

Perspective

Youngsters with Autism and Their Families in the Era of COVID-19

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On the 2nd of April, during the World Autism Awareness Day, the mother of a 23-year-old young adult with autism sent a message to the Prime Minister of Greece through social media, advocating for the needs of people with autism during COVID-19 crisis. The following day she had a teleconference with him and after two days people with autism were excluded from the outside movement restrictions implemented by the Government in order to control COVID-19 pandemic. This event touched many people in Greece and highlighted the challenges that families with children with special needs such as Autism Spectrum Disorder (ASD) faced after the national lockdown on March the 23rd.

People with autism have a concrete cognitive style, require adherence to routine and experience anxiety when this is not possible, struggle to find new things to entertain themselves, may be oversensitive to sensory stimuli, often have sleep problems and present a high rate of comorbid psychopathology [1,2]. During the “stay at home” period they experienced major changes in their daily schedule, personal space at home decreased, sensory stimuli became overwhelming in big families, and bored siblings would pick on them. They lost not only the in-person contact with teachers and therapists but most importantly they lost close contact with grandparents who usually spend long hours with their grandchildren in Greece.

Even from the beginning of the COVID-19 crisis “tips” for helping parents to handle children with ASD were available both locally and internationally [3]. These guidelines, though, could not always address children’s mental health needs; new symptoms emerged or previous ones aggravated and parents had to seek help from child and adolescent mental health services. In Greece, following the national lockdown, mental health services accepted only emergencies but telepsychiatry was available in some settings such as our ASD Clinic. The most frequent symptoms reported by parents were agitation, increase in stereotypies and disruption of the child’s sleep pattern, which resulted in increased requests for prescription of antipsychotic and sedative agents. “Corona-phobia” or excessive unnecessary

handwashing were noticed in some verbal individuals and were related to the literal understanding of the personal hygiene and social distancing measures, and constant exposure to epidemic-related news. Fears for their own, parent’s or therapist’s death, sometimes in the form of obsessions, emerged in some high functioning individuals. Exacerbation of anxiety and obsessive-compulsive symptoms during pandemics has been previously reported [4] and individuals with ASD seem to be particularly susceptible to experiencing this kind of symptoms.

Parents of children with ASD are reported to be psychologically burdened [5]. Without the support of the broader family they experienced even higher levels of stress and feelings of helplessness. Also, the COVID-19 crisis brought back memories of the Greek financial crisis during the last decade when many parents had to cut back on their children’s therapeutic interventions; many parents expressed fears for a possible permanent regression in their child’s behavior. Familiarization with tele-technology was the only positive aspect of the crisis acknowledged by some parents.

Nowadays, that most countries discuss the gradual relaxing of the restrictive measures, individuals with ASD and their families will still be under stress because they will have to adapt to measures and routines that might keep changing every other week. We have, therefore, to plan steps ahead in order to implement long-term individualized strategies and targeted child psychiatric interventions that will meet the needs of the children and empower parents. As it has already been said stepping out of the crisis will be a marathon race and not a sprint for all of us, even more so for families having a member with ASD.

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