

Impact of COVID-19 on autistic people and their families across Europe



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Executive Summary

In March 2020, the World Health Organisation (WHO) classified COVID-19 as a pandemic and urged countries across the globe to implement measures to slow the spread of the virus. The COVID-19 pandemic has had a significant and serious impact on the lives of individuals across the world, especially the lives of people on the autism spectrum and their families.

To investigate and understand the ways in which autistic people have been affected by COVID-19, Autism-Europe conducted an online survey from March 23rd to June 15th, 2020. The survey aimed at assessing the effects of the COVID-19 lockdown on the daily lives of autistic people and their families, including their access to support services, education, employment and healthcare, etc.

This report outlines the findings of the survey, as well as incorporates media reports and findings from our member's associations and academia, to bring awareness to the experiences and challenges of autistic people and their families during the COVID-19 pandemic. We have outlined recommendations for how autistic people and their families can be better supported during the pandemic and beyond.

Effects of the COVID-19 lockdown measures

Across Europe, governments announced strict lockdown measures in order to slow the rate of infection of COVID-19 and keep people safe. The measures brought significant changes to the routines and everyday interactions of autistic people, causing uncertainty and anxiety in many. From our survey, 73% of respondents said that the needs of autistic people and their families were not adequately addressed in relation to the lockdown measures imposed on the population.

During the lockdown measures, reasonable accommodation for autistic people was a significant concern. There was a lack of clarity on the COVID-19 rules and restrictions laid out by governments which made navigating the situation especially difficult for autistic people who often found the information difficult to access and understand. Additionally, our survey found that 41% of the overall respondents experienced difficulties accessing essential facilities.

The pandemic and its subsequent measures have proven to be extremely difficult for autistic people living at home and in institutions. Survey respondents who indicated that they live at home, expressed that lockdown measures have significantly impacted their mental health and families were acutely strained due to the lack of available, adapted support in the community. Those living in institutions experienced very high level of isolation and discrimination, as contact between individuals were restricted to contain virus and visits from family and friends were curtailed.

Thus we recommend governments to ensure the availability of accessible information in a variety of formats, as well as specific measures to ensure autistic people receive the essential support they require during lockdowns. Reasonable accommodation should be provided when it comes to the safety measures put in place to take into account the specific difficulties of autistic people (e.g. regarding mask wearing or circulation). It is important that police forces and the public are properly informed about these exceptions to avoid cases of harassment.

The rights of people living in institutions should be safeguarded at all times and authorities should promote deinstitutionalisation and support community-based services.

Impact of COVID-19 on access to autism-specific services, support, education and employment

It has been repeated that the COVID-19 pandemic is far more than a health crisis: it affects societies and economies at their core. Autistic people and their families have had to adjust to changes and interruption to their services and support as well changes to how they study and work.

Prior to the pandemic, 64% of the survey respondents were able to access autism-specific support. The state of support services for autistic people and their families was dramatically altered when governments began introducing lockdown measures. Around 70% of respondents indicated that their usual support services had been interrupted and only 26% indicated that their usual support services had continued.

It was found that the majority of respondents relied on one main support person (often a family member). The support people were also often considered to be at higher risk for contracting COVID-19 putting them and the autistic people they support in a vulnerable position.

The pandemic forced autistic people to adjust to new ways of remote working and studying and impacted their access to education and employment. The transition to at-home learning was difficult for parents and autistic children as parents struggled to balance work and home-life, while being deprived of support to foster the learning of their autistic children. Online education proved to be inaccessible for a majority of autistic children. Out of our survey respondents, 42% reported that they or their autistic relatives were not able to continue studying or working remotely. Autistic people already face many barriers to employment and the pandemic has worsened the situation, causing many to lose their jobs or face extreme changes to working patterns and communication.

The restrictions have also impacted the financial situation of autistic people and relatives. Just under half (48%) of our survey respondents reported changes to their financial situation with some commenting that they experienced loss of work, reductions in working hours, and forced unpaid leave.

Our recommendations for helping curb some of the negative effects on services, support, education and employment include: ensuring that community-based support services are continuously provided through the allocation of sufficient resources. If in person services have to be interrupted, remote professional advice service should be provided. It is essential to ensure that enough resources are allocated to support the individual needs of autistic children in education, and that existing resources are not diverted to COVID-19 preventive measures. Autistic people and their families should be one of the targets of recovery plans throughout the EU, given that they are more likely to experience unemployment and poverty.

Impact of COVID-19 on health and healthcare

COVID-19 has changed the course of the health and healthcare of autistic people and their relatives. Some autistic people have a greater chance of contracting serious COVID-19 cases due to co-occurring medical conditions. Some also face an elevated risk of infection due to a

reliance on hands-on assistance from other people, which makes physical distancing challenging. To add on to this, care networks and resources for autistic people have been under a lot of strain due to the increase in medical demands caused by COVID-19.

To help answer questions and provide information regarding COVID-19, a number of helplines were created across Europe. Over half of our respondents were unaware that the helplines existed and 63% who did use them reported that their needs were not met. In fact, communicating via telephone can be challenging for many autistic people. Respondents also expressed that they experienced difficulties when accessing healthcare professionals and first aid responders due to the inaccessibility of the process.

Our survey looked at the experiences of autistic people and their families when accessing COVID-19 testing. Just over half of respondents (53%) were not offered reasonable adjustments for their specific needs during testing and some autistic people could not be administered the test due to sensory difficulties, and lack of availability of alternative options.

Triage was also a source of great concern for autistic people and their families who were unsure if they would be excluded from treatments if hospitalisation were to occur as they would not be considered in the priority group due to discriminatory assessment practices. Autistic people living in institutions also faced higher rates of COVID-19 contraction due to the close proximity of the living situation and staff member working across the multiple facilities. Unfortunately, 40-60% of confirmed COVID-19 deaths across European countries with community transmission are believed to have occurred in long-term care facilities, a proportion of which offer residential care for autistic people.

The pandemic has brought with it a mental health crisis. Our survey has provided unique insight into the ways in which autistic people and their families' mental health has been impacted. From our survey, 19% of the respondents found their mental health greatly affected and 33% said that their mental health was at least fairly affected. The top reasons reported for mental health deterioration included disruption to their routines; social isolation and lack of social interaction; worrying for themselves, their family and friends; and lack of necessary support.

To help address some of the challenges in relation to the health and healthcare of autistic people, we recommend ensuring that information is made accessible to autistic people as well as COVID-19 testing and screening; preventing discrimination in relation to access to treatment (notably regarding triage protocols); providing mandatory reasonable accommodation and support to facilitate access to the same standard of care as other individuals; and ensuring the continuous availability of access to personalised, evidenced, community-based and affordable mental health services.

In conclusion, challenges that autistic people and their families faced before the onset of COVID-19 were compounded by a lack of support that has been felt in many European countries. COVID-19 has shed light on the level of discrimination they routinely experience and brought a further fall in quality of life for autistic people and their families in 2020. It has led to poorer outcomes related to health, social, financial, education, or employment issues for autistic people and their families. It is imperative that all stakeholders including decision-makers, healthcare professionals, and communities work together to ensure that autistic people have access to the same treatment and enjoy the same rights as everyone else.

Contents

Executive Summary	2
Introduction	6
1. Impact of COVID-19 lockdown and safety measures	7
1.1 Limited accessible information for autistic people during the lockdown	7
1.2 Impact of lockdown measures on autistic people and their families	9
1.3 The need for reasonable accommodation during the lockdown and adequate awareness-raising actions	12
1.4 The dire situation of people living in institutions	13
1.5 Recommendations	14
2. Impact on access to autism-specific services, support, education and employment	16
2.1 COVID-19 impact on access to autism-specific services	16
2.1.1 Pre-COVID-19 situation of autistic people and their families in relation to support services	16
2.1.2 Access to support services during COVID-19	18
2.1.3 Vulnerability of (family) support persons during COVID-19	19
2.2 COVID-19 impact on access to education and employment	20
2.2.1 COVID-19 impact on access to education	21
2.2.2 COVID-19 impact on access to employment for autistic people and relatives	23
2.3 Financial impact of COVID-19 on autistic people and relatives	24
2.4 Recommendations	25
3. Access to healthcare and impact on health for autistic people and relatives	27
3.1 COVID-19 impact on access to healthcare	27
3.1.1 Access to COVID-19 Helplines	28
3.1.2 Access to testing and first aid responders	29
3.1.4 Hospitalisation and triage	30
3.1.5 Grave concerns over the treatment of people living in institutions	31
3.2 COVID-19 impact on mental health of autistic people and relatives	32
3.3 Recommendations	34
Conclusion	36
References	38

Introduction

Autism-Europe conducted an online survey from March 23rd to June 15th, 2020 to investigate the effects of the current COVID-19 pandemic on the daily lives of people on the autism spectrum and their families in Europe.

The effects of COVID-19 and the restrictions put in place have been both direct and indirect. Those who have had direct contact with the virus have experienced a negative impact on their health, education, employment, and finances. The pandemic has also indirectly affected the quality of life of millions of people through social issues such as loneliness, social isolation, relative poverty and lack of access to essential services.

In this report, we present the prominent results of our survey and shed light on the specific issues and challenges autistic people and their families face as a result of the COVID-19 pandemic. This report also incorporates media reports and findings from our member's associations and academia.

The survey addressed three main areas related to the COVID-19 pandemic including the effects of the lockdowns measures on daily lives, the impact on access to services, support, education and employment and the health of autistic people and their families.

The first wave of lockdowns began in March and April of 2020 and had a significant impact on the ways in which autistic people and their families conduct everyday activities. This section of the report addresses the situation of autistic people living at home and in institutions during the lockdown reasonable accommodation was provided in relation to the measures put in place to contain the spread of the virus.

The survey also considered how COVID-19 impacted access to services, education and employment for autistic people and their families. It looked closely at the pre-existing situation of support arrangements and the ways in which access to support was affected by the COVID-19 crisis for a comparison.

