



Your Roadmap and Guide Back Into the Community

Self-Advocates

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Introduction

Many things have changed since we were asked to stay at home because of COVID-19.

- Our choices of how we live our lives were taken away to help slow or stop the spread of the virus.
- Activities were closed.
- People did not get to see people who did not live in their home.
- When we did see people, we could not shake hands or hug them.
- We could not go to the places we like to go.
- People have been asked to wear masks to protect others in case we have the virus.
- Many people have feelings because of how we are living right now: anxious, disconnected, nervous, frightened, and other feelings.

Now, our state government has plans to allow people to start doing some of the things that were closed or limited.

- Places are starting to reopen
- There are new rules on how things are done in places that are open.
- Some services and activities will start again, and we are planning on what they may be and how they may be done.

This guide may help you:

- Think about what, when and how you will start to do things in the community.
- Share your thoughts with people important to you.
- Look at what you agree with, what you may not be sure about, and what you do not agree with.

Introduction

How to use this guide:

- Look at the questions and answer them.
 - Remember that social distancing and physical distancing mean the same thing - to stay apart from others.
- There are six areas of questions.
- You can answer the questions in any order you want.
- Think about each question, and give your answer.
- You can put any mark under the answer that fits what you think.
- You may not know how to answer a question. That's okay.
- You can add information at the end of each section to explain more if needed.
- You can answer the questions on the computer, or you can print and fill it out by hand.
- You can answer the questions by yourself or ask someone you trust like family, friend, support staff, or supports coordinator to do it with you.
- You can use any part of this guide again as your life and feelings change.

We would like to thank Self-Advocates United as 1 (SAU1) with the Self Advocacy Power Network for All for their invaluable input and suggestions in the development of this guide. Self Advocacy Power Network for All (SAPNA) is a project of the PA Office of Developmental Programs, managed by Self Advocates United as 1.



If you have questions, concerns, or feedback please contact us at aidinpennsylvania@gmail.com

We hope you find this guide helpful!

1 Returning to Activities in the Community

Figure out if you want to do things in the community right now.

Community usually means places to go and things to do outside of your house.

It is okay to have mixed feelings about this. You might be excited and nervous at the same time. Your family and friends might also be both excited and nervous about this.

Questions	Yes	Not Sure	No
Have I learned new things while staying home that I want to keep doing?			
Are the things I liked to do before open now?			
Are there places in the community I feel ready to go to now?			
Are there places in the community that I don't feel ready to go to now?			

Share more information:

2 My Physical Health

Figure out if you have physical health concerns.

Some health concerns may place you at higher risk for COVID-19.

You will need to think about your physical health when deciding what you want to do in the community.

Questions	Yes	Not Sure	No
Did I have health concerns before COVID-19?			
Do I have new health concerns since COVID-19?			
Has a health care provider told me that I need to be extra careful about COVID-19?			
Do I feel sick now?			
Do people understand when I tell them I'm sick?			
Have I been around anyone who is sick?			

Share more information:

3 Staying Healthy and Lowering My Risk

Figure out if you know how to keep yourself healthy.

You can do things to lower your risk for getting COVID-19. These things are called “infection control measures”.

When you're in a store or community building it's important to wear a mask over your mouth and nose. There may be times when you or others can't wear a mask for safety. We need to do what is right for us, but rules like washing hands, are meant to keep us healthy.

Questions	Yes	Not Sure	No
Do I need support with washing my hands and I am comfortable cleaning my hands frequently?			
Do I have face masks and am I comfortable wearing them?			
Do I understand the social distancing rule to stay 6 feet away from others (not family or support staff)?			
Can I cover my coughs and sneezes?			
Can I follow any new rules in place at my job/day program/volunteer work?			

Share more information:

4 Mental Health

Figure out if you have any mental or behavioral health needs.

Mental and behavioral health refers to how people think, feel, and behave.

Stress can impact how people think, feel, or behave. We all experienced stress from dealing with the COVID-19. Some people had very difficult things happen to them like being in the hospital or having a family member die. Very difficult things which cause a lot of intense stress are called trauma.

Questions	Yes	Not Sure	No
Do I have new or worse mental or behavioral health symptoms?			
Am I worried about harming myself or others?			
Have I struggled to manage my anxiety or stress?			
Do I have someone to talk to about how I'm feeling?			
Has someone I care about died recently?			
Have I done things to help me cope that may not be good for me?			

Share more information:

5 Changes in My Routine

Figure out if you need to make changes to your daily routine.

