

COVID-19 and intellectual disability/autism spectrum disorder with high and very high support needs: issues of physical and mental vulnerability

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Abstract

Purpose – The COVID-19 outbreak has profoundly plagued the world, and current health efforts are focused on providing prevention and ensuring access to intensive services for people with the most severe symptomatology. Many reports have already described substantial psychological distress in the general population. Nevertheless, disasters tend to affect vulnerable subjects disproportionately, and individuals with intellectual disabilities/autism spectrum disorder with high and very high support needs (PwID/ASD-HSN) seem to be counted among the hardest hit populations. The present paper aims to provide a comprehensive discussion and evaluation of COVID-19 related issues specific to PwID/ASD-HSN.

Design/methodology/approach – Commentary on available literature and analysis of new preliminary data on PwID/ASD-HSN's physical and psychic vulnerability factors. This knowledge is fundamental to provide families and caregivers special advice to counteract the risks associated with the current pandemic.

Findings – PwID/ASD-HSN represent one of the most vulnerable population to the COVID-19 outbreak and the associated factors of mental distress for several reasons, including multimorbidity, low levels of health literacy, difficulties to understand and communicate, reliance on other people for care, low compliance with complex hygiene rules, the strong need of routine/sameness and low adaptive skills.

Originality/value – In the present work, the authors analyze the specific factors of physical and mental vulnerability in PwID/ASD-HSN, corroborating the dissertation with a discussion on the first data published worldwide and with preliminary data collected on the Italian territory for what concerns prevalence rates of COVID-19 and complications in persons with PwID/ASD-HSN and signs and symptoms of psychic distress during the mass quarantine period.

Keywords Intellectual disability, Autism, Risk factors, Physical health, COVID-19, Psychic distress

Paper type General review

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Introduction

The outbreak of the novel coronavirus disease 2019 (COVID-19) has sickened more than 48,000,000 people worldwide (WHO, 2020). The pandemic and the measures undertaken by most countries to contain its spread determined unprecedented distress factors for health-care systems. Persons with intellectual disability (ID)/autism spectrum disorder with high and very high support needs (ASD-HSN) seem to be among the hardest hit populations (Druss, 2020; Yahya *et al.*, 2020; Armitage and Nellums, 2020; Zhu *et al.*, 2020; Courtenay and Perera, 2020; Iasevoli *et al.*, 2020a).

ID and ASD represent the two neurodevelopmental disorders with the highest impact on personal functioning. They include many different clinical (syndromic) conditions (Salvador-Carulla and Bertelli, 2008), which combine cognitive and relational impairment, with high co-occurrence rates

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(Baio *et al.*, 2018; Maenner *et al.*, 2020), overlapping symptoms and psychopathological vulnerability (Oxelgren *et al.*, 2017; Noterdaeme and Wriedt, 2010; Bertelli *et al.*, 2020).

Notably, the ‘severity levels’ for ASD can be based on the “support needs” as stated in the DSM-5 (American Psychiatric Association, 2013), which focuses on the intensity of needed supports rather than on the level of impairment based on the amount of ASD symptomatology. Accordingly, PwASD-HSN are intended as belonging to the highest severity level.

In Italy, several reports have emerged on infection events with SARS-CoV-2 (Acute Respiratory Syndrome CoronaVirus 2) and severe COVID-19 symptoms and hospitalizations of persons with ID/ASD-HSN (PwID/ASD-HSN) in residential facilities (Ricci, 2020). The lack of official precise and well-defined guidelines addressing the emergency management at the very beginning of the epidemic has probably contributed to difficulties in caring for people in residential settings. Apart from housing solutions, PwID/ASD-HSN can carry additional vulnerability factors to the infection with SARS-CoV-2. Nevertheless, physicians seem not to be perfectly aware of the adjunctive risks of PwID/ASD-HSN in the context of the COVID-19 pandemic. Indeed, a Sermo survey launched on April 2020 by the authors (Sermo is the largest global healthcare data collection company and social platform for physicians across 150 countries) revealed that 45% of the physicians who responded believed that PwID/ASD-HSN are as vulnerable as the general population to COVID-19 complications. Moreover, 20% of them declared that PwID/ASD-HSN are even less vulnerable to the course of the SARS-CoV2 infection. Besides physical vulnerability, PwID/ASD-HSN can also carry additional psychic vulnerability, especially in the context of the COVID-19 pandemic.

The present commentary aims to provide a comprehensive evaluation of COVID-19-related issues in PwID/ASD-HSN, including a discussion on the first data published worldwide and on preliminary data on physical and psychic vulnerability collected during the mass quarantine period in Italy. Indeed, the knowledge of PwID/ASD-HSN vulnerability factors is fundamental to provide families and caregivers advice to counteract the risks associated with the current pandemic, as illustrated by the document titled “Advice 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” that has been signed by the authors and endorsed by the World Psychiatric Association.

Vulnerability to the infection with SARS-CoV2 and to COVID-19 complications

Health care of PwID/ASD-HSN has been a longstanding concern, as these persons show a prevalence of diseases and physical problems about 2.5 times higher than that of the general population (Kinneer *et al.*, 2018; Tyrer *et al.*, 2019; Hand *et al.*, 2020). In adjunction, PwID/ASD-HSN are generally underrepresented in health research, especially during adulthood, a trend that appears to persist during the COVID-19 pandemic (Landes *et al.*, 2020).

Physical multi-morbidity of PwID/ASD-HSN includes endocrine diseases, hypertension, respiratory problems, cancer and other conditions associated with a higher risk for SARS-CoV-2 Acute Respiratory Distress Syndrome and other COVID-19 complications. During the 2009 H1N1 pandemic, similar risk factors were found to be associated with a high number of adverse outcomes in persons with Down Syndrome (Perez-Padilla *et al.*, 2010). Indeed, the Centers for Disease Control and Prevention (CDC) reported specific recommendations for people with cognitive disabilities, stating that this population was at increased risk of becoming infected or having an unrecognized illness (CDC, 2009).

