



Resource Guide to Community Readiness

Parents and Caregivers

TABLE OF CONTENTS

Introduction

Section 1 **Charting the LifeCourse**

Section 2 **Desire to Return to Community**

Section 3 **Physical Health**

Section 4 **Infection Control and Social Distancing**

Section 5 **Mental and Behavioral Health Needs**

Section 6 **Changes in Routine**

Section 7 **Conditions of Supports and Services**

Section 8 **Support Organizations**

Introduction

Many things have changed as a result of COVID-19, and will continue to change in the coming weeks and months. As communities prepare to open up, there will be new rules and guidelines in place to keep people safe and healthy. For individuals with intellectual disabilities and/or autism, this process may be even more complicated.

This guide is designed to provide resources and to help plan a path forward for families and caregivers as you consider the many different ways in which lives have been impacted as a result of COVID-19.

Information within this guide can be used to help plan for services and supports that may be needed, and inform discussions with supports coordinators, service providers and support staff.

Charting the LifeCourse

Charting the LifeCourse is a framework that was developed to help individuals and families of all abilities and at any age or stage of life develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live. Individuals and families may focus on their current situation and stage of life but may also find it helpful to look ahead to start thinking about life experiences now that will help move them toward an inclusive, productive life in the future. The framework is designed to help any citizen think about their life, not just individuals known by the service system.

These tools can be used by families and individuals to help plan across many of the areas reviewed in this guide, and to help in the process of preparing individuals to get ready to go back into their communities.

The LifeCourse Toolkit is a product of the UMKC IHD, UCEDD. More materials at lifecoursetools.com.

Charting the LifeCourse

PA Life Experiences and Questions Booklet: A guide for individuals, families and professionals

<https://lifecoursetools.com/wp-content/uploads/PA-LC-EXPERIENCES-BOOKLET-2016.pdf>

Daily Life and Employment

<http://www.lifecoursetools.com/download/charting-the-lifecourse-daily-life-employment-guide/>

Life Trajectory Worksheet

<http://www.lifecoursetools.com/download/life-trajectory-worksheet/>

Tools for Developing a Vision

<http://www.lifecoursetools.com/download/tool-for-developing-a-vision-individual-and-family-versions/>

Integrated Support Options

<http://www.lifecoursetools.com/download/integrated-support-options/>

Charting the LifeCourse

PA Community of Practice for Supporting Families

<https://www.myodp.org/mod/page/view.php?id=25542/>

Integrated Support Star

<http://www.lifecoursetools.com/download/integrated-supports-star-worksheet/>

Integrated Long Term Service and Support Needs

<http://www.lifecoursetools.com/download/integrated-long-term-service-and-support-needs-template/>

LifeCourse Portfolio

<http://www.lifecoursetools.com/download/my-lifecourse-portfolio-basic/>

Life Stage Guides:

- Early Childhood: <http://www.lifecoursetools.com/download/charting-the-lifecourse-nexus-focus-on-early-childhood/>
- School Aged: <http://www.lifecoursetools.com/download/charting-the-lifecourse-nexus-focus-on-school-age/>
- Transition Aged: <http://www.lifecoursetools.com/download/charting-the-lifecourse-nexus-focus-on-transition-to-adulthood/>
- Adulthood: <http://www.lifecoursetools.com/download/charting-the-lifecourse-nexus-focus-on-adulthood/>
- Aging: <http://www.lifecoursetools.com/download/charting-the-lifecourse-nexus-focus-on-aging/>

Desire to Return to Community

Daily schedules and activities have changed as a result of COVID-19. Schools, day programs, and work sites have all closed to try and prevent the spread of the disease. With the counties across the state starting to open up again, this means people will be able to go back out into the community.

However, not everyone may be ready to head back out as soon as things open. For some individuals, there may be significant anxiety around going back out into the community. One of the most important steps in helping individuals get ready to go back into the community is to first determine if they want to. The following resources can help families and caregivers discuss and plan with their family member how ready they are to resume their community activities once it's safe.

