



Life-long individual planning in children with developmental disability: the active role of parents in the Italian experience

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Abstract

Many young adults with neurodevelopmental disorders experience poor transition outcomes in key areas, including employment, health care, and independent living. Innovative welfare models highlight the importance of involving the local community, and in particular the parents, as important stakeholders capable to generate services and affect local economy. As indicated by the World Health Organization, the availability of person-centered responses, also providing a health budget, appears to be the basis for taking into account person's rights to self-determination. Health services and local stakeholders could play an important role to facilitate the implementation of support networks that are functional for an effective social inclusion. In order to improve current practices in transitioning to adulthood, it is of paramount importance to collect and learn from the living experience of people with neurodevelopmental disabilities and their families.

Key words

- employment
- social value
- services
- neurodevelopmental disability
- entrepreneurship

INTRODUCTION

The growing prevalence of young adults with autism spectrum disorders (ASD) calls for increased efforts to improve transition programs and appropriate support strategies. Researchers in quantitative studies have established an evidence base documenting poor outcomes and identified a range of contributing factors, including a lack of financial resources, low parent expectations and involvement and poor interagency collaboration between high schools and adult service providers (for a review on the transition of individuals with ASD see [1]). In many countries, budgetary spending cuts of the National Health Systems are the most urgent concern, while continuity of care remains another big issue for parents. Difficulties in the recruitment and retention of tutors, mainly due to reduced social care funding and low wages, threaten the relationship with ASD individuals. Constant changes in personnel make it difficult to create stable relationships with the person they support and their family, and to understand what works best for them. In particular, some studies reveal the need for services to help families and young adults preparing for and understanding the transition process [2]. Inappropriate assessments of children's needs have a profound impact on provision of care and life-long individual planning. Living arrangements are a further

important issue that emerges from parents' perspective. Considering that young persons with ASD might need ongoing support in their daily lives, some families accept community home solutions, although a semi-independent flat or studio within the family unit, or even independent living in their own home, represent further aspirations [3].

In Italy, about 5 million (38%) of disabled people aged 15 to 64 years do not work and do not attend training courses [4]. Parents call for policies and services focused on maximising the participation in higher education, employment and independent living, giving opportunities to thrive in the areas of work and study. Environmental intervention and person-centered and individualised approaches could be the right approach to accomplish the best results for their children [3]. Flexible work practices tailored to the needs of the individual with neurodevelopmental disability can facilitate workplace success as well as being advantageous for the individual because employment is a major determinant of well-being and health and has a social and inclusive impact [5]. Although it is agreed that young adults with ASD thrive in flexible and tolerant environments, current options do not always fit the individuals' requirements and personal abilities. Incorporating principles of person-centered planning in adult services and

programs may help practitioners tailor supports to the needs of individuals. Person-centered planning is an approach to supporting people with disabilities that emphasizes individual choice and community engagement (see [6] for school-life transitioning in ASD).

Some authors [7] have noted that microenterprises can be a suitable mean for people to find their own workplace environment, best suiting the needs of the person. Introduction of a personal health budget [8] endorses this microenterprise model where a person with special needs could be involved individually or as a group in a meaningful workplace characterised by a relative control over risks, cost estimates, and outcomes forecast, but providing individually tailored support and social inclusion. In order to achieve this goal, external resources are required and a personal health budget could help meeting support costs. Overall, we need to promote a business model that considers achieving quality of life and inclusion as a mission and a value of the enterprise. This needs enterprises to evolve from an exclusively profit-driven business to a model which includes consideration of social value, alongside economic outcomes. In Italy, these experiences have been consolidated by Third sector, particularly in the agricultural sector (social farms) [9]. Notably compared to other countries, Italy has many examples of work inclusion in the private sector [10].

The closest implementation of a private microenterprise model in Italy has been achieved thanks to the initiative of the parents. These represent sporadic experiences, most of them mediated by groups of parents (associations, cooperatives, foundations), and represent examples of good practices characterised by a high awareness and implementation of the current scientific recommendations and strong flexibility to best fit individual strengths and job skills. These experiences suffer the lack of an adequate network of services and funding, all conditions that put at risk their sustainability, in spite of their ability to produce “social goods”.

Compared to other European countries, the Italian experience is rather peculiar. As an example, in countries such as UK, not-for profit advocacy organizations play a very important role in collecting family voices and needs, as well as coordinating services and opportunities for life planning. In Italy, by contrast, the activity of charities and advocacy groups are scattered, due to geographical and historical as well as political reasons. In the US multi-family group psychoeducation models have been produced which involve education on a variety of topics relevant to transition planning and ASD as well as guided practice in helping families to problem-solve around current difficulties and stress [11].

