

# Independent living and development of personal and social skills for independence. A path of awareness towards adult life for persons with disabilities<sup>1</sup>

## Vita indipendente e sviluppo di abilità personali e sociali per l'indipendenza. Un percorso di consapevolezza verso la vita adulta per persone con disabilità

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*This paper presents data from nationwide research performed in Italy by the University of Bologna on developing Independent Lifestyles within residential services for adults with disabilities. These reflections concern residents' self awareness and awareness of their own well-being, further investigating which basic relational, cognitive, and emotional skills have been acquired during the path to independent living.*

#### Keywords

**adult disability, independent life, autonomous dwelling**

Il presente articolo presenta i dati emersi da una ricerca condotta in Italia dall'Università di Bologna sullo sviluppo degli stili di vita indipendente nell'ambito dei servizi residenziali per adulti con disabilità. Le riflessioni riportate riguardano in particolare gli aspetti legati alla consapevolezza di sé e del proprio benessere dei residenti. Vengono inoltre presentati i dati emersi dall'indagine su quali principali competenze relazionali, cognitive ed emotive sono state acquisite durante il percorso durante esperienze vita indipendente.

#### Parole chiave

**disabilità adulta, vita indipendente, abitare autonomo**

- 1 This paper has been developed and shared by the authors in its entirety. We would like to point out that Valeria Friso drafted sections 1 and 2, while Luca Decembrotto was responsible for sections 3 and 4.

## 1. Introduction

Today in Italy, experimentation with forms of residential services for people with disabilities aims not only to deal with health issues, but is also and even rather an intentional choice to create a time and place offering opportunities, relationships, personal achievement and the acquisition of skills for the widest possible level of independence.

We can state that the experiments in progress in Italy fall under the wider scope of the independent living movement, which was born in California in the 1960s. This movement, which emerged in the period in which civil liberties for various groups were being established, based its activities on some assumptions which can be summarised as follows:

- People with disabilities wish to be free;
- The current or even simply latent abilities which each person with disabilities has can be taken into consideration in real life contexts;
- The desire to use and refine these abilities for a common commitment.

The origins of the independent living movement date back to the early 1960s, when some disabled students at Berkeley University in California were housed in the campus' hospital, albeit in a separate wing of the building and with significant links with the surrounding student environment.

It was specifically the connections to the fervid and multifaceted civil rights movement linked to the major US universities towards the end of the 1960s which gradually gave those students the determination to no longer live in the hospital.

The first developments and attempts to assert these new ideas drove many persons with disabilities living in the US to attempt to take an active part on a local, regional and national level in the decisions on matters concerning their lives.

In Europe, the movement took off in 1989 in Strasbourg as the ENIL (European Network on Independent Living), whose goal was to support and promote this school of thought on the old continent. This movement arrived in Italy 1991.

ENIL proposes ideas which must then take concrete form in different European realities, each with its own specifics, culture and societal model. ENIL does not, therefore, impose choices and models which apply to all, but facilitates debate and spreads consolidated experiences and solutions in order to allow them to be adapted to the different situations. From this point of view, we can state that ENIL's commitment was, from its founding, to offer itself as a tool to build approaches, experiences and initiatives together, thanks to which everyone with a disability can try to find their own route to independence and to live their life in freedom.

## 2. The home as a living space

Various forms of independent living have developed in Italy too, such as light residential facilities, low-threshold residential facilities, farm communities, Ambient Assisted Living (AAL) etc.

“Light residential” means those short or extended residential services offered predominantly for reasons linked, for example, to the illness of a parent or in order to guarantee families the space necessary for personal care. There are, therefore, cases in which the apartment hosts different groups from week to week, supported by the presence of educators.

Farm communities, on the other hand, were created with the goal of providing adult living spaces in a natural setting. Enablement pathways, work experience, and significant social and recreational activities are provided taking into account that planning these aspects can improve quality of life and can genuinely provide meaning to people with disabilities.

Ambient Assisted Living (AAL) refers to a European research program which began in 2007. It focuses primarily on innovative support technologies for vulnerable groups and the disabled in the domestic environment.