Desire to Return to Community

Talking About Going Into the Community

This resource can help you discuss going back out into the community with your family member. It provides tips on how to start the conversation, helps them identify their feelings, and offers activity suggestions based on different levels of readiness.

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

Individualizing Support for Individuals with Autism ID

This resource provides information on how to create a person-centered approach that is focused on individual strengths and abilities when working with individuals.

<https://paautism.org/resource/individualizing-support-services/>

Future Planning

This resource provides information on how to support individuals to plan for their futures.

<https://paautism.org/resource/future-planning/>

Finding Activities in Your Community

This resource provides tips and suggestions for places to find events or activities going on in your community.

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

Desire to Return to Community

Tips to Increase Social Engagement

This resource provides tips and suggestions for families and caregivers on how to potentially increase social engagement.

<https://paautism.org/resource/increase-social-engagement/>

Physical Health

Due to COVID-19, there is an increased risk of becoming sick. However, instead of worrying about the risk, it is important to become educated in how to maintain healthy lifestyles and wellness. Now, more than ever, is the perfect time for families and caregivers to educate themselves, refocus and make physical health a main priority in their lives. In order to protect family members, communities, and maintain safety, it is important that COVID-19 guidelines are followed closely while we make steps reintegrating into our communities.

The following resources have been created in order to help families and caregivers guide and support their family members in focusing on enhancing and protecting their physical health.

Physical Health

Responding to COVID-19 in Pennsylvania

This guide from the Pennsylvania State Government, provides up-to-date information and resources for individuals, families and businesses.

<https://www.pa.gov/guides/responding-to-covid-19/>

Pennsylvania Department of Health COVID-19

This website provides information on symptoms, testing, how to prevent the spread, FAQs, resources and Pennsylvania specific data related to COVID-19.

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

Office of Developmental Programs Coronavirus

This website contains all ODP COVID-19 related information including announcements, webinars and individual/family resources.

<https://www.myodp.org/mod/page/view.php?id=26808>

Preventing COVID-19 and Monitoring Physical Health Status

The purpose of this resource is to provide families and caregivers with ways to prevent getting sick from COVID-19, as well as information about getting tested. This resource also covers information on how this virus is transmitted, the symptoms to look for, and how to monitor the physical health status of individuals and caregivers.

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

Physical Health

Physical Health Resource Collection

This resource collection includes information and tips on regulating sleep, seizure disorders, gastrointestinal issues, and obesity-related conditions.

<https://paautism.org/resource/physical-health/>

Philadelphia Coordinated Health Care (PCHC) Coronavirus Information

This website provides information for families and individuals on safety, coping strategies, and videos related to COVID-19.

<https://www.pchc.org/coronavirus-updates>

Fatal Four: Understanding the Health Risks of Four Common Conditions

This presentation will discuss aspiration, constipation, dehydration and seizures. These conditions are sometimes referred to as the “Fatal Four” due to the high risk that they pose to individuals with intellectual and developmental disabilities.

<https://www.myodp.org/course/view.php?id=1342>

Behavioral Presentation of COVID-19

This presentation provides information on signs of COVID-19 to look for in individuals who have limited expressive language.

<https://aidinpa.org/behavioral-presentation-of-covid-19/>

Infection Control and Social Distancing Measures

While individuals begin reintegrating into communities, families and caregivers will need to take additional steps in supporting their loved ones. It is important that guidelines are followed closely to keep our loved ones and communities safe. Individuals might need to learn new tasks, skills, and behaviors that follow COVID-19 guidelines to maintain health and wellness. These types of new expectations and routines can cause added stressors in some people's lives. As family members and caregivers, finding different ways learn new skills can make adjusting to new situations easier.

The following resources have been created in order to help families and caregivers guide and support their family members in learning new tasks related to COVID-19 infection control measures.

