THURSDAY, APRIL 30
7PM EDT

Coping during a Pandemic
Caring for our Community during COVID-19

• NDSS is the leading human rights organization for all individuals with Down syndrome
• We are committed to providing comprehensive resources to our community during the COVID-19 pandemic
• Visit www.ndss.org to see our in-depth resource list
• Additional Webinars
COPING DURING A PANDEMIC

John Raffaele, MSW
COPING DURING A PANDEMIC

Lucille Esrarelw, Ph.D.
The Role of Direct Support Professionals During the Covid-19 Crisis

And How We All Can Help To Support Them!

John Raffaele
Director of Educational Services

Dan Hermreck
Director of Certification and Accreditation
DSP = Interdisciplinary Professional
“One might summarize the job description of the direct support worker as requiring the wisdom of Solomon, the patience of Job and the caring of Florence Nightingale.”

- Clarence J. Sundram
SKILLS: The CMS Core Competency Areas

Area 1: Communication
Area 2: Person-Centered Practices
Area 3: Evaluation and Observation
Area 4: Crisis Prevention and Intervention
Area 5: Safety
Area 6: Professionalism and Ethics
Area 7: Empowerment and Advocacy
Area 8: Health and Wellness
Area 9: Community Living Skills and Supports
Area 10: Community Inclusion and Networking
Area 11: Cultural Competency
Area 12: Education, Training and Self-Development

These are cross-sector competencies recognized by the Centers for Medicaid and Medicare Services (CMS).
SKILLS: The NADSP Competency Areas

Area 1: Participant Empowerment
Area 2: Communication
Area 3: Assessment
Area 4: Community and Service Networking
Area 5: Facilitation of Services
Area 6: Community Living Skills & Supports
Area 7: Education, Training & Self Development
Area 8: Advocacy

Area 9: Vocational, Educational & Career Support
Area 10: Crisis Prevention and Intervention
Area 11: Organizational Participation
Area 12: Documentation
Area 13: Building and Maintaining Friendships and Relationships
Area 14: Person Centered Supports
Area 15: Supporting Health and Wellness

www.nadsp.org
Supporting Health and Wellness

- Administers medications accurately and in accordance with agency policy and procedures.
- Observes and implements appropriate actions to promote healthy living and to prevent illness and accidents.
- Uses appropriate first aid/safety procedures when responding to emergencies.
- Assists individuals in scheduling, keeping, and following through on all health appointments.
Supporting Health and Wellness

- Assists individuals in completing personal care (e.g., hygiene and grooming) activities.
- Assists with identifying, securing and using needed adaptive equipment (i.e. adaptive equipment) and therapies (e.g., physical, occupational, speech, respiratory, psychological).
- Assists individuals in implementing health and medical treatments.
- Assists individuals to take an active role in their health care decisions.
Communication

- The competent DSP uses effective, sensitive communication skills to build rapport and channels of communication by recognizing and adapting to the range of participant communication styles.
- The competent DSP has knowledge of and uses modes of communication that are appropriate to the communication needs of participants.
- The skilled DSP learns and uses terminology appropriately, explaining as necessary to ensure participant understanding.
Assessment

• The competent DSP initiates or assists in the initiation of an assessment process by gathering information (e.g., participant’s self-assessment and history, prior records, test results, additional evaluation) and informing the participant about what to expect throughout the assessment process.
Assessment

- The competent DSP conducts or arranges for assessments to determine the needs, preferences, and capabilities of the participants using appropriate assessment tools and strategies, reviewing the process for inconsistencies, and making corrections as necessary.

- The competent DSP discusses findings and recommendations with the participant in a clear and understandable manner, following up on results and reevaluating the findings as necessary.
Facilitation of Services

- The competent DSP maintains collaborative professional relationships with the participant and all support team members (including family/friends), follows ethical standards of practice (e.g., confidentiality, informed consent, etc.), and recognizes his or her own personal limitations.
- The competent DSP assists and/or facilitates the development of an individualized plan based on participant preferences, needs, and interests.
Crisis Prevention and Intervention

- The competent DSP identifies the crisis, defuses the situation, evaluates and determines an intervention strategy and contacts necessary supports.
- The competent DSP continues to monitor crisis situations, discussing the incident with authorized staff and participant(s), adjusting supports and the environment, and complying with regulations for reporting.
Permission Granted for Feeling Afraid, Frustrated and even….Angry!

You can't stop being afraid just by pretending everything that scares you isn't there.
--MICHAEL MARSHALL
It is ok to feel OK!
Routine Is Important
Practice your faith or practice something MEANINGFUL to you and do it everyday!

