

Advices for managing the COVID-19 outbreak and the associated factors of mental distress for people with intellectual disability and autism spectrum disorder with high and very high support needs

Version 1.5

SIDiN (Italian Society for Neurodevelopmental Disorders)

in collaboration with

CREA (Research and Clinical Centre), San Sebastiano Foundation
ASMED (Association for the Study of Medical Assistance for People with Disabilities)

Italian Federation for Prader-Willi syndrome

ANGSA (National Association of Parents of Persons with Autism)

Onlus

FIA (Italian Foundation for Autism)

and the Working Groups on Intellectual Disability and Autism Spectrum Disorder of the World Psychiatric Association Action Plan 2021-23



FONDAZIONE
SAN SEBASTIANO
DELLA MISERICORDIA DI FIRENZE
Onlus – Impresa Sociale



PRADER WILLI
FEDERAZIONE ITALIANA DELLE ASSOCIAZIONI



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PER L'AUTISMO onlus



WORLD
PSYCHIATRIC
ASSOCIATION

Italian version 1.5 (22/3/2020)

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The COVID-19 outbreak

Coronaviruses are a large family of positive-stranded RNA viruses that are known to cause diseases ranging from common cold to more serious conditions such as Middle Eastern Respiratory Syndrome (MERS) and Severe Acute Respiratory Syndrome (SARS).

The International Committee on Virus Taxonomy (ICTV), which is the body responsible for classifying viruses, has named the virus causing the current outbreak SARS-CoV-2 (Severe Acute Respiratory Syndrome-CoronaVirus-2) because of its similarity to the virus causing SARS (SARS-CoV).

The disease caused by the new coronavirus has been called "COVID-19", where "CO" stands for corona, "VI" for virus, "D" for disease and "19" indicates the year in which it occurred.

Some people become infected but do not develop any symptoms. The symptoms are usually mild, especially in children and young adults, and develop slowly. The most characteristic symptoms are fever, dry cough and tiredness. About one in five persons with COVID-19 become seriously ill and present breathing difficulties.

An increased risk of a disease progression is seen in elderly and in people with underlying diseases such as high blood pressure, heart problems or diabetes, as well as in immunosuppressed patients (due to a congenital or acquired disease or under treatment with immunosuppressive drugs).

In persons with intellectual disabilities and autism spectrum disorder (ID/ASD), the prevalence of diseases and physical disorders is about 2.5 times higher than in the general population. These diseases may also include the diseases that are risk factors for the development of severe forms of COVID-19.

ID and ASD *per se* do not appear to be risk factors for COVID-19, although specific epidemiological data are not yet available.

Research on previous respiratory viral infections, including H1N1 and RSV, suggests that patients with Down syndrome are more likely to develop complications and require hospitalisation than the general population.

On the 9th March 2020, the Italian Council of Ministers adopted the Prime Minister's Decree "Further implementing regulations of the Legislative Decree No 6 of the 23th February 2020, on urgent measures to contain and manage the epidemiological emergency caused by COVID-19, applicable throughout the country". The decree stipulates that in Italy the measures introduced by the Prime Minister's decree of March 8th are extended to the entire national territory. Any form of gathering of people in public places or places open to the public is prohibited, and the regulations for events and sport competitions are modified. It is also decided that all citizens, including those with ID/ASD, have to stay at home as much as possible and maintain a physical distance of at least one metre between them.

If persons with ID/ASD believe that they have been infected with COVID-19, or a family member/caregiver has reasons to believe that a relative with ID/ASD has contracted COVID-19, they are advised not to go directly to the emergency room, but to contact their GP (family doctor), another trusted doctor or social worker, so that they can mediate with emergency health services and exercise protective measures in regard to people with ID/ASD during triage and any subsequent hospital treatment.

Accessible hygiene rules

ANFFAS (National Association of Families of People with Intellectual and / or Relational Disabilities), Cremona, and the Cooperativa Sociale Ventaglio Blu, also from Cremona, under the supervision of ANFFAS Nazionale, have translated the advices given by the Italian Ministry of Health on how to avoid the transmission of the coronavirus into an easily readable and comprehensible language, in order to make it more accessible to people with ID/ASD.

The PDF file of the translation is available at the following URL:

http://www.anffas.net/dld/files/CORONAVIRUS_10%20CONSIGLI_IN_LINGUAGGIO_FACILE_DA_LEGGERE.pdf

A document dedicated to children, not only those with disabilities, has been produced from the association "La Matita Parlante" in Piacenza and can be downloaded at the following URL:

<https://www.lamatitaparlante.it/il-coronavirus-spiegato-ai-bambini/>.