Infection Control and Social Distancing Measures

Desensitization and Learning to Wear a Mask

The purpose of these resources is to provide information on how to help support a family member to wear a mask so that they can help protect themselves and others from coronavirus. There is also a tool to help loved ones become more comfortable with new tasks in relation to coronavirus guidelines.

<https://paautism.org/resource/desensitization-mask/>

Teaching New Skills

This collection of resources provide information on best practices for teaching new skills, how to break skills down into smaller parts to make them easier to teach, and other important tips and information on helping individuals learn new skills.

<https://paautism.org/resource/teaching-new-skills/>

Adjusting to New Situations

Change is part of everyday life. The ability to change is central to our growth as individuals. For people with autism/ID, who often rely on predictability and routine to feel calm and safe, change can affect them differently. Adjusting to new situations may be met with anxiety, fear, or resistance. Fortunately, there are strategies you can use to ease adjustment to new situations.

<https://paautism.org/resource/adjusting-new-situations-environment-anxiety/>

Infection Control and Social Distancing Measures

Wearing a Mask Social Story

This resource provides a visual guide for individuals with autism/ID about wearing a mask to avoid spreading germs. The resource includes why it's important to wear a mask, as well as information about how to safely wear and remove masks.

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

Coping with Coronavirus

COVID-19 has changed many aspects of everyday life. Given the rapid nature of the virus' spread, it's a good idea to plan ahead. This resource will offer some tips to help individuals and families prepare.

<https://paautism.org/resource/coping-covid/>

Social Distancing Social Story

This resource provides a visual guide for individuals with autism/ID about the importance of social distancing and what it means.

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

Hand Washing Social Story

This resource provides a visual guide for individuals with autism/ID about washing hands.

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

Mental and Behavioral Health Needs

The changes that have happened as a result of COVID-19 have been stressful for everyone. Changes in schedules and routines, activities and events being cancelled, lack of access to services and supports, and limited contact with friends and family can be difficult to manage. Additionally, some individuals may have experienced the loss of friend, family, or support staff as a result of COVID-19. For individuals with autism and/or intellectual disabilities, it may be difficult to understand these changes, and why their lives are so different right now.

These changes and additional stressors can have major impacts on mental health. Add in reduced services and supports, including access to behavioral supports and therapy services, and some individuals may be experiencing new or worsened mental and behavioral health symptoms.

The following resources provide coping strategies, ways to manage grief and trauma, signs of common mental health conditions and suggestions for managing them, as well as relaxation techniques.

Mental and Behavioral Health Needs

How to Support Individuals Process Their Feelings

This resource provides information on how to support individuals to understand and manage difficult emotions they may be having.

<https://paautism.org/resource/processing-emotions/>

Be Well, Think Well

This collection of resources provides information on anxiety and depression. Resources include an overview of anxiety and depression, recognizing signs, ways to support individuals, and treatment options. Included in this collection are relaxation techniques.

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

How to Create a Coping Zone

This tool provides strategies for families to manage stress during the COVID-19 crisis.

<https://paautism.org/resource/how-to-create-a-coping-zone/>

Mindful About Meltdowns

This resource provides information on recognizing meltdowns, tips for how to avoid them and ways to respond.

<https://paautism.org/resource/mindful-about-meltdowns/>

Mental and Behavioral Health Needs

Supporting Safe Behavior

This resource provides information on how to support individuals who may engage in challenging behavior and ways to help keep everyone safe.

<https://paautism.org/resource/supporting-safe-behavior/>

Trauma and Coping

This resource provides information on understanding what trauma is, identifying triggers, and strategies to support individuals who may have experienced trauma.

<https://paautism.org/resource/trauma-and-coping/>

What is Trauma

This social story provides a visual explanation of what trauma is, and what someone may feel if they have experienced trauma. This resource can be used to help individuals understand and process their feelings.

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

Crisis Intervention and De-Escalation

This resource provides helpful strategies for recognizing and responding to an individual when they are escalating, in crisis, or de-escalating.