Notwithstanding the reported models, many experiences have a hard time becoming good practices that can be taken up at the regional or national levels. It is thus of paramount importance to report some of the experiences characterizing ASD transitioning to adult life in Italy. In the present paper three examples of good practices implemented by parents' associations are presented as narrative reports. They describe the attempt to tackle the critical time of transition from the young to the adult stage, when individuals need to move from

school and parents supervision to independent life. These examples, although providing qualitative data, testify, in a narrative way, the importance of fostering participatory networking between the parents, health and social professionals, private microenterprises and not for profit organizations to favour transition of individuals with autism to adulthood.

CASADASÈ. A FLEXIBLE FRAMEWORK TO MANAGE THE TRANSITION TOWARDS AUTONOMY

“Autismo Firenze” was born in 2003 as an association of families with grown up children, already out of school, or about to finish. Our experience of school integration was generally a negative one: none of the children integrated themselves within the class and only a few obtained some results on a personal level; the approach was generic, the work was often improvised, impossible to verify through results and disconnected from everyday life and its great difficulties.

However, school structured their time, it was a place other than home to go to every day, it offered an environment with numerous and diverse people. In the absence of school attendance, many hours of the day remain empty and parents' main occupation became the search for possible activities to put in place: from various “therapies” (hippotherapy/music therapy/art therapy), through outings with specialised educators (who were difficult to find and instruct, and couldn't be relied on for regular availability), to planning family activities around inevitable gaps. We managed to fill up the time somehow or other, but the day was fragmented into many activities, which were not oriented towards a purposeful goal: it lacked a project, which was all the more necessary given the extremely difficult period of transition our children were facing.

A deterioration of their condition over time seemed inevitable to us, while their families would become less and less able to support them due to ageing.

The idea of a Centre, which is today Casadasè, was born from the difficult situation many parents were facing, especially in relation to problematic behaviours that occurred for the first time or were becoming more frequent. At the same time, however, we believed that in all of them there were still many capabilities to develop: at that time, at least among us, discussions on rehabilitation also during adulthood started.

Our Centre would work to achieve the greatest possible autonomy for each young person, in anticipation of adult life, directing educational intervention to tangible and useful objectives, valuable for that individual person, for their needs and preferences; the educational process would be clear in all its steps. A scientifically validated approach, a careful assessment of the person, an individual program explaining objectives and strategies, continuous monitoring through collection and elaboration of data and, at the end of the process, a life plan preferably focused on work either in a natural or protected environment.

We wanted a real focus on families, who partake in the whole educational process starting from the skills evaluation which is videotaped and shared during the

final review meeting. Relatives are asked to work on the generalisation of the skills learnt at Casadasé through specific programs and tools developed for them; potential changes to the ongoing plan would be discussed with them, as well as an annual evaluation in June and a new plan proposal in September. At all times, families have access to meetings with the supervisor (who also carries out regular sessions of parent training), as well as the management and the workers.

A different role for the educators was sought, more active: by focusing on their expertise it has been possible to create a framework with no intermediaries in which educators develop and are responsible for all the stages of the intervention.

Casadasé is a flexible framework: it takes on young people who are at least 18 years old (often one year in advance so that they can adjust to the service while alternating attendance with school). There is not a maximum age limit (given that there are still many young adults who, having finished school, remained at home without any kind of support); it receives individuals with different skill levels, from non-verbal with behavioural problems to high-functioning individuals with peaks of excellence; it envisages varying the frequency of attendance according to the individual plan requirement. Today 40 young adults, 13 of them high-functioning, attend Casadasé. The educational intervention affects all areas of life; self-care and care of their living environment, physical well-being, the cognitive and affective spheres, skills and inclinations towards future work.

We apply an integrated system of intervention based on behavioural standards with reference to applied behavioural analysis and the TEACCH behavioural strategies.

Data collection is a characteristic that runs through all the activities of Casadasé. It seems like a technical matter, but actually it is the result of a call for clarity from the families. Collecting data related to the educational activities means being able to objectively present achievements and provide the families with factual information which is reliable and therefore useful. In relation to work planning, it means being able to evaluate the effectiveness of the intervention in real-time and make any variation promptly, while also ensuring the effectiveness and interchangeability of the educators, by informing them from which point to resume work that may have been carried out by a colleague in the previous session.

The work of Casadasé is integrated within the project "School of Life": the National Rail agreed to loan for use (project "Volunteers in the Station") an apartment in Figline Valdarno, a town about 25 kilometres from Florence. Our young people, in groups from 4 to 6 individuals, spend 24 hours in a natural environment, a house without the visual aids and structure present in Casadasé, with the educators in the role of observers. "School of Life" has proved to be a valuable tool for assessing the process of generalisation of the skills learnt at Casadasé, and more generally, to get to know the young people better and update the ongoing educational projects. Both high-functioning individuals and those at a medium-low level take part in the project. At-

tendance is on a monthly basis and at present there are 4 groups; members are included as soon as they achieve the minimum necessary skills.