- Journaling
- Religion
- Yoga
- Baths
- Nature
- Music
- Meditation
Connect with others; *beyond* the people you support and your co-workers
Seek professional assistance if you really feel you cannot cope
Join us to elevate the status of Direct Support Professionals.

www.nadsp.org/membership

- Discounts on NADSP offerings
- Login to NADSP's members-only website
- Participation in 'Learning Annex' webinars
- Access to Frontline Initiative newsletters
- E-Blasts about NADSP news and updates
- Feature your commitment to DSPs
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FOR MORE INFORMATION
Coping During a Pandemic

PRESENTER: LUCILLE ESRALEW, PH.D.
Unique challenges for individuals with disabilities

- In many ways the response of individuals with disabilities and their needs during this crisis will be the same as for all of us.
- However, there are challenges that may be particularly evident for individuals with disabilities because of the unique challenges posed by their neurodevelopmental disorder:
  - Cognitive inflexibility or limited understanding with which to adapt to changing conditions
  - Social communication problems
  - Any tendency towards behavioral or emotional dysregulation
  - Higher incidence of mental health challenges
Challenges to people with disabilities during COVID

- **Being out of routine** including being out of work, spending 24/7 at home with the same people and not participating in usual day program, work and/or leisure activities
- Having limited understanding of the current public health crisis
- Not being able to visit with relatives, coworkers or friends resulting in increased risk of social isolation
- Being stuck at home with roommates, family members or staff who are not preferred individuals or with whom they may have strained relationships
- Not having access to usual sources of gratification, recreation and support
7 Strategies to Support Individuals through Uncertain Times

- Support understanding
- Offer opportunities for expression
- Prioritize coping and calming skills
- Maintain routines
- Build new routines
- Foster connections (from a distance)
- Be aware of changing behaviors
Try to Answer Questions Simply but Realistically

Many of the individuals whom we support benefit from simple, straightforward answers to their questions:

You might say: “The coronavirus is a type of germ. These germs are small and when they get inside your body, they can make you sick. The germs get in your body through your nose, mouth or eyes. When someone coughs and touches a doorknob, and then you touch the doorknob, those germs might get into your body. It’s helpful to wash our hands a lot and try to stay away from big crowds.”

A rule of thumb is to offer some information but not too much information, which can add to the individual’s worries.
Right now, there is a virus that is making people sick. Because it spreads so quickly, many schools and workplaces are closed. It is important to keep myself and others healthy right now, so I need to change some of my routines. Staying home and staying away from other people will help keep me and others healthy. I also need to wash my hands often and keep my hands to myself.

Doctors and leaders are doing their best to take care of sick people. If I am worried about the virus, I can talk to my parents. I will do my best to stay healthy.
Do the Five to Stop the Spread of Coronavirus:

- **HANDS** Wash them often
- **ELBOW** Cough into it
- **FACE** Don't touch it
- **FEET** Stay 6 feet from others for optimal social distancing
- **COVER** your face with a covering or mask if you cannot stay 6 feet away from others
Let the people whom you support know what to expect

- The rough part for all of us is that we don’t know exactly what to expect in the weeks and months ahead

- **However, we do know some things:**
  - We know we’re going to be seeing a lot less of the people in our lives who are not in our family (e.g. friends, neighbors, relatives not in our households, staff)
  - We know that we’re going to have to find creative ways to pass the time at home
  - We know that we aren’t going to have access to all the foods we like
  - We know we’ll have to work harder to keep ourselves, and our homes, clean.
  - We know that Covid-19 can resemble a typical cold. While there is a potential to get very sick and even die, people have also reported milder symptoms — fever, runny nose and cough.
Greetings - A Social Story

- When I meet new people, I like to shake their hand. When I see people that I know, I like to hug them. Some people do not like to touch when they greet others. Now it is important to find other ways to greet people because we do not want to spread germs.