The provision of an independent living context, at the same time supported by the most advanced technologies, represents an important prospect for living at home independently and safely, with support in day-to-day activities. In particular, these technologies meet the needs of those who have complex, predominantly physical, disabilities. In recent years, dedicated software and hardware solutions have been tested, both at an environmental and personal level, for those who no longer have voluntary control of their bodies due to neurodegenerative illnesses or trauma. Home automation undoubtedly plays an important role in creating innovative aids, and connecting it with the indications provided by universal design are an undoubted priority.

The Universal Design” (as it is known in the US) or “Design for All” (European term) philosophy, pre-dating the UN Convention on the Rights of Persons with Disabilities, is based on the presumption that accessibility is a value for society at large, and is therefore not a right reserved for people with disabilities. In this sense it accurately represents the universalism of the convention as well as – being closely connected to the question of accessibility – aiming to protect fundamental rights such as full participation and social inclusion. This approach had already been adopted by the Constitutional Court of the Italian Republic with sentence no.167 of 10 May 1999 which, looking at the prior legislation on the elimination of architectural barriers, highlighted the universal value of accessibility, which must be an intrinsic characteristic of new-build construction, “regardless of whether it strictly belongs to people with handicaps” (Marra, 2009, p. 82).

The seven principles of Universal Design are:

- 1 Equitable use – can be used by anyone;
- 2 Flexibility in use – adapts to different abilities;
- 3 Simple and intuitive use – the use is easy to understand;

- 4 Perceptible information – conveying the effective sensory information;
- 5 Tolerance for error – minimising undesired risks or actions;
- 6 Low physical effort – requiring minimal effort to use;
- 7 Size and space for approach and use – making the space easy to access and use.

Universal Design presents itself as the only method of construction which respects the third article of the Italian constitution, and with the UN convention it becomes a legally binding principle. Universalism is created as – also from a legal point of view – “today it is no longer possible [...] to interpret accessibility regulations as special legislation to protect persons with disabilities” (Marra, 2009, p. 83). It is certainly not an oversight that we talk of “universal” and not “special” design: the point of view that enters into law with the convention overturns the trend which saw the adoption of “retro-fitted solutions to overcome architectural barriers” with the view of “designing goods, services and spaces which are accessible from the get-go. [...] Accessibility (for all) is the starting point” (Medeghini et al., 2013, p. 169). “For all” means a concept of “expanded usership” from this point of view. As we see in Italian Presidential Decree of 4 October 2013, which ratifies “the adoption of the biennial program of action for the promotion of rights and integration of persons with disabilities”:

The matter of accessibility must represent a way of thinking, the design of any space or object for people which takes into account the requirements of a significant user base, the widest possible, while avoiding “special” solutions and equipment. One of the fundamental aspects of UD is the direct participation of people/users: it is with them, indeed, that the identified solutions must be assessed. Universal design does not, in any case, rule out the use of support devices for particular groups of people with disabilities where necessary.

Accessibility also has a specific section dedicated to it in the article of the UN convention (Article 9), which clarifies the fact that accessibility is a principle to adopt in order to create maximum independence and real parity of access and participation in all areas of life. In this sense, accessibility must be understood in the widest manner possible, since it must include “access to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas”.

There are primarily two main aspects which distinguish independent living projects:

- Relationships with others: in their relationships with others, disabled persons mirror themselves, experiment with their emotional, affective and empathic abilities, and with the boundaries and rules of living together and of respect;
- The support of the professionals and teams, which translates into the ability to provide help and mediation in overcoming difficulties.

As we will see from the following data which are taken from research conducted by the Educational Sciences Department at the University of Bologna, these two characteristics distinguish the different services available, as well as the way that independent living is understood by the people with disabilities themselves.

But the home, like for each and every person, is not just synonymous with a place to live safely. Rather, taking inspiration from what Goussot (2009, p. 65) proposes, it can become:

- Not just a place of refuge in which each person builds and carries out their life, or in which they eat and sleep;
- A space of reference from which to leave and to which to return;
- An intimate and protective space/time;
- A starting point which allows them to achieve the independence and freedom necessary to lead the “dignified life” which Marta Nussbaum talked about;
- A space in which to organise their existence in an individual manner;
- A space in which to meet an essential need, linked to their sustenance;
- Having a wider support network which includes the other residents and neighbours who enter the social network of reference.