We have been working for about 7 years: the project "Autonomy", which envisaged the creation of a Centre devoted to autism in adult age, was presented to the Region in 2008 and Casadasé started its activities in May 2011 as a pilot project. The Association manages the structure through the Board of Governors (*Consiglio Direttivo*) deriving its authority from the members' Assembly, which approves the annual budget and moral report. The operational management is entrusted to the Board of Directors (*Direzione*), formed of the Director of Health, the Coordinator and President of the Board of Governors, who acts as a bridge between the two institutions.

From a technical point of view, since 2001 the framework has evolved and the characteristics we prefigured have gradually been specified and achieved in practice. Activities, strategies and tools are tested and retained or abandoned on a case-by-case basis through a continuous updating process. We produce, for example, specific work tools for each activity area, often studied for individual cases; we have created a "library" of over 500 folders and work kits to date, which are real tools for a structured approach to learning. It is a continuous production and 6 young people, 3 of them medium-low functioning, work on it. Precisely these 3 individuals – who work half a day 5 days a week to photocopy, crop, laminate and assemble the folders – indicate that even with limited skills it is possible to carry on a real job. Our environment is protected, designed to guarantee the best conditions for these special workers, but they work in complete autonomy, asking the educators for help only if needed, just like any worker would do with their team leader. In total, we have achieved 13 socio-therapeutic placements, 3 internships and 5 regular contracts.

For placements outside of Casadasé, our educators are responsible for tutoring for as long as necessary and stay at the disposal of employers to resolve any possible issues. This is a form of "protection", but it is occasional and does not weaken the worker's autonomy and it is a great result for a small price to pay, considering how often even high-functioning individuals lose their jobs, for instance because of unexpected changes in the work environment or social misunderstandings.

Regarding the results, we can say that all of our young people have achieved significant improvement in all areas affected by the educational intervention and that learning has been generalised and in the majority of cases achieved within a small period. The young people have either declared their satisfaction, or their appreciation is otherwise clear, and we have received very encouraging feedback from questionnaires submitted to the families.

The progressive establishment of Casadasé is also due to the increasing recognition from public institutions: we collaborate with the School, Social Services and the Department of Mental Health, which forwards the majority of the requests to join the program. Together with the Town and County Councils, we are carrying out

projects to improve accessibility by training courses for Museums and Public Entities (the project to improve accessibility to Florence airport is already completed). In particular, we studied itineraries for people with autism, both low and high-functioning, for the Uffizi Gallery, the Museum of the Opera Del Duomo and (on a case by case basis) certain exhibitions at Palazzo Strozzi. These itineraries are open to Associations, Centres, Schools and Families.

In the past year, through the process of authorisation and accreditation we stipulated a convention with the Local Health Authority (USL), overcoming the previous economic insecurity stemming from the experimental nature of the initial project. The Convention provides a grant based on the number of standard users (with daily attendance for the whole week) equivalent to the highest number of effective users (with variable attendance during the day and the week). Today there are 16 equivalent users corresponding to 40 effective users.

We are well aware that the issue of effectively taking care of a person with autism is far from being resolved. When we talk about life plans we are aware that they should be developed by many entities with different competencies and that adequate resources are needed to implement them. However, even without talking about such a challenging plan, today there simply are not any places with structured environments, such as day centres or residential centres, for people with severe autism that are not merely assisted living facilities. Casadasé takes charge of only a part of the process, but we believe that when a more appropriate way to take care of people with autism will be achieved, Casadasé could find a functional role within a broader process. After all, we can present the experience of Casadasé precisely because it is confined, concrete, clear and thus easy to replicate if desired.

SOCIAL AND WORKING INCLUSION FOR YOUNG ADULTS WITH AUTISM SPECTRUM DISORDER (ASD) REQUIRING VERY SUBSTANTIAL SUPPORT. THE SOCIAL FARM COOPERATIVE GIUSEPPE GARIBALDI

The Social Cooperative Giuseppe Garibaldi has the objective to promote social and working inclusion of young adults with Autism Spectrum Disorder (ASD) requiring very substantial support. The path that led to the foundation of the Cooperative began during high school. A group of parents of adolescents with ASD requiring very substantial support met each other while their children were attending an agricultural high school (ITAS Giuseppe Garibaldi, Rome).

According to the Italian law 104/1992 [12], every student with a certified disability should be provided with Individualized Educational Program (*Piano Educativo Individualizzato* – PEI). The PEI identifies individualized tools, tactics and methods to accomplish an optimal learning environment in the following dimensions: relationships, socialization, communication, interaction, orientation and autonomy. The same law also establishes a working group for school integration (GLH) for each student with disability enrolled in the school.

The working group is composed of the Headmaster or a delegate, the Class Council or, in its representation, one or more curricular teachers or the support teacher, the healthcare operators following the case and the pupil's parents. In addition, eventual educational-assistance operators and/or technicians provided by the Municipality, school collaborators and desirably all other institutional and professional figures of interest for the inclusion of the pupil participate in the working group.

