

A Guide For Families with A Child with An Intellectual and/or Developmental Disability During the Covid-19 Pandemic¹

*From The STRYDD Center—Supporting Trauma Recovery for Youth with Developmental Disabilities
Long Island Jewish Medical Center, Northwell Health System
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To support your child who has special needs during this time:

1. Help your child understand the changes that are happening. Give your child opportunities to express concerns. Children’s understanding of the challenges we are all experiencing and the changes to their routine will vary depending on their age, developmental status, and special needs issues. Younger children may have worries based on concrete reasoning and beliefs. Young children have a tendency to be “egocentric” in the sense of overestimating the child’s own role in “causing” events. For example, a 6-year-old wondered whether her having had a non-coronavirus illness was why no one could go to her school. An older child may develop misunderstandings based on “all-or-nothing” thinking, such a boy’s belief that because of his (mild) asthma if infected with COVID-19 he would certainly die. Sometimes teens with cognitive delays pass misunderstandings back and forth within their peer group (even if they are only communicating remotely). At all ages, children may have some misunderstandings that need clarifying. We will provide resources available at various developmental levels to explain and reinforce understanding of current changes.

Some general principles:

- Give your child an opportunity to express feelings, ask questions, and voice concerns.
- Some children may not use words to express concerns, but their play or drawings may provide strong clues, such as when a child starts acting out stories about people being sick when the child had not been doing this previously. For some children, expression of concerns is less direct but will be shown in behavior changes (as discussed further below).
- In addressing concerns, choose a time and place that works for you and your child. If you can, address simple questions when your child brings them up, but it is ok to let the child know that you will talk further later. For some children, having a regular time and place will help them develop awareness of thoughts and feelings that they may not think of otherwise. For these children, a visual calendar may help keep this routine as well as reduce anxieties about what comes next in the day or week. (See below re: routines.)
- Give accurate information, but at your child’s level of understanding. Use concrete language for young children, those with cognitive delays, and those with difficulty with abstract language. When possible, do this in a conversation that allows you to check what your child has understood and follow up over time.

¹ To accompany COVID-19 Resources for Parents of Children with Intellectual or Other Developmental Disabilities

- Be honest. It is ok to let your child know when you do not have answers (such as, when school will open). Share that you will let your child know when you find out.
 - For some children, visual support such as a simple social story can be helpful. Also, consider using resources developed in a variety of mediums such as children’s books, simple videos developed to address specific issues and children’s toys to illustrate and to help your child understand. (We provide COVID-19 related stories in our resource materials.) For a child who demonstrates concerns in play, you may also be able to respond, at least initially, in that medium. For example, for the child who is acting out themes about people getting sick, depending on the situations to which the child was exposed, you might role play actions a family member or a doctor takes to help people who are sick get better. You could also read a book or share through words the actions people take. Use materials at your child’s level of understanding that also fit your child’s preferred communication style. For example, a young teen with significant cognitive delay was very proud of his reading skills. He loved reading books designed for much younger children that used pictures and words to address concerns. In contrast, a boy with a significant reading disability and language processing issues was not interested in looking at most of those books, declaring them to be “for babies,” but would talk about issues when they could be related to sports—an area in which he excelled.
 - Limit your child’s exposure to media discussions and adult conversations about COVID-19. The information may be confusing to young children and those with cognitive delays—and too much exposure is likely to heighten anxiety. Try to check what your child heard and what the child understood. Clarify misperceptions and address concerns. Remember that “out of sight” is not necessarily “out of earshot.” For example, a parent who was talking on the phone about the illness of a family friend thought she was having an “adult only” conversation since her children were in a different room; she was startled when her daughter asked a little later how the friend was doing. There is more opportunity for this to happen during periods of COVID-19 “sheltering in place” with many parents and children at home when they would have been at work or school.
2. Consider the changes your child is experiencing. Changes may include losses such as limited contact with important people (for example, grandparents or significant providers), or lost opportunities for activities to which your child was looking forward. Try to help your child with strategies for compensating when this is possible—and remind your child that many of the changes are time-limited.
 3. Maintain structure and routines.
 - Try to maintain routines for your child. Build on old ones when practical, establish new ones when necessary. This helps establish some predictability in a changing world. For example, a mother reported that her family’s days were working better when she restructured “shelter in place” weekdays to follow the family’s school day morning routines about getting dressed, eating, and then going to a specific place set up for learning (but in her house rather than the school building). You know your own child and your child’s best balance between structure and flexibility. To the extent possible, try to honor this.
 - In planning your family schedule, do take into account needs of all family members—including your own!

