an iPhone or Android, click [here](#).
- Does the disaster emergency care plan include information on how to get replacements of essential medications, medical equipment and supplies, and other supports, if needed?
- Does the disaster emergency care plan include copies of insurance cards, prescriptions for medicines, advance directive information, and other important medical information?
- Does the disaster emergency care plan include a schedule of the young adult’s daily care routines (e.g., medications, treatment regimens, diet/feeding schedule, water intake, skin/hygiene care, behavioral care, sleep schedule)?

Disability

- Does the young adult’s disaster emergency care plan include information on transportation support, including availability of accessible vehicles?
- Does the disaster emergency care plan have a list of local emergency management numbers? Does the young adult, parent, and/or support person know how to get local emergency warnings, alerts, and instructions?
- Does the disaster emergency care plan describe the young adult’s communication ability and adaptive communication needs?
- For young adults with behavioral concerns, does the disaster emergency care plan include a behavior plan, including comfort items and ways to keep the young adult safe and calm?

Environment

- Does the young adult's disaster emergency care plan include information on temporary shelter, including needed accommodations?
- For young adults who depend on medical technology, has a critical care application been submitted to the utility company? See [here](#) for an example from Texas.

Lastly, is the disaster emergency care plan feasible for the young adult, parent, and/or support person to implement? Ask them if they have practiced what to do in case of a disaster or an emergency.

STEP 4. Discuss Legal Issues and Wellness and Self-Care

In subsequent appointments, consider asking the questions below in the areas of legal issues and wellness and self-care.

Legal Issues

- Do you have a supported decision-making, power of attorney, or guardianship document? If yes, it should be included in your disaster emergency care plan and a copy should be included in the office chart.
- Do you need a letter or information from the doctor's office allowing parent and/or support person or service animal presence in disaster or an emergency situation? For an example hospital policy statement, see [here](#).
- Is there an out of hospital do-not-resuscitate order or advanced directive in place, if needed? A copy should be included.

Wellness and Self-Care

- Do you have a plan for self-care? Do you have a circle of support to assist and support you in a time of a disaster or an emergency?
- Have you considered and discussed how you will continue your wellness approaches (e.g., exercise, diet, cultural traditions) during a disaster or an emergency?

STEP 5. Ask Yourself Questions about Communication Assistance Needs

Consider asking **yourself** the following key questions about your practice in the area of communication with your young adults with ID/DD and their parent and/or support person.

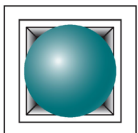
- Do you understand and have noted in their chart the communication assistance needs of your patients with ID/DD?
- Do you have a way to maintain communication between you and your patients with ID/DD in a disaster or an emergency situation, such as an on-call for your office?
- Does your practice have a registry or way to identify and proactively connect with patients with ID/DD in a disaster or an emergency situation, particularly with those who have technology support needs (ventilator, etc.)?
- Are telehealth appointments feasible for your practice during emergencies (consider if there are power outages, patients may not be able to use telehealth)?

Emergency Preparedness for Young Adults with Intellectual and Developmental Disabilities and Their Families:

Areas to Consider and Discuss with Your Doctor

This tip sheet is for young adults, like you, and your parents and/or support persons. It is important to have a plan for what to do in a disaster or emergency. This is called a disaster emergency care plan. With your primary care team, your parent and/or support person, and this tip sheet, you can put your plan together. This tip sheet has:

1. Tips about what should be in your disaster emergency care plan
2. Questions to think about as you put your plan together
3. Suggestions for your parent and/or support person
4. Sample disaster emergency care plans listed on the last page of this tip sheet



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Do you have a disaster emergency care plan?



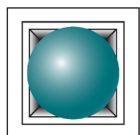
If no:

- Ask your doctor for a disaster emergency care plan that you can use. You can also choose one from the list at the end of this tip sheet.
- Bring it with you to your next doctor's visit. Ask any questions you have.



If yes:

- Is the plan up-to-date?
- Does your doctor have a copy of it?
- Do you have a paper copy available for anyone who might need it?
- Is it part of your medical record at your doctor's office?
If yes, is it online? For example, it could be online in your patient portal.
- Is it easy to grab and go in case of an emergency?
- Would you be able to carry out your plan in an emergency?



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What should be in your disaster emergency care plan?

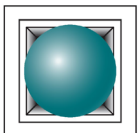
Medical Information



- Your current medical summary. A medical summary describes the medical treatment you get and how it helps you.