A daily routine is how you do things like eating and sleeping each day.

Having a good daily routine helps you feel better. It makes it easier to get things done. Sometimes when people are stressed they have a hard time keeping a good daily routine. This can make it hard to do all the things a person might want to do during the day.

Questions	Yes	Not Sure	No
Have I been able to keep in touch with people who are important to me?			
Are there things I did before COVID-19 that I'm still able to do?			
Are there new things I started during COVID-19 that I want to keep doing?			
Are there things I started during COVID-19 that I don't want to keep doing?			
Am I getting the exercise I want and need?			
Has the amount of sleep or the times that I sleep changed much since COVID-19?			

Share more information:

6 Services and Supports

Figure out if you have the right services and supports.

Things will be different now in the community. There might be new rules to follow for things you like to do. You might have to go different places because some places you like might not be open yet. Your needs may be different now because of this. You may need new or different services and supports to be successful in the community.

Questions	Yes	Not Sure	No
Are my services different now than they were before COVID-19?			
Are there services or supports I want to keep?			
Are there services or supports I don't want to keep?			
Will I need more or different services when I go back into the community?			
Would I like to learn more about assistive technology that might help me going back into the community?			

Share more information:

Support Organizations

Connecting with other people who have similar experiences can be helpful. The organizations below have resources and information that may be helpful for you and your support team in planning for going back into the community.

Self Advocates United as 1 (SAU1)

Self Advocates United as 1 is a group of people who envision a world where people with developmental disabilities and their families are united to share knowledge, empower others, and use their voices to transform their communities and people's lives. <https://www.facebook.com/SAU1PA/>

Health Care Quality Units

The Health Care Quality Units (HCQUs) work to support and improve the health information and knowledge for the intellectual disabilities community by building capacity and competency within the physical and behavioral health care systems. <https://www.myodp.org/mod/page/view.php?id=7699>

Support Groups

This resource provides a listing of known support groups by county, across the state. Most of these support groups are autism-specific, but some are general support groups for a wider disability audience.

<https://paautism.org/support-groups/>

Autism Services, Education, Resources and Training (ASERT)

ASERT (Autism Services, Education, Resources and Training) is a partnership of providers involved in the treatment and care of individuals of all ages with autism and their families.

<http://paautism.org>

PA Family Network

PA Family Network provides information, connections and support through Family Advisors. The PA Family Network can help individuals with planning using the Charting the LifeCourse materials.

<https://www.visionforequality.org/pa-family-network/>

Resources

Here are some resources. There are things that may help you learn more. The more you learn, the more knowledge you have. Remember: Knowledge is Power!

Returning to Activities in the Community

[Going into the Community](#)

This resource provides information about understanding your feelings and steps to get ready to go out into the community.

<https://paautism.org/resource/community-covid-self-advocates/>

[Finding Activities in Your Community](#)

This resource provides suggestions for finding activities in your community for when you're ready.

<https://asdnex.org/resource/activities-community-social-recreation/>

[Trajectory for Planning](#)

This tool highlights past life experiences that are leading or moving you away from your vision and then provides space for goals and things to avoid moving forward.

<https://www.lifecoursetools.com/lifecourse-library/foundational-tools/person-centered/>

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My Health

[Pennsylvania Department of Health COVID-19](#)

This website has information from the Department of Health about COVID-19 and resources for individuals.

<https://www.health.pa.gov/topics/disease/coronavirus/Pages/Coronavirus.aspx>

[COVID-19 and Monitoring Physical Health Status](#)

This resource provides information about COVID-19 and tips for monitoring your physical health.

<https://paautism.org/resource/monitoring-health-prevention-covid/>

[Not Feeling Well Social Story](#)

This social story provides a visual guide for what to do if you're not feeling well.

<https://paautism.org/resource/not-feeling-well-social-story/>

[Checklist for Symptoms of COVID-19](#)

This resource is a checklist that can be used to monitor symptoms of COVID-19.

<https://paautism.org/resource/checklist-symptoms-covid-19/>

[Advocating for My Health During COVID-19](#)

This resource provides tips on how to advocate for your health.

<https://paautism.org/resource/advocating-for-health-covid19/>

[Being a Careful Reader of Coronavirus Information](#)

This resource provides information on where to go for trusted information about COVID-19.

<https://paautism.org/resource/coronavirus-information-research/>

[Advocating for Healthcare Needs](#)

This video provides information on advocating for healthcare needs.