For what concerns respiratory system diseases, people with certain disabilities can also carry a higher risk of getting influenza and influenza-related complications. A few years ago, respiratory infection (including pneumonia) had been reported to be a major cause of

hospital admission in PwID, with a longer duration and higher likelihood of recurrence than in the general population (Chang *et al.*, 2017).

To note, SARS-CoV-2 has been discovered to use the angiotensin-converting enzyme II (ACE-2) as the cellular entry receptor (Wan *et al.*, 2020). ACE-2 is expressed in a variety of different human tissues, including the upper and lower respiratory tract, myocardium and gastrointestinal mucosa (Harmer *et al.*, 2002), and some scientists have hypothesized that a chronic upregulation of ACE-2 in the airways may predispose individuals to increased risk of coronavirus infections (Leung *et al.*, 2020). Interestingly, it has been postulated an association between a higher ACE expression and functionality and risk of autism (Firouzabadi *et al.*, 2016), in accordance with the hypothesis of a central role of inflammation in ASD alongside with the neuroinflammatory and oxidative actions of angiotensin II.

PwASD have also been found to present high pro-inflammatory cytokines (Theoharides and Zhang, 2011), including interleukin (IL)-6, IL-12 and tumor necrosis factor α (TNF- α), whose exaggerated synthesis has been associated with acute severe systemic inflammatory response in the pathogenesis of SARS-CoV-2 pneumonia (Buonaguro *et al.*, 2020). Therefore, PwASD could be at higher risk of developing a “cytokine storm” due to the already increased levels of the implied cytokines (Lima *et al.*, 2020b). Although several reports highlight the alterations mentioned above in PwASD, the literature results are contrasting and do not permit to draw conclusions (Jyonouchi *et al.*, 2001; Malik *et al.*, 2011; Nadeem *et al.*, 2020). In persons with Down Syndrome, high levels of pro-inflammatory cytokines (e.g. IL-6, MCP-1, IL-22, TNF- α) are associated with pronounced complement consumption, resembling changes seen in type I interferonopathies and other autoinflammatory conditions (Sullivan *et al.*, 2017). In Prader–Willi syndrome (PWS), it has been reported that several associated conditions can lead to a possible activation of innate immunity such as obesity and deficient GH secretion. Compared to non-PWS, PWS subjects have been found to show higher plasma concentrations of C-reactive protein, IL-18 and IL-6, suggesting for a low-grade systemic inflammation state (Caixas *et al.*, 2008). Also, in this case, the possibility of a higher susceptibility to SARS-CoV2 infection and a higher risk for complications than the typical population is a matter of debate.

Apart from the previous considerations, several factors can be hypothesized to play an adjunctive role for the high vulnerability of PwID/ASD-HSN to the infection with SARS-CoV2 and to COVID-19 severe presentation, including low levels of health literacy, low compliance with complex hygiene rules, reliance on other people for care.

Indeed, PwID/ASD-HSN can need high personal care assistance from caregivers when they live in the family context, or from the clinical staff when they live in residential facilities. Remarkably, the status of the person’s living or housing accommodations (domestic, residential setting or inpatient status) has been pointed out to impact significantly on SARS-CoV2 spread and possible COVID-19 sequelae (McGonigal, 2020).

For example, adults who reside in congregate care settings share the use of essential living spaces (e.g. bedrooms, bathrooms, kitchens), and are typically close to other residents. Therefore, physical distancing can represent a considerable challenge for PwID/ASD-HSN living in residential facilities that consequently may be at increased risk from SARS-Cov2 infection (Landes *et al.*, 2020).

Obviously, cognitive disabilities can lead to challenges in processing information and making decisions. Therefore, prevention measures such as hand washing, cough and sneeze protection, self-monitoring of illness, and avoiding contact with people who are sick may become a difficult challenge for these persons.

Finally, small social networks, residential instability and homelessness can also raise the risk of infection and make it harder to identify positive cases, follow-up, support and treat those infected among PwID/ASD-HSN (Tsai and Wilson, 2020).

To date, some research studies have started to provide relevant also if still scarce information on SARS-CoV2 spread and COVID-19 sequelae among PwID/ASD-HSN.

For example, the *Journal Virtual Revista Sindrome de Down* has mentioned cases of COVID-19 in patients with Down Syndrome with a variable evolution, from recovery to death, and The Trisomy 21 Research Society is evaluating the evolution of the pandemic in patients with Down Syndrome (Callea *et al.*, 2020).

Moreover, the BrightSpring Health Services, Louisville, KY, an organization that provides continuous support to over 11,000 individuals with Intellectual and Developmental Disabilities in the USA, has recently reported that male individuals with higher numbers of chronic medical conditions were more likely to be hospitalized with COVID-19 in the first 100 days of the pandemic, while most younger, less chronically ill individuals recovered spontaneously at home (Mills *et al.*, 2020).

Finally, the data obtained from the TriNetX COVID-19 Research Network platform contribute to validate the hypothesis that COVID-19 can present a greater risk to people with Intellectual and Developmental Disabilities (Turk *et al.*, 2020). Specifically, a recent study has been conducted to explore the trends in comorbidities, the number of cases and number of deaths, case-fatality rates among patients mainly living on the US territory with Intellectual and Developmental Disabilities that had a positive diagnosis for COVID-19 through May 2020. The results show that people with Intellectual and Developmental Disabilities had a higher prevalence of specific comorbidities associated with poorer COVID-19 sequelae. Interestingly, distinct age-related differences in COVID-19 trends were reported, with a higher concentration of COVID-19 cases at younger ages in people with Intellectual and Developmental Disabilities (Turk *et al.*, 2020). Preliminary prevalence rates of COVID-19 cases and complications in PwID/ASD-HSN have been started to be collected during the mass quarantine through the Italian territory for a total of 660 cases. The data were collected beginning on March 2020 in six Italian regions (Tuscany, Lombardy, Emilia Romagna, Piedmont and Sicily) by filling data sets that listed district of origin of the patient, the living arrangement of the patient, the eventual type of residential facility in which he/she was housed, the total number of patients housed in the residential facility and the number of suspects/positive cases. From these preliminary raw data, it is possible to deduce that PwID/ASD-HSN had severe to critical symptoms in 19–51% of cases, with variability depending mostly on the epidemic area and kind of living arrangements. Therefore, it seems that also the above reported preliminary data could contribute to corroborate the hypothesis that COVID-19 course and complications may severely affect PwID/ASD-HSN.