Another adaptation based on the Augmentative and Alternative Communication (AAC) was made by the digital coach of the Disability section of Open Group and is available at the following URL:

<http://www.opengroup.eu/wp-content/uploads/2020/03/coronavirus-in-caa-mascia.pdf>

A social history is available on the CREA website at the following URL: <http://www.crea-sansebastiano.org/IT/articolo.php?id=332&t=storia-sociale-per-la-covid-19>

A wordless story with very nice pictures, that help people with mild-to-moderate ID to understand what to do if they have COVID-19 and how to keep themselves and those who you care about safe, is available at the following URL: <https://booksbeyondwords.co.uk/downloads-shop/beating-the-virus>.

This story also shows how to safely help others who may be self-isolating.

Stress and worry

During an epidemic caused by a highly virulent and deadly pathogen, it is normal for people to feel stressed and worried. Some persons with ID/ASD may be even more stressed and worried because of their cognitive and affect regulation characteristics, and difficulties in adapting to rapid and drastic lifestyle changes.

The main reasons for distress are listed below:

- Fear of getting sick and dying;
- Fear of quarantine (without important contact persons);
- Fear of using health services for the fear of getting infected;
- Fear of losing one's livelihood;
- Demoralization due to the loss of some of the preferred activities both at work and in leisure time (including sports activities);
- Fear of losing loved ones because of the epidemic and feelings of being powerless to protect loved ones;
- Feeling of helplessness, boredom, loneliness and depression due to isolation
- Tension and suffering of other family members and caregivers
- Inability to understand the reasons for the restrictions related to hygiene rules and the ways in which all rules must be implemented (including Ministerial provisions which limit the travel and outdoor activities);
- Difficulty in changing one's habits and lifestyle to comply with hygiene rules.

Specific stressors related to the COVID-19 epidemic include:

- high risk of becoming infected and high risk of caregivers/family members of becoming infected;
- the fact that how the SARS-CoV-2 virus is transmitted is not entirely clear;
- symptoms of infection similar to the clinical presentation of other health problems (e.g. fever);
- inability to access support and educational services for the condition of disability
- risk of physical and mental health deterioration, especially if health workers are quarantined or services are suspended without the availability of other treatment options and supports.

Persons with ID/ASD can respond in different ways to the COVID-19 outbreak and the hygiene rules adopted to contain it. Examples of reactions to mental distress are:

- physical symptoms (tremor, headache, fatigue, loss or increase in appetite, pain). Caution: If these symptoms are not associated with fever and dry cough, avoid considering that they may be due to SARS-CoV-2 infection;
- crying, sadness and demoralization;
- anguish and fear;
- state of increased vigilance or nervousness;

- a sense of apprehension that something bad is about to happen;
- insomnia and nightmares;
- irritability and anger;
- self-injurious behaviour and/or aggressive behavior towards objects or other people;
- guilt and shame (because they survived, infected others or were not able to help others);
- confusion, emotional numbness or unreal feelings;
- social or communicative retreat (do not answer anymore);
- slowing or psychomotor agitation;
- disorientation (towards oneself, places, time);
- loss of skills/resources (e.g. the subject is no longer able to eat or drink).

Anxiety crisis management

In the current emergency situation due to the COVID-19 epidemic, some persons with ID/ASD may become very anxious or upset, which can lead to acute anxiety or panic reactions. In these cases, they may exhibit mental confusion, severe motor agitation, problematic behaviour and physical reactions such as trembling, breathing difficulties, palpitations, tachycardia, diarrhea, vomiting, pressure changes and more rarely fainting.

Here are listed some techniques to help people with ID/ASD to get out of these crises:

- keep your voice calm and quiet;
- limit your movements while talking to the person and try to position yourself in such a way that both have the possibility to leave the room;
- control your facial expressions and gestures so that they correspond to the reassuring content of your statements;
- try to maintain eye contact with the person while speaking;
- remind the person that you are there to help her/him and that she/he is safe (if that is true);
- if someone seems disoriented or secluded, help him/her to get back to the "here and now" by verbally instructing (or physically supporting) him/her:
 - "put your feet on the ground so that you can feel the soles of your feet"
 - "slowly touch the fingers of one hand or the whole hand with the other hand"
 - "direct your attention to relaxing or non-stressing objects or stimuli in the environment"
 - "focus on your breathing" or "breathe in and out slowly"
 - "describe what you see" (hear, feel, taste, smell...)

