

PLANNING AHEAD FOR WHEN THE "WHAT IF" IS NOW

EMERGENCY PLANNING FOR WHEN A PRIMARY CAREGIVER IS NOT ABLE TO PROVIDE SUPPORT



This tool was developed to help people with developmental disabilities and their families plan for emergency situations when a primary caregiver is not able to provide support. The COVID-19 pandemic increases the urgency to plan. While it's a difficult topic to think about and discuss, it's important to always plan ahead and consider what should be done if a primary supporter/family member is not be able to provide support due to illness, injury, quarantine, hospitalization, or death. Planning ahead will increase the likelihood that your wishes are respected and that you are supported in a way that best meets your needs.

STARTING THE PLANNING PROCESS

This tool is intended to guide people with disabilities and their families through the process of planning for emergencies together. The pronoun "you" is used throughout to promote involvement of the person the plan is for. If a person is not able to contribute to the planning process, families can use this tool with their loved one's needs and preferences in mind, considering observations and experiences, and asking their family member questions they're able to address.

If you run out of room when completing this tool, you can attach additional sheets of paper for sharing with others. The completed tool should be discussed and shared with your Support Coordinator.

- Include family, friends, and others who know you and your family well in helping you plan for what to do in an emergency.
- If you can't meet in-person, or when social distancing prevents this, you can use your phone or web-based platforms like Zoom, Google Meet, Facebook Rooms, or Skype.
- Think about creating a **Circle of Support**.

What is a Circle of Support?

A Circle of Support is a network of the people we value in our lives who come together to listen to, help plan for, and support our dreams. A Circle of Support can include family, neighbors, friends from work, school, or elsewhere, and others dedicated to helping you succeed.

Circles of Support may meet regularly or when needed. Members should discuss how everyone can work together to support you and one another. Circle members may help you plan for and do things like find your own home, meet new people, or even plan for emergencies.



Don't have a Circle of Support?

Learn more about creating one here:
<https://www.iidc.indiana.edu/irca/articles/creating-a-circle-of-support.html>

_____ 'S PLAN FOR EMERGENCIES

Date created:

Date updated:

Plan is to: stay at home with support from _____

go to _____'s home



People to Contact in Case of Emergency

Emergency contacts should be listed in order of who should be contacted first, then next after that, and so on. Think about who will support you if your typical supporters are not able to do so.

1. Emergency Support Contact: *This is the first person to be called in an emergency. This is the person who will be available to come provide assistance in an emergency situation.*

Name:

Relationship to you:

Phone number:

2. Primary Contact: *This may be someone who is simply a contact person to manage things, possibly from afar. This might be secondary to the emergency support contact. This person might be a guardian or other person charge of coordinating/managing hands-on support.*

Name:

Relationship to you:

Phone number:

3. Support Coordinator

Name:

Organization:

Phone number:

4. Other Supporters: *These may be people who will offer supports in addition to the emergency support and/or primary contacts and may be back-ups if the other contacts listed are unable to be reached.*

Name:

Relationship to you:

Phone number:

Important Health-Related Information

Current Medications



Name (exact)	Dosage (<i>mg and how many tabs/ tablets</i>)	Directions (<i>am/pm/with food, water, etc.</i>)	Self-Medicate?	Current Supply (<i>30, 60, 90 days</i>)

Tips for helping me take my medications:

Current Physicians



Name	Type of Doctor	Location	Phone Number	Email Address

Pharmacy



Name	Location	Phone Number

Allergies



What are you allergic to?	What reaction does this cause?	What should people do to help?

Proxy Decision-maker (who will make health-related decisions if you or your guardian are not able to?)

Name	Relationship to You	Over 18 Years Old?	Phone Number	Email Address



- Think about completing a **health passport** to share in the event of an emergency. Here's one from the Florida Center for Inclusive Communities: http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf
- Advance directive/healthcare proxy forms and FAQ are available online from NJ's Dept. of Health: <https://www.state.nj.us/health/advancedirective/ad/forums-faqs/>

Communication

Communication is essential to handling emergency situations successfully. People have different ways of communicating, and some people do not use words to communicate. Sometimes a stranger will be the first person to help in an emergency situation. Complete this section to help someone you don't know or a new supporter understand how you communicate and how they should communicate with you.



