

Autism and Intellectual Disabilities in Pennsylvania

Safely stepping into the community.



Your Roadmap Back Into the Community Parents and Caregivers



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Introduction

This has certainly been a challenging time for our communities. We are all heading into another period of uncertainty as we work together to keep our communities as safe as possible. As community opportunities start to expand when counties reopen in accordance with Governor Wolf's orders with guidance from the PA Department of Health, the Office of Developmental Programs has instructed all supports coordinators to discuss with individuals and their teams to determine:

- If there are any new challenges or worsening of existing needs
- What are the most appropriate services or activities to restart given the current county conditions
- What are appropriate timelines for reintroducing services and activities
- If ISP (Individual Support Plan) changes are need to develop new outcomes or revise goals

You, as a family member and/or caregiver, play an important role in this process as you may have had the most contact with your family member during the stay-at-home phase of the pandemic response and might be the most aware of his/her current strengths, needs, and vision for a good life. You also may have a lot of insight as to how your family member has managed during other significant transition periods in his/her life. You have an important voice when discussing how ready and prepared your family member may be for rejoining community activities and services.

Above all, we are all experiencing a lot of changes in our lives and this change is likely to continue for an extended period as we work together as a community to maintain safety. This may mean that plans for your family member's services and activities may change frequently as the community situation changes and in response to changing orders and recommendations from the governor's office and from health officials.

This tool is meant to help you consider your family member's strengths and needs across six key areas which will guide the team's considerations about how, when, and what services and activities can safely restart.



Instructions

On the following pages you will find the six domains listed. Under each are some important factors to consider as the team discusses restart of services. These are things your family member's supports coordinator may ask you about. Items in bold are particularly important to consider. Each item has suggested parameters as to what might be a "strength", a "concern", or a "need". The team should plan how to address items identified as needs, especially the items in bold. You and the team may also decide that items identified as concerns may also be priority. Items identified as strengths may help guide towards strategies to best help your family member safely restart community services and activities. You can use the buttons in the categories to help you keep track.

This should be an ongoing process as your family member develops new skills or expresses new needs, service providers experience changes, or the community situation changes.

If completing the guide electronically, click the radio button for the area that best describes your loved ones abilities at this time. This will automatically populate the same category (strength, concern, need) in the summary section at the end of the document.

Once all questions are completed, you can include notes and important information on the summary pages to share with team members for planning services and supports.

The guide can be printed and completed by hand as well. Answer the questions in each of the sections and then transfer those to the summary pages at the end of the document. Notes and important information can be written on the summary pages and shared with team members for planning services and supports.

If you have questions, concerns or feedback on the use of this guide please contact us at aidinpennsylvania@gmail.com

We hope you find this "roadmap" helpful.



1 Desire to Return to Community

How eager is my family member return to community activities and services?

Strength	Concern	Need
My family member has clearly expressed (through words or actions) a desire to return to community activities and services.	My family member has expressed mixed feelings (through words or actions) about his/her desire to return to community activities and services.	My family member has expressed a lot of reluctance or unwillingness (through words or actions) about returning to community activities and services.

Is my loved one displaying any anxiety about returning to community activities and services?

Strength	Concern	Need
Any anxiety my family member has expressed appears to be mild and is easily addressed such as offering brief reassurance.	My family member's anxiety appears moderate at times and can be difficult to address effectively.	My family member expresses frequent and/ or intense anxiety about returning to community services or activities.

How do you and other family members or caregivers feel about resuming community activities and services?

Strength	Concern	Need
My family member's family and caregivers are confident in his/her and the team's ability to work together to maintain safety. Working on skills and goals is appropriate at this time.	My family member's family and caregivers have mixed feelings about returning to community activities and services. There are concerns about safety but revising and/or adjusting support and activities is also important.	My family member's family and caregivers have expressed reluctance or significant concerns about safety. Restarting services for community activities and settings does not appear appropriate at this time.

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Physical Health

What is my family member's current physical health status?

Strength	Concern	Need
My family member appears physically healthy or has fully recovered from COVID-19 (illness from coronavirus infection).	My family member has a history of displaying symptoms, such as sneezing from seasonal allergies, which can also be sign of coronavirus infection.	My family member currently has COVID-19 symptoms/ illness or is awaiting the results of COVID-19 screening. A healthcare provider has directed that he/she be quarantined.

