

Network of services facilitating and supporting job placement for people with autism spectrum disorders. The experience of the ASL Piacenza, Italy

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Abstract

The Mental Health Department of Piacenza has recently activated a special program for persons diagnosed with autism spectrum disorders (ASD). The Program engages a number of stakeholders: the users, their families, social and psychiatric services as well as specific associations for autism. The program is aimed to grant a complete and individualized assistance to people with ASD and it is especially focused on the transition to adulthood. In this period, it is necessary to build the "life project" in order to improve functioning and quality of life of users. The elective areas of the individual plan have to deal on how to reach autonomy in daily living and related skills, obtaining and maintaining a job, as well as starting and reinforcing significant relationships. This paper is especially focused on job placement for people with ASD.

Key words

- autism spectrum disorders
- adulthood
- transition
- life project
- job placement
- individualized program

INTRODUCTION

Piacenza and its region account for about 280 000 citizens. The Mental Health Department serves this population and treats about 2% for mental illness.

The psychiatric unit, called *Psichiatria di Collegamento e Inclusione Sociale* (PCIS), is a Rehabilitation Psychiatric Unit that works like a server for all the other Psychiatric Units of the Mental Department. Its mission is to improve the functioning and the quality of life of users followed by psychiatric services. Then the elective areas of work concern autonomous daily living and related skills, obtaining and maintaining a job, as well as beginning and reinforcing significant relationships. The Psychiatric Unit has in its mission the improvement of physical health of people with serious mental illnesses and the reduction of social stigma through specific interventions in secondary schools.

From 2014, PCIS has started a special program (*PDIA Autismo: Percorso Diagnostico-Terapeutico-Assistenziale Autismo*) for persons diagnosed with autistic spectrum disorder (ASD). This involves all the stakeholders: users, their families, social and psychiatric services and specific associations for ASD persons. The program aims to provide a complete and individualized assistance for people with ASD. The focus is especially

on the transition from adolescence to adulthood, when the risk of missing users is particularly high: during the period from 16-18 years users and their families are in charge of both the child neuropsychiatry and the psychiatry unit (autism transition team, ATT). After the age of 18, only the PCIS takes care of these users. In the same period of two years, the team of PCIS repeats a general assessment: diagnostic, cognitive and neuropsychological, and, specially, an assessment of the functioning in the main areas for independent life and the preferences of the user. The repeated questions posed to users from the operator is: "What do you want to do now? And in next ten years from now? The belief is that the age between 18 and 30 is crucial to make the fundamental choices for future life. This is especially true for people with ASD, because they are generally less autonomous, less likely to be employed, more isolated than their peers, also compared to people diagnosed with intellectual disability [1-3]. Practically, this period of transition is dedicated to building up the life project of the user. Of course, this fragile age deserves major attention from the psychiatric service through a holistic approach [4].

In the same period, we divide the ASD population we counsel according to 3 functioning levels, following

the DMS 5 classification: high (level 1), middle (level 2) and low functioning (level 3). In making this classification we use some flexibility with the ultimate goal of directing the users to those activities they are more inclined to. Level 3 users are managed in collaboration with the social service of the local municipality.

From the beginning of the PDTA Autism, we have been aware that there is an underestimated prevalence of ASD in the population in the range 18-30 years. Data suggest that many undiagnosed cases are assessed in the PDTA Autism that have escaped previous assessment by the child neuropsychiatry unit and by doctors from other specialties.

JOB DEVELOPMENT AT THE PCIS OF THE PSYCHIATRIC UNIT OF PIACENZA

In this paper, we specifically consider the paths and the outcomes of job development for people with ASD in our mental health department.

Only ASD persons in levels 1 and 2 according to DMS 5 have a real job. Those in level 3 do not qualify for a real job, have occupations consisting of a helpful and significant work and a minimum wage. We know that there are a lot of obstacles for people with ASD, like the “benefits trap”, rigidity in their preferences and routines, an uncomfortable working time and specially the self-stigma or the lack of trust on their own resources: the family is often the first to report this lack of trust. The operators must be aware that these are real obstacles to habilitation or rehabilitation of the user and must actively recognize and bring about the positive personal resources of each individual. Indeed, special interests represent second core symptoms of the disturbance and they can be a source of desire and development, especially in the job area. Unfortunately, many users with ASD ended the secondary school with the belief that they are less capable than their peers to hold a normal job. Alternatively, in reverse, some people with ASD think that working is not for them because of their differences from “normotypic” people: the consequence of these attitudes will be a progressive marginalization, isolation and, sometimes, discrimination. For many people with ASD the aim of a normal job will not be reached because of the lack of trust in their own capability, despite they might show normal or even higher intelligence, compared to an average person without ASD.