- How do you communicate? (for example: do you use a communication device/ technology, words, gestures, American Sign Language, facial expressions, etc.?)
- Do you read and/or write? Do you need support to read or write? If so, how?
- How do you prefer for others to communicate with you?

How do you let someone know?	What do you say or do?	What should others say or do?
You're not feeling well/ in pain?		

- How do you let someone know? (cont'd)

What do you say or do?

What should others say or do?

Something is wrong

You're happy

You're sad

You're scared

You're angry/frustrated

You want something

You agree

You disagree

Other:

If you are someone who does not use words to communicate, or uses Augmentative and Assistive Communication (AAC), you should prepare some personalized, low-tech communication supports to express what you want, need, and ask any questions you have during an emergency. Examples include:

- An alphabet board with important messages
- Word board to express medical or support needs and ask questions
- Communication board with pictures to express medical or support needs and ask questions
- Dry erase board

You can find more resources for supporting communication here:
<https://www.patientprovidercommunication.org/covid-19-free-tools.htm>

Mobility Supports

- What information do others need to have about adaptive equipment you use or support you need to move around?





How to Support Me

- What are important things others need to know to keep you healthy and safe? *This may include things like support needs with eating, using the restroom, hygiene, being left alone or not, etc...*
- What do supporters need to know and do to assist you and make you feel at ease?
- What behaviors should supporters be aware of?

When this happens...	I do this...	You can support me by...

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- Who do you want to stay connected to? *This might include people in addition to the people on the list of emergency supporters.*
- How can supporters help you stay connected to people you care about? *Think about using Zoom, Skype, Facebook, etc.*
- What activities do you enjoy doing at home?
- What activities do you like to do and can safely do outdoors?

**If there are additional support needs that are important for others to know about, include an additional piece of paper with this information.*

OTHER MATERIALS TO PREPARE IN ADVANCE

Important Papers

There are important papers or documents that you may need to prove who you are and to provide vital information about you. You and your family should gather these documents together, place them in a waterproof bag, and store them in a safe place that can be accessed in case of any emergency. Examples of documents you should have together and ready to go in case of an emergency are:

- Copy of driver's license or non-driver identification card
- Social Security card
- Legal papers like birth certificates and guardianship documents
- Insurance policy numbers and information
- Health passport
- Healthcare proxy/advance directive documents
- NJ Individual Service Plan and Person-Centered Planning Tool
- Bank account/credit card information
- Copies of current prescriptions
- Manuals and warranties for any medical or adaptive equipment
- Copy of a utility bill or other mail with your name and address to prove where you live

Make sure someone knows where your safe place for storing these documents is.

Preparing for different kinds of emergencies, such as natural disasters, will require adding more things to your Go Bag. To learn more about this, visit: <https://www.ready.gov/disability>.

Make a Go Bag

A Go Bag is a bag, backpack, or suitcase that contains all of the things you'll need to leave your home in an emergency. It's also a convenient place for someone who doesn't know you well to find what they need to support you if you need to stay at home. Having these items prepared in advance can be helpful. When it's not possible, be certain to share where these items can be found if they are not in the bag.

What needs to be in my Go Bag? Where can I/my supporters find these items?

Your Go Bag should include:

- A copy of this document
- Laminated sheet with contact information for your doctors and pharmacy
- Copies of current prescriptions/supply of clearly labeled essential medications (make sure they are not expired)

If not in your Go Bag, where can these be found?

- Adaptive equipment
If not in your Go Bag, where can these be found?
- Copy of your health passport
If not in your Go Bag, where can this be found?
- If needed, personalized low-tech communication supports (like a communication board with letters, words, or pictures to help express needs, wants, and ask questions)
If not in your Go Bag, where can these be found?
- Health/dietary items
If not in your Go Bag, where can these be found?
- Personal Protective Equipment (like masks or gloves) for you or your supporters
If not in your Go Bag, where can these be found?
- Things you enjoy to keep you busy (like books, magazines, or games)
If not in your Go Bag, where can these be found?