How confidently and reliably can potential emerging symptoms of coronavirus illness, such as fatigue, cough, sore throat, fever, and shortness of breath, be detected and reported for my family member

Strength	Concern	Need
My family member can clearly and reliably express (through words or other means) any potential emerging symptoms. Family members and/or caregivers are consistently available and reliable to monitor his/her health status.	My family member cannot reliably express potential emerging symptoms but there are reliable family members/caregivers available consistently to monitor his/her health status.	My family member cannot reliably express potential emerging symptoms. Family members and/or caregivers are not consistently or reliably available to monitor his/her health status.



2 Physical Health

Does your family member have any risk factors—such as older age (over 65), obesity, diabetes, asthma, and/or high blood pressure—which may place him/her at high risk for complications from COVID-19?

Strength	Concern	Need
No risk factors.	1-2 risk factors but overall good health (treatable conditions are medically well managed).	Multiple risk factors and/or physical health status is challenged (one or more risk factors are medically unstable and/or has a suppressed immune system)

Can your family member and others supporting him/her keep up to date with latest guidance and recommendations for monitoring health status?

Strength	Concern	Need
My family member and/or his/	My family member and/or his/	My family member and/or his/
her supporters check at least	her supporters inconsistently	her supporters do not or rarely
weekly reputable sources,	check (less than weekly) or	check for updated
such as the CDC or PA Dept. of	consult potentially non-	information. This may be due
Health, for updated	reputable sources for updated	to they do not know how to do
information.	information.	SO.



3 Infection Control and Social Distancing Measures

How well can my family member cooperate with recommended hand washing and sanitizing practices?

Strength	Concern	Need
My family member can independently or with supports consistently follow all recommendations for hand washing and sanitation.	My family member is inconsistent with recommended hand washing and sanitation even with supports.	My family member rarely performs recommended hand washing and sanitation even with supports.

How well can my family member cooperate with recommended face mask wearing when in the community?

Strength	Concern	Need
My family member can independently or with supports consistently follow all recommendations for wearing face masks and for as long as is needed for the duration of his/her community activities (target 30 minutes).	My family member is inconsistent with recommendations for wearing face masks even with supports. He/she may struggle to wear the mask for the duration of some community activities but is able to wear a mask for at least 5 minutes.	My family member does not tolerate or rarely wears recommended face masks, even with supports. He/she currently cannot wear a face mask for longer than 2 minutes.



3 Infection Control and Social Distancing Measures

How well can my family member cooperate with recommended social distancing practices when in the community?

Strength	Concern	Need
My family member can independently or with supports consistently follow all recommendations for social distancing. (No more than one support staff in close proximity to him/her needed to be successful with this.)	My family member struggles with recommendations for social distancing. He/she may need multiple staff to be successful or may not always respect the recommended distance.	My family member does not or rarely follows recommended social distancing even with supports.

How well can my family member cough or sneeze into their elbow?

Strength	Concern	Need
My family member consistently coughs or sneezes into his/her elbow.	My family member is inconsistent with coughing or sneezing into his/her elbow but responds to cues from others to do so.	My family member does not cough or sneeze into his/her elbow and does not respond to cues to do so. (May be physically unable to do this).

Are there other infection control measures my family member will need to do for specialized community and/or employment settings? (will not apply to everyone)

Strength	Concern	Need
My family member can independently or with supports consistently follow all additional needed infection control measures for these settings.	My family member inconsistently follows all additional needed infection control measures for these settings even with supports. He/she may also be able to follow some but not all of the additional needed measures.	My family member does not follow any of the additional needed infection control measures for these settings. He/she may have shown resistance to doing so even with supports.

This project is funded by the Office of Developmental Programs, Department of Human Services.



4 Mental and Behavioral Health Needs

Are there any new mental health needs for my family member?

Strength	Concern	Need
No new or worsening of existing mental health needs identified.	New and/or worsening of existing mental health needs identified which appear to be in the mild-moderate range regarding intensity or effect on functioning	New and/or worsening of existing mental health needs identified which appear to be in the moderate-severe range regarding intensity or effect on functioning

Are there any potential trauma issues for my family member?

Strength	Concern	Need
No new trauma exposures or worsening of existing trauma recovery needs identified.	New trauma exposure and/or worsening of existing trauma recovery needs identified which appear to be in the mild-moderate range regarding intensity or effect on functioning	New trauma exposure and/or worsening of existing trauma recovery needs identified which appear to be in the moderate-severe range regarding intensity or effect on functioning

Are there any potential grief issues identified?

Strength	Concern	Need
No new or worsening of existing grief needs identified.	New and/or worsening of existing grief needs identified which appear to be in the mild-moderate range regarding intensity or effect on functioning	New and/or worsening of existing grief needs identified which appear to be in the moderate-severe range regarding intensity or effect on functioning



4 Mental and Behavioral Health Needs

Does my family member's crisis/behavior support plan appear appropriate for current conditions and needs? (may not apply to everyone)

Strength	Concern	Need
Current crisis plan appears appropriate.	Minor revisions to crisis plan appear indicated.	Significant revisions to crisis plan appear indicated.