In our psychiatric unit, at the end of the transition period from adolescence to adulthood, we try to offer all ASD persons a variety of working possibilities, respecting the preferences of any user for a certain kind of job.

We have available 3 main paths: a) internship; b) social cooperation and c) IPS (individual placement and support).

The first two are a kind of sheltered route. They are the traditionally paths for people with psychiatric illnesses (and especially for people with ASD) that want to start a job. Actually, it is the mainstream for most of our users.

a) The *internship program*, in particular, takes place in various work contexts, predominantly involving manual

work, where there is a lower demand for intellectual performance. This working context could be positive for people with ASD because it is often repetitive and rigid. Many users with ASD do not disdain a working place where they can do cyclic tasks. The limitation of this approach is that the training before the real job is often too long: job recruitment happens many years after the beginning of the internship or does not happen at all. In the last years, the rules for recruitment have become stricter preventing the person to finally gain a real job, a very different condition than in other countries as northern Europe where the path is much facilitated.

b) *Social cooperation* has a long tradition in Italy and in our region; there are a number of social cooperatives: many of these receive users from the mental health services. Normally after a period of internship, the cooperative hires the users who have demonstrated a specific ability in the tasks required. This characteristic allows users with ASD to find a job close to their special interests. The limitation of this approach is that the social cooperative that has to produce goods needs to be productive and follow the hard rules of the free market requiring a good balance between workers with good working skills and workers with disabilities. Notwithstanding these difficulties, the users – especially ASD people who work in the social cooperative find a good social environment that extends their relationship network.

c) *IPS* uses an evidence-based method to job placement for people with mental illness developed in USA by Bob Drake about 20 years ago [5] and later in the last ten years also in Europe [6]. In Italy, IPS has an ongoing development: in our department, the number of IPS users is increasing while the number of internships diminishes. The IPS has actually a few extensions for people with ASD, because this method requires that the potential worker has the ability to search for a job by himself, with the help of a job tutor. The difficulty in social interactions characterizing ASD persons limits this approach and it is mostly people with the highest level of functioning, high IQ users (Asperger syndrome or high functioning autism) that are the recipients. The limitation of this approach is that searching for a job in a labor free market is highly stressful for ASD persons. However, the user can receive the constant help of the job tutor. Furthermore, if the path to obtain a work in the labor market is difficult and long, having a “regular” work with a “regular” wage is a powerful thrust to self-efficacy and satisfaction [7]. In recent literature, there is a proof that a specific cognitive remediation may increase the effectiveness of IPS also in people with intellectual disability and with ASD [8].

The keystone of the organization of every path is the work operator. He suitably belongs to the psychiatric unit and represents a different figure from the case-manager. The latter manages the rehabilitative relationship with the user, including in the housing and social areas, but not the job area. This area is given to the work operator, who's expert both in psychopathology and the labor market. Every work operator is specialized only in

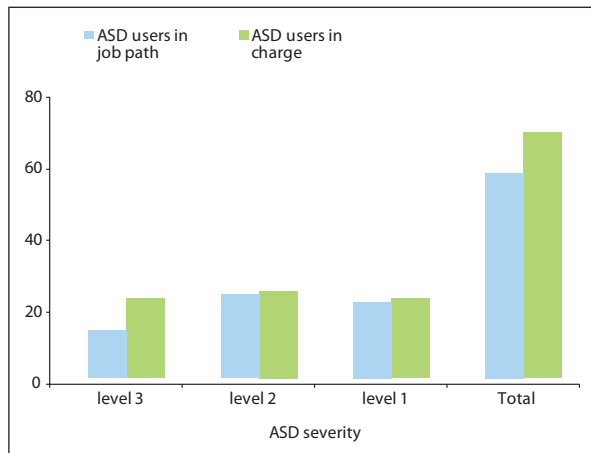


Figure 1 Percentage of ASD adult users in-charge of ASL Piacenza attending the job path by ASD severity level (according to DSM 5). Data from December 2018.