During the high school years, with the help and supervision of The Department of Social and Developmental Psychology of Sapienza University, a group of parents and their children were able to experience, by their PEI, habilitative and support interventions, such as Parent training, Parent counseling and Peer mediated intervention (PMI). All of these interventions are object of research studies that indicate positive evidences, though a restricted number of controlled studies are available.

For the parents who, later, founded the Cooperative, PEI and GLH were the preparatory resources for planning the social and working inclusion after school. The efforts of these parents showed that a good use of these tools, guaranteed by the Italian legislation, are able to prepare the continuity of social inclusion during the transition from school to work. The Individual Project (*Piano Assistenziale Individuale* - PAI, as defined by the Italian law 328/2000 [13], represents the keystone for this continuity. According to the law, the local authority (Municipality), together with the local sanitary district, individualizes the social and health services to the specific needs of the individual with disability to develop the Individual project. The objective of the Individual Project is the successful inclusion of the person with disability in family, social, educational and working contexts.

When high school came to an end for this group of adolescents, their parents had no support to continue their children's habilitation process from a legislative and institutional viewpoint. The only opportunity given by the national health system was the adult day care service, where one health worker or one educator takes care of various individuals with disabilities. Nevertheless, the activities offered by this kind of services do not consider social and working inclusion as a central goal, on the contrary this was the main objective for this group of parents for their daughters and sons, so they needed a different option.

Therefore, the critical moment for the foundation of the Cooperative was the end of high school. The parents obtained the management of a part of the field belonging to the agricultural high school previously attended by their children and established the Social Cooperative Giuseppe Garibaldi in which half of the members of the Cooperative are young adults with ASD requiring very substantial support. The main Cooperative business is agritourist service and agricultural production. Every family has its own resources and has an active role in their management. Young adults with ASD receive disability pensions. Additionally, these families requested and obtained the activation of a specific type of assistance (indirect assistance through a small voucher),



active in the city of Rome, namely the Autonomy and Social Inclusion Service of the Person with Disability (SAISH), for their children. This service can be provided either directly through an operator, chosen by the social assistance system, or as indirect assistance, through the definition of a financial support which allows the family to choose their own operator. The SAISH service is usually considered a home care assistance service for non-self-sufficient individuals. The families of the Cooperative requested and obtained that this service could be given to the individual not only at home, for personal autonomy needs, but also in other contexts, where these operators can be of support for social and working inclusion, opening the way for new welfare solutions. However, it should be emphasized that in the case of the families of the Cooperative the individual project is completely projected and self-managed by the families and does not require any services, except for the indirect assistance above mentioned. This indirect financial assistance is weighted on the degree of disability and covers the cost of individual care attendant, who has the role of individual tutor in the Cooperative activities. The Cooperative has not formal agreement with Local Health Authority or Municipality to provide services to people with disabilities. The Cooperative is made up of the individual projects brought in by the children.

The Cooperative supports the individualization of the habilitative process following the principle that the objectives and the strategies to accomplish them must be tailored on the specific individual's needs and abilities. In line with this principle of individualization, in the last few years the Cooperative has been using the Collaborative Model for Promoting Competence and Success (COMPASS) in an adapted version for young adults and working contexts [14]. This model has been successful in improving accomplishment of individual educational planning goals in pre-school and elementary school settings [15]. The adaptation was provided by The Department of Developmental and Social Psychology of Sapienza University, that has subsequently been monitoring the Cooperative activities through the years and after the transition to post-school experience. This model allows for the individualization of the goals and the selection of specific educational strategies. The accomplishment of the goals of each individual is continuously monitored and the goals are regularly updated.

The Cooperative has collaborated with research institutions, such as Sapienza University and Istituto Superiore di Sanità (ISS), for the implementation of a project financed by the European Community (i.e. European Social Fund) aimed at implementing innovative strategies for individual planning of disabled people in rural context. Through the years, the support of these institutions has been central for the adoption of a scientific monitoring of the of the Cooperative actions, in addition to providing training opportunities for families and tutors.

The good practices of the Cooperative include: i) every young adult with ASD has his/her own tutor, who has the role to facilitate the habilitative process and the accomplishment of the individualized goals, ii) the family actively participates in the habilitative process, iii)

team work (parent-educator-consultant psychologist-young adult) is promoted.

The Cooperative activities are aimed at integrating practices used in individual rehabilitation. Thus, the foundation and growth of the Cooperative gradually developed a real inclusive reality, which has been more and more open towards the citizens and the local community, such as the schools, in addition to attracting volunteers from foreign countries.

Recently, the results of a survey performed by the economy, management and social innovation Master of the University Tor Vergata, clearly indicate that the Cooperative is better described as a "Community Cooperative" rather than a "social enterprise". As such, it relies on the production of the "social goods" rather than "economic goods". Its sustainability relies on the individual contribution of the partners and donations which limit its economic sustainability and its further development with social disabilities into agriculture. The central goals are social and working inclusion of individuals with ASD, but these activities also have the objective of promoting educational and cultural services to support families and educational institutions. The Cooperative maintains a new and different idea of enterprise, more responsible and linked to the needs of local communities. This path is made possible through the particular nature of social agriculture, which consists in the production of public goods connected to the life of the community and the territory. The fact that the Cooperative is a real agricultural company promotes an open attitude: the members of the Cooperative, with and without ASD, interact with the people living and working in the local area by selling agricultural food products in the city farmers markets, by serving the tables in the Cooperative restaurant and by working in the field side by side with the people growing vegetables in an urban vegetable.

