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THE IMPACT OF COVID-19 PANDEMIC ON SERVICES FOR PERSONS WITH NEURODEVELOPMENTAL DISORDERS: AN ITALIAN CASE

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Abstract. *The COVID-19 pandemic has had severe effects on social health services worldwide. Many people with neurodevelopmental disorders have lost their professional support. The interruption of supportive assistance has been devastating since it has negatively affected their continuity of care as well as their social inclusion and socialization. This paper aims to illustrate the impact of the COVID-19 on an Italian Public Social Health System Services for people with disability. It highlights and discusses the strategy that was adopted in order to ensure the continuity of care assistance provided to the service clients as the organization of emergency remote support and individual support services for independent living. An exploratory study was conducted involving the entire population of people with neurodevelopmental disorders (n=333) included in the Disability System Services of Udine (Friuli Venezia Giulia Region, North-East Italy) to analyze the main repercussions occurred on the organization of services during the pandemic period. A comparative analysis of the number of persons enrolled in the different types of support services and of individuals' support needs, evaluated throught the Support intensity scale (SIS), pre- and post-pandemic crisis (January 2020 – January 2021) was conducted. The data shows that, despite the enormous difficulties, the adopted strategy has succeeded in limiting the risks of isolation and the negative impact on individual interventions, and opened the way to new alternative and innovative strategies for planning and implementing support.*
Keywords**:** *covid-19, neurodevelopmental disorders, intellectual disability, autism, social-health services, support needs.*

Introduction

People with neurodevelopmental disorders (ND) represent one of the groups most vulnerable to COVID-19 on account of their associated pre-existing health conditions, mental disorders, and social disadvantage (Emerson & Hatton, 2008; Buonaguro & Bertelli, 2021). Cognitive and adaptive behavioral impairment also pose barriers in understanding information and implementing basic measures for reducing the risk of contagion (Courtenay & Perera, 2020). During the pandemic

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period, important obstacles in ensuring the continuity of interventions emerged because of serious disruptions to the services they rely on (WHO, 2020).

Many people with disabilities have temporarily lost access to qualified support interventions, and currently face uncertain situations regarding the return of baseline services (Constantino, Sahin, Piven, Rodgers, & Tschida, 2020). The day care centers (DCC) that previously defined the weekly agenda of many people with ND were suddenly faced with the need to radically change, if not close down entirely. The resulting service interruptions and the enforced confinement of these people, as everyone else, to their own homes threatened to drastically slow down processes aimed at increasing their social inclusion and reducing their sense of isolation (den Houting, 2020).

Previous studies, conducted before the COVID-19 pandemic, indicated that drastic changes in daily routines (e.g. the interruption of activities, access to places, and interpersonal relationships), forced coexistence, loss of support, and perception of loneliness, can result in regression, loss of ability, and psychological and physical distress in people with ND (Hedley, Uljarević, Wilmot, Richdale, & Dissanayake, 2018; Wormald, McCallion, & McCarron, 2019). In people with ND who have severe cognitive and communicative difficulties, psychological distress is very often associated with significant behavioral changes and the aggravation of behavioral disturbances (Bertelli, Rossi, Scuticchio, & Bianco, 2015; Hurley, 2006; Hurley, 2008). For these reasons, throughout the year 2020, social health care services had to rapidly devise solutions to ensure the continuity of care and limit the risks of isolation of people with ND and their families (Mills et al. 2020).

The Impact of COVID 19 on Disability Services in Italy

In Italy, the first lockdown measures began to be applied on February 21st. On March 9th, the Italian government imposed a national quarantine through a series of decrees stipulating urgent measures to be taken for the containment and management of the COVID-19 epidemiological emergency. The lockdown lasted until May 18th 2020. The emergency situation continued throughout the year 2020, and protective and restrictive measures were adopted according to the relative spread of the infection. In respect to the activities undertaken by the social and health services to manage the pandemic crisis, three main phases can be identified:

- *First wave of contagion and lockdown (February-May 2020)*. In this period, all DCC programs were suspended, and consequently people with ND were entrusted entirely to the care of their families. Government policy was aimed at balancing the priority of reducing the risk of the contagion spread with the need to ensure continuity of care, with the conversion of DCC programs into *home care support*, and *at*

distance (phone calls and remote assistance) or *in presence interventions*.