We can therefore state that the manner of living in a home takes on not just a personal meaning, since it is the disabled person who chooses how to live in the home, on the basis of their living requirements, but also a social one, as it experiments with shared spaces, interests and a relationship of reciprocity with those with whom they live.

### 3. Pedagogical research in the field of Independent Living

A research project entitled “Indagine autonomia abitativa in Italia” (Investigation of Independent Living in Italy) was carried out between 2016 and 2017 at the Educational Sciences Department of the University of Bologna. The research, some of whose results will be detailed in this paper, aimed to investigate the different types of independent living experiences present around Italy, investigating the aspects of personal and social independence which these experiences allow to develop.

This contribution shall focus its attention primarily on the second part, on the development and reinforcement of social independence. The results would seem to be significant in terms of highlighting the many experiences of independent living present around Italy and the way with which they have built connections with the life project, with the goal of promoting and developing skills for self determination.

As we will see in the following paragraphs, the Italian panorama is rather diverse, and “independent living” is taken to mean many different situations which are distinguished essentially by:

- Type of structure used: Some premises of the daycare centre, apartments owned by the co-operative, apartments;
- Use of the structure: Weekend, weekly hosting, permanent residential, some weekends per year etc.;
- Professional figures present: Educators, healthcare workers, social workers, family volunteers;
- Number of hours per day/week these professionals are present: 24/7, only at certain times of day, only on certain days of the week etc.;
- Economic sustainability: The apartment expenses are covered by: the residents themselves, public bodies, families etc.

This research on independent living in Italy was conducted by distributing an anonymous questionnaire consisting of 41 questions, divided into multiple sections, aimed at organisations which manage healthcare and residential structures recorded in regional registers at the national level (social co-operatives, foundations, providers of personal services or public consortia, associations). Data was gathered on 97 structures located in central-northern Italy, predominantly in the regions of Lombardy, Emilia-Romagna and the Veneto.

The apartment complexes analysed were organised largely as permanent residences (78.3%), with the exception of a small number of cases which hosted residents at weekends (6.5%), a few weeks per year (8.7%) or a single week at a time (6.5%) as support to daily living at another location.

The experiences of 38 people with disabilities involved in these projects were examined; 19 of these were female and 18 male (1 with no response for gender), with an average age of 43.5 years (the youngest was 24 and the oldest 67). Of these, 60.5% have a stable residence in an apartment (or complex) for the whole week, and only 5.3% have a “residual” experience while living primarily elsewhere, staying in the apartment (or complex) only at the weekend. Other forms accounted for 13.2% of the residents, including “short” weeks or months of residence. No response was provided in 21.0% of the cases.

**Table 1: Disabilities present in the diagnosis**

Down's Syndrome	34.2%
Light-medium learning disabilities	18.4%
Serious learning disabilities	15.8%
Paresis (tetraparesis or paraparesis)	10.6%
Schizophrenia	2.6%
Cervical hydrocephalus, Chiari malformation, white matter hypoplasia, medium intellectual disability	2.6%
Serious developmental disorder Complex partial epilepsy. Serious visual impairment with hypermetropic astigmatism with strabismus and amblyopia	2.6%
Intellectual disability with substance dependency (alcohol)	2.6%
No response	10.6%

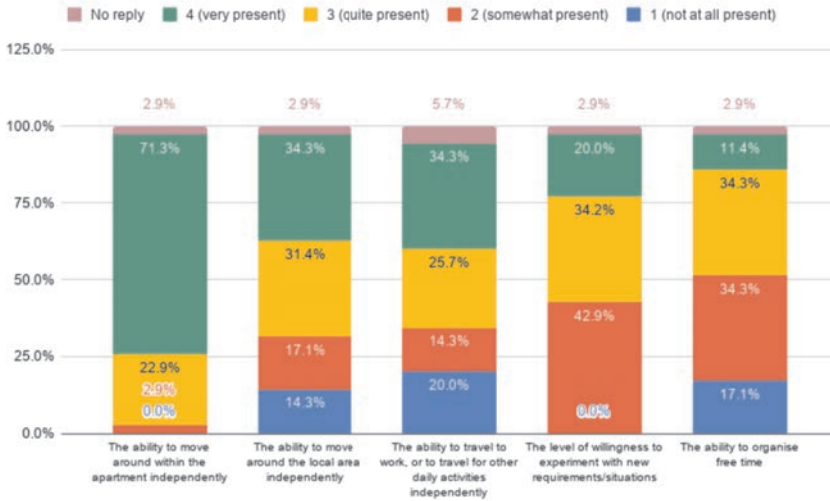
As regards employment, nine of them (23.7%) are employed with subsidised or assisted schemes (1 grant-assisted, 3 “socialisation” internships, 3 training internships, 2 volunteer positions in co-operatives), while 4 of them (10.53%) are employed under typical or atypical contractual conditions (2 with permanent part-time contracts, 1 with a project-based contract, 1 with a seasonal contract). Prior to these jobs, half of them (2) had taken part in job placement programmes through “socialisation” and training internships, of one- or four-year duration, while the others (2) had not made use of such placement programmes. The average monthly pay for employment which was not seasonal and not through a placement programme was 550.