The opportunity for social and working integration for a group of young adults with ASD is made possible through the active action of the cooperative members to keep the Cooperative active, despite administrative and economic management difficulties. Hopefully, in a near future, the public administration, as it has already happened in other Italian regions, will play a more active role in favoring the network of services which may facilitate active involvement of the individual and her/his parents, in promoting the sustainability of these spontaneous initiatives.

THE FONDAZIONE MARINO PROJECT: FORGING THE PATH TOWARDS AN INDEPENDENT LIFESTYLE FOR PEOPLE WITH INTELLECTUAL AND NEURODEVELOPMENTAL DISABILITIES

Autism is a disorder leading to a permanent disability and manifests itself in different ways and with different levels of severity. We often think of autism as a developmental disorder, forgetting that the child will eventually become an adult affected by autism: the sooner we intervene on it, the better the outcomes will be. Thinking about a child's future means building adequate and competent paths, which could lead him/her to the adult

life with cognitive, relational and professional tools useful to express him/herself and fully live his/her life.

In recent years, research advances in the conceptualization of the disorder, has contributed to prevent families from feeling directly responsible for their children's disorder, framing it as a complex and definite diagnostic entity, with an organic base in which genetic and environmental risk factors concur in manner. However, families still carry the burden of organising a comprehensive support which although explicitly stated in one of the most complete regulatory frameworks in the international scene, is still slow to become a reality. Therefore, families are left alone in trying to think about and build the future of their children.

The Marino Foundation for Autism ONLUS

The Marino Foundation for Autism ONLUS is a high-integration, residential health facility with rehabilitation and enabling purposes, which has been operational since the 4th August 2008. It is currently accredited by and agreed upon the Provincial Health Authority (ASP 5) of Reggio Calabria as a residential centre, which provides people affected by autism with continuous care. It also delivers cognitive-behavioural interventions, in line with the international scientific recommendations and evidences.

The Marino Foundation for Autism ONLUS was started by a couple of parents having two children affected by autism to create an environment to foster their children, creating an environment that could help them also in the transition to adulthood. This family wanted to interpret the needs and difficulties of other families who find themselves foreseeing what would happen in the future, when their children will be alone in the desert of a social care system, which does not respond to the life-time perspective of autism. The model of the Foundation follows a main philosophy: the search for well-being and the highest level of self-determination for each of the young people living there.

The realization of the Marino Foundation's residential service did not start from a pre-established model; it is rather based on the idea of a parent, who developed the design and suggested precise choices, which move from the reality of a family that has been living in contact with autism. The Marino Foundation shares and adheres to the principles established by the Convention on the Rights of Persons with Disabilities adopted by the UN in December 2006. It has a Code of Ethics to which all users are bound.

The aspects that acted as a framework in the fulfilment and sustainability of the project concern:

- the presence of the family in the management of the service;
- location and size;
- specificity and adequacy of the intervention in the various stages of adulthood;
- acquisition and enhancement of capabilities;
- job placement;
- social inclusion.

The philosophy and practice of intervention is defined first and foremost by the direct involvement of parents in the management of the service, putting in

place the professional and personal experience deriving from their direct contact with and knowledge of the autistic disorder from within. No professionalism can ever equal the attention in care, assistance and rehabilitation of a parent, who always looks for a higher and higher level of professional skills and humanity. This element differentiates Marino Foundation from a prevalent bureaucratic-administrative and rehabilitative management, including an interest centered on the fulfilment and well-being of the person affected by autism, which represents the regulating principle for all those people who contributed to build such an enterprise. In order to promote this kind of management the Marino Foundation, by statute, takes the form of a Social Enterprise participated by the community to guarantee continuity and cautious management. In addition to the founding partner registers the participation of the Province of Reggio Calabria, the Municipality of Melito Porto Salvo, and the Parish in the figure of the Archpriest as supporting members. Each of them owns the right to appoint a representative in the Board of Directors and to take charge of the management in case the founding partner is absent, through the appointment of the Board of Directors and its Chairman.

The choice of an adequate residential area represents a complex and delicate topic: this choice is often accompanied by a certain mental rigidity due to – and justified by – the vision and experience of a residence that does not resemble a typical home, excluding participation to the social environment and to life itself. In this regard, the Marino Foundation follows the perspective of building a real home, a personal place including affections, history, choices and acquisition of skills. In this home, the family has a relevant role in the path towards the acquisition of independence outside the household, showing its continuous presence to the child during this phase. Parents can access the facility at any time and without a pre-announcement when they desire to share small daily moments with their child; they can participate in the drafting of their child's life project by suggesting precise choices and indications and are regularly informed about the child's progresses.