Lastly, the impact of COVID-19 on the healthcare and general health of autistic people and their families was explored through key issues such as accessibility to COVID-19 helplines, testing, triage, treatment, hospitalisation and the mental health of autistic people.

The survey targeted a mix of people including persons on the autism spectrum, support person on behalf of the autistic person (in most cases the parent of an autistic child), professionals and non-professionals who have an interest in autism.

The survey was disseminated to members across the Autism-Europe network who, in turn, passed it on to their national and regional networks. The results in the report are based on a sample of 1811 participants (mean age = 40, range: 2-78; 1233 female), of which 392 reported that they have a formal clinical diagnosis of autism spectrum disorder (ASD).

Participants in the survey came from 38 different countries and the results displayed in the report are the combined data of all participants. It is important to note that results were similar when analysing the data for residents on a country-by-country basis.

For clarity and respect in the survey and throughout this report, we refer to autistic people in line with our [acceptable language guidelines](#)¹. Some questions showed more concrete data than others, in numerical terms.

The findings from this report were utilised to develop recommendations to help autistic people and their families navigate through this difficult time and to address possible challenges that may arise in the future.

1. Impact of COVID-19 lockdown and safety measures

COVID-19 affected millions of people as lockdown policies were first enforced across many EU countries in March of 2020. These security measures were restrictive and enforced in an effort to curb the infection rate of COVID-19. Autistic people who live at home and autistic people living in institutions at the time were impacted greatly by the restrictions. In many cases, those living in institutions experienced even more restrictions than usual to their fundamental rights to move freely outside, to receive visits from friends and family, and be included in society.

The issue of reasonable accommodation for autistic people in relation to the safety measures was a significant concern for many in the autism community. There was a lot of confusion regarding the COVID-19 rules and restrictions laid out by governments especially for autistic people who found the information difficult to access and understand. The lack of clarity and accessible information triggered fear and anxiety in many autistic people.

COVID-19 security measures meant that usual day-to-day interactions drastically changed in public spaces. However, for countries around the world, not all of these measures were applied in the same period nor were they enforced properly. The level of inconsistency across European borders regarding travel created confusion and was a leading factor in the spread of the virus.

Countries also saw disruption in their political processes due to COVID-19. The measures introduced in areas with a high population density restricted movement and therefore affected citizen's ability to protest. New legislation for COVID-19 was passed in an emergency drafting and many groups including disability groups were not involved in the process. There was no opportunity to provide feedback on the legislation and as a result the legislation faced less scrutiny from civil society and in turn from the disability movement. The majority of COVID-19 legislation drafted does not adhered to the European disability movement's motto "nothing about us, without us"². The lack of deliberation around new policy developments is a concern for all people with disabilities.

1.1 Limited accessible information for autistic people during the lockdown

In Europe, countries began to lockdown their populations soon after they had started to see an increase in COVID-19 infections. The 'lockdowns' involved the closure of all non-essential businesses, international borders, and places where people would interact with others in non-essential ways, such as shopping centres. What constituted 'essential' and what was not, has been the subject of many heated debates.

Governments throughout the EU took the following measures for the general population during lockdowns and followed them by a gradual relaxation process:

1. Access to services for basic needs: closing non-essential shops and services including healthcare services;
2. The adoption of "social distancing" with one person having to stand at least 1.0, 1.5, or 2.0 metres from the nearest person;
3. Closure of international borders to restrict the movement of people on non-essential journeys;
4. The wearing of a facemask to prevent coughing or sneezing possible tiny corona particles onto someone else;
5. Interdiction of close contact greetings;
6. Regular handwashing with hot, soapy water was recommended as the best way of stopping the transmission of the virus;
7. Provision of alcohol(anti-germ) gel at entry and exit points to any enclosed space;
8. New queuing systems for enclosed spaces and the introduction of one-way systems for people in buildings, train/bus stations with the closure of side entrances, allowing for control of access;
9. Self-isolation for anyone who has any symptoms of COVID-19 (fever, flu-like symptoms, loss of taste/smell).

Many countries in Europe began their lockdowns in March 2020 with **Italy and Switzerland** locking down in the first two weeks of the month. Most other European countries locked down in the middle of the month namely **Austria, Belgium, France, Spain, Germany** and most others. These countries were then followed by **Greece, UK and Romania**.

Out of the 1505 respondents, 85% (1282) respondents said that there were official measures for the population to stay at home during the spread of COVID-19. 10% (147) respondents said there were no official measures and 5% (76) saying that they did not know if there were measures or not.

The introduction of these measures triggered widespread confusion especially for autistic people and their families who were unsure of what they could and could not do legally. For example, in **Belgium**, the problem was so often mentioned that an autism organisation stressed the need for clarity, specifically for autistic citizens.³

It is evident that in many countries the new rules came without clear or detailed explanations. One respondent mentioned that they "need more support for families, facilities and centres with clear and practicable guidelines".

Autistic people do not have a 'one-size-fits-all' care plan. They can have complex or less complex support needs. An autistic person from the **Netherlands** highlighted the lack of specialised support, "The visitors' arrangement in disability care is a disaster for me. Since [beginning of May] it has been relaxed, but not at all adequate and inappropriate for me as an autistic person with lesser support needs. It seems to be mainly focused on [people with

disabilities who have higher support needs]. Communication about what is and what is not allowed outside and inside the 'institution' (read: assisted living facility) is very poor and it is not at all clear what exactly is and is not allowed. In practice there seems to be self-censorship, because the rules are not laid down on paper, but are only verbally passed on. Very disturbing and worrying! (...)”

One respondent from the **UK** highlighted their experience: “In some ways it is helpful that people are social distancing and I don't have to worry about being kissed or touched by others. However, I have a non-autistic child to care for and I worry that I am not doing everything right because I might not understand all the appropriate information: health, school work, administration, mental health of a teenager etc.”

Autistic-friendly information was scarcely made available by governments. The dissemination of public information has come under scrutiny during the COVID-19 pandemic for being ambiguous and overly alarming. Research shows that “government advice, often unclear and rapidly changing, is rarely provided in easy-read formats. As a result, autistic adults with intellectual disabilities may be left unable to access vital public health advice”⁴.

Instead, some Non-Governmental Organisations (NGOs) created social and visual aids to describe the COVID-19 situation to autistic people. Autistic-friendly helplines were set up in Ireland, France⁵ and Spain⁶ when lockdown measures were introduced (see Section 3.1.1 for more information). At the international level, the WHO's Myth busting page² is useful to dispel myths on what can help people against COVID-19 but unfortunately it is not available in an accessible format for autistic people and their families.

1.2 Impact of lockdown measures on autistic people and their families

I. Access to essential goods and services

We looked whether autistic people and their families experienced difficulties in accessing essential facilities such as shops and pharmacies, as it can have a large impact on the quality of life of autistic people and their families.

Keeping supermarkets and pharmacies open during lockdowns, was a relief for autistic people but they encountered challenges such as supermarkets being too busy and confusing one-way systems in-store. As a result, autistic people would spend less time in these spaces as a precaution to avoid being infected with the virus.

Our survey found that 41% of the overall respondents experienced difficulties accessing essential facilities such as shops. For respondents who self-identified as autistic, almost half (48%) of the 356 respondents experienced difficulties.

Our survey took samples from people describing their own experiences from across Europe. One autistic person from **Germany** stated that the issue was pre-existing and pointed out that: “Generally [I] have difficulty with access to anything. But not less due to the COVID-19 situation (except closed shops). (...) I inform myself on internet and that is accessible for me (for other disabilities there are problems).”

The issue of hoarding particular items such as toilet rolls caused anxiety for autistic people who feared that they would be left without such items. Some countries, like **Belgium**, prohibited grocery stores to sell these items in bulk for a lower price.⁸

Moreover, we looked at the impact COVID-19 had on accessing essential groceries that autistic people and their families would typically buy from supermarkets. It was revealed that autistic

people and their relatives were not able to get their preferred groceries or other essential items from supermarkets open during lockdown measures.

From a sample of 595, 41% of respondents experienced difficulties in accessing essential facilities and almost three quarters (72%) did not get their preferred food items. For respondents who self-identified as autistic, 60% did not get their preferred food items.

Difficulty with shopping and not being able to access a certain food or drink items can have a major impact on an autistic person's day-to-day life and anxiety levels⁹, in particular due to the fact that they can have a restricted diet, eating only a limited range of food. One female autistic person from **Germany** commented "(...) Sometimes there is a lack of goods that I NEED in everyday life because I really have quite autistic issues with food. With some products, I simply have no alternative. So other people's hamster purchases sometimes massively disturb my eating habits, which in turn leads to difficulties at home. For example, I usually cook around 6 pm, but now I didn't get MY schnitzel and bought turkey schnitzel as a substitute. It took a day of not eating and an evening of overcoming until 10 pm until I managed to make and eat one of my dishes with turkey instead of the usual pork schnitzel."

Of course, not being able to access essential goods was only one part of the difficulties experienced during the lockdown.

II. Disruption of daily routines, social isolation and impact on families

The restrictions linked to the lockdown have disrupted daily routines, causing even greater disruption for autistic people due to their specific needs. The COVID-19 outbreak has been difficult for households who have had to spend more time together than they ordinarily would without adequate support.

There were also challenges for autistic people who had to be confined for extended periods of time. One female autistic person from **Germany** commented on this issue: "In terms of my mental health, the fact is that I do not live alone and therefore I have no quiet retreats. [...] The apartment is too small." Furthermore, one autistic person from **Italy** mentioned that during lockdown "The inability to go for walks or cycling also causes great stress."