Adapt your communication to the respective communication level or method of the persons concerned, according to what previously defined through professional assessment and personal experience (e.g. augmentative and alternative communication, pictograms, social stories, etc.).

Barriers

Persons with ID/ASD and their caregivers face barriers that may prevent them from accessing essential care and information to reduce personal and social risks during the COVID-19 epidemic. Such barriers may include:

- *Environmental*
 - Risk communication is essential to promote health and prevent the spread of the infection and reduce stress in the population, however information often is not adequately developed and shared with people with cognitive and communicative disabilities.
 - Many health centres are not accessible to people with physical or cognitive disabilities.
- *Institutional*
 - Lack of protocols dedicated to the care of people with disabilities in precautionary quarantine and with confirmed infection.

- Lack of protocols on how to deal with the lack of care staff or even entire rehabilitation centres or residential homes.

- *Attitudinal*

- Prejudice, stigmatization and discrimination of persons with ID/ASD, including the belief that they cannot contribute to the response to the pandemic or make their own decisions.

These barriers can cause additional stress to persons with ID/ASD and their caregivers during the pandemic.

Overcoming barriers

Considering the voices and needs of persons with ID/ASD when planning and implementing responses to the pandemic and related emergencies, it is essential to guarantee both physical and mental health and reduce the risk of infection:

- There is a need to make information accessible and use forms of communication adapted to the characteristics of persons with ID/ASD (sensory, intellectual, communicative and psychosocial).

- If caregivers are to be moved into quarantine, plans must be made to ensure continuous support for persons with ID/ASD.

- Organization and community leaders can be useful partners in communicating and supporting persons with ID/ASD who have been separated from their families and caregivers.

- Persons with ID/ASD and their carers should be involved in all phases of the response to the epidemic.

Mental vulnerability

In persons with ID/ASD, psychiatric disorders are associated with up to four times higher rates and earlier onset of illness than in the general population, even under normal environmental conditions. Persons with ID/ASD have at least one psychiatric disorder during their lifetime in the 25-44% of cases, 21% experience two psychiatric disorders and 8% have three disorders. Undiscovered psychiatric co-morbidity is also very high, with prevalence rates that can exceed 50% even in specialized institutions that benefit from psychological support. Anxiety disorders and affective disorders are the most common. The prevalence of psychopathology continues to increase in people with ID, if additionally, ASD is diagnosed. In these cases, the probability of developing an additional psychiatric disorder is up to five times higher than in persons with ASD or ID only.

The distress related to the COVID-19 pandemic and the hygiene rules that have to be adopted in order to contain it, may increase this vulnerability.

Risks associated with isolation

In order to counter the progress and complications of the COVID-19 pandemic, in Italy it has been ordered that all citizens - including those with ID/ASD - have to stay at home as far as possible and maintain a physical distance of at least one metre.

Numerous studies have shown that prolonged isolation is a risk factor for the loss of everyday practical skills and the development of physical and mental illnesses and disorders, particularly depression, anxiety and suicidal thoughts. Even if it does not lead to serious health problems, isolation is still often associated with negative feelings such as sadness, intolerance, irritability or anger, as well as problematic behaviour such as aggravating stereotypes, aggression or oppositionality.

Certain behaviors can aggravate the aforementioned isolation risks, such as:

- not communicating with others using all available technologies;

- alter the rhythms and domestic activities that can be maintained unchanged from the period prior to isolation;
- spending a lot of time at the computer, watching TV or playing video games;
- avoidance of the few short trips from home that are still possible;
- oversleep or sleep at times other than usual;
- eating too much or too little (more rarely).