<https://aidinpa.org/advocating-for-your-healthcare-needs/>

Resources

Staying Healthy and Lowering My Risk

[Wearing a Mask Social Story](#)

This is a visual resource that explains the importance of wearing a mask and finding one that's comfortable.

<https://paautism.org/resource/wearing-mask-social-story/>

[Social Distancing Social Story](#)

This is a visual resource that explains social distancing, how to maintain a safe distance and when you need to social distance.

<https://paautism.org/resource/social-distancing-social-story/>

[Hand Washing Social Story](#)

This is a visual resource that explains the importance of hand washing, and how to properly wash hands.

<https://paautism.org/resource/hand-washing-social-story/>

[Hand Washing for Self-Advocates](#)

This is a set of videos that explains hand washing and a demonstration of how to properly wash hands.

<https://aidinpa.org/handwashing-for-self-advocates/>

[Changes in the Community](#)

This resource provides information about change that you may come across when you go back into the community.

<https://paautism.org/resource/changes-in-the-community/>

Resources

Mental Health

[What is Trauma Social Story](#)

This is a visual resource that explains what trauma is and when someone may experience trauma.

<https://paautism.org/resource/trauma-social-story/>

[Be Well, Think Well Mental Health Resources](#)

This is a collection of mental health resources with information about anxiety and depression. Relaxation and coping strategies are included.

<https://paautism.org/resource/be-well-mental-health/>

[Finding and Choosing a Therapist](#)

This resource provides information on how to find and choose a therapist.

<https://paautism.org/resource/finding-choosing-therapist-services-provider/>

[Managing Stress and Emotions](#)

This video provides information and tips on how to manage stress and difficult emotions you may experience.

<https://aidinpa.org/managing-stress-and-emotions/>

[Dealing with Negative Thoughts](#)

This video provides information on how to manage negative thoughts.

<https://aidinpa.org/dealing-with-negative-thoughts-and-maintaining-a-sense-of-control/>

[ASDNext Blog: The Journey of Grief](#)

This blog, written by a young adult with autism, talks about dealing with grief after the loss of a loved one.

<https://asdnnext.org/blog/grief-learning-and-healing/>

[ASDNext Blog: Art and Expression in Times of Stress](#)

This blog by a young adult with autism talks about using art as a way to deal with stress.

<https://asdnnext.org/blog/art-and-expression-stress/>

Resources

Changes in My Routine

[New Rules in Familiar Places](#)

This video provides information about some of the new rules that may be in place when you go out in the community.

<https://aidinpa.org/new-rules-in-familiar-places/>

[Being Flexible and Starting New Routines](#)

This video provides information and tips on starting new routines and learning to be more flexible.

<https://aidinpa.org/being-flexible-and-starting-new-routines/>

[Visual Resources](#)

This is a collection of resources about visuals schedules that can be helpful in keeping routines and schedules.

<https://paautism.org/resource/visual-supports-autism/>

[ASDNext Blog: Time to Change](#)

This blog was written by a young adult with autism about how they handle changes.

<https://asdnext.org/blog/time-to-change/>

[ASDNext Blog: Can't Sleep](#)

This blog was written by a young adult with autism about how they manage difficulty sleeping because of the changes related to COVID-19.

<https://asdnext.org/blog/cant-sleep/>

[Quick Guides in the Life Experiences Series.](#)

<https://www.lifecoursetools.com/lifecourse-library/exploring-the-life-stages/>

These guides can help you think about what you want your days to be like and how your routines can lead you to the life you want.

- [Focus on Transition to Adulthood](#), download from link above
- [Focus on Adulthood](#), download from link above
- [Focus on Aging](#), download from link above

Resources

Services and Supports

[Telehealth](#)

This resource provides information about using telehealth to stay connected to services and supports during social distancing.

<https://paautism.org/resource/telehealth-covid19/>

[Staying Connected at Home](#)

This resource provides information on staying connected to friends, family, and support staff during times of social distancing.

<https://paautism.org/resource/staying-connected-home-covid/>

[ASDNext Blog: Staying Connected](#)

This blog was written by a young adult with autism about how they are staying connected to others during times of social distancing and isolation.

<https://asdnnext.org/blog/staying-connected/>

[Person Centered Portfolio for Planning](#)

This portfolio is designed as a booklet printed on 11x17 paper. It includes the Trajectory Planning Tool and the Integrated Supports Star. This tool can help you communicate your vision to support and service providers.

<https://www.lifecoursetools.com/lifecourse-library/foundational-tools/person-centered/>