Homebound children and adults with disabilities can experience additional difficulties as they lose access to their usual activities and support services. Behaviour issues of autistic individuals with cognitive difficulties can also be challenging for families at home. This was accentuated by the fact that they were unable to move around freely in places of leisure due to restrictions on the amount of time allowed outside and prohibitions on driving in cases of geographical remoteness.¹⁰

Several studies highlighted the deep impact of COVID-19 on families such as the study on the parental experience of COVID-19 lockdown from **Serbia**¹¹. The media also played a role on shedding light on how autistic people struggled with the COVID-19 pandemic with news reports on the issue from the **UK**¹², **Spain**¹³, **Italy**¹⁴ and **France**¹⁵.

During the COVID-19 pandemic, a study from the **UK** found that 86% of parents of autistic children felt a lack of government support during lockdown and 70% reported that their daily routines are still significantly different since the pandemic began¹⁶.

The overuse of technological devices by autistic children was also an issue as "parents stated that in the quarantine process, children with ASD are glued to the technological tools (tablet, computer, phone, etc.), which they spend a lot of time on normally¹⁷."

An impact study from the UK found that “whilst 58% of participants confirmed they still had access to at least one type of specialist support during lockdown, the survey identified a wide range of new worries and challenges that parents and family carers faced¹⁸.”

We wanted to explore what impact COVID-19 was having on the social lives of autistic people and their families. Social contact also fulfils a role of support for autistic people and their relatives.

An autistic person from **Switzerland** commented “I am used to self-isolation through my autism, only this time it is something different, i.e. isolation was forced in contrast to self-chosen free self-isolation!” Another autistic person from the **Netherlands** agreed: “I am an autistic person and I have a lot of trouble with social contacts, but still I have a huge need to see and speak to people in real life.” While an autistic person from **Germany** found: “On the question, whether I can take up contact at present, I wrote no, because friends I have none, with colleagues it is difficult, because they are not nice, so I go only now and then with family.”

A respondent from **Malta** indicated: “It is [usually] important to go out, but staying indoors to avoid contact with virus, [I] miss meeting other students and work placement colleagues, also grandparents and relatives.”

An autistic person from **Germany** highlighted that isolation has been experienced as a relief: “It is not my intention to disregard the suffering of many people, but for the first time my disability is an advantage. To retreat into my shell is not a limitation, but a desirable normal state, and if I am forced to go outside, then almost no one is outside [now], which is a great relief. Nevertheless, I hope that it will pass quickly and that as few people as possible will have to suffer or even die. I can always withdraw again, but the poor [non-autistic] are really badly off now.”

However, it seems that most autistic people and their relatives felt more vulnerable because of social isolation and limitations on social interaction officially imposed due to COVID-19. Generally speaking, autistic people experience more loneliness than non-autistic people¹⁹(also see the part dedicated to mental health in section 3)

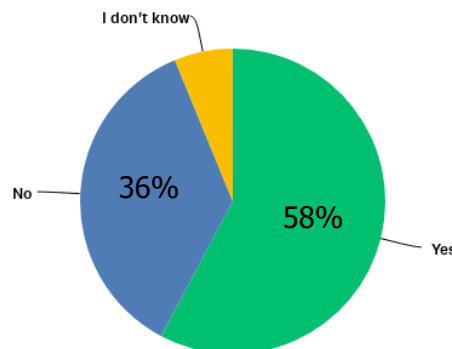
We asked if autistic people and their families felt more vulnerable due to social isolation and limitations on social interaction during the COVID-19 lockdown.

More than half (58%) of the 1.393 respondents felt that they or their autistic relatives are more vulnerable because of social isolation and limitations on social interaction that were officially imposed due to the COVID-19 lockdown.

While only every third (36%) respondent reported that they or their autistic relatives didn't experience feeling of vulnerability.

Our members from the UK highlight a very difficult situation that “nine out of ten autistic people have worried about their mental health during lockdown. Compared to the general public, autistic people were seven times more likely to be chronically lonely during June and July and six times more likely to have low life satisfaction²⁰.”

Q32 Are you feeling more vulnerable because of social isolation and limitations on social interaction officially imposed due to COVID-19?



A Belgian musician named “DJ Peter Harvey” plays dance music from his own home during the COVID-19 lockdown as a morale-booster for his local community in Ixelles (a lively neighbourhood in Brussels)²¹.

The young autistic man became well known for his initiative, which involves playing a list of dance classics from his balcony so his neighbours can listen and enjoy.

1.3 The need for reasonable accommodation during the lockdown and adequate awareness-raising actions

As highlighted above, being confined to their homes, without the possibility to go outside or just in a very restricted perimeter can be a great challenge for many autistic people. Mask wearing is also difficult for many due to sensory difficulties.

In many countries, at least initially, there was a total lack of reasonable accommodation for autistic people and their families. Following pressures from autism and other disabled people’s organisations some specific measures were adopted.

Out of the 1505 respondents, 60% (755) respondents said that there were special provisions for autistic people to be allowed outside during the spread of COVID-19, 28% (356) respondents said they were no special provisions and 11% (145) said they did not know if they were or not.

In **Greece**, one respondent from our survey said that “in the midst of a pandemic, people with autism were allowed to go on walks without restrictions and with a companion when necessary. Another highlighted their struggle saying that “there has never been a more difficult time for an autistic person than this.”

In **Spain**, the Health Ministry permitted autistic people to access the streets and avoid mask wearing during the COVID19 lockdown. This exception came about due to advocacy efforts from our members Autismo Espana and Cermi Estatal²². In **France**, President Macron also outlined the need for an adapted lockdown for autistic people and their families due to the

severity of the problem²³. The new measures to allow flexibility for autistic people during lockdown were announced on World Autism Awareness Day²⁴. In **Italy**, various arrangements were made for autistic people²⁵, it was also the case in **Czechia** regarding mask-wearing.²⁶

In **Germany**, guidelines on mask wearing exemptions were available²⁷ with **Switzerland** offering the same information²⁸. At times, the information from the government on issues such as mask wearing was unclear. An article from **Belgium** discussed issues of clarity on mask wearing for autistic people²⁹. An article from **Ireland** reported that Autism-Europe's member organisation AsIam requested the government of Ireland to make mask-wearing exemptions the norm for autistic people as some spaces, such as schools, still mandated mask wearing for autistic people³⁰. Autism-Europe's member from **Luxembourg** created a guide on mask wearing due to the strict government rules in certain spaces³¹.

Allowing autistic people to go outside and benefit from exemptions posed some difficulties as the general public and the police force were not sufficiently informed about specific exemptions. Autistic people reported being harassed in various countries for not respecting the rules.

To address this issue, Scottish Autism established a cooperation with their Police department to ensure an adequate response to exemptions that exist for people on the autism spectrum³². It was in response to concerns and reports from various communities of being inappropriately challenged by the public during the Covid-19 pandemic. Police Scotland urged the public to consider the fact that some groups of people are exempt from certain Covid-19 guidelines. They also issued guidance to frontline police officers and staff to ensure they are mindful of these exemptions when engaging with people.

1.4 The dire situation of people living in institutions

In the meantime, persons with disabilities who require assistance to be fed, clothed and washed found COVID-19 containment measures, such as social distancing and self-isolation, "impossible" according to Ms. Catalina Devandas Aguilar, UN Special Rapporteur on the rights of persons with disabilities³³. Autistic people living in institutions were left particularly vulnerable. She spoke out on the situation of people with disabilities in institutions, psychiatric facilities and prisons. "For them, there is a high risk of infection from COVID-19 coupled with the lack of external oversight, exacerbated due to emergency COVID-19 legislation."³⁴

Some institutional care settings became hotspots for coronavirus and the least safe place to be as previous other viral outbreaks have shown. "like the H1N1 virus outbreak [in 2009], carers posed the greatest risk of infection to the residents as vectors of the infection³⁵". The lockdown measures did not address all aspects of the situation and put vulnerable people at risk. The restrictions were also detrimental to the deinstitutionalization movement, which promotes the transition from institutional-based care to family and community-based settings³⁶.

The COVID-19 outbreak has been extremely difficult for people living institutions³⁷ as government measures restricted contact between individuals to contain the virus. The situation shed light on the level of discrimination they routinely experienced. They saw visits from family or friends curtailed, access to outdoor spaces restricted, greater powers given to the institutions regarding isolating and a decline in the general treatment of individuals. These measures are designed to prevent infection spread in 'high risk' long-term care facilities,

notably due to low capacity for testing and PPE provisions. However, loss of contact with relatives may cause distress for autistic people and increase uncertainty and loneliness.³⁸

Thus the COVID-19 outbreak created new, challenging situations and exposed pre-existing issues. Difficulties arose when staff at the institutions found themselves sick and could not work. This led to a shortage of workers and an increase in the number of residents also falling ill. A professional from **Spain** working with autistic people and their families commented, "I am a worker [in] a residential home run by a regional autism association and I am doing telework from home because I belong to the at-risk population."

One professional from **Belgium** highlighted that "one autistic person from **France** living in an institution in Belgium with their primary residence and family in France, was not able to be visited by their family". Autism-Europe's member Sésame Autisme reported that "the agreement between France and Belgium only allows visits if the establishment agrees and the movement of families from France to Belgium is possible". This example highlights how COVID-19 has magnified an on-going issue concerning the lack of community-based available services for autistic people in France. The situation has forced thousands of disabled French people, many of whom are on the autism spectrum, to be "exiled" in Belgium. The French government has still to deliver on its commitment to provide adequate services in France³⁹, to ensure that people in this position can freely choose their place of residence. There are cases where service users have not been able to receive visits from their families since March of 2020. But unfortunately, this case is not specific to relations between Belgium and France. Many families of people living in institutions across Europe had to decide between bringing their child home or going for long periods without seeing them.