Counteracting the risks of isolation

Below are listed some activities that can help a person to avoid the risks associated with isolation:

- try to maintain the usual physiological rhythms (do not go to bed too late, wake up at the same time every morning, have breakfast, lunch and dinner at the usual times);
- expose yourself to sunlight (e.g. go out into the garden, on the terrace or opening the window), especially at the awakening or in the early hours of the day;
- continue to follow routines for your own hygiene and self-care (washing, shaving, combing, dressing, etc.);
- exercise at home; videos showing every step of the exercises and in general numerous repetitions of explanations can help the person to correctly exercise; a kitchen timer, an alarm clock or a hourglass can be used to help the person see the time spent exercising; scheduling and recording in a diary the exercises sessions can have motivational value;
- maintain contact, by telephone or computer, with the teachers (if the person attends school), with the rehabilitation staff (if the person attends rehabilitation centres) and people who are important to him/her;
- use social networks, like Facebook or Instagram, with moderation, to stay in contact with groups of people;
- carry out occupational, recreational and sports activities within one's home in order to maintain some commonality with the ways in which they were carried out before the obligation to remain at home;
- repeat at least once a day the reasons why it is important to respect the insulation and all other hygiene and containment standards for the COVID-19 epidemic;
- in cases that the person with autism cannot tolerate the impossibility of going out, it can be useful to take a walk in the neighborhood, taking care to avoid getting close to other people, or a car ride (for many people with autism being in a moving car has a relaxing effect); to protect the exits (which in any case must remain limited), pursuant to the Italian DPCM 11/3/20, it is possible to ask one of the referring physicians of the person with ID/ASD to produce a certificate of the state of necessity, in support of self-certification. A facsimile is reported below.

Considering the high probability of always being in contact with persons during the emergency period, it is useful to remember that persons with ID/ASD might need to spend some time alone and therefore the possibility of privacy should be given.

Certificate pursuant to the Italian Prime Minister's Decree of the 11th March 2020, in support of the self-certification of state of necessity:

I certify that, born on, is affected by (i.e. Autistic spectrum Disorder with high need for support). As a consequence of that condition, to reduce anxiety, hyperactivity and prevent disregulatory behavior, it can be indicated, to go out on foot or by car, with accompanying family members, even for times longer than an hour.

Risks associated with drastic changes in everyday living places and lifestyles

The drastic restriction or interruption of habitual activities, of relationships with important persons of interpersonal exchange (or the impossibility of avoiding forced shared housing/cohabitation) and, more generally, of freedom, can promote regression, loss of abilities, feelings of confusion, loneliness, fear and frustration in persons with ID/ASD. For some of them, the mere interruption of the daily routine and necessity to leave the places usually frequented is a cause of deep confusion and suffering. Knowing in advance what will happen in the day and in the week is a way to make the present and the immediate future predictable for people with ID/ASD and, consequently, to reduce anxiety.

The risks associated with these emotional experiences can lead to depressive and anxious syndromes and problematic behavioral reactions such as heightened stereotypes, self-stimulation, aggression towards oneself, objects and others, or oppositional behaviour.

Prolonged loss of physical and sporting activity can have negative effects on weight and metabolism, which in turn are risk factors for the development and aggravation of certain diseases.

Counteracting the risks associated with drastic changes in everyday living places and lifestyles

The best way to facilitate the adaptation to the changes of persons with ID/ASD imposed by the COVID-19 emergency is to gradually replace the routine that can no longer be maintained with a new routine. The new routine needs to take into account the space available and the planning of different activities during the day, keeping in mind the individual's preferences. The space available can be significantly limited (one's own home), and this means that it is necessary, even in limited space, to try to differentiate some of the areas so that they can be associated with a specific event or activity: it can be more reassuring for the individual to know that he can spend some time at the computer in the morning, then move to the kitchen to prepare lunch with a caregiver, and then be able to rest after lunch than having to face a day that must be passed like many others but without a defined schedule.

Below, some helpful activities are listed to reduce risks associated with drastic changes in everyday living places and lifestyles:

- do everything possible to keep persons with ID/ASD active by re-planning a daily schedule that incorporates activities that can be carried out at home, including occupational, motor, and recreational activities (e.g. self-care and personal hygiene, tidying up the bedroom, taking care of a pet, and exercise); using a "visual agenda" can be a great help, with the inclusion of sequences of images, drawings, or written messages that illustrate, in advance, what will happen during the day; other visual aids, such as personalized calendars, may be used to plan one week;
- maintain, to the extent possible, a daily routine (e.g. alarm clock at the same time, breakfast, activities at a desk or work table, relaxation, lunch, activities at a desk or work table, relaxation, and dinner);
- in order to increase the probability that persons with ID/ASD are motivated to be active, they should be involved in the planning process;
- it can be useful and reassuring for the person with ID/ASD to know where are the people who are usually part of his/her: for example, clarify that the sister who came to take the individual to the cinema every week is now required to stay in her home; the use of video calls can reinforce these messages and help to reassure the person with ID/ASD;
- in the event of problem behaviors not otherwise manageable, evaluate with a specialist the possibility of prescribing a new medicine or increasing the dose of any medication already being taken.