Obviously residential services (RS) remained open and continued to operate their established intervention activities, but those living in residential services were subjected to the lockdown provisions like any other citizen, thus precluding social interactions, social activities outside the residence, and meetings with family members.

- *End of lockdown and resumption of activities (May-September 2020).* As a consequence of the reduction in the spread of infection in the country, the government ordered the gradual recommencement of all productive and social activities. At the same time, a regional plan for the gradual reactivation of DCC programs through adherence to the individual alternative interventions was ratified.
- *Second wave of contagion (October-December 2020).* Following a second outbreak of contagion, new social restrictions were imposed by the Government. During this phase, DCC programs have not been interrupted, but the repeated occurrence of COVID-19 contagions (among persons with ND, family members, and operators) have made it necessary to implement several suspensions of the programs. In contrast, the same level of lockdown restrictions was reapplied in relation to RS facilities.

Conversion of Day Care Centers Programs during the Pandemic Period

During the lockdown period, the following alternative interventions were offered to all individuals and families included in the DCC:

- *Phone calls*: all users and family members were periodically contacted to provide telephone support, to assess needs, and to plan alternative services.
- *Remote assistance* (Tassé, Wagner & Kim, 2020; Bertelli et al. in press), was used with the aim of maintaining learning, adaptive, cognitive, and motor training programs already defined in the individual plans; it was proposed to people with communication and IT skills and individual characteristics compatible with the activity.
- *Home care support*: provided access to the DCC's operators at home to realize personalized educational or assistance programs.
- *In presence interventions*: interventions realized in the DCC with staggered access (i.e. imposing time slots and alternating days), without creating aggregation, and while ensuring adherence to all measures of protection from contagion risks (i.e. implementing rotation plans for the

use of rooms, avoiding activities in large groups, distancing, obligation to use face masks, systematic disinfestations of the environments).

- *Independent living services programs* (UN, 2006; European Union Agency for Fundamental Rights, 2018): the impossibility of accessing the care facilities due to the risks of contagion, has led to the possibility of redirecting personalized programs in smaller structure, apartments or at person's home where independent living programs were provided.

The choice of the most appropriate type of intervention was based on the characteristics of the individual's functioning, their support needs, and their socio-family context. Their activation was subordinated a) to the person and their family's acceptance and agreement, through subscription to an individual plan, and b) to the evaluation of an order of priority in relation to the intensity of the persons' problems (e.g. support needs level, behavioral disturbs, psychopathological disorders, fragility of caregivers and support network).

Individual Supports Provided to Persons with ND

During the pandemic crisis the following support interventions for people with ND was implemented: a) communication and explanation of the issues and risks associated with the COVID-19 emergency situation, and the rules to follow in order to avoid contagion risks; b) constant monitoring of specific signs of distress; c) management of the distress, fear, and anxiety of people related to the changes in their social routines and life context; d) implementation of new daily agendas and appropriate activities delivered by alternative methods and solutions (Istituto Superiore di Sanità, 2020). Individual support was provided with reference to Applied Behavior Analysis (ABA) techniques (Cooper, Heron, & Heward, 2019) and to the following support systems practices:

- *Augmentative and Alternative Communication (AAC):* visual communication methods used to overcome the difficulties of people with ND in producing or understanding spoken or written language (Beukelman & Mirenda, 2013; International Society for Augmentative and Alternative Communication, 2020)
- *Structured teaching - Treatment and Education of Autistic and Communication Handicapped Children (TEACCH)*: devised in order to ensure predictability and the positive management of anxiety and stress, set up new daily routines, and foster positive adaptation to the changes that had occurred (Schopler, Mesibov, & Hearsey, 1995).

Methodology and Objectives

The study was conducted in the Public Social Health Disability System Services of Udine (Friuli Venezia Giulia Region, North-East Italy). The Disability System Services of Udine is targeted at people with ND (intellectual disability (ID) and autism spectrum disorders (ASD)) in adulthood. At the end of February 2020, 20 DCC and 9 RS were being provided to 333 people, of whom 247 were entered in DCC programs and 86 were in RS. These services had been assigned according to the support need intensity level of the subjects, evaluated through the application of the Support Intensity Scale - SIS (Thompson et al., 2004), along a continuum ranging from services for people with a high intensity of support needs (in which protection and assistance interventions are a priority) to services for people with a low intensity of support needs (in which independence and social inclusion are the principal targets).