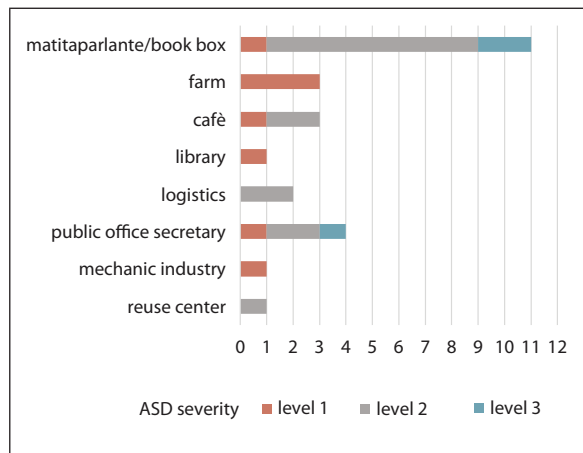


Figure 3 ASD users in internship by activity area and ASD severity. According to DSM 5.

one working path: internship, social cooperative or IPS. This is why every work operator must have mastered every method applied to the user. The work operator maintains regular contact with the labor companies and their employers.

In December 2018, there were 89 adult users in charge of the psychiatric unit, 68 of which were in treatment and 21 under the transition team. There was an equal distribution between the three levels of ASD severity (level 1, 22; level 2, 24; level 3, 22). It is important to note that the number of cases not coming from the ATT but directly referred to the adult psychiatric unit are one third (n. 8) of cases referred to ATT.

The main outcome of the PDTA Autism is that most adult ASD users are occupied with some form of job (n.

57; 83%) (Figure 1). These users receive a monthly wage of € 528 (median € 300), with a very high standard deviation because of the high differences in various jobs.

About half of those with a job (Figure 2) are employed in sheltered work (internship or social cooperative), while the two smaller groups are engaged in free labor market and in completing educational training. In all these cases, the user has a work operator (or study operator) who follows and assists him to cope with the difficulties of the job (or of the study). A restricted number of users at level 3 (n. 11) have a job and of these only 2 users are paid for their job.

If we analyze the number of users in the internships, we can see the variety of labor contexts (Figure 3): mechanical industry, secretarial, logistics, library, café,