Protective environments

During the COVID-19 pandemic, a strong focus should be placed on the strength and resourcefulness of communities rather than on weaknesses and vulnerabilities.

Efforts should be made to create or maintain safe and protected environments for care and to use existing resources and strengths, while individual actors and the community should ensure that all actions protect and promote well-being.

All interventions should be inspired by key psychosocial principles, such as hope, security, calm, morality, respect, and reciprocity between individual and community.

Particular attention should be paid to the protection of the most vulnerable subgroups of the population, such as children, people with disabilities, the elderly, immunosuppressed, those with serious chronic diseases, the stigmatized, discriminated, and marginalized.

Toll-free telephone numbers could serve as an effective tool to support people in the community who are feeling worried or afflicted. It would be important to ensure that staff/volunteers are trained, supervised, and provided with up-to-date information about the COVID-19 outbreak in order to be able to act appropriately and avoid undue damage to callers.

Social media and other forms of technology (e.g. WeChat, WhatsApp) can be used to establish support groups/get social support, especially for isolated people.

Recommendations for caregivers

Here are some tips for persons who are the primary caregivers of persons with ID/ASD. Some of these may be more useful for young children and adolescents, while others may be more applicable to adults.

- Help the person with ID/ASD find positive ways to express disturbing feelings such as fear and sadness. Everyone has his/her own way of expressing feelings. Sometimes the practice of a creative activity, such as playing and drawing, can facilitate this process. Many persons with ID/ASD feel relieved when they can express and communicate their disturbing feelings in a safe and supportive environment.
- Share simple facts about what is happening and clear information about reducing the risk of infection in a simple language. Repeat the information every time it is necessary. Instructions should be communicated clearly, concisely, respectfully and patiently, and should be displayed in a written form or through images. Involve the family and other support networks in providing information.
- Teach the person with ID/ASD the recommended hygiene practices through training sessions and provide physical or verbal assistance when necessary. Supervision is recommended. In addition, it is possible to inform and guide persons with ID/ASD by using instructional videos (preferably played by peers) or image-communications methods. It is important that these actions are positively reinforced (tangible satisfaction, social satisfaction, etc.) to increase behavioral contingency.
- Keep children close to their parents and their family if this is considered safe for the child, and, as far as possible, avoid separating children from their usual carers. However, priority should always be given to preventing infection. If conditions are not safe, the physical interaction between caregivers and children should be suspended. If a child needs to be separated from its primary caregiver or nursing staff, make sure that there is adequate and continuous alternative care. Also ensure that there is regular contact with parents and caregivers during the separation period, for example, through scheduled phone or video calls twice a day or other age-appropriate communications (e.g., social media depending on the child's age).
- Maintain the family routine in daily life as much as possible, especially if children stay at home. Offer age-appropriate activities for children. As far as possible, encourage children to continue playing and talking with others, even if only within the family.

- In periods of stress and crisis, it is common for children to seek more intimacy and make higher demands on parents. It is advisable to discuss the COVID-19 emergency with your children with honest and age-appropriate information. If your children have doubts, it is best to talk to them together to allay their fears. The children will observe the behaviour and emotions of the adults to get advice on how to deal with their emotions in difficult times.
- Older adults, especially those in isolation and those with cognitive impairment/dementia, may become more anxious, angry, stressed, agitated and withdrawn during the epidemic/quarantine. It is strongly recommended that they receive practical and emotional support by informal networks (families) and health care workers.
- Encourage older adults with skills, experience and strengths to respond to the COVID-19 epidemic by becoming mentors for other peers, always respecting the rules of hygiene and individual protection.
- Where possible, introduce working hours that provide a certain amount of rest for the carer. In fact, the continuous management and care of persons with ID/ASD can lead the carer to burn-out, especially in the case of intensive and continuous problematic behaviour; the exhaustion of a significant caregiver has a negative impact on the whole family and/or the care system.
- For people with syndromes for which specific guidelines have been developed (such as Prader-Willi syndrome), their caregivers are strongly recommended to consult with experienced professionals to ensure the best possible adaptation of the same guidelines to current needs.

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"... e quindi uscimmo a riveder le stelle" ("... and thence we came forth to see again the stars")
Dante Alighieri, Inferno XXXIV, 139