- How to get your:
 - Medicines
 - Medical equipment and supplies. This includes styles and serial numbers.
 - First aid kit
 - Batteries and chargers
 - Other supports you need



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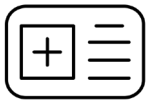


What should be in your disaster emergency care plan?

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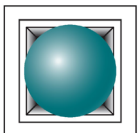
Medical Information

(continued)



- Copies of your:
 - Insurance cards
 - Prescriptions for medicines
 - Any other important medical information.
This includes your ID, birth certificate, social security card, and advance directive information.
 - Individualized Educational Plan, 504 Plan, or Individual Service Plan

You or a trusted family member or other support person can keep all of these copies in one place.



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What should be in your disaster emergency care plan?

(continued)

Disability Resource Information



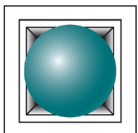
- Information on transportation support and how to find accessible vehicles



- List of local emergency numbers. This includes your utility company that brings power and electricity to your home. This list also includes your local FEMA regional offices.

Tip for a parent and/or support person:

Contact your local emergency resources, such as first responders, law enforcement, fire department, and power companies, to receive emergency alert notifications and let them know about your young adult's disability.



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What should be in your disaster emergency care plan?

(continued)

Environmental Information



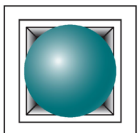
- Cash, food, water, and essentials for you and pets or service animals. Bring food for a special diet, if you have one.



- Information on temporary shelter and needed accommodations



- Clothing, blankets, flashlight, whistle, battery operated radio, chargers



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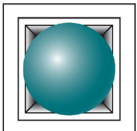
Questions to help plan for a disaster or emergency

It is important to think about how a disaster or emergency will affect different areas of your life. Here are some questions to think about.



Legal Issues

- Do you have a supported decision-making, power of attorney, and/or guardianship document? If yes, make sure to share it with your doctor. Also put it in your disaster emergency care plan.
- Do you have a letter from your doctor allowing a parent and/or support person to be present in an emergency? If yes, make sure to put it in your disaster emergency care plan. See [here](#) for an example policy statement about allowing caregiver presence.
- Do you know how to contact your state Protection and Advocacy Systems, if needed? They provide legal support for those with disabilities.



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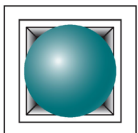


Questions to help plan for a disaster or emergency *(continued)*

Relationships and People You Trust



- Who are the people who support you?
- How will they help you during an emergency?
- Does everyone know what they are supposed to do?
- How will you keep in touch with family, friends, and coworkers during an emergency?



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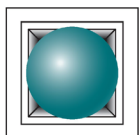


Questions to help plan for a disaster or emergency *(continued)*

Communication Support



- Do you need help communicating with people because of a disability?
- Do you use assistive communication devices? What is your plan if you lose access to these?
- Do you need help communicating because English is not your first language?
- Do you know how to reach your doctor during or after an emergency?
- Can you communicate with your doctor via phone or video?
- Do you have access to your patient records online?
- What is the information that first responders and others might need to help you in an emergency?



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Questions to help plan for a disaster or emergency *(continued)*

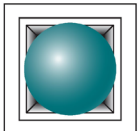


Wellness and Self-Care

- What activities do you like to do? Do you like social groups, exercise, dance, music, computer games? How can you keep up with these activities during an emergency?
- Do you have a list of services and supports you use? These could include your job, day supports, names of direct care workers.
- What are some cultural traditions within your home or community that help you cope in stressful situations?
- What are you going to take with you to help you be okay? Headphones? Sensory boxes for soothing?

Questions for Caregivers:

- What options are available for your own self-care?
- What are triggers that bring on or worsen your young adult's stress and response behaviors? What strategies help you and your young adult cope with them?



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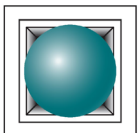
Helpful Resources

Sample Disaster Emergency Care Plans

1. The Arc Emergency Preparedness Workbook for People with Disabilities
 - a. English: click [here](#)
 - b. Spanish: click [here](#)
2. CDC Complete Care Plan:
 - a. English: click [here](#)
 - b. Spanish: click [here](#)
3. American Red Cross Family Disaster Plan
 - a. English: click [here](#)
 - b. Spanish: click [here](#)
4. FEMA Family Emergency Plan:
 - a. English: click [here](#)
 - b. Spanish: click [here](#)

Personal Ability Self-Assessment

An assessment on pages 31-42 of this toolkit [here](#) can help you learn what help you may need before and during an emergency.



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