The widespread discontent with the governments' response to the COVID-19 pandemic became apparent all across Europe. For example, in the **UK**, the government handling of the COVID-19 pandemic response was criticized as 22,000 disabled people died from coronavirus between 2 March and 15 May making up two-thirds of all COVID-19 related deaths⁴⁰. A later official inquiry found out that researchers estimated that the mortality rate of people with learning disability had been 6.3 times higher than the general population, and that the rate of COVID-19 deaths for adults in residential care was higher than the rates of COVID-19 deaths of adults with learning disabilities generally.⁴¹ (see also section 3.1.5)

1.5 Recommendations

Based on the results of our survey and the experiences of respondents, Autism-Europe has developed recommendations for providing support and improving the situation for autistic people and their families during lockdown.

I. Providing accessible information

We recommend that public advice campaigns and information from national authorities be made available to the public in sign language and other accessible means, modes and formats.

Attention should be given to provide very clear guidelines. Information about the current COVID-19 rules and restrictions should be communicated in formats which people with disabilities can understand such as easy-to-read, plain language, and augmentative and alternative modes of communication.

II. Providing reasonable accommodation

Autistic people should be provided with different types of reasonable accommodation when implementing measures linked to lockdown.

Types of reasonable accommodation for autistic people living at home include allocations to go outside to walk, no limitations on exercising, exceptions for mask wearing, information about COVID 19 rules in accessible formats. It is important that police forces and the public are properly informed about these exceptions to avoid cases of harassment.

Shops should also be made more accessible for autistic people and their families. This can be achieved by designating specific shop hours reserved for autistic people and their families and by discouraging so called "hoarding/panic-buying" so that they can get the types of food they need. For example, shops can forbid the sale of multiple quantities of the same product. It would be helpful to advertise specific shopping times as autism-friendly, or a buddy system pairing autistic individuals with a buddy who can shop for them.

III. Protecting the rights of people living in institutions and preventing further institutionalisation

Authorities should promote deinstitutionalisation and support community-based services instead. Doing this will reduce the number of people living in large residential and psychiatric institutions and at the same time, decrease the likelihood of infection in large institutions. Persons with disabilities in residential institutions should have equal access to treatment. They should not be institutionalised as a consequence of quarantine and should be treated on an equal basis with others.

If residential and psychiatric institutions are not closed, authorities should urgently ensure that strict hygiene and prevention measures are guaranteed. Authorities should conduct systematic visits and carefully monitor the activities of institutional care facilities to ensure that residents are not left abandoned or put in danger by staff shortages and absence. Residents should be protected through continuity plans in case of reductions in the number of staff. Residents should have access to information on their rights and means to report violations.

Children and persons with care/support needs should be allowed to safely return to their families for the duration of the epidemic and families should be provided with the support they need to do so. Restrictions on visitation to residential care settings must be balanced with flexible options for alternative communication, such as regular and consistent access to video or telephone contact.

Emergency social security measures should be created for families caring for people with long-term needs and persons in need of care or support, families and their representative organisations should be involved in the planning and implementation of such emergency measures.

Funding during the recovery period should be allocated to disability services and organisations. Recovery funding must be specifically allocated to community-based disability support and services.⁴²

2. Impact on access to autism-specific services, support, education and employment

This section looks at the impact of COVID-19 on the lives of autistic people and their families, in a range of domains. First, our survey highlights the COVID-19 impact on access to autism-specific support persons and services as well as the impact on access to education and employment, and on the financial situation of the respondents.

Generally, the COVID-19 spread and governmental policy to contain the virus severely affected the situation of autistic people and their relatives across Europe. The overall response to the survey was overwhelmingly negative, showing that government policy did not serve autistic peoples' interests. A few positives were counted with the "general relentless pressures of ordinary life"⁴³ not applying anymore.

Social challenges that autistic people and their families faced before the onset of COVID-19 were compounded by a lack of support that has been felt in many European countries. COVID-19 has brought a further fall in quality of life for autistic people and their families in 2020 and has also led to poorer outcomes related to health, social, financial, education, or employment issues for autistic people and their families⁴⁴.

2.1 COVID-19 impact on access to autism-specific services

Since the beginning of the pandemic, autistic people and their families have seen restrictions in access to autism-specific support. Autism-Europe's survey aimed to find out to which extent support services have been affected by COVID-19.

The survey found that COVID-19 caused severe failings in the provision of various services for autistic people and their families. Results showed that out of the 1505 respondents, 73% (1096) respondents said that the needs of autistic people and their families were not adequately addressed during the spread of COVID-19 and 11% (163) of respondents said they were addressed adequately with 16% (246) saying that they do not know if they were or not.

At the time of the survey many autistic people and their families across Europe had lost most of their support including social workers, speech therapy, access to psychologists, employment coaching, additional educational support, and care assistants. There was little or no indication of when this support would restart, "[autistic] children and their families, who are already isolated from public life, are being asked to distance themselves even further, potentially heightening and compounding their isolation"⁴⁵. In our survey, one respondent from **Greece** stated that "[...] these people (autistic people) have been away from their program for a long time, which is important for them and their family to function in their daily lives."

2.1.1 Pre-COVID-19 situation of autistic people and their families in relation to support services

In order to better understand the effects of COVID-19, it is necessary to examine what the situation of autistic people and their families looked like prior to the pandemic. According to our survey, before the spread of COVID-19 across Europe, 64% of overall survey respondents indicated that autistic people received autism-specific support. Around one-third (33%) of respondents said that autistic people did not receive any autism-specific support.

Broken down by identity, the numbers showed an even clearer picture of the situation for autistic people. Almost half of the total respondents for this question had self-identified as autistic. Of these respondents, more than half (55%) reported that they did not have autism-specific support. This data **highlights a pre-existing gap in service provision for autistic adults.**⁴⁶

An autistic female respondent from **Germany** commented, "My husband and I need support in everyday life, but currently have none." An autistic male from the **UK** mentioned, "The main emphasis in the UK has been on "highly vulnerable" people. Provision for people with disabilities has taken a very distant second place."

Autism-Europe's survey looked at what type of autistic-specific support respondents were using. While relatives responding to the survey pointed out that autistic people receive mostly autism therapies, autistic respondents reported they usually receive counselling and coaching.

When asked which type of autism-specific support respondents were using prior to the pandemic we found that:

- 43% of the 1,084 respondents indicate that autistic people receive autism therapies.
- Just over a quarter (27%) indicate that they need personal assistance.
- Out of 164 respondents self-identified as autistic, 52% have autism-specific counseling or coaching.
- About 7% received supported living services
- A little over 7% were in residential institutional care
- 5% were in supported employment

Participants were asked if they need support for daily activities. In this sense, 'support' could be quite broad and was not explicitly defined as it was previously. From the data, we know that around two thirds (67%) of autistic people need at least occasional support for daily activities.

Our survey also found that:

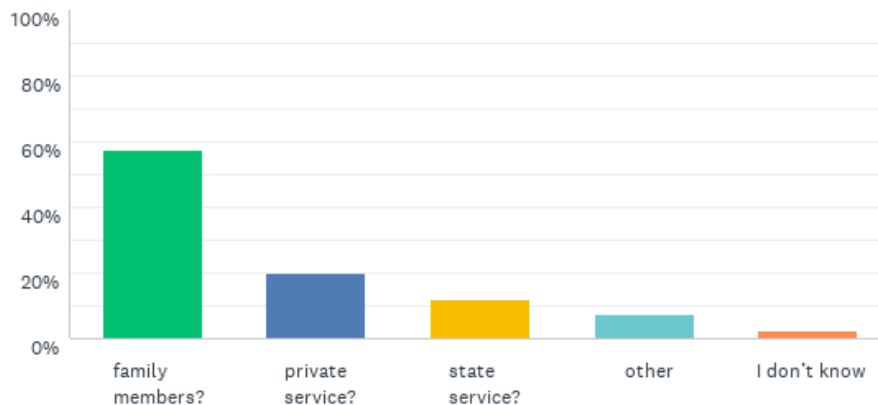
- 35% of the 1,710 respondents indicated that they needed support for daily activities every day.
- 32% of the respondents indicated that they occasionally needed support for daily activities.

Regarding support for daily activities, we asked respondents who provided their support. Support, whether occasionally or daily, is mostly provided by family members (57%), then through private service (20%), followed by state service (12%), and from other sources.

When broken down by identity the picture is the same for autistic respondents. Out of around one thousand respondents, almost 200 of whom self-identified as autistic, (57%) are supported by family members.

We know that family support usually takes place due to lack of community-based support services. ⁴⁷This leads informal family carers and their autistic relatives being put in a vulnerable position.

Q12 If yes, is this support provided by



ANSWER CHOICES	RESPONSES	
family members?	57.30%	620
private service?	20.15%	218
state service?	12.20%	132
other	7.67%	83
I don't know	2.68%	29
Total Respondents: 1,082		

2.1.2 Access to support services during COVID-19

The survey assessed the state of support services for autistic people and their families since COVID-19 lockdown policies took effect.

Autism-Europe's survey found that:

- Around 70% of the 978 respondents indicated that their usual support services had been interrupted.
- Only around a quarter (26%) indicated that their usual support services had continued.

Just a few support services for autistic people have continued and it impacted on the mental health of autistic people and their relatives (cf. mental health subsection in next section).

A relative of autistic person from **Malta** commented that "One to One sessions such as CDAU (Child Development Assessment Unit) and speech therapy at school should continue (but have stopped). School should be opened and there should be limited people." In addition, an autistic parent from the **UK** wished "they provide(d) speech therapy and occupational therapy at home."

Another autistic parent from **Italy** regretted to share that "To cancel all health services dedicated to autistic people, without thinking or trying alternative strategies to maintain the "relationship", shows a serious organizational deficiency and lack of real attention to the needs of autistic people, who have been abandoned to themselves and their families. Thus, the most capable and enterprising families, without financial difficulties, get by, the others (autistic people with low income and better networks) drown."

