

Caring for Autistic Adults. A Qualitative Analysis Under the Lens of Capability Approach

Stefania Bari, Rossella Tisci, Roberto Burlando, Roberto Keller

How to cite

Bari, S., Tisci, R., Burlando, R., Keller, R. (2018). Caring for Autistic Adults. A Qualitative Analysis Under the Lens of Capability Approach. [Italian Sociological Review, 8 (2), 243-264] Retrieved from [<http://dx.doi.org/10.13136/isr.v8i2.189>]

[DOI: 10.13136/isr.v8i2.189]

1. Author information

Stefania Bari

Adult Autism Clinic, Local Health Authority (LHA), ASLTO2, Turin, Italy

Rossella Tisci

Department of Sociology, Macquarie University, Sydney, Australia

Roberto Burlando

Department of Economics and Statistics Cognetti De Martiis, University of Turin, Turin, Italy

Roberto Keller

Adult Autism Clinic, Local Health Authority (LHA), ASLTO2, Turin, Italy

2. Author e-mail address

Rossella Tisci

E-mail: rossella.tisci@hdr.mq.edu.au

Roberto Burlando

E-mail: roberto.burlando@unito.it

3. Article accepted for publication

Date: October 2017

Additional information about
Italian Sociological Review
can be found at:

About ISR-Editorial Board-Manuscript submission

Caring for Autistic Adults. A Qualitative Analysis Under the Lens of Capability Approach

Stefania Bari*, Rossella Tisci**, Roberto Burlando***, Roberto Keller****

Corresponding author:
Rossella Tisci
E-mail: rossella.tisci@hdr.mq.edu.au

Corresponding author:
Roberto Burlando
E-mail: roberto.burlando@unito.it

Abstract

The issue of the well-being and quality of life assessment of autistic people – especially autistic adults – and of their families (representing in most of the cases the main caregivers) is still rather underexplored, both in medical and in social disciplines. In this research we tackle the argument using the capability approach. At first we highlight the advantages, at the methodological level, of this approach and then present the study and its findings. The first phase of the study aimed at finding out the main needs of autistic people and of their families interviewing various members of 56 families of 59 autistic adults (in total we interviewed 86 individuals) resident in Italy, in the area of Turin city and its province. The second phase involved 30 autism support workers, mainly professional educators, with whom we further discussed and deepened the issues previously analysed with the families. For the respondents of our research the most important opportunities (capabilities) enabling people to live a dignified life are work, identity and social relations, and autistic adults often miss these opportunities in their life, for a number of reasons. From the exploration of these

* Adult Autism Clinic, Local Health Authority (LHA), ASLTO2, Turin, Italy.

** Department of Sociology, Macquarie University, Sydney, Australia.

*** Department of Economics and Statistics Cogneetti De Martiis, University of Turin, Turin, Italy.

**** Adult Autism Clinic, Local Health Authority (LHA), ASLTO2, Turin, Italy.

reasons the study proposes to rethink the current approach of interventions. In particular the approach should switch from cure to care, in order to consider the autistic person not as a patient in need of medical treatments but as an agent seeking for his/her own well-being.

Keywords: autism, capability approach, quality of life.

1. Introduction

Autism spectrum disorders (ASDs) indicate a group of genetic and early-onset neurodevelopmental disorders. The ASDs occur on a continuum of severity going from cases in which the intellectual and socio-relational abilities of people affected from this group of disorders are significantly compromised to cases in which these people have average to above average intellectual abilities though their socio-relational abilities remain deficient. In the majority of cases ASDs are permanent and, starting from adulthood, further problems related both to clinical aspects – such as diagnostic errors and comorbidity (Luciano et al., 2014; Keller et al., 2015) – and to policy ones – such as the lack of specific interventions targeting autism – occur.

In this scenario, families, especially aging parents, are often left alone to cope with the difficulties affecting the lives of their autistic relatives as they become adults.

The issue of the well-being and quality of life assessment of people with autism – especially of adults with autism – and of their caregivers is still rather underexplored both in medical and in social disciplines.

The capability approach, formulated by the economist Amartya Sen and moral philosopher Martha Nussbaum, is a theoretical and methodological framework that can bring new insights within the field of disability studies, including the ASDs studies. The capability approach played a pivotal role in the redefinition of the traditional views of well-being. The old approach focused exclusively on the quantitative dimensions of well-being whereas the capability approach embraces an integrated view in which also qualitative dimensions – such as human relations, freedom of choice, empowerment and agency – matter (Sen, 1999). In particular, capabilities represent ‘*notions of freedoms in the positive sense: what real opportunities you have regarding the life you may lead*’ (Sen, 1987: 36).

Over the years the capability approach has been applied to several fields of social research, including disability studies. Despite the strong empirical evidence on the relevance of the capability approach in the field of disability studies (Burchardt, 2004; Terzi, 2005; Mitra, 2006; Biggeri, Bellanca, 2011a,

2011b) its application to the specific category of autistic people remains underexplored. This study aims at contributing to fill this research gap.

The research focus is twofold. From the methodological point of view, it looks at the reasons for which the capability approach is a suitable framework for analysing the well-being and the quality of life of autistic people and of their families. In terms of policy implications, the research aims at exploring the main problems autistic adults and their families face on a daily basis.