Vulnerability to psychopathological sequelae in the context of COVID-19 pandemic

Research on previous epidemics has revealed that outbreaks can have a broad spectrum of psychological effects. They can precipitate new psychiatric symptoms in people without psychiatric disorders (Chew *et al.*, 2020), aggravate the condition of those with pre-existing psychiatric disorders (Yao *et al.*, 2020; Lima *et al.*, 2020a) and cause distress to the caregivers of affected individuals. During SARS, Ebola and H1N1 epidemics, the rate of psychological symptoms and psychiatric disorders was quite high: anxiety and fears were reported to vary between 3.2 and 12.6%, depressive symptoms from 3.0 to 73.1%, anger and irritability from 2.3 to 56.7% and post-traumatic stress symptoms around 25.8% (Chew *et al.*, 2020). Recently, the COVID-19 pandemic is causing a parallel epidemic of panic disorders, anxiety, insomnia and depressive symptoms (Torales *et al.*, 2020). Moreover, the level of distress perceived by patients with severe mental illnesses due to the COVID-19 outbreak and mass quarantine periods is higher than that perceived by the general population (Iasevoli *et al.*, 2020b). The psychiatric vulnerability of PwID/ASD-HSN is elevated even in normal environmental conditions and the prevalence rate of psychiatric disorders has been repeatedly reported to be up to four times higher than in the general population (Bertelli *et al.*, 2012; Cooper *et al.*, 2007a; Nylander *et al.*, 2018; Marino *et al.*, 2019; Mazza *et al.*, 2020). Indeed, 25–44% of PwID/ASD-HSN have

at least one psychiatric disorder during the life span, 21% have two psychiatric disorders with different characteristics and 8% have three psychiatric disorders (Cooper *et al.*, 2007b; Russell *et al.*, 2016; Strunz *et al.*, 2014). The prevalence of psychopathology further increases for people who meet both the criteria for ASD and ID (Bradley *et al.*, 2004; Cervantes and Matson, 2015).

Anxiety, mood disorders and post-traumatic stress disorder (PTSD) are the most frequent psychiatric co-occurring disorders in PwID/ASD-HSN (Cooper *et al.*, 2007a; Baudewijns *et al.*, 2018; Hudson *et al.*, 2019; Russell *et al.*, 2016; Strunz *et al.*, 2014).

Despite these high prevalence reports, psychiatric disorders in PwID/ASD-HSN have been scarcely studied for most specific clinical characteristics, such as presentation, course and vulnerability factors (Bertelli *et al.*, 2015), as PwID/ASD-HSN are almost always excluded from clinical trials on psychiatric disorders, and their voice and experience are not captured (Humphreys *et al.*, 2015; Shepherd *et al.*, 2019).

A complex combination of biological, psychological and social factors has been hypothesized to contribute to this increased psychopathological vulnerability (Bertelli *et al.*, 2015). Among psychological factors, weak coping strategies, lack of environmental mastery, low self-esteem, low adaptive skills and abuse experiences have been highlighted (Lindsay *et al.*, 2015; Krabbendam *et al.*, 2014). Among social factors, adverse life events, stigma and prejudice, low economic conditions and social isolation have been reported (Martorell *et al.*, 2009; Tint *et al.*, 2017).

Environmental and social changes associated to the pandemic and the measures adopted to contain its spread (i.e. lockdown) can amplify these vulnerabilities to psychological distress and psychiatric disorders as well as other more specific factors, such as difficulties to understand abstract concepts (i.e. appraisals of threat) and the strong need of routine/sameness (i.e. frustration with activities cancelled and low tolerance of boredom and insulation).

Drastic changes in daily routine (i.e. restriction or interruption of the usual activities, places and interpersonal exchanges), forced coexistence, loss of support and prolonged perception of loneliness have already been shown to favor regression, loss of skills, psychological distress, physical ailments, suicidal ideation and psychiatric disorders in PwID/ASD-HSN (Merrick *et al.*, 2005; Dodd *et al.*, 2016; Hedley *et al.*, 2018).

The risks associated with these emotional experiences also include the worsening or developing of problem behaviors (PBs) such as increased stereotypies, self-stimulation, self-injurious behavior, aggressive behaviors toward objects or people and other oppositional behaviors. Indeed, seclusion itself may exacerbate PBs. Noteworthy, the high prevalence of PBs in PwID/ASD-HSN has been associated to a proportionate frequency of psychiatric disorders, and several studies demonstrated a relationship between PBs and the presence of psychopathological conditions (Emerson *et al.*, 2001; Felce *et al.*, 2009; Hemmings *et al.*, 2006; Kishore *et al.*, 2005). Indeed, the clinical presentation of mental health issues in PwID/ASD is often very different from the one of the general population particularly in those with more severe ID and/or co-occurrence of ASD, who present the highest difficulties in conceptualizing and communicating their psychic suffering (Bertelli *et al.*, 2015; Hurley, 2008). Therefore, it has to be noted that PBs worsening or emergence could also be related to this atypical presentation of a psychiatric disorder, apart from possibly constituting a broader stress-related response (Bertelli *et al.*, 2015).