The Marino Foundation facility has a particular location and particular dimensions. The structure is located on the slopes of a hill, adjacent to an urban settlement. It is 1800 metres from the sea and includes a park of 6000 square metres around. The small size of the town in which it is located facilitates the processes of inclusion, keeping away the frenetic pace of the city; however, it is possible to reach the city centre in a few minutes. Its architecture is similar to that of a common house with welcoming and safe environments, fitting the needs and difficulties of children and meeting the safety standards. The structure is built on three floors: the ground floor is entirely dedicated to work activities. It includes structured environments within which the activities foreseen by individualized projects drawn up on the basis of the needs and emerging skills of the child are carried out daily. In order to achieve the goals foreseen by these projects, cognitive - behavioural procedures are performed. On this floor, there is also a gym for physical activities.



The first floor includes a medical office, rooms for social and psycho-educational assessments, a dining room, a kitchen, a music and relaxation room, a television room. Here, there is also a wide courtyard; part of the courtyard is covered by an insulated roof and another part is cultivated with grass lawn. On the second floor there are bedrooms and a laundry service. Each bedroom has two beds with independent sanitary facilities. On this floor there is also a room equipped with a monitoring system linked to all bedrooms, which is occupied by an operator at nights and through which it is possible to control the children constantly and discreetly. The monitoring system represents a valid working tool, and allows the families to view the child's room from home, by connecting to the system through the internet.

The structure is equipped with a swimming pool that is used both by the children who carry out various activities followed by a specialized operator, and by external people for their motor and hydrotherapy rehabilitation. The idea of providing a service that is open to the community stems from the desire to open the doors to a new culture of illness and disability. Only by knowing the disability and, above all, by knowing people with disabilities, we can learn to love them, accept diversity and avoid labels. The workspace extends to an outdoor area, surrounded by greenery, where are held the laboratories of horticulture and production of ceramics, paper and pasta.

The maximum number of people that can be admitted to our facility is ten; this low number responds to one of the starting hypothesis, supported by international research, to give the residence the aspect of a condominium in order to prevent the "pulverization" of the medical and enabling intervention. This makes it possible to guarantee an increased attention and quality of services to each of our guests.

The current dedicated organizational model clearly reflects our de-medicalized perspective of the intervention, promoting a strongly educational approach; as a matter of fact, our staff includes seven professional educators, three health and social care workers and an auxiliary. More specifically, the general operating staff is composed of a coordinator of the psycho-educational team, a psychologist, a general practitioner, a social worker, a psychiatric rehabilitation therapist, six educators, three health and social care workers, an auxiliary and a gardener. The Marino Foundation has preferred not to include the figure of a professional nurse in its staff, favouring the presence of one more educator and a full time-employed psychologist. The psycho-educational team is responsible for carrying out the functional assessment and for drafting the individualized project that must be read and shared by the family. The choice to include a qualified doctor in the staff stems from the awareness that the person affected by autism, can also contract other various diseases as any non-disabled person during the course of his/her life; the only drawback is represented by the serious communication difficulties of an autistic person, who often cannot reveal the symptomatology, which is expressed through problem-behaviours. By direct observation of

the children, a consistent number of pathologies have been detected which could have led to dysfunctional behaviours. The consequent observation and treatment of these pathologies has eliminated the discomfort and drastically reduced the issue of problem-behaviours, improving children's quality of life. The enabling and rehabilitative activities are structured according to the psychoeducative model based on efficiency/effectiveness parameters [16].

An individualized project is realized considering each child's strengths, weaknesses and attitudes. These are specified by a functional diagnosis that indicates the emerging or absent abilities, which represent the enabling goals for the child to be pursued, in the medium or long term, in different contexts of life (rehabilitation, free time, etc.). The project foresees individualized or small group interventions; while the skills already present in the child represent the main points on which the entire treatment will be based. "Intelligent", non-accidental learning is favoured by the fact that the individualized training activities for the acquisition of specific skills are accompanied, on a daily basis, by "generalization" activities that are carried out in different laboratories: the flora- nursery laboratory, the laboratory for the processing of ceramics, or the greenhouse that is used for the winter cultivation of vegetables and flowers. The laboratories complete the employment and work space of the Marino Foundation. The so structured rehabilitation intervention, promotes the autonomy and independence of the children, increasing their level of freedom and awareness of the environment they live in.

The choice of the occupational activities not only depends on the various specific skills and competences we want the child to improve, but also on other equally important variables. Considering that the child is approaching adulthood, it is fundamental to promote activities, which are respectful of this aspect; this will make them feel an active part of their community.