2. Assessing the well-being of people with autism: why the capability approach?

The issue of the well-being and quality of life assessment of autistic people still needs additional in-depth analysis. This issue has been addressed only recently by the philosopher I. Robeyns (2016), who analysed the features that makes the capability approach a suitable framework for conceptualising the well-being and the quality of life of these persons.

The main aspect is the vision of well-being embraced by this approach. According to the capability approach, in fact, people's well-being is intrinsically multidimensional and each relevant dimension is unique and incommensurable with any other, not to mention reducible to a common measure. All human beings, and especially autistic people, can experience very low levels of well-being on some dimensions and very high ones on another dimensions. One-dimensional approaches to well-being cannot not grasp this fundamental aspect. For instance, according to mainstream well-being theories, which consider the gross domestic product as the only well-being indicator, the quality of life of a high income autistic person would be higher than that of a lower income neuro-typical person even if the latter has the chance to access many opportunities which are inaccessible (or scarcely accessible) to the autistic person. Moreover, *ceteris paribus*, an autistic person might need a higher amount of resources and commodities to achieve the same level of well-being of a neuro-typical person.

Secondly, within the capability approach diversity is recognised as a peculiar aspect of the human experiences. Human beings differ from one another in their personal characteristics, values, goals, environment and ability to convert resources in well-being (Sen, 1999). In this perspective, autism can be included among the differences characterising the humankind (Terzi, 2005). The central role of human diversity within the capability approach leads to fully acknowledge that everyone has special needs, an orientation that, at the policy level, ask for customised interventions (Mitra, 2006; Biggeri, Bellanca, 2011a, 2011b). In order to take the real needs of people into serious

consideration, it is necessary to involve them both in the selection process of relevant well-being dimensions and in the impact evaluation of interventions on the identified dimensions (Burchardt, 2004; Terzi, 2005; Mitra, 2006; Biggeri, Bellanca, 2011a, 2011b).

However, there are some cases – such as those of people with severe intellectual disabilities or very young children – in which the above-mentioned involvement is very difficult, if not plainly impossible. In these cases we need to shift the focus of the analysis from individuals to the relations between individuals and their caregivers, who will be the ones entitled to select the relevant dimensions of well-being on the behalf of the subjects in need of care. The capabilities resulting from this relation are called external or social capabilities (Foster, Handy, 2008). As underlined by Sen (2008), in fact, being a capabilities holder does not mean only being provided with more power to improve one's own life; it also means being provided with more power to improve the lives of other human beings, especially those of vulnerable subjects.

The active involvement of intended beneficiaries in planning, monitoring and evaluation of interventions targeting them is in line with another key idea of the capability approach, i.e. the focus on the achievements process rather than on the achievements themselves (Sen, 2009).

This participatory approach not only allows the analysis to be focused on real people's goals, needs and values; it also guides people to reflect on their lives and to become aware of their own potentialities, enlarging their capabilities. In the capability approach perspective, in fact, what matters is not only how much people are free to expand their capabilities but also how much they are aware of this expansion (Testi, Biggeri, Libanora, 2011).

A further contribution of the capability approach in this area depends by its complementary role to both medical and social models of disability (Terzi, 2005). This is due to the fact that autism and disability studies carried out using this framework focus more on the consequences disability imposes on people's biographies and daily experiences – i.e. on how disability impacts people's capability-set – than on the causes of disability as do the studies carried out within the medical model and social models (Dubois, Trani, 2009). This reinforces the prescription that analyses carried out using the capability approach should aim at giving voice to autistic people and their caregivers.

3. Research methodology

The research presented here involved a number of caregivers of autistic adults living in Italy, in and around the area of Turin, including both families

and autism support workers (mainly professional educators). The data have been collected over a period of ten months through semi-structured interviews (both for families and for autism support workers) and through an on-line questionnaire¹ (used only for the workers)².

Since within the capability approach perspective people's participation is a fundamental aspect of their quality of life, a qualitative methodology has been used to carry out the research. This made it possible a greater involvement of respondents in the discussions on the themes under investigation.

For each question, both in the questionnaires and in the interviews, participants have been asked first to attribute a numeric value (on a scale from 1 to 10) to their opinion on each specific issue and then to discuss their answer. More precisely, research participants have been asked to provide their opinion on the importance, effectiveness or conformity (depending on the question) of specific items. In order to simplify the communication of the findings, quantifications from 1 to 4 have been considered as NON important/effective/compliant; those from 5 to 6 as LITTLE important/effective/compliant; those from 7 to 8 as important/effective/compliant; those from 9 to 10 as VERY important/effective/compliant.

The following discussion aimed at understanding the narrative accounts and life stories of the participants. To facilitate such understanding the interviews were carried out within an empathic emotional climate, characterised by a proactive listening and by the attempt to understand the feelings beyond the verbal information.

In particular research participants have been given the chance to further deepen their narrative accounts through some questions (such as 'Is there anything else you want to add?' or 'Do you have any suggestion?') and to suggest policy options. As to the latter the focus was especially on the management of available services and programs for autistic adults and the 'after us' issue, i.e. what will happen to autistic people after the death of their caregivers.

¹ The questionnaire was sent via mail to the autism support workers prior to their interview, asking them to identify the capabilities all human beings – regardless of autism and disability – should have to lead a life worth living. The same question was asked to the families during the interview. In the case of autism support workers, we needed such a list of capabilities prior to the interview in order to use it, during the interview, to check whether the services provided by the organisations/cooperatives for which they were working were enhancing the selected capabilities. This issue deserves a further investigation. Only 20 autism support workers (over the 30 contacted) returned the completed questionnaire.

² Both methods have been drawn from the structure of a survey on the capability approach and disability conducted in Tuscany (Italy) by Biggeri and Bellanca (2011b).

The data collected in these ways have been then analysed thematically. Four core themes have emerged from the interviews: *i*) capabilities; *ii*) life planning; *iii*) training; *iv*) services.

The interviews, both with families and with autism support workers, have all been face to face ones. The themes discussed with families have been revisited and further deepened with the workers in view of their professional experience in the area of autism.

For instance, regarding life planning, they have been asked to briefly outline who are, in their view and irrespective of the current situation, the stakeholders who should be involved in the realisation of a life plan for autistic people and what are the main features this should have. Regarding the services, they have been asked to provide some suggestions on how to improve the interventions that target autism and on how to make the communication between families and services providers more effective.

In general, the families have been interviewed in the city of Turin, in the spaces made available by the Adult Autism Spectrum Disorder Clinic. In some cases, especially when respondents were resident in towns within the province and not in the city of Turin, the interviews took place in the spaces made available by some local organisation or cooperative working on autism, in order to facilitate their participation to the study.

The autism support workers have been interviewed in the spaces made available by the organisations and cooperatives they were working for, whether within the city or in the province of Turin.

Each formal interview lasted between 30 and 40 minutes; but the interviewers allowed more time (up to a total of 1 hour for each respondent) letting everyone to speak freely and without interrupting the flow of words (often emotionally imbued).

The research had been presented through a letter delivered via e-mail or in person during some training courses on autism and family meetings. Several associations and organisations working on autism in the Turin area played a crucial role in promoting the research, encouraging their members and users to contribute to the study. The respondents have finally been recruited on a volunteer basis, through telephone calls they themselves made to a psychologist with expertise in the area of autism in order to schedule an appointment for the interview. Before starting the interview, each participant was provided with an informed consent form, stating the purpose and the method of the research and guaranteeing the data anonymity and the right of withdrawal from the study at any time.

In the case of families whenever possible at least two relatives (in general the parents) of the autistic person were interviewed in order to grasp the differences in opinions and in possible gender-based perspectives.

In the first phase (from September 2015 to March 2016), the study involved 56 families of 59³ autistic adults aged 18-46, for a total of 86 persons interviewed.

In the second phase (from March 2016 to July 2016), the study involved 30 autism support workers – mainly professional educators – working for 6 different organisations/cooperatives located in the Turin area.

The 86 people interviewed were aged 37-84, the majority of them (64%) were female and autistic adults' mothers. 63% of respondents were living in the city of Turin whilst the remaining 37% in the surroundings. 50% were employed whilst the remaining ones were retired or, in the case of female respondents, housewives. More precisely, 22% of the respondents were housewives (all women); 28% were retired (eleven women and thirteen men); 21% were working as office workers/ employees (seven women and eleven men); 10% were working as teachers (seven women and two men); 7% were workers (three women and three men); 5% were working as managers/officials (three women and one man); 3% were working as health professionals (two women and one man); 2% were working as freelance professionals (one woman and one man) and 2% were working as entrepreneurs (all men).

The 30 autism support workers interviewed were aged 27-59. The majority of them (77%) were female. 93% of the respondents were working as professional educators whilst the remaining ones (7%) were working as technicians in specific workshops for autistic adults.

4. Findings

4.1 Capabilities

Families reported that, in order to be guaranteed the right to a dignified life, all human beings (disabled and not) should be entitled to the following opportunities (capabilities): work activities (70%); identity (39%); social relations (24%); love and care (20%); life and health (20%); education and training (17%); leisure and sport activities (9%); time-autonomy (9%); shelter and environment (8%); participation (8%); respect (8%); body integrity and safety (6%); and spirituality (2%).

Autism support workers mentioned similar capabilities: work activities (79%); social relations (74%); education and training (63%); love and care (58%); time-autonomy (58%); identity (47%); life and health (37%); respect

³ Among the respondents, there were three families with two autistic relatives.

(16%); leisure and sport activities (10%); participation (10%) and shelter and environment (5%).

According to the respondents, the above-mentioned capabilities are important or very important in their personal life as well as in that of the autistic people they care for.

However, the autism support workers underlined that in the case of autistic people it is necessary to understand on a case-by-case basis what are the opportunities on which it is worth to stay more focused, depending on the peculiarities of the autistic person.

For both families and workers in the life of autistic people it is of fundamental importance the capability termed 'identity', i.e. the opportunity to fulfil themselves in several areas of life according to their own peculiarities and to feel respected and appreciated by the society as they are. An educator observed that autistic people are often stereotyped based on their diagnosis, and this is an attitude that often prevents society from seeing their potentialities, even when these are quite evident. Thus, the path to discovering the talents of autistic people is both a matter of social justice and of better allocation of resources. According to the workers, another fundamental capability in the life of an autistic person is the time-autonomy⁴.

But is the enhancement of these capabilities actually supported by the institutions?

Most respondents replied negatively to this question: according to 44% of respondents among the families and 42% of respondents among the workers, the enhancement of the selected capabilities receives only a little support at institutional level, whilst according to 43% of respondents among the families and 16% of respondents among the workers these capabilities do not receive any support at the institutional level. Only for 9% of respondents among the families and for 5% among the workers the enhancement of the selected capabilities is being somehow supported at institutional level and only for 1% of respondents among the families the institutions are fully supporting the enhancement of these capabilities. 7% of respondents among the families and 37% of respondents among the workers were unable to reply to the question.

The discussions with the respondents evidenced the opinion that this support exists merely at an abstract level; de facto the institutions are driven by an economic logic which prevents them from seeing what are the real needs of people, both of autistic (or other disabled people) and neuro-typical.

Several respondents underlined that the institutions tend to consider the professional growth exclusively in terms of the achievement of a high socio-

⁴ In this respect it is crucial to bear in mind that the concept of autonomy is impossible to standardise and varies from person to person, even for neuro-typical people

economic status, whilst for an autistic person even the satisfaction deriving from a little progress in a handicraft laboratory can be seen as a professional growth. In the former perspective, investing in the creation of job opportunities for autistic people is perceived as a waste of resources since these people probably will never reach a sufficiently high socio-economic status.

If we consider the activities carried out by the autistic relatives and care receivers of the respondents, we observe that only 10% of them have the chance to work, whereas the capability to work has been mentioned as one of the most important opportunities in the life of human beings. Moreover, the percentage of 'idle' autistic adults, i.e. the ones who are involved neither in work activities nor in training activities, was quite high (39%)⁵.

A serious lack of intervention by the institutions, highlighted by the respondents and classified within the capability of love and care, relates to the work-family conciliation, which is not receiving any support on an institutional basis. Many relatives of autistic people, especially mothers, have been forced to quit their job (not without difficulties and frustration) in order to guarantee to their autistic relatives the care and support needed.

4.2 Life planning

Developing a life plan for autistic people is very important for 94% of responding families and for 77% of the workers interviewed. Only for few of the latter (6%) it is of little importance, mainly because for them developing a life plan for autistic people is a double-edged sword. In general, this group maintains, the caregivers (especially the parents) tend to set goals which are too high for autistic people, provoking a feeling of frustration in their life. So the risk is that the life plans developed for autistic people is not really their own but rather someone else plan.

So it risks to be a sort of social compromise, which is desired more by caregivers and society than by the autistic people themselves. While caring for an autistic person, the ultimate goal must be the well-being of the person and not her/his life plan.

The idea of freedom of choice is a leitmotiv in discussions concerning the rights and the quality of life of autistic people. But, as reported by many autism support workers respondents, autistic people are often prevented from making choices by their caregivers, especially parents, who often seem frightened by the idea that their autistic children can decide for themselves and lead independent lives. For instance, it seems that autistic people are often

⁵ 23% of autistic adults are involved in laboratory activities; 15% of them are still studying and 13% of them are doing an internship.

not entitled to take a break from daily activities, as if for the relatives their well-being and quality of life would depend on the number of activities performed.

Despite such considerations, according to the large majority of respondents setting (and resetting) life goals is fundamental for all human beings, including autistic people. In this specific case a set of goals is particularly needed to define a policy orientation that could make interventions targeting autism more effective.

Life planning is fundamental especially at the end of the schooling age, when the autistic child needs to be helped in finding a path enabling him to lead a dignified and meaningful life as an autistic adult.

Some autism support workers underlined that in the case of autistic people, it would be more appropriate to speak in terms of life orientation rather than in terms of life planning. A life plan requires a certain level of complexity which often frightens autistic people and their families whilst a life orientation is more simple and concrete, clear enough to guide autistic people in their choices but less binding. Moreover, several workers stated that the life plan should not be created but should emerge (more or less directly depending on the severity of autism) from the autistic person herself and, after that, developed by the network of people surrounding her.

It is interesting to notice that autism support workers have an idea of network which is broader than the one outlined by the families. In their words, in fact, the network should encompass the autistic person, the family (broadly speaking), the educators, the social services, the Local Health Authority, the school and gradually the entire society. For them it is fundamental to involve as many actors as possible in the process of structuring the life plan for an autistic person, in order to minimise the risk to set goals which are unsuitable for the very person.

For the families, the network should basically encompass the autistic person, the families and educators and the Local Health Authority.

Moreover, whilst for the families the network that should be in charge of developing the life plan for the autistic person is inserted in a pyramid-shaped structure at whose vertex there is the Local Health Authority, for the workers the above-mentioned network takes the form of a ring shaped structure in which the autistic person and her caregivers (families and educators) play a pivotal role in structuring the life plan.

The life plan should be person-centered taking into account the abilities, interests and aspirations of the autistic person. The focus should be on the autonomy, socialisation, affectivity, respect and inclusion (at the degrees allowed by the characteristics of the person herself) and on the acquisition

working skills aimed at integrating (where possible) the person into the labour market.

Moreover, the plan should be flexible but at the same time it should respect the life patterns of the person, envisaging both simple short term goals (such as learning to deal with daily life activities) and more complex middle term goals, within a perspective of personal growth.

4.3 Training

Another important aspect investigated in this research concerns the availability on the Turin area of training courses targeting either families of autistic people or autism support workers.

Several training courses focused on autism are available in Turin both for families and workers, organised by different organisations/cooperatives and by public and private institutions and most respondents (81% among families and 100% among autism support workers) were aware of it. Nevertheless, at the moment of the interviews, whilst almost all the autism support workers (97%) were attending the training courses made available to them, a high number of respondents among families (54%) were not attending any training course, either because they were running during working times or because they were organized in the city of Turin, not always easy to reach for people living in the surroundings. These training courses have been evaluated rather well by the respondents (both families and autism support workers).

Among families, 61% of respondents evaluated the families training courses as compliant or fully compliant with their needs, while 27% evaluated them as little compliant and for the remaining 12% they were not compliant at all.

Among autism support workers, 59% of respondents evaluated the training courses available to them as compliant or fully compliant with their needs, while for 34% they were little compliant and for 7% they were not compliant at all.

Several respondents among families remarked that the training courses they attended were excessively theoretical and repetitive and that an authority coordinating these courses was needed in order to avoid such repetitiveness.

Autism support workers have been asked, in view of their specific expertise, to provide more in-depth reflections on the main weaknesses characterising the training courses on autism, both the ones addressed for them and for the families.

According to them the main weaknesses characterising families training courses are:

- the tendency to overgeneralise specific realities. This overgeneralisation represents a risk for autistic people who need a case-by-case evaluation. Several educators reported that they have been asked by some parents to provide their autistic daughter/son with some specific interventions they heard about in a training course, which were completely ineffective and/or inadequate to that particular case of autism;
- they are too theoretical. A learning by doing training would be more useful;
- they represent an answer to the anxieties rather than to the needs of families. The training courses for families should be aimed at supporting them in coping with the impact of autism on the family structure. However, some of them seem to be aimed at transforming the parents/relatives of autistic people in autism therapists;
- they tend to be focused on autistic children or on high-functioning autistic adults, raising unrealistic expectations in the parents of low-functioning autistic adults;
- several courses are open to both families and autism support workers and this creates problems because different skills and tools to deal with autism are needed by the two types of caregivers.

In turn the main weaknesses characterising autism support workers training courses are:

- the free courses are rather generic and repetitive. More advanced courses which would be more appropriate and interesting to the category of professional educators – are available only upon payment and they are often very expensive;
- they tend to be focused on autistic children or on high-functioning autistic adults;
- they are often based on excellence models, which are not reproducible in all working contexts;
- they are often biased, reflecting the point of view of their promoting organisations /cooperatives/ institutions;
- they are often open to everyone, whilst each category of caregivers/autism professionals would need different kind of training courses;
- several courses which are open to professional educators are actually addressed to the doctors. The respondents reported an excessive medicalization of autism, resulting in a lack of recognition of the role that professional educators have in support and advice for autism.

However, workers underlined that in general even if imperfect the training courses are useful because they represent a moment to create a network for both families and autism support workers.

4.4 Training

One of the findings of this study is that public services targeting autism do not provide adequate answers to the needs of autistic people and of their families. Thus, families need to rely on services provided by the private sector, often incurring in large expenses that overburden low-income households. Therefore these are further discriminated. The data from our interviews show that the public sector is considered particularly weak in the supply of social services and that this is especially true for autistic adults. To the contrary, clinical services are provided by the public sector all along the life of autistic people.

TABLE 1. Services targeting autism in the Turin area according to the responses to our interviews

	Public		Private		Public-Private Mix		No services
	Clinical	Social	Clinical	Social	Clinical	Social	
Childhood	88%	37%	69%	15%	3%	8%	2%
Adolescence	84%	44%	47%	30%	8%	34%	2%
Adulthood	84%	29% ↓	30%	32%	3%	61% ↑	0%
Tot: 59							

Families reported that becoming aware of the availability of territorial services targeting autistic people has been very difficult (55%) or difficult (19%). Very often they became aware of such services by word of mouth or by personal initiative, and even the respondents for whom it was easy (19%) or very easy (7%) to gain access to such services declared that it was a matter of luck rather than a matter of effective communication by the proper institutions.

The issue of effective communication by the specialised institutions was also discussed with the autism support workers, who recognized the problem, especially by public institutions. The main problems affecting the quality of the communication between families and public institutions have been identified as:

- the number of employees of the public institutions is scarce in relation to the number of users who need information about the available services;
- there is a lack of coordination between the institutions working on autism;
- even in the cases in which families are provided with information about the services they are entitled to, they face a lack of support by the institutions in accessing the above-mentioned services.

The communication between families and specialised institutions providing private or mixed public-private services seems more effective because here there is a more direct relation. Nevertheless, there are communication problems even in these cases, due to the business attitude of taking advantage of the needs of autistic people and their families in order to make profits. Often this means 'selling' their services claiming that they are the best ones for the case, even when they are not so in term of the well-being of autistic people.