To date, almost no data have been published on the psychopathological sequelae of the COVID-19 pandemic in adults with ID and/or ASD living independently or in residential facilities. Only one retrospective study evaluated the impact of COVID-19 restrictions on PBs in a cohort of 18 young adults with severe ASD attending a daycare center (Brondino *et al.*, 2020). Signs and symptoms of distress to the COVID-19 mass quarantine are currently the object of an ongoing Italian survey open to caregiver/health-care workers of

PwID/ASD-HSN proposed and approved by the scientific committee of the Italian Society for Neurodevelopmental Disorders (SIDiN; special section of the Italian Society of Psychiatry). The survey started on 25 April 2020 and was conceptualized as online questionnaires to be completed anonymously. Specifically, two brief and easy to fill questionnaires were developed: the first was aimed to be completed by caregivers/family members of PwID/ASD-HSN aged above 15 years that were spending mass quarantine period at home; the second was aimed to be completed by expert health-care workers that were working in residential facilities in which PwID/ASD-HSN were spending the mass quarantine period.

Preliminary results on questionnaires completed by caregivers/family members during mass quarantine have highlighted that PwID/ASD-HSN were experiencing increased agitation (53.8% of the sample), increased irritability (52.3% of the sample), changes in sleep hours (54% of the sample), increased appetite (43.1% of the sample), increased tics/stereotypies (43.1% of the sample), followed by increased soliloquy (30.8% of the sample) and increased isolation (27.7% of the sample). Moreover, 29.2% of the PwID/ASD-HSN quarantined at home needed changes in their pharmacotherapy to better control behavioral manifestations. This finding supports the British colleagues' clinical impression on an increased request for psychotropic medication to manage PBs during the COVID-19 pandemic (Courtenay, 2020).

For what concerns PwID/ASD-HSN living in residential facilities, 21.4% of the sample experienced increased irritability, 14.5% increased agitation. Finally, 93.9% of the sample stayed on the same doses/types of psychotropic medication prescribed before the mass quarantine.

In general terms, it can be deduced that observed behavioral changes could mirror an increased condition mainly linked to anxiety manifestations in both PwID/ASD-HSN quarantined at home or in residential facilities. Indeed, increased irritability, agitation and increased tics/stereotypies have been listed among the typical behavioral equivalents of anxiety in PwID/ASD-HSN (Bertelli *et al.*, 2012). Moreover, and especially in the population quarantined at home, also signs of mood distress have been reported (including increased isolation, appetite modifications, insomnia) (Bertelli *et al.*, 2012; Baudewijns *et al.*, 2018). This finding could also be linked to the lack of the previous routine activities during the mass quarantine. Therefore, it could be speculated that the changes in daily routine and social interactions to which PwID/ASD-HSN quarantined at home were used contributed to the increased behavioral manifestations relevant not only to anxiety but also to mood disorders.

In summary, behavioral changes can be expected during the COVID-19 emergency in PwID/ASD-HSN, possibly related and secondary not only to the pre-existing vulnerability to stress and psychiatric comorbidities but also to the restrictions imposed to prevent the spread of the infection in the general population.

What now? Considerations and recommendation for research/policy/health-care service response

The COVID-19 pandemic has critically impacted health care delivery in a short period.

As an example, many organizations providing care and/or specialized educational programs for PwID/ASD-HSN have temporarily closed worldwide, either voluntarily or because of mandates.

Therefore, PwID/ASD-HSN receive fewer therapy hours (i.e. behavioral therapy, occupational therapy) than they normally would. Moreover, in the context of a general economic crisis, funding delays and cuts on community-based providers are predicted to force these organizations to definitively close, with the result of placing the health and safety of PwID/ASD-HSN at risk. Despite the current pandemic challenges, the collective

experiences with coping may reveal opportunities for creating more flexible and better care systems in the future. Accordingly, PwID/ASD-HSN represent potential users of telemedicine services together with persons suffering from psychiatric disorders, chronic diseases requiring constant contact with health-care structures and practitioners including psychological supports, or people who require treatments that are usually managed by territorial services or residential structures. Although more research is needed, clinical trials and systematic reviews have shown telehealth interventions to result in promising health-care strategies under the circumstances of limited access to in-person services (Ameis *et al.*, 2020). There is an urgent need for additional research in this area to improve telemedicine services specifically toward PwID/ASD-HSN, with the multiple purposes to target from tele-diagnostics to tele-therapy and tele-support for families and caregivers.

Another fundamental point is to spread the knowledge of PwID/ASD-HSN vulnerability factors to provide families, caregivers and health-care workers special advice to counteract the risks associated with the current pandemic. Moreover, PwID/ASD-HSN are to be included in research studies, especially on the psychopathological sequelae due to the COVID-19 emergency, as the adult population is greatly underrepresented in this research field.

Meanwhile, one initial recommendation would be to provide education to all health-care professionals on communication strategies for the intellectually disadvantaged population, to reduce the distress of PwID/ASD-HSN in health settings and to appropriately give information related to the measures and rules to be adopted during the COVID-19 pandemic. In an effort to provide PwID/ASD-HSN and their caregivers specific advice, in Italy, the CREA (Research and Clinical Centre) unit of Misericordia di Firenze (Florence, Italy) and the SIDiN promptly set up a panel of experts and self-advocates to start Delphi processes for two documents aimed at providing PwID/ASD-HSN, their families and health-care workers with the most useful recommendations to deal with pandemic physical and mental-related risks. The first document, titled:

Advice 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 1.4.

was published on March 16, 2020, and immediately endorsed by some of the most relevant national scientific and family associations. At the time of the writing, the version 1.5 has been translated into English and other eight languages and endorsed by the Working Groups on Intellectual Disability and Autism Spectrum Disorder of the World Psychiatric Association Action Plan 2021–2023. The document includes accessible information on COVID-19, such as hygiene rules, anxiety crisis management, overcoming barriers, mental vulnerability, counteracting the risks of isolation and drastic changes in everyday life, and recommendations for caregivers (the document can be downloaded from the WPA's COVID-19 Resource Library www.wpanet.org/covid-19-resources?lang=it). The second document explicitly addressed to health-care workers caring for PwID/ASD-HSN during the COVID-19 outbreak, is titled "COVID-19 Emergency. Advice for healthcare workers caring for people with intellectual disability and autism spectrum disorder with high and very high support needs - version 1.3" and has been published on May 10, 2020, in Italian language and available on the SIDiN official website (www.sidin.org/2020/05/scudo-psicologico-per-gli-operatori-sanitari/). This document gives specific advice to clinicians to cope with work-related stress during the COVID-19 emergency.