The SIS is an assessment tool specifically designed to scientifically measure the level of practical support required by people with ND in relation to the activities of daily life. It also measures their supplementary medical and behavioral support needs. In the Disability System Services of Udine, the SIS is systematically evaluated, by staff operators, during the initial assessment phase of the person and then annually thereafter, in order to monitor individuals and plan the appropriate level of support in their programs.

Both DCC and RS services included from a minimum of 4 to a maximum of 22 individuals.

Graph 1 shows the distribution by age group of people entered in the services. A wide age range can be observed, from minors aged under 18 to those aged over 60. In general, RS included people with a higher age than those included in DCC programs.

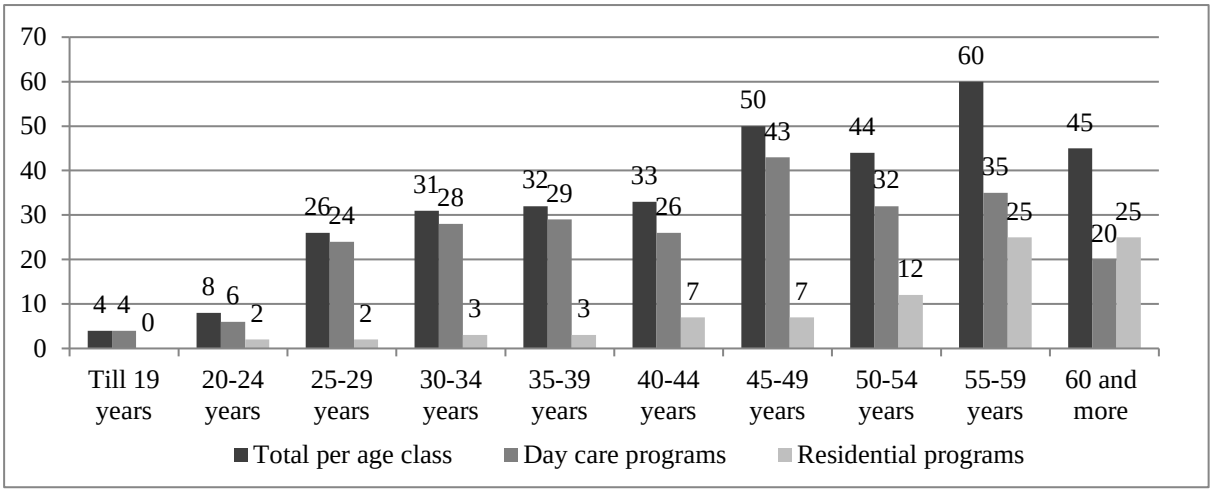

Figure 1 ***Distribution of People Admitted to DCC an RS by Age Group***

The aim of this paper was to illustrate the coping strategies that were implemented in order to limit the negative effects of the pandemic crisis in a Public Social Health System's Services for persons with ND during the year 2020. An exploratory study was conducted involving the entire population of people with ND included in the Disability System Services of Udine in order to analyze:

- alternative solutions and interventions to DCC programs adopted in order to ensure the continuity of care, and to limit service interruptions and isolation risks;
- the main repercussions of the pandemic crisis on the organization of system services, evaluated through a comparative analysis of the number of people enrolled in the different types of services in January 2020 (before the pandemic crisis) and in January 2021;
- the changes in individual support needs, evaluated through the SIS, pre- and post-pandemic crisis by means of a comparative analysis of the differences in support needs recorded in January 2020 (prior to the pandemic crisis) and in January 2021, using the non-parametric Mann-Whitney *U* test in SPSS 21.

Results

Overall, during the year 2020, 37 people with ND were infected with COVID-19, of whom 5 were hospitalized and 2 died. Due to contagions, 11 interruptions of day care interventions were necessary, in addition to the lockdown. Around 50% of DCCs in which alternative interventions were realized have experienced at least one outbreak after the time of the lockdown. At the end of the year 2020, the total days of interruption in the DCC programs equaled 1151 out of a total 4400 days of operation in a normal year (220 days per year per DCC).