Are the appropriate mental health providers available for my family member?

Strength	Concern	Need
No new service providers needed (either no overall need or existing ones able to appropriately address all identified needs).	Need for new service providers identified and appropriate referrals made or reestablished contact with previous providers.	Need for new service providers identified. Appropriate providers not identified and/or referrals still in process.

5 Changes in Routine

Did my family member's sleep schedule and habits change during the stay-athome orders?

Strength	Concern	Need
Good sleep habits and regular sleep schedule maintained.	Minor changes in sleep habits and/or sleep schedule.	Major changes in sleep habits and/or sleep schedule.

Did my family member's use of legal psychoactive substances—such as alcohol, nicotine, caffeine, and/or medical marijuana—or illegal psychoactive substances change?

Strength	Concern	Need
Maintained typical use of legal substances and no use of illegal substances.	Mild-moderate increase in use of legal substances and/or maintained typical use of illegal substances.	Major increase in use of legal and/or illegal substances or new use of illegal substances.

Did my family member's overall level of activity change?

Strength	Concern	Need
Maintained typical or near typical levels of physical activity and exercise.	Minor changes to typical levels of physical activity and exercise.	Major changes to typical levels of physical activity and exercise.



5 Changes in Routine

Did my family member's eating habits change?

Strength	Concern	Need
Maintained typical or near typical levels of intake and nutrition.	Minor changes to typical levels of intake and/or nutrition.	Major changes to typical levels of intake and/or nutrition.

Did my family member's cooperation with taking medication change?

Strength	Concern	Need
Maintained typical cooperation with taking prescribed medications and no more than 1 dose per 2 weeks missed/late.	Minor changes to cooperation with taking medication and/or 1-2 doses per week missed/late.	Major changes to cooperation with taking medication and/or more than 2 doses per week missed/late



6 Conditions of Supports and Services

Did my family member continue any supports or services during the stay-at-home orders?

Strength	Concern	Need
Participated in at least 5 hours/week if services either in-person or remotely.	Participated in some (less than 5 hours/week) of services either in-person or remotely. Duration challenge could be due to lack of offered services or inability to sustain participation.	No in-person or remote services.

How familiar is my family member with the staff who will be working with him/her?

Strength	Concern	Need
My loved one is very familiar with all identified staff.	There are some new or less familiar staff will be working with my loved one.	Mostly new or less familiar staff will be working with my loved one.

How familiar is my family member with the community activities and settings currently available?

Strength	Concern	Need
All anticipated familiar community activities and/or settings remain accessible.	Some anticipated community settings and/or settings are not currently accessible.	Many or key anticipated activities and/or settings are not currently accessible.



6 Conditions of Supports and Services

Have any staff or community training needs been identified?

Strength	Concern	Need
Any minor staff or community training needs easily accomplished.	Moderate training needs identified. Plan to address these needs has been created but not implemented.	Significant staff or community training needs identified. Plan to address these needs to be developed.



Summary

Use the sections below to summarize the factors you have considered regarding your family member's current status. You can use this page to communicate strengths and need's with your family member's support coordinator and/or team members.

1. Desire to Return to Community Activities and Settings Question Strength Concern Need Eagerness to return to community Anxiety about returning to community Family member feelings about returning to community

2. Physical Health Status			
Question	Strength	Concern	Need
Current physical health status			
Detecting symptoms of COVID-19			
Risk factors for COVID-19			
Follow guidance and recommendations			

Notes:

Notes:



3. Infection Control and Social Distancing			
Question	Strength	Concern	Need
Cooperate with hand washing			
Cooperate with wearing mask			
Cooperate with social distancing			
Cough/sneeze into elbow			
Additional infection control measures			

Notes:

Notes:

4. Mental and Behavioral Health Needs			
Question	Strength	Concern	Need
New mental health needs			
Trauma concerns			
Grief concerns			
Crisis plan needs			
Mental health provider availability			



5. Changes in Routine			
Question	Strength	Concern	Need
Changes in sleep habits			
Use of legal/illegal substances			
Changes in activity level			
Changes in eating habits			
Taking medications as prescribed			

6. Conditions of Supports and Services

Question	Strength	Concern	Need
Services continued during stay at home orders			
Familiar with staff			
Familiar with community settings and activities			
Staff/community training needs			

Notes:

Notes: