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# Creating a new space for people with autism spectrum disorders in the Mental Health Department

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## Summary

In this paper we will epitomize and share the internal and unofficial guidelines for the clinical management of people with Autism Spectrum Disorders (ASD) at the Mental Health and Addiction Department of Pavia, Italy. We will provide suggestions to implement our approach in other Mental Health and Addiction Departments, as ASD is a common but highly specific condition that psychiatrists need to consider in their daily clinical practice.

## Introduction

Considering the recent "autism epidemic" [1], treating people with autism spectrum disorder (ASD) in general psychiatry practice has gradually become more common in the last decade. Therefore, as psychiatrists we cannot anymore tell our adult patients with ASD: "it's not my job/I do not know how to treat you". Nevertheless, professional competences and expertise encompassing the whole life span of ASD are still quite uncommon among Italian adult psychiatrists. This could probably be ascribed to the legacy of the DSM III and ICD-9 training, when ASD was described only as "infantile", confined to childhood [2,3] and totally ignored in terms of healthcare when people with autism grew up.

It is well known that the word "autism" was firstly created by Eugen Bleuler, as a core symptom of schizophrenia. Bleuler defined it as the "detachment from reality together with the relative and absolute predominance of the inner life'' [4]. For decades, autism and schizophrenia have been strongly interconnected, even after the seminal papers of Leo Kanner [5] and Hans Asperger [6,7]. Of note, the two first editions of DSM (DSM-I 1952, DSM-II 1963) [8,9] mention "autism" and "autistic" only when describing schizophrenia and/or schizoid personality. Autism as a diagnostic entity for itself first appeared in the DSM III (1980) [2] and moved to be a subtype of the Pervasive Developmental Disorders Cluster from the DSM IV onwards. The concept of an autism spectrum was introduced systematically only with the DSM 5 [10].

In any case, autism is a strange kind of illness, full of controversies. Firstly, it is still debatable if it is a disease and not only a peculiar human condition [11] in which the individual/environment relationship follows rules different from Aristotle's assumption of man as a "social animal". People with autism often behave breaking unwritten social rules in their everyday life, both because of their own peculiarities and because of others' reaction to their social hindrance. Secondly, dealing with any kind of environment, not only the mental health one [12], can be particularly challenging for people with ASD when their unique communication, sensory, and safety/behavioral needs are unaddressed [13]. Understanding

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*Conflict of interest*
The Authors declare no conflict of interest.

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these needs is hence the starting point to deal with them successfully. We will approach this topic by retracing the recent history of our service, which has been constructed in an "autism friendly" way, since the end of the last century.

## Materials and Methods

### *Sample*

All subjects with a diagnosis of ASD followed-up by our clinical-academic (Azienda Socio-Sanitaria di Pavia and Università di Pavia) centre were included in the present analysis.

### *Outcome variables*

The present study reported the results of two main outcomes: diagnosis of ASD in a clinical setting and clinical management of subjects with ASD.
The first outcome will be presented as a description of the catchment area (number of referrals, psychometric assessment, differential diagnosis and prevalence of comorbid diagnoses in our catchment area). The second outcome will point out the available options for the treatment of ASD patients (case management, focused interventions, personalized approach), which could be implemented in a general psychiatric setting.

### *Catchment area*

The Department of Mental Health and Addiction of Pavia provides mental health treatment for half a million inhabitants over an area of 3.000 km$^2$, partly urban and partly rural, located in northwestern Italy. The province of Pavia and consequently the Mental Health Department includes three subregions, namely Lomellina, Oltrepo and Pavese. Each region has a child and adolescent unit, an adult outpatient service, an addiction ambulatory, a psychiatric ward and some rehabilitation facilities. As a legacy of autism history, each child and adolescent psychiatry unit has good expertise in ASD and at least one MD or one psychologist trained in the administration of the standardized interview for ASD, the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview-Revised (ADI-R). The adult units of the service are supported by a clinician expert in ASD and ADOS/ADI-R trained.
Referrals are accepted by mail or telephone and could be done by the subject, relatives or health professionals.

## Results

### *Number of referrals*

In the last three years, the outpatient service has received some 321 referrals from psychiatrists, GPs as well as self-referral from the Pavia area, but also from other provinces in Lombardy or from other Regions (Tab. I).

**Table I.** Characteristics of referral to the Pavia ASD (n = 321) team in the last three years (2018-2020)

| Variables | Mean ± Standard Deviation or % (counts) |
|---|---|
| Age, years | 36.11 ± 17.71 |
| Gender, male | 75.7% (n = 243) |
| Referral | |
| Self | 22.1% (n = 71) |
| Relatives or friends | 44.8% (n = 144) |
| Health professional | 33.1% (n = 106) |
| Origin | |
| Lombardy Region | 87.8% (n = 282) |
| Other Regions | 12.2% (n = 39) |
| Medication, yes | 54.2% (n = 174) |
| Cognitive impairment, yes | 33.9%(n=109) |

The assessment of referrals consists of two/three sessions in which subjects will undergo a clinical interview, ADOS (and ADI-R if caregivers are available), IQ and/or adaptive abilities evaluation and sensory assessment. If necessary, more specific evaluations will be conducted to investigate specific areas of functioning (for instance, cognitive functioning, empathy, social cognition). If a psychiatric comorbidity/primary diagnosis is suspected, a DSM 5 interview will be conducted. The overall assessment process is quite time consuming, lasting for three to four hours.

### *Diagnosis and psychometric assessment*

Diagnostic criteria for ASD have changed dramatically over the past 70 years. However, the gold standard for ASD diagnosis is still the clinical interview conducted by a clinician expert in autism: the clinical judgment should be supported by standardized tests which may rely on direct observation of the subject such as the ADOS or on caregiver-reported symptoms in infancy such as the ADI-R. This protocol (standardized tests plus expert judgment) is aimed at improving diagnostic sensitivity/specificity in every mental health service.

### *Differential Diagnosis*

In fact, autism can be both under- and over-diagnosed, especially in selected populations [14,15], mainly because of the overlapping of clinical symptoms or conditions and because of a suboptimal instrument reliability [16,17]. For instance, it could be difficult to distinguish a person with a schizotypal personality disorder from a person with ASD, especially when there are no trustable informants about the early childhood of the subject. Moreover, the diagnostic process becomes even more difficult when ASD co-occurs with a psychiatric diagnosis (i.e. psychosis, depression, obsessive-compulsive disorder), especially in adulthood, as prevalence of psychiatric conditions in an ASD adult sample is higher than in the general population. In the last three years, we observed a vast majority of appro-

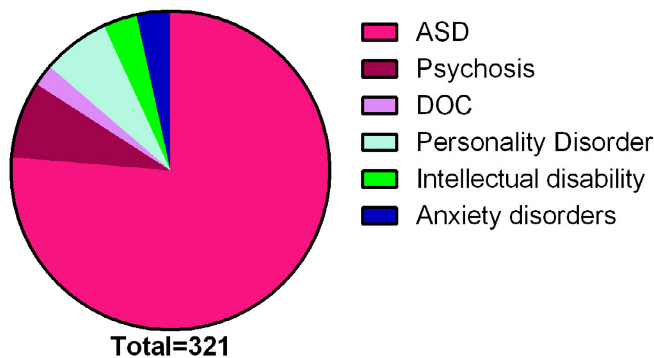


**Figure 1.**
Diagnosis types after referral to ASD service.

priate referral while in a small number of cases a no-ASD diagnosis was made (Fig. 1).

### *Comorbid Conditions*

The assessment of comorbidities is crucial, since along the whole life circle, individuals with ASD have been found to have higher rates of various psychiatric as well as medical conditions [12,18] and are thus subjected to higher healthcare utilization. Additionally, comorbid conditions could trigger problem behaviors, unresponsive to medications. In our centre, medical comorbidities are usually investigated by a specialized team of physicians, using prioritized pathways to care and a dedicated nurse. Psychiatric comorbidities are of difficult detection, as questionnaires and interviews are usually not validated in an ASD sample and therefore the training of psychiatrists should be a turning point in the timely detection and treatment of these conditions.

### *Diagnosis communication*

After assessment, ASD people will receive a formal diagnosis during a specific session. This usually represents the first step of a brief psychoeducational program for both the ASD people and their loved ones. If the subjects do not have a referring mental health service, they are taken on by the team composed by the psychiatrist and a clinical psychologist at a sustainable frequency determined by their clinical needs.

### *Therapeutic options*

#### *Case Management*

The appointed clinicians will maintain close relationships with patient's relatives, monitor emergent therapeutic targets (distress, anxiety, depression, etc) and develop a life project for the patient according to the predefined level of functioning and expectations for the future.

## Psychoeducational Interventions

Our Community Mental Health Centre provides psychoeducation group interventions (twice a week according to level of functioning) which are focused on social skills training as well as emotional management in different contexts. Additionally, single psychoeducation sessions are provided if needed. All people with ASD are accompanied in their acquisition of insight about their condition. Parent training is also offered through group training as well as self-mutual help groups. We offer a coaching service to support people with ASD through the identification of their strengths, promoting soft skills and work-related abilities that can facilitate job placement. A special focus is also helping people with ASD dealing with their sexuality.

### *Pharmacological management*

Despite the absence of medications effective on ASD core symptoms (social impairment as well as restrictive and repetitive behaviors), appropriate pharmacological management appears a priority in the management of problem behaviors associated with ASD. A large majority of ASD subjects are on psychotropic medications [19], but the response to these drugs is quite different from the one which general psychiatrists are used to. In fact, efficacy of almost all psychotropic compounds is lower in subjects with ASD with higher levels of side effects. Despite this evidence, people with ASD are usually treated with complex pharmacological strategies with a higher risk of interaction effect. Additionally, subjects with ASD usually use multiple complementary and alternative methods, which should be always investigated and which sometimes could be extremely deleterious.

### *Emergency services*

Explosive, uncontrolled, aggressive behavioral crises may also concern people with ASD and normal cognitive functioning. Such eventualities are quite unusual but may potentially cause important distress as usual psychiatric interventions are ineffective. The Mental Health Department of Pavia received specific fundings by Regione Lombardia for the management of such crises (project EARL: Emergenze Autismo in Regione Lombardia). Three lines of intervention were designed and implemented:

- a telephone helpline available 10 hours/six days per week;
- the possibility to provide a bedplace in a "autism friendly" psychiatric ward with a dedicated trained staff member 24/7 (eg. for acute phase with the need of hospitalization);
- the possibility to provide a dedicated room with trained staff in a sheltered house (eg. for post-acute phase or acute phase with no need of hospitalization).

At the present day, this service is available for the whole region and will last till October 2021.

### *Residential and semi-residential services*

While a small percentage of all people with ASD could reach independence, almost half of our sample will be still

requiring various levels of support, ranging from supported living to residential or semi-residential services. This is particularly true for patients with ASD and comorbid cognitive impairment. A recent survey of the 15 semi-residential facilities (Day Centers for the Disabled, DCD), located inside the Mental Health Department catchment area re-evaluated patients (N = 344) present at the time of the site visit. Of the 344 patients screened, 47 (14%) were registered with a diagnosis of autism, which was confirmed; one, despite having a diagnosis of autism, did not meet the expected criteria (false positive); 38 (11%) were evaluated as having ASD (false negatives). Thus, overall, one in four people present in accredited DCDs in our province has a validated diagnosis of Autism Spectrum Disorder.
Two independent, specialized facilities for ASD young adults are located among the same catchment area. Both facilities follow several principles which have inspired their development (i.e. structured ecological environment; contact with nature; favor natural circadian and seasonal rhythms; active involvement of people with ASD in farming activities). Cascina Rossago (frazione San Ponzo Semola, Pontenizza, PV) is the first farm-community for people with ASD in Italy and welcomes 24 adults with severe ASD and comorbid cognitive impairment. The semi-residential centre "Il Tiglio" (Sant'Alessio con Vialone, PV) is a DCD welcoming 20 subjects with ASD. Both facilities are constructed according to the knowledge of the autistic mind and activities and spaces are tailored as the most tolerable for patients. Specific training in all unspecialized DCD and residential facilities is also being conducted in order to provide more specific information and help the healthcare professionals in constructing a more personalized life plan for each subject.