Health disparities and health-related specific supports are other critical points to be taken into account for PwID/ASD-HSN. As an example, home-based SARS-CoV2 testing for PwID/ASD-HSN should be seriously taken into account worldwide. Moreover, in the event of an individual with ID and/or ASD becoming ill, compliance would be another critical issue, especially when specialized care (e.g. respiratory support) should be needed. Although the

suggestion can result inconsistent with many policies in place in health care facilities, it should be considered to allow caregivers to remain with PwID/ASD-HSN as they receive health services, as it would result in better patient-centered care with lower risks of distress and PBs.

Conclusions

PwID/ASD-HSN represent vulnerable populations to the COVID-19 outbreak and COVID-19-related mental distress. Several factors are responsible for this high vulnerability, including multimorbidity, low levels of health literacy, difficulties in understanding and communicating, reliance on other people for care, low compliance with complex hygiene rules, the strong need of routine/sameness and low adaptive skills. Physical multimorbidity includes endocrine diseases, hypertension, respiratory problems, cancer and other conditions associated with a higher risk for SARS-CoV-2 Acute Respiratory Distress Syndrome and other COVID-19 complications.

Psychopathological vulnerability is expressed by a higher (up to four times) prevalence rate and earlier onset of psychiatric disorders than in the general population. In the context of the current pandemic, behavioral changes can be expected in PwID/ASD-HSN, possibly related and secondary not only to the pre-existing vulnerability to stress and psychiatric comorbidities but also to the rules and restrictions imposed to prevent the spread of the infection.

A prompt consideration of these high health needs of PwID/ASD-HSN in health-care system planning and reorganization is desirable to develop special strategies to avoid the contagion and to prevent adjunctive psychic distress in this population, also considering that the mental health effects of COVID-19 might shape health-care system for many years, long past the events that are precipitating them.

References

- Ameis, S.H., Lai, M.C., Mulsant, B.H. and Szatmari, P. (2020), "Coping, fostering resilience, and driving care innovation for autistic people and their families during the COVID-19 pandemic and beyond", *Molecular Autism*, Vol. 11 No. 1, p. 61.
- American Psychiatric Association. (2013), *Diagnostic and Statistical Manual of Mental Disorders*, American psychiatric association, Washington, DC.
- Armitage, R. and Nellums, L.B. (2020), "The COVID-19 response must be disability inclusive", *The Lancet Public Health*, Vol. 5 No. 5, p. e257.
- Baio, J., Wiggins, L., Christensen, D.L., Maenner, M.J., Daniels, J., Warren, Z., Kurzius-Spencer, M., Zahorodny, W., Robinson Rosenberg, C., White, T., Durkin, M.S., Imm, P., Nikolaou, L., Yeargin-Allsopp, M., Lee, L.C., Harrington, R., Lopez, M., Fitzgerald, R.T., Hewitt, A., Pettygrove, S., Constantino, J.N., Vehorn, A., Shenouda, J., Hall-Lande, J., VAN Naarden Braun, K. and Dowling, N.F. (2018), "Prevalence of autism spectrum disorder among children aged 8 Years – Autism and developmental disabilities monitoring network, 11 sites, United States, 2014", *MMWR Surveill Summ*, Vol. 67, pp. 1-23.
- Baudewijns, L., Ronsse, E., Verstraete, V., Sabbe, B., Morrens, M. and Bertelli, M.O. (2018), "Problem behaviours and major depressive disorder in adults with intellectual disability and autism", *Psychiatry Research*, Vol. 270, pp. 769-774.
- Bertelli, M.O., Rossi, M., Scuticchio, D. and Bianco, A. (2015), "Diagnosing psychiatric disorders in people with intellectual disabilities: issues and achievements", *Advances in Mental Health and Intellectual Disabilities*, Vol. 9 No. 5, pp. 230-242.
- Bertelli, M.O., Salvador-Carulla, L., Munir, K.M., Scattoni, M.L., Azeem, M.W. and Javed, A. (2020), "Intellectual developmental disorder and autism spectrum disorder in the WPA next triennium mainstream", *World Psychiatry*, Vol. 19 No. 2, p. 260.
- Bertelli, M., Scuticchio, D., Ferrandi, A., Lassi, S., Mango, F., Ciavatta, C., Porcelli, C., Bianco, A. and Monchieri, S. (2012), "Reliability and validity of the SPAID-G checklist for detecting psychiatric disorders in adults with intellectual disability", *Research in Developmental Disabilities*, Vol. 33 No. 2, pp. 382-390.