- When I meet people, I should ask how they want to be greeted. I can wave and just say “hi”. Asking before greeting can help everyone feel safe.
Offer Opportunities for Self Expression

- Frequent check ins
- Be mindful that individuals may be very concrete in their language skills, have limited language or may be non-verbal
- The people whom you support may not initiate conversation with you; they may not let you know they are worried, sad or need assistance
- Keep journal
- Draw/Color
- Dance
- Sing
- Create your playlist
Prioritize Coping and Calming Skills

- Everyone reacts differently to stressful situations
- How you respond to the outbreak can depend on your background, the things that make you different from other people, and the community you live in
- Practice desensitizing uncertainty for individuals with disabilities.
  - Uncertainty triggers fear for many individuals with disabilities who may depend upon others to get their needs met. At a time when everything is up in the air, it’s important to help the people whom you support feel less sensitive toward the unknown.
  - You can try using games of chance or improvisation to practice reacting to outcomes that aren’t predictable. You can also create a Social Story to explain parts of the day that may be unstructured. Introducing this thought process can help people manage anxiety and reduce stress responses when unexpected circumstances occur.
I CANNOT CONTROL
(So, I can LET GO of these things.)

IF OTHERS FOLLOW THE RULES OF SOCIAL DISTANCING
THE AMOUNT OF TOILET PAPER AT THE STORE

I CAN CONTROL
(So, I will focus on these things.)

THE ACTIONS OF OTHERS
PREDICTING WHAT WILL HAPPEN
OTHER PEOPLE'S MOTIVES

MY POSITIVE ATTITUDE
HOW I FOLLOW CDC RECOMMENDATIONS
MY OWN SOCIAL DISTANCING

TURNING OFF THE NEWS
LIMITING MY SOCIAL MEDIA

FINDING FUN THINGS TO DO AT HOME
HOW LONG THIS WILL LAST

MY KINDNESS & GRACE
HOW OTHERS REACT

Clipart: Carrie Stephens Art
TheCounselingTeacher.com
Positive Coping

- Ways to cope with stress
  - Take breaks from watching, reading, or listening to news stories, including social media. Hearing about the pandemic repeatedly can be upsetting.
  - **Take care of your body.**
    - Take deep breaths, stretch, or meditate.
    - Try to eat healthy, well-balanced meals.
    - Exercise regularly, get plenty of sleep.
    - Avoid alcohol and drugs.
  - Make time to unwind. Try to do some other activities you enjoy.
  - Connect with others. Talk with people you trust about your concerns and how you feel.
Stay Active at Home

- If you sit for long periods of time, take a 3-5-minute break every 20-30 minutes.
- Make time in your daily schedule to be physically active. Setting a routine will help you stay active every day.
- Record your activity on a weekly chart so you can see your progress.
- Look for online classes for yoga, aerobics, dancing, and other activities you can do at home.
- Set goals or commit to a plan with a family member or virtually with a friend. Encourage each other to stay active every day.

Adapted from the World Health Organization: https://www.who.int/news-room/q-a-detail/be-active-during-covid-19
Stress Management

- Slow Down
- Meditation, deep breathing, mindfulness exercises and gentle activity can help you relax
- Hypnotherapy podcasts: HelloMind
- Yoga videos available on YouTube,
- Self-massage
- www.calm.com
  https://www.pocketmindfulness.com/6-mindfulness-exercises-you-can-try-today
- www.Headspace.com
Try to Maintain a Normal Routine

- It’s not easy to “stick to routine” when workplaces, programs and usual activities are closed.

- Try to establish a new routine, as best you can. Some individuals are frightened and overwhelmed by big changes in their environments.

- Allow the individual whom you support time to adapt to a new routine or new system.

- A picture calendar may help the person whom you support get into a new household-bound routine.
Build New Routines

- It may take a week or two to discover a schedule that works for everyone in the household

**Schedules should include:**

- wake-up and bedtime
- getting dressed,
- Meals: breakfast, lunch and dinner
- Schedule snack breaks and physical movement breaks,
- Use photographs, preferably of the person, in creating a visual schedule for the week/daily schedule
- Establish house rules and review during weekly family/house meetings
- New routines should reflect the current use of space within the household with everyone home (i.e. use of TV, computers, areas for quiet time)
Give individuals power and responsibility

We all feel less anxious and do better when we have some power/control in a situation:

- We all do better when we believe what we do makes a difference. We can help our neighbors and loved ones stay safe and healthy if we frequently wash their hands with soap and water for 20 seconds, or as long as it takes to sing “Happy Birthday” twice.
- Everyone needs to remember to wipe down their devices often, as well, and to cough or sneeze into their elbows or a tissue.
- You might want to reinforce that hand-washing is an important protective action to take against coronavirus, and hand-sanitizer is a perfectly good stand-in when soap and water are not available.
New Routines for entering/exiting the residence
Be Alert to Behaviors that compromise safety or QOL

- Individuals with disabilities may have displayed behaviors of concern prior to the pandemic, and may experience heightened states of agitation or distress that lead to increased frequency of behavior problems.
- Living in close quarters with people 24/7 may lead to heightened conflict with members of the household or with staff.
- Having limited or no access to family, friends, work, recreation and usual sources of support and gratification may increase behaviors of concern.
- Behaviors such as aggression, self-injury, elopement, etc., may increase in frequency or intensity during this period of heightened stress for all of us.
- You may notice changes in your own behavior!
What are the opportunities?