Autism support workers provided also some suggestions in order to improve the communication between families and specialised institutions:

- institutions/organisations working on autism should dedicate more time to support the families;
- the autism professionals should use simpler and clearer ways to communicate with families, as sometimes their current approach is affected by technical rigidity;
- all autism professionals ought to be provided with more specialised training focused on how to support families in coping with the impact that autism has on family life and relationships. Families are often seen as an obstacle by autism professionals whilst, when well supported they could represent a fundamental resource in the care of autistic people. Families should in particular play a role in creating a supporting environment, characterised by positive and constructive emotional relationships and they should receive all the necessary help to do so. There is, at times and in an attempt of freeing the institutions from their responsibility, a tendency to transform parents and relatives of autistic people in autism professionals, and this contributes to intensify the sense of frustration of families members and to negatively affect the family environment;
- a greater collaboration between specialised institutions – public, private and mixed ones – is urgently needed;
- the role of educators, in particular their role as mediators between families and specialised institutions, should be better acknowledged among autism professionals;

- bureaucracy within public institutions should to be reduced;
- families should to be warned against unprofessional information, especially that obtained via the web, especially when they do not have the proper tools to filter such information which is often false or just inadequate to their specific case.

The services that autistic adults are currently receiving⁶ have been valued as compliant with their needs by 45% of respondents among families and by 47% of respondents among autism support workers; little compliant by 37% of respondents among families and by 33% of respondents among autism support workers; not compliant at all by 18% of respondents among families and by 20% of respondents among autism support workers.

Autism support workers have been asked to briefly analyse whether the services offered by the organisations/cooperatives they were working for were able to positively influence the selected capabilities reported in the previous paragraphs. According to 97% of respondents, the capabilities of life and health, leisure activities, time-autonomy, respect and bodily integrity and safety were positively affected by the services provided to autistic adults; according to 3% of respondents instead these capabilities were little affected.

According to 87% of respondents, the capabilities of participation and social relations were positively affected by the services, while according to 13% they were little affected.

Similarly, according to 83% of respondents the capabilities of shelter and environment and education and training were positively affected while that of love and care was positively affected according to 80% of respondents.

Less positive evaluations have been provided about the contribution by the services on the capabilities of identity, work and spirituality (not affected according to respectively 67%, 83% and 97% of respondents).

In a progressively more multicultural society these latter capabilities need obviously more attention but, at the moment, they are not a priority in the area of autism, as other capabilities taken to be more urgent.

The respondents of our interviews were well aware that more could/should be done for autistic people.

Families reported a lack of planning within the services targeting autism, highlighting that they often function as mere '*pastimes*'. Moreover, several respondents reported that their relatives were not receiving services designed to address the specific needs of autistic people while they were provided with some rather generic services for disabled people. In some cases such services

⁶ The services that adults with autism are currently receiving in the Turin area relate to occupational therapy, leisure and sport activities, social therapy and psycho-education and family support.

were so unsuitable that they jeopardize the positive effects resulting from other, more effective, services (especially at school level).

Of course, the usual lack of economic resources contributes to make services targeting autism ineffective but several autism support workers evidenced that the problem is rather more complicated than that.

TABLE 2. Macro-areas for autism services in the Turin area in need of growth

RESOURCES OPTIMISATION	AWARENESS	INCLUSION (SOCIAL-EDUCATION-EMPLOYMENT)	FAMILY	SERVICES	TRAINING
Greater investment in autism research to reduce the risk to design interventions and policies which do not meet the real needs of autistic people and their families.	Importance of autism sensitisation in the society and more specifically in the labour market.	More job opportunities for autistic people, both high-functioning and low-functioning autistic people (in a sheltered environment for them).	More psychological support to families of autistic people.	More specific services for low-functioning autistic adults.	More organic and context-sensitive training paths for autism professionals.
		More social housing projects addressing the autistic adults' need for autonomy.		Creating/strengthening a network for autism professionals in order to improve the communication between institutions and families.	Training courses must be more practical (importance of increasing the amount of internship hours).
		Bringing high-functioning autistic adults out of autism 'ghetto' encouraging and supporting them to live and work alongside neurotypical people.			Specific training on autism for teachers, especially for special educational needs teachers
		Reviewing the educational system.			

As already mentioned, sometimes the supply of services seems to be driven by interests that are not those of autistic people. Moreover, while the educational system should play a pivotal role in supporting autistic students in the transition process to adult life, at the moment the Italian schools are not

so autism-friendly. More resources need to be invested in training teachers, and especially special educational needs teachers, on autism.

Autistic adults (or their caregivers in case of adults with a severe intellectual disability) are not really free to choose the services they are entitled to and are instead provided with pre-packaged services.

The table 2 summarises the main six macro-areas in which more should be done in order to improve the lives of autistic people and their families.

5. Discussion

The capabilities that are relevant for non-autistic people are also relevant for autistic people. However, the data resulting from this research suggest that the services received by autistic people and the capabilities identified for them by their caregivers do not seem to row always in the same direction. More could and should and could be done to help autistic people and their families lead a flourishing life.