Many community-based services across Europe (e.g. day services, workshops, supported employment) are provided by the private sector and non-profit organisations. These organisations have reported experiencing acute financial instability due to COVID-19 and are not always eligible to claim reimbursement for appointments that have been shifted to online delivery though see flexible legislation from Belgium), meaning some have been forced to close completely. As a result, for some autistic people, relatives and other caregivers are currently the only available support person.⁴⁸

2.1.3 Vulnerability of (family) support persons during COVID-19

Autism-Europe wanted to know how COVID-19 would potentially affect the availability of carers or support assistants. We asked respondents to tell us about the risk status of their carers or support assistants. For example, if their carer or support assistant may be vulnerable to contracting COVID-19 and thus, unable to offer support to the autistic person. We also questioned if their support person had a replacement carer in the event that they become infected by COVID-19.

The results showed that the majority of respondents relied on one main support person and that availability and continuity of support from the same person(s) was not consistent.

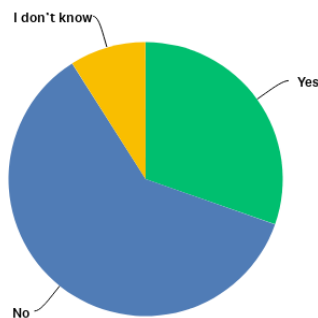
Our survey found that:

- More than one third (35%) of the total respondents consider the support person(s) for themselves or their autistic relative to be at higher risk for COVID-19;

When respondents were asked whether they themselves or their autistic relative have another support person(s) if the current one gets infected:

- Almost two-thirds (61%) of the 978 respondents indicated that they do not have another support person in case the current one gets infected.
- Only 30% suggested that they have another support person.
- 9% of respondents do not know whether they have another support person.

Q16 If your support person(s) get(s) infected, do you have another support person?



2.2 COVID-19 impact on access to education and employment

The measures put in place due to the pandemic have greatly changed the way people study and work. With our survey, we wanted to uncover the ways in which COVID-19 has impacted autistic people and their families access to education and employment.

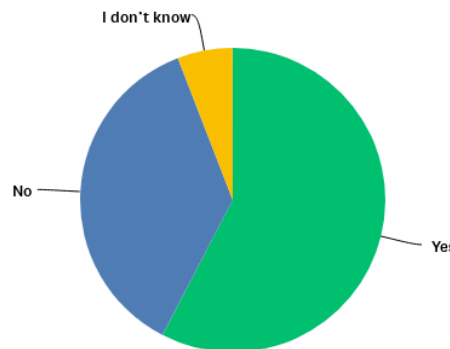
We found that before the onset of COVID-19:

- 28% of respondents indicated that they usually work.
- 18% of respondents indicated that their autistic relative goes to primary school.
- 9% that their autistic relatives are in pre-school education.
- 11% of respondents indicated that they or their autistic relative go to secondary school.
- 25% were not in education nor in training.
- 5% were in training.
- 3% of respondents were attending university.

From respondents that self-identified as autistic, 44% said that they are usually working. This number is not necessarily representative of the experience of the majority of autistic people in Europe. Figures from the UK show that only 16% of autistic people are in full time employment. This number has not changed over the last 10 years⁴⁹. At the moment, there are no official statistics on the issue across Europe, but estimates see up to 90% of autistic people are unemployed.

The survey found that just over half of respondents (57%) were able to continue studying or working from home during the pandemic.

Q22 Is it possible for you to continue studying/working from home during the Covid-19 spread?



ANSWER CHOICES	RESPONSES	
Yes	57.62%	847
No	36.53%	537
I don't know	5.85%	86
TOTAL		1,470

2.2.1 COVID-19 impact on access to education

The lockdown due to the COVID pandemic saw a major shift in the delivery of education and other learning practices. With primary, secondary and tertiary education establishments closed, teaching duties had to be taken on by parents or primary caregivers or for those families who could afford it, private tutors. In the survey, one autistic parent from **Italy** said "With three children, two autistic, without rehabilitation centre and school, and being the only caregiver of my children, the difficulties are countless."

The loss of the social aspect that in-person school and class environment provides, has been detrimental to autistic learners social learning and development. One study showed that "online learning environments, [...] do not provide a suitable educational environment for most children with special needs such as [learners with] ASD"⁵⁰. Moreover, the transition from the new normal "home-schooling" back to formal school settings will also be challenging for many autistic learners⁵¹ as their routines are disrupted and they are forced to re-adjust to new environments with more stimuli.

With the transition to online and at home learning, parents of autistic children reflect on the struggles their children face. A parent of an autistic child from the **UK** commented, "My almost 5-year-old daughter attends a private preschool dedicated to autistic children. During the lockdown, they are still providing their services online. It will never be enough though."

Another point of view was shared by a parent of autistic child from the **UK**, "I'm an autistic mother who is studying at a university. Trying to teach my child while preparing for exams has

been fairly brutal. I could in theory ask for support, but in that case I would have to identify myself as autistic and thereby invite scrutiny and misunderstandings. I would really have appreciated a bit of help, in an ideal world where [autistic people] did not have to deal with discrimination.”

According to a study from **Italy**, parents of autistic children faced severe problems balancing work and home life. Approximately one out of four parents had to stop working due the emergency outbreak (26.1% of mothers and 27.5% of fathers). The large majority of them evaluated the current period of change and restrictions as challenging or very challenging (93.9%) and more challenging than before the emergency outbreak (77%)⁵².

Some parents from **Italy** stressed that their work from home commitments, coupled with the constant care of their autistic children has put a severe strain on their mental health and marriages⁵³. This was exacerbated by those parents who lived in urban setting as opposed to those who lived in rural settings.

Norway's inclusive school system was not severely affected and continued without very many disruptions. **Italy** has a very inclusive school system, but in many cases, the COVID-19 lockdown made remote learning for autistic people close to impossible. In **Belgium**, in-person learning did not take place for special needs children before the summer break.

Despite the severe impact in **Spain** and **Portugal**, a lot remained vague and unclear regarding the education of autistic children after the summer break. A report from Autismo Espana highlights that families have reported significant difficulties in the continuation of their autistic children's education during lockdown. In many cases they have indicated that autistic learners needs have not been taken into account when adapting to remote education and that their autistic children have not had any kind of support since the interruption of face-to-face attendance at schools.⁵⁴

Looking more in-depth at the example of **Ireland**, a new summer provision was created for 2020 to prevent regression among children with special needs. The Education Ministry of Ireland expanded their summer programme offered to autistic children with complex support needs⁵⁵. The programme offered additional education over four weeks at the end of the school year. According to AE member from Ireland, AsIam 86% of autistic children attend mainstream school (of this 21% are in a special autism class within the school) and 14% attend special school. During COVID-19, remote learning was being provided by teachers however the evidence suggests this form of learning did not work for many of our young people and, in some instances, wasn't provided by teachers/schools in a diligent manner, or at all.

AsIam survey released in September 2020 indicated that:

- 32% autistic learners had not engaged in learning since the lockdown began.
- 53% did not benefit from the Summer Provision Programme (which provided in-school or home-based tuition for 40 hours during the Summer).
- 42% did not receive support from school during the lockdown.
- 68% were anxious about the return to school.
- 68% had experienced a greater number of overloads and meltdowns during the crisis⁵⁶.

As students returned to classrooms in September 2020, AsIam relayed concerns around two principal areas:

"1) That the very important safety measures include reasonable accommodations for autistic young people who need them. For example, exemptions for young people who cannot wear face coverings, ability to use "chewies" and ear defenders from home, access to special teaching time and movement breaks, the ability for those in special classes to be included in mainstream classes where appropriate as normal (even if the young person is then in two "pods"). It appeared that there was lack of guidelines on many issues and on others there is guidelines but schools are uncertain or don't know how to implement them

2) That special education resources (such as teachers providing one to one support within school) could be used to deal with the need for smaller classes or substitution. The level of SNA (classroom assistant) allocations appeared to be the same as the previous year despite evidence of significant increased need in the population. We are concerned that young people who are overwhelmed, distressed or who experience meltdowns will not get the support they need or may even be dealt with in a disciplinary manner if appropriate resources are absent."

These concerns had not been adequately addressed by the end of 2020. ⁵⁷

More rarely, some parents found that the school closures lessened pressures and brought about ease as in-person learning can be difficult for autistic children. A relative of an autistic person from the **Netherlands** shared, "For my 14-year-old daughter, who only goes to school for a very limited amount of time due to over-stimulation, it is nicer not to have to go to school at all."

Autistic respondents from our survey expressed concern for their future. An autistic student from the **Netherlands** revealed, "I am not sure when I will be able to finish my studies and how I will proceed with looking for a job or PhD." The state of the job market worried an autistic person from **Germany**, "I recently completed my studies (physics), the career start as an [autistic person] is now twice as difficult."

2.2.2 COVID-19 impact on access to employment for autistic people and relatives

The COVID-19 pandemic has caused a surge in unemployment across the globe and autistic people have been disproportionately affected. Autistic people already face many barriers to employment and the pandemic has worsened the situation, causing many to lose their jobs or other working opportunities, and there is reason to expect that "some neurodivergent employees will be particularly exposed to the deep downturn in the labour market."⁵⁸

Autism-Europe's survey looked at the picture across Europe with regards to access to employment for autistic people and their families. Training and employment programmes such as internships are vital for autistic people to gain skills necessary for the working world. A relative of autistic person from **Italy** explains, "I am the father of a 32-year-old boy with

Asperger's Syndrome; social services have not had any contact with him since the beginning of the emergency; he had to interrupt an internship in a public library and is currently studying to prepare for possible future competitions." That's particularly challenging for autistic people as many of them benefit from learning soft skills through job placements and internship. Indeed, they already face substantial obstacles to making a successful transition from school to the workplace, and may need extra support during the transition.