- Bradley, E.A., Summers, J.A., Wood, H.L. and Bryson, S.E. (2004), "Comparing rates of psychiatric and behavior disorders in adolescents and young adults with severe intellectual disability with and without autism", *Journal of Autism and Developmental Disorders*, Vol. 34 No. 2, pp. 151-161.
- Brondino, N., Damiani, S. and Politi, P. (2020), "Effective strategies for managing COVID-19 emergency restrictions for adults with severe ASD in a daycare center in Italy", *Brain Sciences*, Vol. 10.
- Buonaguro, F.M., Puzanov, I. and Ascierio, P.A. (2020), "Anti-IL6R role in treatment of COVID-19-related ARDS", *Journal of Translational Medicine*, Vol. 18 No. 1, p. 165.
- Caixas, A., Gimenez-Palop, O., Broch, M., Vilardell, C., Megia, A., Simon, I., Gimenez-Perez, G., Mauricio, D., Vendrell, J., Richart, C. and Gonzalez-Clemente, J.M. (2008), "Adult subjects with Prader-Willi syndrome show more low-grade systemic inflammation than matched obese subjects", *Journal of Endocrinol Invest*, Vol. 31, pp. 169-175.
- Callea, M., Cammarata-Scalisi, F., Galeotti, A., Villani, A. and Valentini, D. (2020), "COVID-19 and down syndrome", *Acta Paediatrica*, Vol. 109 No. 9, pp. 1901-1902.
- CDC (2009), "2009 H1N1 flu information for people with disabilities and their caregivers or personal assistants", available at: www.cdc.gov/h1n1flu/disabilities/ (accessed 8 April 2010).
- Cervantes, P.E. and Matson, J.L. (2015), "Comorbid symptomology in adults with autism spectrum disorder and intellectual disability", *Journal of Autism and Developmental Disorders*, Vol. 45 No. 12, pp. 3961-3970.
- Chang, C.K., Chen, C.Y., Broadbent, M., Stewart, R. and O'Hara, J. (2017), "Hospital admissions for respiratory system diseases in adults with intellectual disabilities in southeast London: a register-based cohort study", *BMJ Open*, Vol. 7 No. 3, p. e014846.
- Chew, Q.H., Wei, K.C., Vasoo, S. and Chua, H.C., Sim, K. (2020), "Narrative synthesis of psychological and coping responses towards emerging infectious disease outbreaks in the general population: practical considerations for the COVID-19 pandemic", *Tropical Journal of Pharmaceutical Research*, Vol. 61 No. 7.
- Cooper, S.A., Smiley, E., Morrison, J., Williamson, A. and Allan, L. (2007a), "An epidemiological investigation of affective disorders with a population-based cohort of 1023 adults with intellectual disabilities", *Psychological Medicine*, Vol. 37 No. 6, pp. 873-882.
- Cooper, S.A., Smiley, E., Morrison, J., Williamson, A. and Allan, L. (2007b), "Mental ill-health in adults with intellectual disabilities: prevalence and associated factors", *British Journal of Psychiatry*, Vol. 190 No. 1, pp. 27-35.
- Courtenay, K. (2020), "Covid-19: challenges for people with intellectual disability", *Bmj (Clinical Research ed.)*, Vol. 369, p. m1609.
- Courtenay, K. and Perera, B. (2020), "COVID-19 and people with intellectual disability: impacts of a pandemic", *Irish Journal of Psychological Medicine*, pp. 1-21.
- Dodd, P., Doherty, A. and Guerin, S. (2016), "A systematic review of suicidality in people with intellectual disabilities", *Harvard Review of Psychiatry*, Vol. 24 No. 3, pp. 202-213.
- Druss, B.G. (2020), "Addressing the COVID-19 pandemic in populations with serious mental illness", *JAMA Psychiatry*, Vol. 77 No. 9.
- Emerson, E., Kiernan, C., Alborz, A., Reeves, D., Mason, H., Swarbrick, R., Mason, L. and Hatton, C. (2001), "Predicting the persistence of severe self-injurious behavior", *Research in Developmental Disabilities*, Vol. 22 No. 1, pp. 67-75.
- Felce, D., Kerr, M. and Hastings, R.P. (2009), "A general practice-based study of the relationship between indicators of mental illness and challenging behaviour among adults with intellectual disabilities", *Journal of Intellectual Disability Research*, Vol. 53 No. 3, pp. 243-254.
- Firouzabadi, N., Ghazanfari, N., Alavi Shoushtari, A., Erfani, N., Fathi, F., Bazrafkan, M. and Bahramali, E. (2016), "Genetic variants of Angiotensin-Converting enzyme are linked to autism: a Case-Control study", *PLoS One*, Vol. 11 No. 4, p. e0153667.
- Hand, B.N., Angell, A.M., Harris, L. and Carpenter, L.A. (2020), "Prevalence of physical and mental health conditions in medicare-enrolled, autistic older adults", *Autism*, Vol. 24 No. 3, pp. 755-764.
- Harmer, D., Gilbert, M., Borman, R. and Clark, K.L. (2002), "Quantitative mRNA expression profiling of ACE 2, a novel homologue of angiotensin converting enzyme", *FEBS Letters*, Vol. 532 Nos 1/2, pp. 107-110.