"SPITI TI STOLI" – HOLIDAY HOME

The values of solidarity, participation and attention to others and to the complex problems that families have to face, led the Marino Foundation to take on another project with the purpose to give families relief and help them detach from the difficulties of everyday life. In 2016, the Holiday Home "Spiti Ti Stoli" was inaugurated: it is an apartment on the sea confiscated from the mafia, which offers a temporary residential service. It was especially readjusted and structured to accommodate people affected by autism from all over Italy, with the intention to give relief to their families and, at the same time, allow each child to continue to carry out enabling activities in a protected environment, followed by specialized personnel. For what concerns laboratories, activities linked to everyday life have been privileged, so much so that they can be considered real work within an existential perspective.

"LOCANDA TRE CHIAVI" – SOCIAL CANTEEN

The Marino Foundation, has not only carried out and implemented rehabilitation programs, but has also launched a methodological-operative model for the

purpose of a protected job placement for the young people it hosts, creating a fundamental collaborative network in the reference territory. Therefore, as well as making use of efficient educational and enabling methods that lead to an improvement in the quality of life as a final goal, the job placement for children, now adults, has been set as a goal and as a good practice. This is how Locanda Tre Chiavi was born in 2014, after three years of intensive training, adaptation, acquisition of social, cognitive and professional skills by the children. Here, three of the Marino Foundation's young people are employed, supported by a supervisor who acts as coordinator. The work activity carried out by each child working in the Locanda was chosen based on personal inclinations, from manual and sensorial skills, to cognitive ability and attitudes. A child completed his studies, attending a hotel school, where he learnt to work as a waiter and obtained a diploma. The Locanda Tre Chiavi is a social canteen and offers up to 40 hot meals a day to poor people for free. Our children take care of the reception of guests, the arrangement of the room where meals are served (setting and clearing the table, local cleaning ...), the supply of the food that will be cooked (going to the supermarket to buy bread, fruit, vegetables ...), table service. The Locanda is the place where the acquired skills are expendable for oneself and for others and have a clear purpose: achieving personal autonomy, emancipation, solidarity and self-determination. The Locanda is a place where the concept of disability is turned upside down: the person affected by autism is no longer a burden for the society, someone who needs assistance; he becomes an active element for the territory he lives in, he can express himself and become a source of help. Moreover, the possibility for the child of being able to buy what he wants with the money he gained by himself makes him feel motivated and happy. Work is the springboard for adult life that has made it possible to strengthen many unexpressed skills, to acquire adherence to the task, to interact with others, to stimulate the ability to manage time. The Locanda is a workplace where you can smell pasta and dignity.

Since the very beginning, the Marino Foundation has adopted an innovative approach in the realisation of its main goal, which has become a real mission: searching for children's well-being as a result of the combination of different factors contributing to the fulfilment of a life project in which the residences represent only a starting point, rather than places where all dreams and expectations could end. Focusing just on the perspective of "what will happen to our children when we will not be present anymore", the choice of a residence could be seen as a forced act, as a sad handover of an adult person from his/her family environment to a facility supplying the services and assistance this person needs. However, this perspective does not take into account the existential paradigm, which is at the basis of such a choice. The Marino Foundation was created to become a place able to satisfy, at the same time:

- he search for autonomy and independence of families, no longer able to cope with the needs of their children becoming adults affected by autism;
- the need of these children to acquire autonomy de-

spite their disability and far from their family environment, in order to achieve self-determination through personalized paths, according to their age and skills.

The model of life and work offered by Marino Foundation represents a laboratory for organizing independent services for people affected by autism. It inspires a model of emancipation for the achievement of an autonomous life, supported by a protected job placement; this leads to easier housing solutions, maintaining a continuity of care with the residential structure of origin. A new Decree of Accreditation by the Regional Administration of Calabria (DCA 81/2016) originated from this experience; this Decree establishes the construction of a Multifunctional Centre for each Provincial Health Authority, consisting of 4 modules. The housing module as well as the day care centre module are connected to two housing communities with the purpose of creating a living environment for those who have achieved a good level of autonomy through the acquisition of skills within the residence or day care centre; these people can live in a protected environment, which will have a lower burden of care, giving them a higher possibility of self-determination in approaching the lifestyle of a non-disabled person. Work, free time, personal autonomy and quality of life are central and essential elements for the sustainability of the multi-purpose centre. A person-oriented approach gives value to various aspects of life and to the individual perception of satisfaction. The skills acquired or their enhancement through specific projects are key element for accessing services or activities with a lower need for assistance, having the possibility to live in a protected environment.

In order to face the continuous changes concerning the needs and achievements of the adult affected by autism, it is necessary to imagine multi-faceted housing solutions, organized in standardized way, but open to changes, with a certain flexibility in budget management, allowing differentiation of care costs and foreseeing the possibility to allocate in itinere resources for specific objectives.

The outcome would be positive for many aspects:

- economic: cost rationalization;
- effectiveness: adequate service response to the demand;
- quality of life and opportunities: anyone, regardless of the severity of his/her initial impairment, can have an opportunity for redemption.