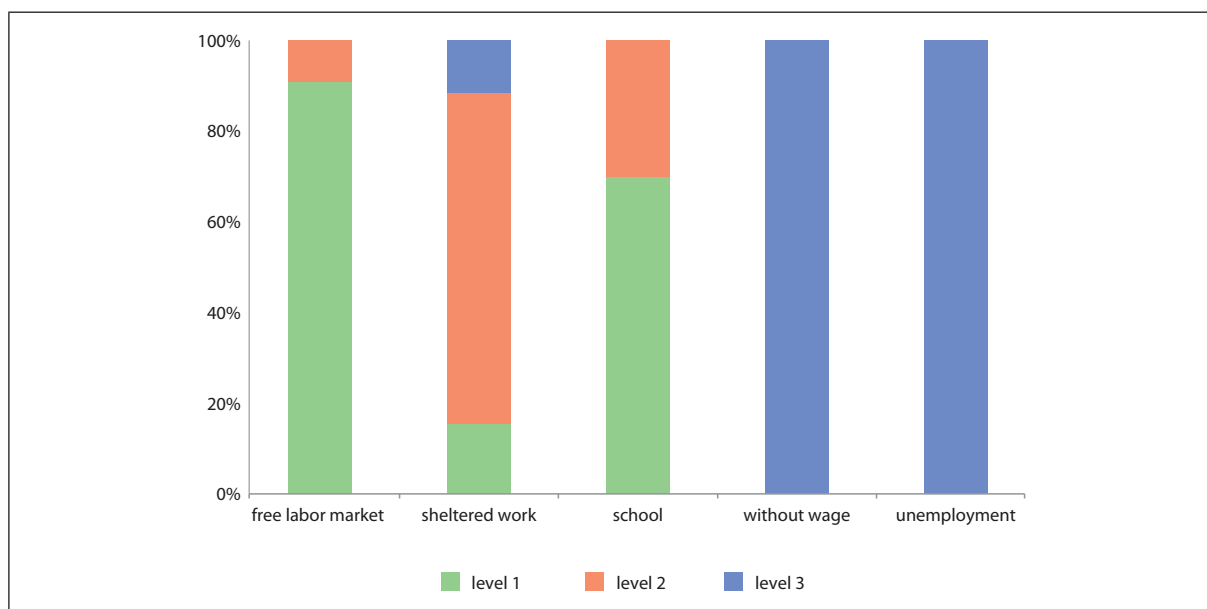


Figure 2 Percentage of ASD adult users in-charge of ASL Piacenza by employment and ASD severity level (according to DSM 5). Data from December 2018.

farm, etc., this means that the users may choose the labor context desired and that they often can find it. Furthermore, the average number of hours worked is 20 hours/week, that is quite good and engaging for people with social disabilities.

In this way frequently, the users may take advantage of their special interests, because the job is fit for them (Table 1). Persons with ASD have difficulties in interacting socially. The labor context can cause problems in the relationship with the colleagues, with the employer, or simply with respecting with the rules of cohabitation in the workplace. For this reason, we provide a set of social skills training weekly and the users – if they want – can freely participate. The arguments treated are how to accept criticism, how to manage anxiety or anger, how to be on time, how to ask for help to perform a task, how to dress properly, how to respect roles and hierarchy and – last but not least – how to cope with failures or how to exploit successes. A group leader helps the users to learn adequate behaviors using role-playing.

Between the various work contexts, we have three experiences directly promoted from the psychiatric unit that are important to describe: Book Box, “Matita Parlante”, The Perinelli farm.

Book Box (www.bookbox.it/) is a special initiative (conceived from an idea of Marilena Zacchini, which is spreading to many Italian centers): the aim is building a service to provide books in waiting rooms of offices or public places. In these contexts, special containers are placed – they are called book box – where anyone can give away and put their own books. The workers of the Book Box project periodically empty the boxes and change the old books with new ones. Therefore, users of public places or visiting an office can read a new book whenever they come. This work represents a service for the community that allows participation of users with different levels of severity.

“Matita Parlante” (literally The Speaking Pencil, www.lamatitaparlante.it) is another special work initia-

tive: the aim is drawing up book texts, made of symbols instead of words, through the augmentative and alternative communication (AAC, [9]), that is an intervention technique for those who have an inability to communicate vocally). A group of ASD users, with a specific interest for drawing or writing stories, make up the editorial staff. The “Matita Parlante” has already edited some books written with the language of CAA or translated some book from verbal to CAA language. The group has begun to sell some books that have been edited.

The Perinelli farm (www.consorziocascinaclarabella.it/cooperative/i-perinelli) is a social cooperative, promoted and managed directly from the Mental Health Department. The farm is a wine company. The workers grow vines, harvest the grapes and produce excellent quality of wines, which they sell at local markets or to restaurants. The users are hired as agricultural workers, work in a collaborative way and follow the seasonal rhythms that wine production requires.

The challenge, for all the three experiences cited, is to create ex novo a social business, which can satisfy the special interests of the workers and grant them a certain salary. All the three forms of jobs try to deal with the labor market through the production of some new product. This is very difficult but feasible!

To assess the subjective satisfaction of user workers, we administered a simple questionnaire: the Indiana Job Satisfaction Scale [10], of 33 items, that measures 6 areas: general satisfaction, wage, career opportunities, interaction with colleagues and the manager, feelings related to work. The results show that the main reasons for working are: a: the salary which is however judged by many to be not sufficiently high; b. to feel useful; c. to be busy; d. have a good working time. Furthermore, the relationship with colleagues and the manager or the director is judged positively and the workers mostly appreciate when they receive praises for their efforts or positive feedback.