Where is my Go Bag Located?

Is it ready to go, or are there items to grab last minute to make it complete before you leave with it? Some people may have medications or adaptive equipment that they use regularly and cannot store in a Go Bag, but should be added before leaving with the Go Bag.

My Go Bag is located:

Who else knows where your Go Bag is?

Name:

Relationship to you:

Phone number:

SHARING YOUR PLAN



What should I do with my plan?

Keep your plan in a place where others can find it easily and make sure people know where the plan can be found. Using a binder or folder that is labeled and easy to recognize can be helpful.

Who do I share this plan with?

- Immediate & extended family when applicable
- Friends/Circle of Support
- Neighbors
- Emergency Medical Services (EMS)
- Support Coordinator- you should discuss with your Support Coordinator and ask that this information is included in your NJ Individualized Service Plan

Did you know?

NJ Register Ready allows New Jersey residents with disabilities or access and functional needs and their families, friends, and caregivers an opportunity to provide information to emergency response agencies so emergency responders can better plan to serve them in a disaster or other emergency. To learn more NJ Register Ready, visit: <https://www.nj211.org/special-needs-registry>.

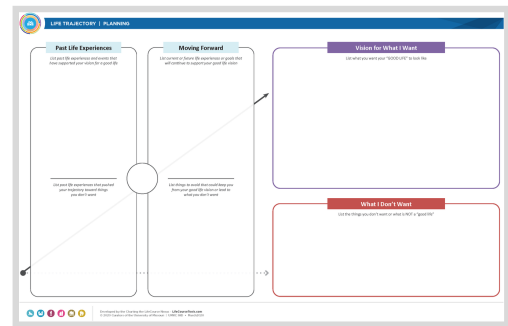
WHAT'S NEXT?

Future Planning

What are some things you're not sure of yet, but need to figure out? You might use some of these **Charting the LifeCourse** resources to help you think about and discuss planning for the future.

LifeCourse Trajectory Worksheet

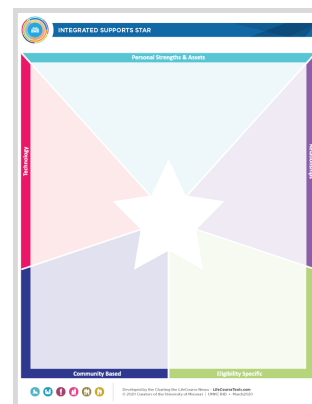
The LifeCourse Trajectory can be a helpful tool to plan for a variety of situations, including emergency situations. It can be used to think about what you want your life to look like or what you want to make sure doesn't happen should an emergency arise. Past life experiences can be used to think about what experiences you've had that have been helpful during challenging times and those that have not been. You can also use this tool to identify what you need to do "moving forward" to help plan ahead for potential emergencies. Doing this will help you to make sure you don't forget to figure things out.



https://www.lifecoursetools.com/wp-content/uploads/LifeCourse_PC-Trajectory-for-Planning.pdf

Integrated Supports Star Worksheet

This tool can help people with disabilities and families brainstorm the supports that they already have or might need to access throughout life or for specific life events. For thinking ahead for emergency situations, this tool can be used to identify the supports the person may want to have ready should the need arise. It can also be useful to help identify strategies to help the person stay connected or be supported to stay connected to people s/he cares about throughout the period of social distancing.



https://www.lifecoursetools.com/wp-content/uploads/CtLC-IntegratedSupportStar_2020.pdf

Tools Developed by the Charting the LifeCourse Nexus - LifeCourseTools.com© 2020
Curators of the University of Missouri | UMKC IHD • March2020
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Preparation of this document was supported by the NJ Department of Human Services,
Division of Developmental Disabilities (Contract #04ME20C)
May, 2020

RUTGERS

Robert Wood Johnson
Medical School

The Boggs Center on Developmental Disabilities
Department of Pediatrics
Rutgers, The State University of New Jersey
Liberty Plaza, 335 George Street
New Brunswick, NJ 08901

rwjms.rutgers.edu/boggscenter
p. 732-235-9300
f. 732-235-9330