Despite the fact that various interviews have been useful in providing an overview of the main problems affecting the life of autistic adults and their caregivers in the Turin area, each interview contains a rather singular story. The words of the caregivers of autistic adults have been precious to understand their real needs and would deserve to be listened in order to provide better designed approaches and services.

In order to convey a sense of this and to make the information provided more concrete below are reported some particularly significant statements.

'He is involved in many activities... But what are the goals?', This is what a mum thought for herself and then told us, evidencing one of the main problems remarked within the present study, i.e. the common tendency to 'park' the autistic adults in general day-care centres or to involve them in numerous activities, often expensive ones. Some of them appear well organised and even likable but most of them seem not to set specific goals, especially in terms of autonomy and self-determination.

'Is this the right option? No, this is what we were given, it could be fine, but what is the life plan?', This is the remark of another parent, highlighting the fact that the territorial services targeting autistic adults not always provide the best option but often are the only available one.

Similarly, some educators remarked:

There is the risk to believe that our goals are also their goals. But we should understand that they are not us; their goals are different from our goals and from the goals of their families... It is important to set life goals for people with autism but it is also dangerous because sometimes families or autism

professionals set for them goals which are not achievable, provoking a sense of frustration both in the person with autism and in her family.

The lack of a life plan orienting autistic adults and their families towards autonomy and self-determination goals, indispensable at the present time but especially with an eye to the future, is a leitmotiv in the talks of the families. Who should be responsible for planning the life and the future of an autistic person? On the one side families tend to be largely responsible for planning the life of their autistic relatives, on the other they are aware that this is a complicated task to take on without the autism professionals' contribution. So families demand to be involved in making decisions about their autistic relatives but at the same time they cannot bear this burden alone and they feel the need to be able to rely on a '*strong Local Health Authority*', to borrow the words of some of them. This means that the Local Health Authority should provide families with some guidelines orienting them in choosing the most suitable services and activities for their autistic relatives.

'Goals should be simple and well-defined', a father asserted underlying that people with autism need clarity and precision, features that should be taken into account when a life plan for them has to be designed.

Another crucial aspect which needs considering in designing a life plan for autistic people is that this plan should be customised, able to evolve with the person, thus subject to on-going revisions. As reported by an educator: *'Setting goals which are too rigid is not good for autistic people. We need to be flexible'*.

The puzzling issue of the integration into the labour market of autistic people is a key point in each life plan. Whereas this is one of the most urgent needs for autistic people and their families, its accomplishment sounds often impossible. Actually, integrating autistic people into the labour market is a reachable goal if all the stakeholders would work together for this purpose, under the supervision of a proper public institution.

In particular, a careful evaluation of the autistic person's strengths and weaknesses, as well as an in-depth knowledge of the supposed working environment, are the first steps for the above-mentioned integration. In general, families do notice that their autistic relatives feel more engaged and rewarded exactly while performing those activities – such as meals preparation, handicraft laboratories or even internships within companies – which require tasks very similar to the ones required to perform a real job.

'Institutions have a prejudice against him. He can do many things but they do not recognise it', a mum said. Similarly, an educator said: *'Employers judge them based upon their diagnosis and not upon their skills; they seem frightened from the autism diagnosis'*, and indeed autistic people can be precise, loyal and reliable, find

creative solutions to problems and perform repetitive tasks for so many hours without getting bored, which are all valuable qualities in an employee.

'He needs to be treated as an adult, now', a mum underlined, explaining the reason why the issues of the integration into the labour market and of the 'after us' are considered so crucial.

'We treat them as if they were eternal children. Not by chance, we keep on referring to them as boys and girls even if they are men and women' – an educator said; *'They have right to autonomy, no matter at what degree. An adult life without autonomy is not a dignified life'* – another educator stated.

We are talking about adults, maybe young adults, but no longer children or adolescents for whom it makes sense to focus mainly on the present needs. Autistic people's needs, as well as the needs of non-autistic people, change over time and even the way to address them cannot be the same used back in school.

'When they turn 18, they get only lowball offers', families explained. Once school ends, autistic people have many free periods and the days seem endless to whom who are their full-time caregivers. That is why families tend to 'park' their autistic relatives the best they can. The end of school represents a real drama for many families of autistic people since it requires a serious reflection on their relatives' future. In particular, families complain about a lack of specific services for autistic adults. *"When you have an autistic son, your main goal is to survive"*, parents ironically said when they have been asked what their goals and the goals of their autistic children were. The most common experience among these families is the one of loneliness, the conviction that *'you fight your own battles'*, as a father clearly said.

Besides success stories and small achievements, there are also many stories characterised by a sense of frustration and distress, which cannot be ignored. In particular, these are the stories of those parents who realise they are getting old and still have to outline a life plan for their autistic children, a plan able to reassure all family's members.

'It was a nightmare', many respondents declared and to conclude, it is hoped that this research, having outlined through the voice of families and autism support workers the issues where more reflection and actions are needed, can contribute to change the depicted reality, even partly. *'When it comes to my son, I am happy with a draw'*, a father said, but it is hoped that autistic people and their families can start playing to win.