Table 1
Special interest of ASD users and current internship (names are imaginary)

User	Special interest	Internship
Marco	foreign language	library
Federica	english language	library
Paolo	tranzports (train timetable, bus, etc.)	trade union
Riccardo	software programming	IT company
Miguel	software programming	IT company
Alfredo	agricultural studies	farm
Francesco	barman course	café
Giovanni	restaurants	ice-cream shop
Pietro	agricultural studies	wine farm
Simone	interest in order and repetitiveness	megastore
Claudio	art historian	café
Gabriele	interest in order and repetitiveness	inserting bolt and screws
Simone	sport (ping pong, basketball)	sport megastore
Bartolomeo	forging knives	blacksmith



DISCUSSION

It is known that people with ASD, despite sometimes having good skills and the desire to work [11], continue to remain unemployed or underemployed [12]. Early adult outcome studies have demonstrated a poor employment situation for individuals with ASD. Whitehouse, et al. [13] reported an employment rate of 18% in a UK study. However, Eaves and Ho [14] illustrated that 56% of a Canadian sample had found an employment after reaching adulthood. The Australian Bureau of Statistics asserts that the labor-force participation rate for people with ASD was 42%, compared with the 53% for people with disabilities and 83% for people without disabilities [15]. In conclusion, there is evidence that people with ASD in the world work less than all other persons with mental psychiatric disabilities. This happens because the social context of work is “normotypic” and therefore ASD persons find it difficult to perform and maintain a job. Furthermore, the transition from childhood to adulthood, when most adolescents conclude the course of studies and orientate themselves to some kind of work is particularly tricky. Difficulty in social interaction, specific and rigid interests, or a firm trend to sameness, as well as frequent problematic forms of communication challenge people with ASD in this delicate phase. All these abilities are essential to find and maintain a job. Specific and structured intervention are needed to answer with these difficulties.

Persons with ASD usually don't do as well in school as their cognitive abilities allow and often do not finish the degree course. For this reason, it is important to sustain the user who wants to conclude the course of study or convince him to do it.

Another big concern is the organization of mental health services in Italy. There are different psychiatric services in adolescence and adulthood; this disorients the adolescent, with the risk of loss of the needed relationship when a new operator ensues. It is for this reason that it is important to share the case between the two teams, in our experience from the ages of 16-18 years.

The cited considerations show that the mental health services attribute an insufficient emphasis on employment for all kind of mental diseases. “Who is not ready?” was the title of an article of 2007 in which the author underlined that the enhancements to supported employment are no doubt needed, such as the additional cognitive intervention [16]. This is even more true for people with ASD, who holds a great potential workforce without being able to express it. In our psychiatric unit, the first question to the user – independently from the problem or diagnosis he has – is “Do you want to

work? What kind of work would you like to do?”. These questions precede any question about the user's working skills. Motivation is the strongest push to reach the goal of a job. This task involves not only the user but also all the family, who often does not trust the user's possibilities.

Recently some factors that influence the outcome of the employment in ASD people have been highlighted: a more advanced age, a higher level of education, the absence of comorbidity [17]. Therefore, it seems of particular importance to pay attention upon completion of the study course (supported education) and treat as soon as possible the onset of some psychiatric problem. However, mostly it appears important to pay attention and sustain the job search and its maintenance endowing the user with a dedicated operator. He must monitor the work habits of the user with ASD, the working style, his work independence, the sensory responses and needs, the routine daily activities and the interpersonal skills [18]. There is a growing interest for supported employment that can become an important tool through which the person with autism can be brought to work [19]. The key factors to reach these objectives are the matching of the user's skills and the job request; an adequate level of education and training; the employment supported by dedicated and specifically prepared operators [20].

Our Psychiatric Unit, of PCIS, chooses the philosophy of “place and train” opposite to the outdated philosophy of “training and place”, that expresses a waiting attitude and is not very promising for those who really want to find a job.

The psychiatric organization however must provide different types of work and the possibility to change from one to another when the user desires it. The transition from one form to another form of work is accompanied by the change of work operator, but not of the case manager, who maintains the reference to the user.

In our recent experience, for people with ASD the more effective type of work is the internship. The social cooperative represents also a valid but less effective tool to gain a job. Finally, the IPS has an undoubted effectiveness for people with high functioning ASD. Our intention is to develop mostly the latter, also through the help of a specific cognitive remediation method [8].

Conflict of interest statement

The Authors declare that they have no conflict of interest.

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