The residence becomes the fulcrum of habilitation and civilization and the Marino Foundation has given proof of this.

CONCLUSIONS

The examples of good practices reported in this contribution place particular emphasis on some of the key points addressing the need of young and adults with autism spectrum disorders. The experiences described here are necessarily focused on specific issues, since we are aware that when we talk about life plans, these should be developed in connection with social and health services and implemented with adequate resources. However, today there are no places with structured environments, such as day care or residential centres for



people with severe autism that are not merely assisted living facilities. Casadasé, Cooperativa Garibaldi and Fondazione Marino are the answer to the lack of a network of services capable to sustain and stimulate a life project for people with autism. They create settings and provide competent support and opportunity for the development of those individual outcomes that promote quality of life of persons with autism. These experiences aim to manage the transition towards autonomy, and, remarkably, they produce solutions strongly dependent upon the resources available in their territory. Meanwhile, they all share the same guidelines that allow accounting for the needs and achievements of young and adults affected by autism. The three experiences are best described as: a self-managed special school that becomes a “school of life”, a social farm offering sheltered employment to young people with severe autism

and promoting urban regeneration caring for a public green space converting it into a small farm, a multifaceted residential housing for a small group of young and adult people with autism that looks ahead, aiming for quality of life and opportunities for anyone, regardless of the severity of the impairment. Hopefully, in the near future, the public administration will play a more active role in favouring the birth of a network of services which may promote sustainability of parents' spontaneous initiatives [9, 10].

Conflict of interest statement

The Authors declare that they have no conflict of interest.

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REFERENCES

1. Anderson KA, Sosnowy C, Kuo AA, Shattuck PT. Transition of individuals with autism to adulthood: A review of qualitative studies. *Pediatrics*. 2018;141(Suppl. 4):S318-S327. doi: <https://doi.org/10.1542/peds.2016-43001>
2. Camarena PM, Sarigiani PA. Postsecondary educational aspirations of high-functioning adolescents with autism spectrum disorders and their parents. *Focus Autism Other Dev Disabl*. 2009;24(2):115-28.
3. Thompson C, Boëlte S, Falkmer T, Girdler S. To be understood: transitioning to adult life for people with autism spectrum disorder. *PLoS ONE*. 2018;13(3):e0194758.
4. ISTAT. *Inclusione sociale delle persone con limitazioni funzionali e invalidità gravi*. Roma: ISTAT; 2013.
5. Scott M, Falkmer M, Girdler S, Falkmer T. Viewpoints on factors for successful employment for adults with autism spectrum disorder. *PLoS ONE*. 2015;10(10):e0139281.
6. Everson JM. Using person-centered planning concepts to enhance school-to-adult life transition planning. *J Vocat Rehabil*. 1996;6(1):7-13.
7. McCausland D, McCallion P, Brennan D, McCarron M. In pursuit of meaningful occupation: Employment and occupational outcomes for older Irish adults with an intellectual disability. *J Appl Res Intellect Disabil*. 2019;00:1-12. doi: 10.1111/jar.12681
8. Reddington T, Fitzsimons J. People with learning disabilities and microenterprise. *Tizard Learning Disability Review*. 2013;18(3):124-31.
9. Camoni L, Picardi A, Venerosi A. New mode of care. Value and limit of the person-centered care planning for people with mental disability. *Ann Ist Super Sanità*. 2020;56(2):193-205.
10. Borgi M, Correale C, Grizzo A, Orlich R, Cirulli F. Social agriculture as contextual factor to promote health, autonomy and inclusion. *Ann Ist Super Sanità*. 2020;56(2):206-14.
11. Smith LE, Anderson KA. The roles and needs of families of adolescents with ASD. *Remedial Spec Educ*. 2014;35(2):114-22. doi:10.1177/0741932513514616
12. Cappa C, Figoli M, Rossi P. Network of services facilitating and supporting job placement for people with autism spectrum disorders. The experience of the ASL Piacenza, Italy. *Ann Ist Super Sanità*. 2020;56(2):241-6.
13. Italia. Legge 8 novembre, n. 328. Legge quadro per la realizzazione del sistema integrato di interventi e servizi sociali. *Gazzetta Ufficiale – Serie Generale n. 265, 13 novembre 2000, Suppl. Ordinario n. 186*.
14. Ruble L, McGrew JH, Toland MD. Goal attainment scaling as an outcome measure in randomized controlled trials of psychosocial interventions in autism. *J Autism Dev Disord*. 2012;42(9):1974-83. doi:10.1007/s10803-012-1446-7
15. Ruble L, McGrew JH, Snell-Rood C, Adams M, Kleinert H. Adapting COMPASS for youth with ASD to improve transition outcomes using implementation science. *Sch Psychol*. 2019;34(2):187-200. doi:10.1037/spq0000281
16. Moderato L. *Modello superability. Un approccio globale alle disabilità intellettive, ai disturbi pervasivi dello sviluppo e all'autismo*. Firenze: Vannini; 2009.