4. Support emotional expression and emotional coping skills. Acknowledge and accept your child's feelings—for example, saying that you can understand that your child might be sad (about missing someone the child cannot see or something the child cannot do) or might be frightened by some part of the situation. The resource materials provide many suggestions for aiding emotional expression and coping. Tailor them to your child's skills and preferences. For example, the mother of a ten-year-old boy who has autism noticed that her son—although very verbal—could express feelings and talk about them more readily when he could draw simple illustrations (often with simple cartoon-like stick figures). He made a poster of strategies he knew, including ones developed with his school counselor, to help him calm down and then was able to discuss which ones would work best at home.
5. Remember that **all behavior is communication**. If you are seeing an increase in behavioral problems such as irritability, a return to less mature behaviors, disruption in sleep or eating patterns, or physical complaints that on checking do not seem to have a physical basis, consider the following:
 - Is there something in the current situation that is confusing or frightening to your child? (Please see first section on talking with your child).
 - Is the behavior, although seeming like a step backwards, actually a request for reassurance that can be ok (on a temporary basis) for this situation—such as a child who had been sleeping on her own seeking the reassurance of coming into her parents' bed?
 - How are you doing with providing some structure and routines for your child?
 - How are you doing with self-care? Your needs are very important and should be balanced with those of your child. Most children will pick up on and react to a parent's level of stress. Manage your own anxiety – breathe, take a break, talk to someone, don't expect too much of yourself or your child at this time.
6. Cope with the move—at least temporarily—to a virtual world for education and many resources.
 - On-line access: We provide information about a resource for families with limited on-line access.
 - Education: With many school systems moving at least temporarily to virtual learning, parents are reporting a range of experiences for their children who are supposed to receive educational accommodations or related services such as speech therapy or occupational therapy.
 - If you have access to your providers, please work with them on expectations and guidance for services for your child. Discuss any special issues you may be having, such as dealing with your child's understanding of or compliance with on-line learning.
 - If you do not have access to your providers, we list and briefly describe some of the many sites that provide support for structured learning activities.
 - Educational entitlement: As of April 2020, schools that are providing instruction are still required to provide accommodations for your child's special needs, as specified on IEPs and 504 plans—although there is discussion of possible future “waivers” (at least temporary changes in some of the rules). We provide links regarding educational rights and issues.
 - Other services you may be receiving: Your child may have been receiving Applied Behavior Analysis (ABA) services, or your family may be entitled to other in-home services. Check with

your service providers about what they are able to offer, which can depend on a range of factors. Some in-home services are considered “essential services” that may be provided during social distancing, when providers are available. Some providers may be able to provide “virtual” (on-line) consultation during social distancing. Know your rights. (See information under educational access in the accompanying resource list).

7. Reinforce your child’s skill development—by everyday activities as well as formal learning.
8. Maintain socialization and social skills
 - Encourage “play dates” or check-ins via video meeting software or other means, where possible.
 - Use appropriate cautions concerning supervision of children’s interactions online including online gaming – there is a great deal of socializing going on right now. Children with disabilities can be teased, bullied, or manipulated – they may also obtain much needed social support on such platforms. This might mean supervising or considering parental controls to monitor/control access to sites. See [Parents' Ultimate Guide to Parental Controls](#).
9. When needed, get information about how to deal with children’s health issues, including special health care needs in the current context: Many children with disabilities have special health care needs. Dealing with these needs can be challenging and may be more stressful during the pandemic. We provide resources to help address this issue.
10. Support your child with serious illness or death of a loved one: Your family may be experiencing the loss of people who have played an important role in your child’s life—such as a parent, grandparent, or extended family member, or teachers and other significant individuals. This can have a strong effect on children—including very young children and those with significant delays. We provide material on addressing your child’s response to separation, illness and loss.
11. Parent self-care: You are responding to your child with special needs in the context of your family’s other challenges. In addition to ongoing individual and family needs, many parents are coping with new work challenges (such as working at home, risks as an “essential worker,” or loss of work), financial uncertainties and hardships, and/or illness and loss of loved ones. Remember that taking care of yourself is critical for being able to also respond to your child’s needs. We provide resources that address issues of self-care and balancing needs.

The accompanying resource guides provide information relevant to the above issues. Some resources address all children’s needs; some were developed specifically for children with I/DD and/or Autism. Resource information is divided into five areas:

- Expert Advice and General Resources
- Tools for Helping Children Cope
- Access to Internet, Health, Education and Other Special Needs Services
- Tools for Maintaining Skills and Behavior
- Activities for Learning and Fun