- *Alternative interventions to the DCC programs*. Table 1 shows the numbers and percentages of alternative interventions carried out during the different phases of the pandemic in the year 2020.

During the 8.5%, in presence intervention 3.2%, and independent living services programs 2.8%), while 33.6% of people received remote assistance intervention. At the end of the lockdown, the provision of direct interventions increased (in presence interventions 46.2%, and independent living services programs 8.5%), although home care support decreased. During the second wave of contagion phase, in presence intervention and independent living services programs further increased (to 49.8% and 11.3%, respectively), while the provision of remote assistance interventions continued at the same rate.lockdown period, the families of the 247 people included in the DCC programs received telephone support, and 48.1% of users also received an alternative type of

individual intervention. Of these, 14.5% received direct interventions by qualified personnel (home care support

- *The main repercussions of the pandemic crisis on the system of services*.

Table 1 ***Number and Types of Alternative Interventions Provided in the Different Phases of the COVID-19 Emergency***

Phases / Types of alternative interventions		Lockdown (February - May 2020)		End of lockdown and activities reprise (May - September 2020)		Second wave of contagion (October-December 2020)	
		no.	%	no.	%	no.	%
At distance	Phone calls	247	100	As required	-	As required	-
	Remote assistance	83	33.6	22	8.9	22	8.9
Direct	Home care support	21	8.5	6	2.4	2	0.8
	In presence interventions (DCC)	8	3.2	114	46.2	123	49.8
Tot.	Support services for independent living	7	2.8	21	8.5	28	11.3
	Total direct interventions	36	14.5	141	57.1	153	61.9

Table 2 shows a comparative analysis of the number of people entered in the different types of services in January 2020 (before the pandemic crisis) with that in January 2021.

Table 2 ***Comparison Analysis of System Services Organization Pre- and Post- pandemic Crisis***

Type of Services		January 2020		January 2021		Differences	
		no. of services	no. of persons	no. of services	no. of persons	no. of services	no. of persons
DC program	Day care center for high level of support needs	5	54	5	45	0	-9
	Day care center for medium level of support needs	6	78	4	27	-2	-51
	Day care center for low level of support needs	7	96	7	55	0	-41
	Support services for independent living	2	19	4	30	2	11
	Remote assistance	-	0	-	22	-	22
	Tot	20	247	20	179	0	-68

RS	Protected residence for high level of support needs	1	23	1	23	0	0
	Housing residence for high level of support needs	5	38	5	37	0	-1
	Housing residence for medium-low level of support needs	2	21	2	21	0	0
	Cohousing apartment for independent living	1	4	1	4	0	0
	Tot	9	86	9	85	0	-1

Table 3 ***Comparison Analysis of Distribution of Persons Admitted to DCC and RS by Age Group Pre - and Post - pandemic Crisis***

Age class	January 2020			January 2021				Differences	
	Total per age class	Day care prog-rams	Resi-dential prog-rams	Total per age class	Day care programs		Residen-tial programs	Day care prog-rams	Residen-tial programs
					In presenc e-DCC	Remote assistan-ce			
Till 19 years	4	4	0	4	4	0	0	0	0
20-24 years	8	6	2	8	4	2	2	0	0
25-29 years	26	24	2	27	21	2	4	-1	2
30-34 years	31	28	3	33	23	4	6	-1	3
35-39 years	32	29	3	33	16	9	8	-4	5
40-44 years	33	26	7	34	22	4	8	0	1
45-49 years	50	43	7	40	23	1	16	-19	9
50-54 years	44	32	12	29	15	0	14	-17	2
55-59 years	60	35	25	34	20	0	14	-15	-11
60 and more	45	20	25	22	9	0	13	-11	-12
Tot.	333	247	86	264	157	22	85	-68	-1