COVID-19 also brought a shift in culture concerning employment and working practices, as face-to-face contact was restricted. Workers across Europe have had to embrace working from home where possible. While home office might work well for some, it is not always suitable for everyone. A relative of an autistic person in **France** disclosed that, "Remote working is not easy for autistic people who have hypersensitivity". Another autistic person from **France** commented, "Teleworking is particularly difficult for people with autism in employment because of the increased difficulty in social interaction over the telephone."

Experts emphasized that working at home has inevitably led to an increase in the use of alternative communication systems. However, using new modes of communication could be a potential challenge for autistic employees. Organisations need to be proactive in supporting the transition to online platforms and regularly schedule check-ins between line managers and their autistic employees.⁵⁹

For those who have jobs, changes to working patterns and communication may also adversely affect their experience at work. Regular meetings to keep track of progress, establish goals and respond to any potential challenges early are essential for autistic employees. Managers will need to make alternative arrangements to stay up to date with employees.

However, some felt the need to point to a better quality of life because their situation was not optimal with regard to education, employment and general social communication before the outbreak of COVID-19⁶⁰. Indeed, working and studying from home has sometimes proven easier for some autistic people. For example, an autistic respondent from **France** highlights that he has been quite productive during this time "It's been 2 months that I've been teleworking 100%, and it's going very well. The management even acknowledged that they didn't expect such a level of activity from their employees (including the large non-autistic majority). I'm finally going to be able to negotiate a bit more than the 2 days per week currently tolerated."

The company Auticon who employs a majority of autistic IT specialists, indicated that "People with autism often prefer to communicate via a precise text or email; verbal or face-to-face conversations, which involve body language and emotional expression, can be more subjective and challenging. Some of our team members who aren't comfortable making eye contact in person found that they were able to do so on Zoom calls, giving them a new way to connect."⁶¹

2.3 Financial impact of COVID-19 on autistic people and relatives

The spread of COVID-19 has impacted the financial situation of many, including people with disabilities. Autistic people and their relatives reported very different individual reasons for changes to their financial situation. Some respondents who took our survey experienced loss of work, reductions in working hours, and forced unpaid leave.

Our survey took samples from people on their own experiences from around Europe. An autistic person from the **Netherlands** commented, "Due to COVID I had to return earlier from

my internship abroad. Financially this cost me an extra flight ticket (approximately 600 euro) from Canada back to the Netherlands.”

More generally, a parent of autistic child from the **UK** knew that, “No official support for autistic person or family. [...] This has led to a greater burden on the family but there is no financial or any other help available.”

In **Malta**, one respondent noted that, “Financial support for parents and some time off work should be offered since autistic children can’t attend school and parents have to be with the child 24/7”.

Autistic people and their families require different types of support and the results of our survey show that COVID-19 has led to a significant need for more financial aid.

Our survey found that:

- Just under half (48%) of the 1435 respondents said the financial situation of respondents had been affected.
- Over one third of autistic respondents had been affected financially.
- The spread of COVID-19 affected autistic families’ finances in a variety of ways.

Our survey also looked at the reason for these effects:

- Over a quarter (28%) of respondents said they were unable to work from home.
- More than half (54%) had other unstipulated reasons as to why their financial situation was affected.
- 10% had to take a leave from work to care for a relative
- 7% were laid off from work.

For autistic respondents only:

- A quarter of autistic respondents (25%) were affected financially because they could not work from home.
- Two-thirds (64%) of autistic respondents had other unstipulated reasons
- 10% were laid off from work.

It should be noted that it is a snapshot of the situation in the first half of 2020, but that the situation might have worsened considerably since then.

2.4 Recommendations

- I. Fostering the availability and continuity of community-based support and autism-specific services

Many autistic people rely on their relatives for support, due to lack of available services. It is essential to ensure that the provision of community-based support services is enhanced

through adequate investment, including EU funds. The provision of community-based services should be continuously maintained through adequate funding, including the European Solidarity Fund, so that services can be provided in safe conditions.

Supporting availability of remote professional advice service for autistic people as well as relatives and carers also proves helpful, along with ensuring that autistic children and adults have access to support that is tailored to their needs and delivered by individuals that they know. It has been demonstrated that outcomes of telehealth assessment and interventions for autistic people were broadly comparable to face-to-face consultations and superior to comparison groups who received no consultation at all. They may be particularly useful for people who live in areas where support services are scarce. To ensure that telehealth fulfils its future positive potential to improve the quality of healthcare for autistic people, it must be implemented in an accessible way.⁶² In particular, it should be taken into account that some autistic people experience anxiety on voice or video calls, and would rather communicate via chat (i.e. text-based messaging) and in any case prefer in person contact.

II. Safeguarding access to education and employment

Educational needs of autistic learners should be adequately addressed during this public health crisis, whatever their type of schooling. It is thus key to address the digital gap in education and provide reasonable accommodation for learning and access whether online or in person. Families should be provided with guidance and distance support to assist in setting up equipment and to support the education program of their children with disabilities. Some schools have refused to allow young autistic people to come back for risk reasons, even when schools have re-opened. Others have not put individual plans in place that autistic children need in order to cope with massive changes to their routines. It is imperative that enough resources are allocated to support autistic children, and that existing resources are not diverted to COVID-19 preventive measures.

Autistic people and their families should be one of the targets of recovery plans throughout the EU, given that they are more likely to experience unemployment and poverty. We also recommend providing financial support, such as tax credits to ensure to employers, so that they can provide the necessary equipment and support required for teleworking when applicable. Employers should also pay particular attention to support autistic workers to prepare for the transition from office-based environments to communicating using online platforms. It is important to schedule regular check-ins between line managers and autistic employees to support the transition to working remotely.

III. Protecting decent income for autistic people and their families

Autistic people are less likely than others to be employed and when employed, they are more likely to be employed in low-paid positions. As a consequence, they have less access to social insurance based on employment which decreases their economic resilience in case of crisis. They also often rely on family support, that might also be impacted by COVID-19 measures, lowering the overall income of the whole household.

Thus, we recommend members states to provide financial aid for persons with disabilities without any income, while increasing existing disability entitlements, including advancing payments to cover extra costs as well as automatically extending any soon-to-expire disability related entitlements. It is also key to ensure that financial assistance programmes for persons

who stop working are in place so that they can continue to support their family member(s) with disabilities.

3. Access to healthcare and impact on health for autistic people and relatives

The pandemic tested the robustness of national healthcare systems and highlighted key structural challenges that arise in the face of emergency. The inadequacy of the provision for healthcare in European countries was highlighted by EAPN's impact study on COVID-19 from July 2020⁶³.

Nearly 9 out of 10 networks stated that their healthcare system was "problematic for certain groups or regions" (**Austria, Belgium, Czechia, Finland, France, Germany, Greece, Iceland, Italy, Lithuania, Norway, Portugal, Slovenia, Spain** and the **United Kingdom**) or was "problematic in general" (**Hungary, Ireland, Poland and Serbia**). Only **Croatia, Denmark** and **The Netherlands** reported that their healthcare performed well.

Generally, autistic people face a number of healthcare barriers. A 2017 study found that "[t]op barriers were fear or anxiety, not being able to process information fast enough to participate in real-time discussions about healthcare, concern about cost, facilities causing sensory issues, and difficulty communicating with providers"⁶⁴.

3.1 COVID-19 impact on access to healthcare

We wanted to know the impact that the COVID-19 pandemic has had on healthcare for autistic people and their relatives. People with intellectual and developmental disabilities, including autistic people, have a higher prevalence of multiple co-occurring conditions which have been associated with poorer COVID-19 outcomes⁶⁵. To add on to this, care networks and resources for autistic people have been threatened due to the increase in medical demands caused by COVID-19⁶⁶. Some of autistic people also face an elevated risk of infection due to a reliance on hands-on assistance from other people, which makes physical distancing challenging.

We asked autistic respondents whether they considered themselves at high-risk during the COVID-19 pandemic:

- Just over a quarter (26%) of respondents said they were in the high-risk group.
- Less than two thirds (63%) of respondents said they were NOT in the high-risk.
- The rest (11%) said they did not know.

Our survey asked respondents around Europe about their experience of accessing healthcare during the spread of COVID-19. One autistic person from **France** found that, "We [autistic people] suffer from medical isolation." Also a parent of autistic child from the **UK** commented, "My daughter is struggling with the fact she cannot go outside as she has other health problems and has to shield until the government says it's ok."

A number of COVID-19 helplines were created across Europe, and we made it a goal of our survey to assess who organised these helplines but also, to what extent they were helpful and accessible to the autism community.

The survey also looked at how autistic people and their families received medical treatment for COVID-19 and whether they had any problems communicating with the healthcare professionals responsible for their treatment.

We also wanted to know about the hospitalisation of autistic people for suspected COVID-19 cases and if any reasonable adjustments were made. Lastly, we looked at the mental health of autistic people during the COVID-19 spread. We asked respondents if their mental health was affected and to what extent.

3.1.1 Access to COVID-19 Helplines

We asked respondents about their awareness of the existence of helplines to offer support during the spread of COVID-19. We found that a majority of respondents were not aware of helplines.

Our survey found that:

- 56% of the respondents of this question are not aware of helplines that help autistic people and their relatives where they live.
- 37% of respondents were aware of helplines.
- Around (7%) did not know.

For respondents who identified as autistic:

- Two third of respondents are not aware of helplines that help autistic people and their relatives where they live.

Of the people that are aware of helplines:

- Almost half (48%) indicated that they are a private initiative.
- More than one quarter (28%) know that they are a public initiative.

We wanted to know what sort of experience users had with the helplines, and what difficulties they encountered if they had a negative experience with them. A total of 63% of respondents reported a negative experience with the helplines and indicated that the helplines didn't match their needs.

Many autistic people find communicating via telephone difficult. An autistic respondent who became infected with COVID-19 found using phone services when in distress impossible. At that time, phone services were the only type of support offered and they could not access it.