### *Supporting talents*

According to Happè and Frith expertise [20], one in three people with autism have some kind of talent, irrespectively of IQ. Our approach to disability is to focus on unsuspected talents, to foster and train special abilities, avoiding any "circus freak" phenomenon and improving self esteem. Changing perspective represents a crucial point when taking care of people with ASD. An evocative example of this is, for instance, the discovery of the undetected non-compositions of a gifted piano player transcribed and edited in Playing with Autism 1.1 [21,22].

### *Academic support for ASD*

ASD students are particularly at risk of career interruption. Approaching university studies, with a less restricted and constant environment, introduces uncontrollable variables in their lives, causing deep discomfort, performance problems, or even actual psychopathological decompensation. For this reason, the SAISD (Assistance and Integration Service for Disabled Students) center at the University of Pavia has undertaken a collaboration with our clinical center to support undergraduate and postgraduate students with high-functioning autism. Assistance is delivered by a team composed of a psychiatrist and a clinical psychologist who are experienced both in autism and learning disabilities. Following an evaluation of personal educational needs and potential, our team will formulate a sustainable, individualized project designed to enhance study skills. During 2020, for example, the SAISD center served a total of approximately 380 students with motor impairment, ASD, and learning disabilities. In addition, our clinical center has followed dozens of other cases, although not yet certified, providing support with difficulties encountered during their academic journey.

### *Networking*

As constructing a constant and coherent environment is the key for a successful management of ASD, we have developed a network with other local healthcare services which do not pertain to the Mental Health Department of Pavia but are currently dealing with people with ASD. All these local healthcare services are periodically reached for staff training, clinical support and development of research projects. This interaction has been fundamental to avoid fractures in the therapeutic continuum of people with ASD and to involve these individuals and their families in shared activities to avoid isolation.

### *Research*

Knowledge on ASD is still limited: a better characterization and phenotyping are thus crucial to tailor individualized and effective interventions. In addition to the clinical level, our research unit is involved in several projects with the aim to shed new light on the neurobiological substrates of ASD [23-25]. This is particularly true when considering the impact of the recent Covid19 pandemic on the life of people with ASD [26].
In any case, research concerning ASD is still lacking a solid methodology. In particular we need affordable, specific measurement tools in order to evaluate the supposed variations in symptoms, behavior, or function. The available outcome measures remain highly heterogeneous and non specific, while a significant number of studies about ASD lacks a clear primary aim [27].

## Discussion and Conclusions

To conclude this extensive survey, we believe that, considering an approximate prevalence of 1:100 of ASD among the general population, any Mental Health Departments should be aware of:

- the possibility of detecting hidden or misunderstood autistic patients among service users;
- the importance of facilitating the transition of ASD people from childhood into adolescence and from adolescence into adulthood;
- the relevance of preventing behavioral complications among ASD people who have never been treated and who lived a more or less normal life

- the significance of a program for job support dedicated to people with ASD.

What did we learn from taking care of this peculiar population, moving from the original and creative work of Francesco Barale and Stefania Ucelli di Nemi [28]? There are, in our opinion, two major issues. ASD needs in any case a paradigm shift. Autism was firstly identified as a symptom (1911), then we recognized the syndrome (1943), only later we detected the spectrum (1980). We believe that this timeline prevented us, for such a long time, from understanding and appreciating the "positive" elements in ASD. It will be challenging for the future generation of clinicians and researchers to learn how positive could be cooperating and interacting with neurodiverse people, being conscious of the point of strength and weaknesses of belonging to both populations, the neurotypical and the neurodiverse. Secondly, we learnt that treating a person with ASD, without taking care at the same time of her environment (family, school, job place, community, etc), is always frustrating and hopeless. The communication difficulties grow in the middle of the relationship between a person with ASD and her environment, involving the two members. Therefore, the therapeutic work with the environment is, at least, as important as the therapeutic work with the individuals. In this light, multiple and continuous levels of assessment and treatment on both sides of the intervention are crucial to provide effective therapeutic strategies.

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