From the stories narrated during the interviews it is clear that families had to face several hindrances to arrive at a correct diagnosis and treatment for their relatives. Each respondent is bearing his/her own burden of suffering, resulting both from the stress of running the family – which includes not only the autistic person but also other members that may be in need of attention,

such as old parents in need of care – and from the lack of the personal space needed for their own well-being. The stifling bureaucracy and the lack of suitable services, often accompanied by high-cost private services, make the picture even worse.

6. Conclusions

The aim of this research was to provide an overview of the main problems affecting the quality of life of autistic adults and their families living in Turin area.

The data have been collected using the analytical framework of capability approach. In this perspective, the autism spectrum disorders are not to be considered as an impairment to cure but rather as one of the features of human diversity to care about. The well-being of autistic people corresponds to an enhancement of their capability-set through interventions focused on a creative adaptation (exaptation) process promoting their agency. The relation between autistic people and their caregivers plays an important role in this process.

From the point of view of policy implications, the capability approach encourages to rethink interventions targeting autistic people moving from cure to care in order to transform the autistic person from a patient in need of medical treatments to an agent seeking for his/her own well-being.

In the case of autistic adults, the interventions aimed at improving their quality of life should be focused on the promotion of skills acquisition, in particular those skills which are necessary for the achievement of daily living tasks. These interventions, in general, take the form of individual or group psychoeducational activities that can take place either in day-care centres or in community or private homes. In order to be effective, it is important that these interventions occur at the earliest possible stage. Moreover, they should be customised depending on the strengths and weaknesses of the autistic person, and flexible in order to reschedule the strategies implemented where appropriate (Barale, Ucelli di Nemi, 2006).

Another category of interventions that are very helpful for autistic adults is the one of group-based rehabilitative interventions. These interventions differ from person to person and based upon the typology of autism. For example, social skills trainings are indicated for autistic adults with average or above average intellectual functioning; the instrumental enrichment cognitive intervention programs are indicated for autistic adults with moderate intellectual impairments instead. For autistic adults with severe intellectual impairments, it is necessary to create a positive context enabling an 'autistic

adulthood' in which the person has an authentic life and real job opportunities, for example within the farming sector (Barale, Ucelli di Nemi, 2006).

This scenario surely envisages a strong support to the families, frequently left alone in performing the difficult task of taking care of their autistic relatives in order to guarantee them a dignified life.

References

- Barale, F., Ucelli di Nemi, S., (2006), 'La debolezza piena', in Ballerini, A., Barale, F., Gallese, V., Ucelli di Nemi, S. (eds), *Autismo: L'umanità nascosta*, Einaudi, Torino, 51-106.
- Biggeri, M., Bellanca, N. (2011a), *L'approccio delle capability applicato alla disabilità: dalla teoria alla pratica*, accessed September 1, 2015 http://www.oxfamitalia.org/wpcontent/uploads/2011/07/Umanamente_Interno_Copertina_@.pdf
- Biggeri, M., Bellanca, N. (2011b) *Dalla relazione di cura alla relazione di prossimità. L'approccio delle «capability» alle persone con disabilità*, Napoli, Liguori Editore.
- Burchardt, T. (2004), 'Capabilities and disability: the capabilities framework and the social model of disability', *Disability and Society*, 19(7), 735-751.
- Dubois, J. L., Trani, J. (2009), 'Enlarging the Capability Paradigm to Address the Complexity of Disability', *ALTER-European Journal of Disability Research*, vol. 3, n. 3, 2-28.
- Foster, J. E., Handy, C. (2008), *External capabilities*, OPHI working paper series.
- Mitra, S. (2006), 'The capability approach and disability', *Journal of disability policy studies*, vol.16, n. 4, 236-247.
- Keller, R., Bari, S., Aresi, A., Notaro, L., Bianco, F., Pirfo, E. (2015), 'Valutazione diagnostica dei disturbi dello spettro autistico in età adulta', *Journal of Psychopathology*, vol. 21, n.1, 13-18.
- Luciano, C. C., Keller, R., Politi, P., Aguglia, E., Magnano, F., Burti, L., Muraro, F., Aresi, A., Damiani, S., Berardi, D. (2014), 'Misdiagnosis of High Function Autism Spectrum Disorders in Adults: an Italian Case Series', *Autism Open Access*, vol. 4, n. 2, 2-8.
- Robeyns, I. (2016), 'Conceptualising well-being for autistic persons', *Journal of Medical Ethics*, vol. 42, n.6, 383-390.
- Sen, A. (1987), *The Standard of Living*, New York, Cambridge University Press.
- Sen, A. (1999), *Development as Freedom*, Oxford, Oxford University Press.
- Sen, A. (2008), 'The idea of justice', *Journal of human development*, 9(3), 331-342.

- Sen, A. (2009), *The Idea of Justice*, Cambridge, Massachusetts, The Belknap Press of Harvard University Press.
- Testi, E., Biggeri, M., Libanora, R. (2011), *Valutare l'impatto dei progetti di cooperazione internazionale seguendo l'approccio allo Sviluppo Umano*, accessed December 15, 2015 http://www.arcolab.org/wordpress/wp-content/uploads/2012/06/2-ValutareImpatto_RepDominicana-copia.pdf
- Terzi, L. (2005), 'A capability perspective on impairment, disability and special needs: towards social justice in education', *Theory and research in education*, vol. 3 n. 2, 197-223.