A substantially unchanged situation in regards to the number of services (difference = 0) and in the number of people entered in RS programs (difference = -1) is highlighted. On the other hand, a significant reduction in the number of people included in the DCC programs was recorded (difference = -68). However, while there has been a significant decrease in participation in DCC programs for medium and low levels of support needs (difference = -51 and = -41), there has also been a notable increase in the services offered and the number of people included in independent living services programs (differences = 11) and in remote

assistance (differences = 22) that were not available before the pandemic and that have continued since the end of the lockdown. This means that for 33 of the 101 people no longer included in the DCC programs, new types of services were provided. In contrast, for the remaining 68, it was not possible to provide any other type of service. Table 3 shows the age group distribution of people included in both DCC and RS programs before and after the pandemic crisis. A significant decrease in DCC programs can be observed, especially in the age groups between 45 and 60 and more years.

- *Pre-post pandemic crisis comparative analysis of support needs.*

Graph 2 and Graph 3 show the comparison of the raw mean scores of the support needs of the two surveys (2020-2021) conducted on all subjects of DCC and RS programs. The levels of support needs have changed in all areas between the years 2020 and 2021. The results of the non-parametric Mann-Whitney *U* test data analysis show a significant difference in all areas of daily life, medical, and behavioral support needs (interval .000 - .015, with a significance level of .05).

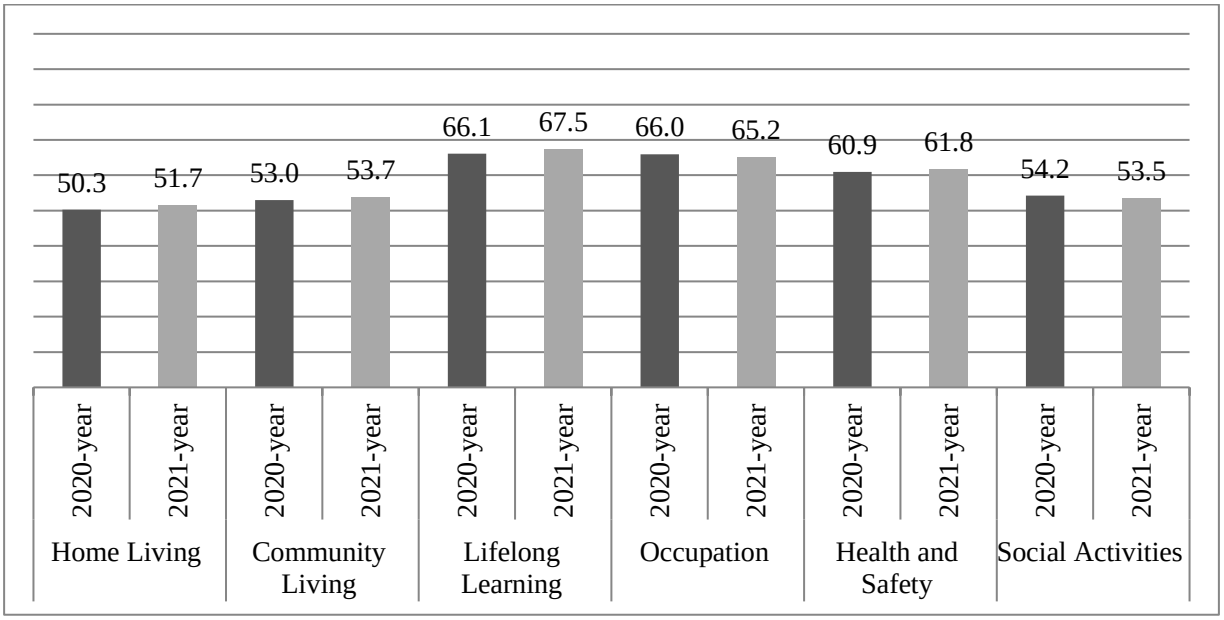

Figure 2 ***The Comparison Analysis of the Raw Mean Scores of the Support Needs in the Day Life Activities***