- This may be the time to for all of us to learn new skills:
  - self-calming
  - cooperation
  - following instructions
  - Being more independent (less reliant on family or staff)
  - Having a good relationship with others in the household
  - Problem Solving
  - Conflict Resolution
Extreme Stressors

- Infectious diseases, like any life stressor, challenge the way we cope. Whether we learn about them on television or experience them personally, we can feel upset, fearful and anxious as a result, both for our own personal safety and that of our family, friends, colleagues, and community.

- Stressful events can also bring up feelings and memories of previous traumatic events thereby compounding the distress that we feel.
Assessing Risk

- Avoiding others, even within the confines of social distancing
- Experiencing headaches, stomach problems, neck or back pain
- Crying
- Talking less
- Feeling anxious, depressed or having panic attacks
- Feeling angry, guilty, helpless, numb, or confused
- Problem getting to sleep or remaining asleep
- Not wanting to get out of bed
- Having difficulties concentrating
- Excessive eating
- Drinking more alcohol or taking more prescription drugs
Recognize the need for referral for mental health services

- Help connect people with family and loved ones to help lower distress and feelings of social isolation.
- Let individuals know it is common for people to feel distressed during a crisis. Remind them that asking for and accepting help is a sign of strength.
- Most people will experience stress within manageable limits and not require professional attention.
- Have a procedure and referrals ready for anyone who shows severe distress or expresses a desire to hurt him- or herself or someone else.
- See SAMHSA Coronavirus (COVID-19) Resources and Information external icon
Responding to COVID-19 can take an emotional toll on you

- There are things you can do to reduce your stress reactions:

  - Acknowledge that we are all affected by the current public health crisis, the disruption to daily routine and the anxiety of the unknown
  - Learn the symptoms including physical (fatigue, illness) and mental (fear, withdrawal, guilt).
  - Allow time for you and your family to recover from responding to the pandemic.
  - Create a menu of personal self-care activities that you enjoy, such as spending time with friends and family, exercising, or reading a book.
  - Take a break from media coverage of COVID-19.
  - Ask for help if you feel overwhelmed or concerned that COVID-19 is affecting your ability to care for your family and others as you did before the outbreak.
Take Care of Yourself!

These are anxiety-producing times. Be sure to take care of yourself:

- Turn off the news; too much discouraging news is bad for everyone’s health.
- Obtain your information from reliable sources such as the CDC, WHO and state and local public health agencies.
- Run a bath; light candles; take a walk or a long afternoon nap; meditate. Look for sensory experiences—pet the dog or cat, flip through a family vacation album, put on some music or bake cookies.
- Do whatever you can to calm your own nerves so that you have the reserve to assist your family or the individuals whom you support.
Essential Worker Self-Care

- https://emergency.cdc.gov/coping/responders.asp
- It is not selfish to take breaks.
- The needs of others are not more important than your own needs and well-being.
- Working all of the time does not mean you will make your best contribution.
- There are other people who can help in the response.
- Limit working hours to no longer than 12-hour shifts.
- Work in teams and limit amount of time working alone.
- Talk to family, friends, supervisors, and teammates about your feelings and experience.
- Maintain a healthy diet and get adequate sleep and exercise.
- Know that it is okay to draw boundaries and say “no.”
- Avoid or limit caffeine and use of alcohol.
For Family Not in the same Household as your relative…

- Establish regular phone or video contact with your relative
- Establish a regular phone or video check-in with staff
- Write down your questions and refer to them during your regularly scheduled check-ins with staff
- Keep your relative in phone or video contact with other members of the family
- Find ways to Zoom-connect for important events like birthdays and anniversaries for which you would normally gather to celebrate
- Mail care packages to your relative with favorite games, gift cards with which they can purchase items on-line
Foster Social Connection with your relative who is not with you...

- Video or phone calls (FaceTime, Skype, Google Groups)
- Play virtual games (apps like House Party, Uno! Online, virtual jigsaw puzzles)
- Write a letter or email
- Zoom meet ups
- on-line social groups
Questions?

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Questions?

You can submit questions/comments through the questions feature
For more information:

- Visit www.ndss.org
- Email us at info@ndss.org
- Follow NDSS on social media