In **France**, the government established a nationwide helpline for autistic people which was announced by President Macron on 2 April 2020 on the occasion of World Autism Awareness Day⁶⁷. 41% of all the respondents from France knew of such a helpline.

A relative of an autistic person from Germany recounted that, "In Germany a hotline phone number was announced at the end of May. I am active within the self-help sector so I phoned this number to make an inquiry about alternative ways of getting in touch for people on the autism spectrum who experience difficulties carrying out phone calls. The person on the other end of the line was not officially informed about this barrier. I asked for an email address that questions or comments could be directed to and I was provided with one. I will post the address in Autism and Aspergers Facebook groups, so that autistic people and their relatives are aware. (...)"

3.1.2 Access to testing and first aid responders

We wanted to know the experience of autistic people and their families regarding getting tested for COVID-19. We asked respondents if they received adequate information on the testing process and if there were any reasonable adjustments made for them in order to be tested appropriately.

By June 2020, only a small minority of respondents (6%) had been tested for COVID-19, amongst them 72% received adequate and accessible information about getting tested. However, it should be noted that adequate and accessible information was mainly provided by non-governmental organisations. One relative of an autistic person from **France** pointed out: "Only the association Santé BD has issued a dedicated document [on COVID-19 in Easy to Read] (...)."

While most respondents reported to have had access to adequate and accessible information about testing, few had reasonable accommodation during testing. We know that there was not much awareness on reasonable adjustment for autistic people during testing for COVID-19.

Our survey found that from the respondents who got tested for COVID-19:

- 53% of respondents were not offered reasonable adjustments for autism-specific needs during that testing.
- 25% of respondents were offered reasonable adjustments for testing COVID-19
- 22% did not know of any reasonable adjustments.

For many autistic people and their families, there was a concern due to the invasiveness of the COVID-19 testing which is done with a swab to the inside of the throat and nose. This type of procedure could cause a severe reaction for some autistic people.

A relative of an autistic person from Malta recounted, "I wanted to get my son tested but there was no way to get this done without sedating him. This was not provided by the doctors and it was such a traumatic experience. He ended up not doing the test after 1.5 hrs of trying and quarantined instead for 2 weeks." This example also showed quite drastically that the lack of reasonable accommodation has a direct effect on autistic people's mental health.

Our survey also found that the majority of respondents experienced difficulties when accessing healthcare professionals and first aid responders due to the inaccessibility of the process.

Respondents reported that:

- 44% experienced difficulties in contacting healthcare professionals or first aid responders.
- 54% said they did not experience difficulties.
- The rest (2%) did not know.

From respondents who experienced difficulties contacting healthcare professionals/first aid responders, over two thirds (67%) experienced problems due to the inaccessibility of the process e.g. contact made via phone.

Some respondents expressed a wish to be tested but were not given a test. For example, a relative of an autistic person from the **Netherlands** shared, "My husband, son and I want to be tested so we can let our son come home." A relative of an autistic person from **Spain** pointed out, "I've been sick and after 6 weeks I've been labelled a suspect case for COVID-

19, but I've never been tested, not even at first when I reported living with an autistic family member."

An autistic person from the **UK** said, "The lack of tests being done to detect the illness or if one is immune is heavy. I have what is probably a simple throat infection but my doctor isn't even allowed to check or look at it any more. She has to say to anyone who comes in with whatever cold, hay fever... that it has to be regarded as COVID-19. Okay, she did say since I have no real other symptoms of it (in her opinion) that it probably isn't but now the idea (COVID-19) has been planted in my mind and made me scared (...)"

One **relative of an autistic person from Ukraine** recounted, "I'm the mother of an autistic child, with multiple health issues. I got pneumonia together with my youngest daughter. I received outpatient treatment, no one checked for the virus and a nurse was hired for the injection. The treatment was at my own cost, I myself had to go get the medicines with no help in the city even if you have a temperature of 40C."

3.1.4 Hospitalisation and triage

We also wanted to know about the hospitalisation of autistic people who suspected they had COVID-19 and if any reasonable adjustments were made.

By June 2020, only a very small sample of respondents (1%) were hospitalised and, amongst them, only 13% knew of reasonable adjustments.

They indicated that the following adjustments were available:

- 27% of respondents said Sensory adjustments were available.
- 27% said accessible communication was available.
- 36% indicated allowing the presence of a support person.
- Only (9%) said there were other forms of reasonable adjustment.
- Around 18% of respondents said they do not know.

Some respondents reported that were hospitalized for other health issues and were insufficiently tested or treated for COVID-19 like this autistic woman from **Switzerland** hospitalized with acute abdominal cramps, "On the spot, the nursing staff took my temperature and, worried, they did not know what to do: whether to put me in separate room, because I could have COVID-19, or not. I was in Emergency Room for six hours, the doctors deliberated my case, and in the end I was not tested. During the whole process, I was mute, paralysed. So I wonder if there is a way to communicate with medical professionals about everyone's situation without adding to the medical professions workload."

An autistic person from the **UK** feared hospitalisation and said, "The big thing is the fear of being alone in the hospital without my partner being allowed to come and see me or me to visit him if he is in hospital. He is the only person I have as family and who is someone who understands my needs or on who I can rely and can get me calm."

It has become evident that there are not enough reasonable adjustments for autism-specific needs during hospitalization. One autistic person from Germany demanded, "It is imperative to train the clinic staff in dealing with autistic patients." Respondents also feared mistreatment. An autistic parent from France commented, "I have concerns in case my autistic son has to be

hospitalized and then managing the follow-up of this care but also who will care for my autistic son if I need to be hospitalized.”

COVID-19 has raised the issue of triage protocols, which is the assignment of degrees of urgency to wounds or illnesses to decide the order of treatment of a large number of patients or casualties.

When it comes to treatment and hospitalisation for COVID-19 there is concerns over the deprioritisation of autistic people. The media reported existing cases where families of autistic people were told that their relatives would not be treated if there were not enough intensive care units like in **Belgium**⁶⁸.

In fact, several European countries have triage protocols which includes considering the ‘functional status’ and/or using ‘frailty assessments’ including the UK, Republic of Ireland, France, Netherlands, Italy, Belgium, Austria and Germany. These assessments were originally designed with reference to elderly populations, to indicate individuals with very poor prognosis for recovery from their current illness. Despite this, concerns have been raised over ambiguity in some current guidance on the application and interpretation of frailty assessments, whereby the support needs of some autistic people may be conflated with ‘frailty’. As an example, frailty assessments refer to an individual’s dependency on others for support with daily care needs and personal care. Similarly, the assessment of functional status often includes quality of life outcomes, which are known to vary considerably between autistic people, but may also be broadly underestimated due to a reliance on ‘neurotypical’ indicators of wellbeing.⁶⁹

In light of these concerns - and in response to challenges by advocacy groups, such as the National Autistic Society, and a proposed judicial review - on 25th March 2020, the UK National Institute of Health and Care Excellence amended their recommendations to specify that ‘frailty assessments’ should not include young autistic people. Similar clarifications have been published in the Netherlands but not all across Europe.

Moreover, the Working Group of Bioethics of the Spanish Society of Intensive, Critical Medicine and Coronary Units published triage guidance that explicitly specifies “severe baseline cognitive impairment” as exclusion criteria for ICU care. Similar guidance from the COVID-19 Paris region recommends attention to a patient’s previous condition, including neurocognitive status – mildly or severely impaired cognitive functions

Many autistic people were worried about the triage issue. A middle-aged autistic man from **Switzerland** pointed out the concern for priority treatment in hospital, “I am afraid of the usual misunderstandings in communication with doctors, should I have to go to hospital because of COVID-19. I am also afraid that as a mentally impaired recipient of a disability pension, during possible triage I will be rated worse than those capable of working of the same age (ableism) should there be shortages of medical care.”

3.1.5 Grave concerns over the treatment of people living in institutions

Michelle Bachelet, United Nations High Commissioner for Human Rights, stressed: “Persons with disabilities face even greater threats in institutions, as care facilities have recorded high fatality rates from COVID-19 and horrific reports have emerged of neglect during the pandemic. Now is the time to support community-based arrangements, wherever possible.”⁷⁰

Early in the COVID-19 pandemic, many regions with testing shortages initially prioritised essential workers and those hospitalised with suspected COVID symptoms. In the Republic of Ireland and UK, care home residents (including asymptomatic cases) were not officially added to the list for priority access to COVID testing until 17th and 29th April 2020, respectively –at least two months after the first confirmed COVID-19 cases in these regions (27,34). Similarly, other countries that did not initially do so, now identify individuals in residential care settings as priority for testing-including the Netherlands and Belgium. By September 2020, no additional published guidance, nor strategies, for prioritising autistic people living in 'high risk' settings for access to testing across have been identified.⁷¹

At least 40-60% of confirmed COVID-19 deaths across European countries with community transmission are believed to have occurred in long-term care facilities, a proportion of which offer residential care for autistic people⁷². Approximately 5-25% of autistic people live in residential care and up to a further 27% in supported accommodation. It is a result of the "the characteristics of these settings (i.e., shared bedrooms, bathrooms, and common space) and of their residents (e.g., with medical comorbidities, cognitive impairment, or dysregulated behaviour)" as well as "staff working across the facilities [might have] also accelerated the spread."⁷³ While quarantine against COVID-19 is necessary, it should not be used as a pretext for further institutionalisation in residential care homes.

3.2 COVID-19 impact on mental health of autistic people and relatives

This section looks at how the mental health of autistic people was impacted during the COVID-19 pandemic. Statistics show that autistic people are more likely to experience mental health problems than the general population. Autistic people are also at a greater risk of suicide than non-autistic people⁷⁴. In general, events such as pandemics have a negative impact on public mental health, but autistic people are particularly affected.