- Hedley, D., Uljarevic, M., Foley, K.R., Richdale, A. and Trollor, J. (2018), "Risk and protective factors underlying depression and suicidal ideation in autism spectrum disorder", *Depression and Anxiety*, Vol. 35 No. 7, pp. 648-657.
- Hemmings, C.P., Gravestock, S., Pickard, M. and Bouras, N. (2006), "Psychiatric symptoms and problem behaviours in people with intellectual disabilities", *Journal of Intellectual Disability Research*, Vol. 50 No. 4, pp. 269-276.
- Hudson, C.C., Hall, L. and Harkness, K.L. (2019), "Prevalence of depressive disorders in individuals with autism spectrum disorder: a Meta-Analysis", *Journal of Abnormal Child Psychology*, Vol. 47 No. 1, pp. 165-175.
- Humphreys, K., Blodgett, J.C. and Roberts, L.W. (2015), "The exclusion of people with psychiatric disorders from medical research", *Journal of Psychiatric Research*, Vol. 70, pp. 28-32.
- Hurley, A.D. (2008), "Depression in adults with intellectual disability: symptoms and challenging behaviour", *Journal of Intellectual Disability Research*, Vol. 52 No. 11, pp. 905-916.
- Iasevoli, F., Fornaro, M., D'Urso, G., Galletta, D., Casella, C., Paternoster, M., Buccelli, C., DE Bartolomeis, A. and Group, C.-I.P.S. (2020a), "Psychological distress in patients with serious mental illness during the COVID-19 outbreak and one-month mass quarantine in Italy", *Psychological Medicine*, pp. 1-3.
- Iasevoli, F., Fornaro, M., D'Urso, G., Galletta, D., Casella, C., Paternoster, M., Buccelli, C., DE Bartolomeis, A. and Group, C.-I.P.S. (2020b), "Psychological distress in serious mental illness patients during the COVID-19 outbreak and one-month mass quarantine in Italy", *Psychological Medicine*, pp. 1-6.
- Jyonouchi, H., Sun, S. and Le, H. (2001), "Proinflammatory and regulatory cytokine production associated with innate and adaptive immune responses in children with autism spectrum disorders and developmental regression", *Journal of Neuroimmunology*, Vol. 120 No. 1-2, pp. 170-179.
- Kinnear, D., Morrison, J., Allan, L., Henderson, A., Smiley, E. and Cooper, S.A. (2018), "Prevalence of physical conditions and multimorbidity in a cohort of adults with intellectual disabilities with and without down syndrome: cross-sectional study", *BMJ Open*, Vol. 8 No. 2, pp. e018292.
- Kishore, M.T., Nizamie, S.H. and Nizamie, A. (2005), "The behavioural profile of psychiatric disorders in persons with intellectual disability", *Journal of Intellectual Disability Research*, Vol. 49 No. 11, pp. 852-857.
- Krabbendam, L., Hooker, C.I. and Aleman, A. (2014), "Neural effects of the social environment", *Schizophrenia Bulletin*, Vol. 40 No. 2, pp. 248-251.
- Landes, S.D., Turk, M.A., Formica, M.K., McDonald, K.E. and Stevens, J.D. (2020), "COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York state", *Disability and Health Journal*, Vol. 100969.
- Leung, J.M., Yang, C.X., Tam, A., Shaipanich, T., Hackett, T.L., Singhera, G.K. and Dorscheid, D.R., Sin, D.D. (2020), "ACE-2 expression in the small airway epithelia of smokers and COPD patients: implications for COVID-19", *European Respiratory Journal*, Vol. 55 No. 5.
- Lima, M.E.S., Barros, L.C.M. and Aragao, G.F. (2020b), "Could autism spectrum disorders be a risk factor for COVID-19?", *Medical Hypotheses*, Vol. 144, p. 109899.
- Lima, C.K.T., Carvalho, P.M.M., Lima, I., Nunes, J., Saraiva, J.S., DE Souza, R.I., DA Silva, C.G.L. and Neto, M.L.R. (2020a), "The emotional impact of coronavirus 2019-nCoV (new coronavirus disease)", *Psychiatry Research*, Vol. 287, p. 112915.
- Lindsay, W.R., Tinsley, S., Beail, N., Hastings, R.P., Jahoda, A., Taylor, J.L. and Hatton, C. (2015), "A preliminary controlled trial of a trans-diagnostic programme for cognitive behaviour therapy with adults with intellectual disability", *Journal of Intellectual Disability Research*, Vol. 59 No. 4, pp. 360-369.
- Maenner, M.J., Shaw, K.A., Baio, J., E.D.S., Washington, A., Patrick, M., Dirienzo, M., Christensen, D.L., Wiggins, L.D., Pettygrove, S., Andrews, J.G., Lopez, M., Hudson, A., Baroud, T., Schwenk, Y., White, T., Rosenberg, C.R., L.E.E., L.C., Harrington, R.A., Huston, M., Hewitt, A., P.H.D., Esler, A., Hall-Lande, J., Poynter, J.N., Hallas-Muchow, L., Constantino, J.N., Fitzgerald, R.T., Zahorodny, W., Shenouda, J., Daniels, J.L., Warren, Z., Vehorn, A., Salinas, A., Durkin, M.S. and Dietz, P.M. (2020), "Prevalence of autism spectrum disorder among children aged 8 Years - Autism and developmental disabilities monitoring network, 11 sites, United States, 2016", *MMWR Surveillance Summaries*, Vol. 69 No. 4, pp. 1-12.
- Malik, M., Sheikh, A.M., Wen, G., Spivack, W. and Brown, W.T., L.I., X. (2011), "Expression of inflammatory cytokines, Bcl2 and cathepsin D are altered in lymphoblasts of autistic subjects", *Immunobiology*, Vol. 216 Nos 1/2, pp. 80-85.