<https://paautism.org/resource/crisis-intervention-de-escalation/>

Mental and Behavioral Health Needs

Get SAFE and be SOUND

This resource provides information for parents who may be experiencing stress and ways to manage that stress to create a calm environment at home.

<https://paautism.org/resource/get-safe-and-be-sound/>

Changes in Routine

As a result of statewide Stay at home orders, there have been major changes in everyone's daily activities. Schools, daycares, businesses, churches, and stores have been closed. Leaving people without their usual daily structure and routines. While most people have adapted to these changes, individuals with autism and/or intellectual disabilities may have a harder time adapting to new routines.

As communities begin to reopen, more changes will arise. The following resources provide tips and suggestions on how to help individuals manage these changes, as well as tools to help them start to develop new routines.

Changes in Routine

Adjusting to New Situations

Adjusting to new situations may be met with anxiety, fear, or resistance. These are strategies you can use to ease adjustment to new situations.

<https://paautism.org/resource/adjusting-new-situations-environment-anxiety/>

Social Story Resource Collection

Social stories can be a helpful tool for individuals to prepare for and understand different situations. This bundle is a collection of social stories developed by ASERT and other professionals.

<https://paautism.org/resource/social-stories/>

Visual Resources

This collection of resources includes information about visual schedules and using visual schedules.

<https://paautism.org/resource/visual-schedules/>

Supporting New Habits

This resource provides information on how to help teach new skills and support new habits.

<https://paautism.org/resource/supporting-new-habits>

Conditions of Supports and Services

Many services and supports were disrupted as a result of COVID-19. In-home supports were stopped to help prevent the spread of the disease. For some individuals, services were able to start again through telehealth, while others may have had no access to any services during this time. For some individuals, they may have new staff working with them that they haven't had a chance to meet in person yet.

Other families may have used these changes as an opportunity to develop natural supports within their communities in order to support their family members.

Service providers will begin to figure out how to safely provide in-person supports, and families and caregivers will need to carefully consider an individual's support needs. The following resources provide information on using vision boards to explore community supports, how to engage individuals through telehealth, and maintaining connections in the community.

Conditions of Supports and Services

Using Vision Boards to Find Community Supports

This resource provides information on using vision boards to find supports within a community such as meet-up groups and activities.

<https://paautism.org/resource/vision-boards-community-supports/>

Supporting Engagement at Home

This resource provides suggestions to maintain or increase your loved one's engagement in their community and household, while staying home. It includes tips on how to have successful telehealth appointments, meeting new staff virtually, and maintaining connections in the community.

<https://paautism.org/resource/supporting-engagement-home/>

Telehealth

This resource provides information about changes to the rules for telehealth during the COVID-19 pandemic.

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

Support Organizations

Connecting with other families and individuals during times of change can help helpful for a number of reasons. Being able to share information and resources with others who are going through similar experiences can be a great way to learn about new opportunities and options. Connecting with others can also be a great coping strategy for families, caregivers and family members during times of stress.

The organizations on the following pages provide different opportunities to connect, as well as share information and resources with families and caregivers.

Support Organizations

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/>

PA Family Network

The PA Family Network provides information, connections and support through Family Advisors and networking opportunities. They support families' needs using the "Charting the LifeCourse Tools".

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

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 service system by building capacity and competency within the physical and behavioral health care systems as well as the stakeholders of the ID system. There are 8 HCQUs across the state.

<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/>

Support Organizations

Parent to Parent of Pennsylvania

This organization matches families of children and adults with disabilities or special needs with parent volunteers who have had similar experiences and are willing to share their knowledge.

<http://www.parenttoparent.org/>

Autism Services, Education, Resources and Training (ASERT)

ASERT (Autism Services, Education, Resources and Training) is a partnership of medical centers, centers of autism research and services, universities, and other providers involved in the treatment and care of individuals of all ages with autism and their families. ASERT was developed to bring together resources locally, regionally, and statewide.

<http://paautism.org>