A study conducted in the UK shows that 9 out of 10 autistic people worried about their mental health during COVID-19 lockdown; 85% said their anxiety levels got worse⁷⁵. Challenges associated with COVID-19 are greater for autistic adults, who are *"already more likely than non-autistic adults to face loneliness and social isolation, and [...] a well-established association between social isolation and mental illness, any reduction in access to our often-minimal support networks may have significant mental health consequences"*⁷⁶. We note with concern that the mental health of autistic people and their relatives, especially parents⁷⁷.

According to our survey, for 42% of the respondents their mental health had worsened due to the lack of necessary support. For 38% of the respondents their mental health had deteriorated because they could not use their usual coping strategies. Loss of income as a reason for mental health deterioration was indicated by more than one fifth (22%) of respondents. A total of 13% of respondents indicated other reasons for mental health deterioration.

The COVID-19 crisis has shown how autistic people's needs are simply not being met during this time. Small changes could have been instrumental. In one study, it was shown that some form of daily exercise could mitigate problem behaviours generated by the anxiety of the COVID-19 pandemic for autistic children⁷⁸. AE member AsIam also found high anxiety levels in autistic people during COVID-19 in their Ireland-wide survey⁷⁹. Similar reports have been made across various countries both for children and adults.^{80 81}

Our survey found that from 1426 respondents:

- 19% of the respondents found their mental health greatly affected.
- And 33% at least fairly affected.

For respondents who self-identified as 'autistic':

- 28% of autistic respondents found their mental health greatly affected.
- 34% of autistic respondents found their health fairly affected.
- while 24% were not affected.

We asked why the mental health of autistic people was affected. Respondents highlighted more than one reason:

- 71% of respondents said due to the disruption of their routine.
- 53% of the respondents said social isolation and lack of social interaction.
- 49% of the respondents said they worried for themselves, their family and friends.
- Around 44% said they had difficulty sleeping which affected their mental health.
- Similarly, 43% said they had lack of necessary support which affected their mental health.
- 41% said they had the stress of caring for dependent relatives which affected their mental health.
- 38% said they found it impossible to use their usual coping strategies.
- 21% said loss of income affected their mental health.
- Around 12% said they had other reasons as to why their mental health was affected.
- The rest (1%) said they did not know how their mental health was affected.

For those who self-identified as 'autistic':

- 82% of autistic respondents saw their mental health greatly or fairly affected because of the disruption of routine.
- 57% of autistic respondents saw their mental health affected for worrying about themselves, family or friends.
 - 53% of respondents saw their mental health affected because of social isolation and lack of social interaction.
 - 52% because of the impossibility to use coping strategies.

Despite the obvious restrictions to daily life, the changes in interactions have sometime brought a calmer approach to life that some autistic people prefer. An autistic person from **Germany** said, "My mental health situation has improved due to the COVID-19 crisis. People keep their distance, you don't have to shake hands any more, it is emptier on the streets, and forced

appointments that cause me stress and fear are cancelled. I put less pressure on myself because a lot of things are not working right now.”

However, overall fear and anxiety were the norm from the onset of COVID-19. With alarming news reports and snooping on neighbours’ whereabouts during the lockdown contributing to a tense climate in society. This distressing climate spread further anxiety in an already greatly affected group in society. In the **UK**, one respondent from our survey was worried about leaving the house during the lockdown in case a neighbour told the police, even if their reason for going outside was legitimate.

The unpredictability of the COVID-19 spread and accompanying government policies led to an increase in anxiety. Some autistic people are also worried about the long term effects of COVID-19 on society and are unsure about what will happen in the future. An autistic person from **Switzerland** commented, “In Switzerland, relative lockdown does not cause me anxiety, but relaxation of lockdown does, particularly with regard to public transport and working conditions (in particular break times)”. A female autistic person from **Spain** explained: “My husband was admitted to hospital for two days. He turned out to have viral pneumonia. But they also tested him for COVID19, which was negative. (...) In a fortnight, they'll repeat the COVID-19 test. Please, give us the doctors’ report. Don't leave people, patients, days in and days out, in our case for 15 days, without knowing anything, but by two days please have the test results. Uncertainty creates a lot of anxiety.”

From our survey, 44% of respondents reported that changes to their mental health showed up in the form of difficulty sleeping. 41% respondents saw their mental health affected by stress from caring for a dependent.

One female autistic person from **Netherlands** commented, “My husband and I have been in quarantine for 4 weeks because of suspicion of corona (by general practitioner). No fever, but severe symptoms (e.g. coughing and short breath) that's why no test. The uncertainty in combination with the loss of all structure and predictability made it extra difficult. I have panic attacks and still sleep badly. I prefer to stay working at home and stay indoors until there is a vaccine because I notice that people don't play by the rules, for example in shops, and I have a lot of stress from that.”

An autistic person from **France** treated for depression explained, “I have telephone appointments once a week with my psychologist, which is more often than before lock down. It has been necessary for me. I have had an increase in dark thoughts, stress and poor sleep. No phone calls with my colleagues, just emails. I'm scared of telephones.”

In some cases, mental health deterioration correlated with suicidal thoughts. An autistic person from **France** commented “suicide seems to me to be the only way out of all this”. Another autistic person from Netherlands says “No good help, loneliness, want euthanasia”.

3.3 Recommendations

I. Ensuring access to information, COVID-19 testing and screening

Information about testing should be made available in accessible formats for autistic people by public authorities, via publicly-funded helplines and other accessible means.

Autistic people should be considered for priority access to testing and screening (even when apparently asymptomatic) in cases of insufficient testing capacity, in particular if living in 'high risk' settings for disease transmission like residential care and supported accommodation or if they have co-occurring medical conditions. Carers should also be prioritised as they provide essential support.

Accessibility of testing procedures should be enhanced by providing preparatory materials to demonstrate the procedure in advance and considering reasonable accommodation (such as quiet waiting areas). Alternative test procedures should also be offered (e.g. saliva vs. swab testing) to take into account the sensory needs of autistic people.

II. Preventing any kind of discrimination in relation to access to treatment (notably through discriminatory triage protocols)

Autistic people should not be subjected to discriminatory assessments preventing them from accessing lifesaving treatments. Intensive care unit triage protocols across Europe require urgent review and update, in consultation with stakeholders (e.g. intensive care and autism communities), in order to design a European strategy on the fair allocation of resources in public health emergencies that does not discriminate against any individual or groups of individuals on the grounds of pre-existing characteristics or difficulties.

III. Providing the necessary accommodations and support to facilitate access to the same standard of care as other individuals.

Healthcare professionals and first aid responders should be trained to provide autism-specific reasonable accommodation, including provision of accessible and easy-read healthcare information and communication toolkits.

Introducing mandatory consultation with autistic people so they can provide prior information about themselves, their preferences and healthcare needs, in case they become unable to communicate on admission to hospital.

Publishing regularly updated formal guidelines and training for all healthcare providers, co-developed with autistic people to make sure their needs are addressed.

Introducing flexibility to some regulations (where appropriate), such as allowing a caregiver or support person to accompany the individual into hospital.

IV. Addressing mental healthcare needs

Prevent abrupt interruptions to standard health and social care, including mental health interventions. Ensure the availability of access to personalised, evidenced, community-based and affordable mental health services, such as autism adapted counselling or low-level psychological therapy support (services) for mental health dedicated to autistic people and their relatives.

Many autistic individuals that did not need regular support before, have reported that they now need it due to COVID-19, but they are not aware of how to access relevant services. Autistic people indicate the need for continued support, even if this is online, but face-to-face support is generally preferred when possible.

Conclusion

The results of our survey on the impact of COVID-19 have highlighted the need to pay specific attention to the challenges of autistic people and their families, as they have been particularly affected by the repercussions of the pandemic.

Autistic people have faced additional barriers and discrimination with regards to access to public information, necessary support, education and employment since the beginning of the epidemic. Even more worrying, discriminatory practices have meant that they have been more prone to be denied life-saving treatments, not least for people living in institutions.

It is thus essential that reasonable adjustments are provided to take into account the challenges that they face. To avoid confusion and anxiety, autistic people should be well-informed about the COVID-19 situation, information should be communicated in a clear manner through accessible formats. Autistic people and their families are significantly affected when they cannot access the essential food, products and medication they require. Therefore, specific measures should be in place designed to help autistic people easily receive the essentials they require during lockdowns. Our survey has showed that autistic people and their families require special flexibility regarding the lockdown measures, in particular when it comes to the limitation on circulation and the safety measures, such as mask wearing.

Autistic people's usual support services have been heavily disrupted due to many contributing COVID-19 factors. And our survey illustrates the over-reliance on the support provided by family carers who also find themselves in vulnerable positions, due to health, or socio-economic factors. Given this, it is imperative that community-based support services are further developed and continuously provided in order to support autistic people. Indeed, it is more evident than ever that institutions are not an acceptable solution, during the pandemic they have often become hotbeds for infection and the isolation measures have led to many personal tragedies.

The pandemic has mainstreamed studying and working remotely. These practices may have some positive aspects for autistic people. However, it turned out that in most instances remote learning has only widened the gap between autistic learners and their counterparts due to a lack of adequate support. Parents of autistic children thus reported difficulty balancing work and home-life since the transition to at-home learning. Many autistic people and their relatives have faced job loss and extreme changes to their working patterns and communication. Providing decent income to autistic people and their families, will alleviate some of the stressors and challenges caused by the pandemic.

When it comes to the health and healthcare of autistic people, necessary support in relation to COVID-19 testing, accessing treatment and mental health care should be addressed in order to avoid discrimination and ensure fair access. Discriminatory practices, such as triage protocols, should be amended.

A coordinated effort is required to help address the many complex challenges that autistic people and their families continue to face as a result of COVID-19. By taking the time to more fully understand the situation of autistic people and their families, we can better help create innovative solutions to meet their needs.

For the post-COVID-19 society, we also need to reflect on what we have learned during the pandemic and see how we can build on new practices that autistic people may benefit from, such as the remote-nature of employment or e-health services.

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