- Marino, M., Scala, I., Scicolone, O., Strisciuglio, P. and Bravaccio, C. (2019), "Distribution and age of onset of psychopathological risk in a cohort of children with down syndrome in developmental age", *Italian Journal of Pediatrics*, Vol. 45 No. 1, p. 92.
- Martorell, A., Tsakanikos, E., Pereda, A., Gutierrez-Recacha, P., Bouras, N. and Ayuso-Mateos, J.L. (2009), "Mental health in adults with mild and moderate intellectual disabilities: the role of recent life events and traumatic experiences across the life span", *The Journal of Nervous and Mental Disease*, Vol. 197 No. 3, pp. 182-186.
- Mazza, M.G., Rossetti, A., Crespi, G. and Clerici, M. (2020), "Prevalence of co-occurring psychiatric disorders in adults and adolescents with intellectual disability: a systematic review and Meta-analysis", *Journal of Applied Research in Intellectual Disabilities*, Vol. 33 No. 2, pp. 126-138.
- Mcgonigal, M. (2020), "Providing quality care to the intellectually disadvantaged patient population during the COVID-19 pandemic", *Critical Care Nursing Quarterly*, Vol. 43 No. 4, pp. 480-483.
- Merrick, J., Merrick, E., Lunsky, Y. and Kandel, I. (2005), "Suicide behavior in persons with intellectual disability", *The Scientific World Journal*, Vol. 5, pp. 729-735.
- Mills, W.R., Sender, S., Lichtefeld, J., Romano, N., Reynolds, K., Price, M., Phipps, J., White, L., Howard, S., Poltavski, D. and Barnes, R. (2020), "Supporting individuals with intellectual and developmental disability during the first 100 days of the COVID-19 outbreak in the USA", *Journal of Intellectual Disability Research*, Vol. 64 No. 7, pp. 489-496.
- Nadeem, A., Ahmad, S.F., Attia, S.M., Al-Ayadhi, L.Y., Al-Harbi, N.O. and Bakheet, S.A. (2020), "Dysregulation in IL-6 receptors is associated with upregulated IL-17A related signaling in CD4+ T cells of children with autism", *Progress in Neuro-Psychopharmacology and Biological Psychiatry*, Vol. 97, p. 109783.
- Noterdaeme, M.A. and Wriedt, E. (2010), "[comorbidity in autism spectrum disorders – I. Mental retardation and psychiatric comorbidity]", *Zeitschrift Für Kinder- Und Jugendpsychiatrie Und Psychotherapie*, Vol. 38 No. 4, pp. 257-266.
- Nylander, L., Axmon, A., Bjorne, P., Ahlstrom, G. and Gillberg, C. (2018), "Older adults with autism spectrum disorders in Sweden: a register study of diagnoses, psychiatric care utilization and psychotropic medication of 601 individuals", *Journal of Autism and Developmental Disorders*, Vol. 48 No. 9, pp. 3076-3085.
- Oxelgren, U.W., Myrelid, A., Anneren, G., Ekstam, B., Goransson, C., Holmbom, A., Isaksson, A., Aberg, M., Gustafsson, J. and Fernell, E. (2017), "Prevalence of autism and attention-deficit-hyperactivity disorder in down syndrome: a population-based study", *Developmental Medicine & Child Neurology*, Vol. 59 No. 3, pp. 276-283.
- Perez-Padilla, R., Fernandez, R., Garcia-Sancho, C., Franco-Marina, F., Aburto, O., Lopez-Gatell, H. and Bojorquez, I. (2010), "Pandemic (H1N1) 2009 virus and down syndrome patients", *Emerging Infectious Diseases*, Vol. 16, pp. 1312-1314.
- Ricci, G. (2020), "Coronavirus, i centri per disabili sono il fronte dimenticato dell'emergenza", *Corriere Della Sera*.
- Russell, A.J., Murphy, C.M., Wilson, E., Gillan, N., Brown, C., Robertson, D.M., Craig, M.C., Deeley, Q., Zinkstok, J., Johnston, K., Mcalonan, G.M., Spain, D. and Murphy, D.G. (2016), "The mental health of individuals referred for assessment of autism spectrum disorder in adulthood: a clinic report", *Autism*, Vol. 20 No. 5, pp. 623-627.
- Salvador-Carulla, L. and Bertelli, M. (2008), "Mental retardation' or 'intellectual disability': time for a conceptual change", *Psychopathology*, Vol. 41 No. 1, pp. 10-16.
- Shepherd, V., Wood, F., Griffith, R., Sheehan, M. and Hood, K. (2019), "Protection by exclusion? the (lack of) inclusion of adults who lack capacity to consent to research in clinical trials in the UK", *Trials*, Vol. 20 No. 1, p. 474.
- Strunz, S., Dziobek, I. and Roepke, S. (2014), "Comorbid psychiatric disorders and differential diagnosis of patients with autism spectrum disorder without intellectual disability", *Psychotherapie, Psychosomatik, Medizinische Psychologie*, Vol. 64 No. 6, pp. 206-213.
- Sullivan, K.D., Evans, D., Pandey, A., Hraha, T.H., Smith, K.P., Markham, N., Rachubinski, A.L., Wolter-Warmerdam, K., Hickey, F., Espinosa, J.M. and Blumenthal, T. (2017), "Trisomy 21 causes changes in the circulating proteome indicative of chronic autoinflammation", *Scientific Reports*, Vol. 7 No. 1, pp. 14818.
- Theoharides, T.C. and Zhang, B. (2011), "Neuro-inflammation, blood-brain barrier, seizures and autism", *Journal of Neuroinflammation*, Vol. 8 No. 1, p. 168.

- Tint, A., Maughan, A.L. and Weiss, J.A. (2017), "Community participation of youth with intellectual disability and autism spectrum disorder", *Journal of Intellectual Disability Research*, Vol. 61 No. 2, pp. 168-180.
- Torales, J., O'Higgins, M., Castaldelli-Maia, J.M. and Ventriglio, A. (2020), "The outbreak of COVID-19 coronavirus and its impact on global mental health", *International Journal of Social Psychiatry*, p. 20764020915212.
- Tsai, J. and Wilson, M. (2020), "COVID-19: a potential public health problem for homeless populations", *The Lancet Public Health*, Vol. 5 No. 4, pp. e186-e187.
- Turk, M.A., Landes, S.D., Formica, M.K. and Goss, K.D. (2020), "Intellectual and developmental disability and COVID-19 case-fatality trends: triNetX analysis", *Disabil Health J*, Vol. 100942.
- Tyrer, F., Dunkley, A.J., Singh, J., Kristunas, C., Khunti, K., Bhaumik, S., Davies, M.J., Yates, T.E. and Gray, L.J. (2019), "Multimorbidity and lifestyle factors among adults with intellectual disabilities: a cross-sectional analysis of a UK cohort", *Journal of Intellectual Disability Research*, Vol. 63 No. 3, pp. 255-265.
- Wan, Y., Shang, J., Graham, R., Baric, R.S. and Li, F. (2020), "Receptor recognition by the novel coronavirus from Wuhan: an analysis based on decade-long structural studies of SARS coronavirus", *Journal of Virology*, Vol. 94 No. 7.
- WHO (2020), "Coronavirus disease (COVID-19) situation reports", WHO, available at: www.who.int/emergencies/diseases/novel-coronavirus-2019/situation-reports (accessed 23 May 2020).
- Yahya, A.S., Khawaja, S. and Chukwuma, J. (2020), "The impact of COVID-19 in psychiatry", *Prim Care Companion CNS Disord*, Vol. 22.
- Yao, H., Chen, J.H. and Xu, Y.F. (2020), "Patients with mental health disorders in the COVID-19 epidemic", *The Lancet Psychiatry*, Vol. 7 No. 4, p. e21.
- Zhu, Y., Chen, L., Ji, H., Xi, M., Fang, Y. and Li, Y. (2020), "The risk and prevention of novel coronavirus pneumonia infections among inpatients in psychiatric hospitals", *Neuroscience Bulletin*, Vol. 36 No. 3, pp. 299-302.

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