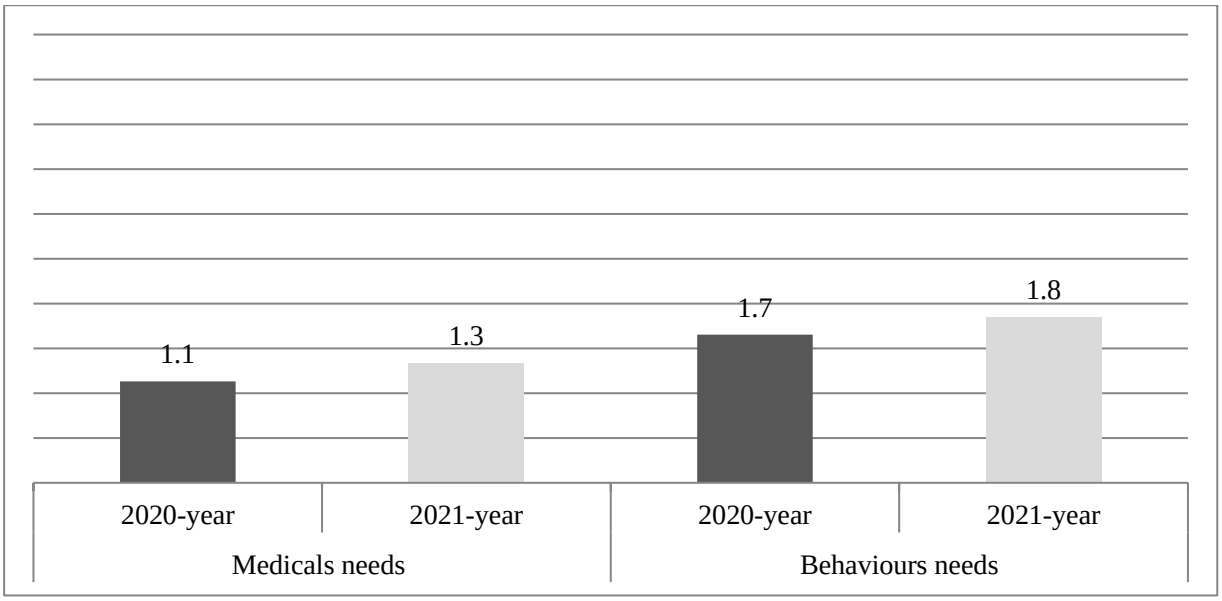

Figure 3 ***The Comparison Analysis of the Raw Mean Scores of Medical and Behavior Support Needs***

Conclusion

This paper reported the effects of the pandemic crisis in relation to one Public Social Health System's Services for people with ND. Despite the limited size and representativeness of the sample of users and services on which this research was based, the data obtained confirm the effectiveness of individual alternative interventions (home care, at distance or in presence interventions) for reducing the negative impact of the pandemic emergency on support services for people with ND. The coping actions that were adopted have succeeded in limiting the severity of the contagion. It is probable that the small number of people per DCC and RS (from 4 to 22) has favored the containment of his spread. The situation of RS has not changed and the impact on people has been attenuated. The alternative interventions adopted reduced the risk of isolation and ensured the continuity of care of persons with ND entered in DCC programs, although about 25% of them have not returned to the centers following the end of the lockdown. For those who have ceased to draw on care services, a significant proportion of the families involved have expressed concern about the risks of contagion. Furthermore, for those people with ND who are still enrolled in health system services in the year 2021, individual support needs have changed from what they were in the year 2020 in regards to every aspect of daily life, medical treatment, and personal behavior. The pandemic crisis is still ongoing, and needs are continuously evolving. However, despite the enormous difficulties and negative repercussions, the pandemic crisis may give rise to improvements in the provision of system services, exploiting the current complex situation to review past approaches and

potentially find new solutions. In fact, the paradigmatic changes that have occurred in the last few years in accordance to the UN convention on the rights to social inclusion, participation, and empowerment of people with disabilities (UN, 2006), had made some parts of DCC programs obsolete even before the pandemic outbreak. Instead, during the crisis, certain types of alternative interventions that had not previously been realized, such as remote assistance and independent life support programs, have been implemented and expanded. Paradoxically, then, this unwelcome and highly complex situation might ultimately be seen as an "accelerator" of positive change in the services. Going forward, we must draw on the experience gathered from this crisis and learn to incorporate the positive features into best practice. At the same time, innovative organizational solutions for improve these practice must stil be found, and the need remains for additional research to be carried out on these iusses in the future.

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