In order to represent the level of personal independence, various indicators were taken into consideration (see Graph 1), numbered on a scale from 1 (not at all present) to 4 (very present):

- The ability to move around the apartment independently;
- The ability to move around the local area independently;
- The ability to travel to work, or to travel for other daily activities, independently;
- The level of willingness to experiment with new requirements/situations
- The ability to organise their own free time;
- The level of linguistic development allowing for effortless interaction with other residents;
- The level of cognitive ability allowing for effortless interaction with other residents;
- The level of emotional competence allowing for effortless interaction with other residents;
- The use of problem solving and appropriate management of more complex situations;
- Complying with rosters within the apartment, depending on their own abilities;
- Combining of freedom, sharing and socialisation.

The results of the survey showed that the ability to move around within the apartment was considered particularly solid by the respondents (71.3% very present), although the other indicators were generally positive: The ability to move around the local area independently (34.3% very present, 31.4% quite present), the ability to travel to work, or to travel for other daily activities, independently (34.3% very present, 25.7% quite present), the level of willingness to experiment with new requirements/situations (20.0% very present, 34.2% quite present), although in the latter case a lack of willingness was also particularly significant (42.9%). On the other hand, the ability to organise free time was less present: in this case an inability to organise these times and spaces independently was higher (34.3% not very present, 17.1% not at all present) in the various declared activities: social activities (dinners or drinks organised with friends or volunteers, visits with relatives, meetings

with their partner, trips to the seaside or mountains, parochial events, frequenting public premises), games and hobbies (collecting, recreational computer use, sports, listening to music, painting, reading, cooking, cinema, playing an instrument), exercise (walking, cycling, sports training), reading about or watching sports, spiritual activities (participation in religious functions) and personal care.

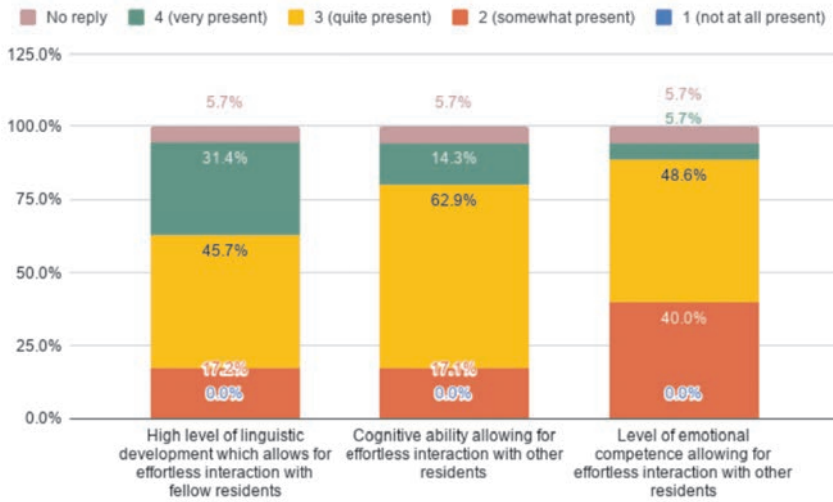


Graph 1: Some indicators of levels of domestic and social independence

Other indicators linked to the abilities and skills required to interact with the other residents of the apartment were taken into consideration (see Graph 2). In this case, a score of zero was never assigned and generally positive assessments were made, but with significant differences: there is certainly a high level of linguistic development which allows for effortless interaction with fellow residents (31.4% very present, 45.7% quite present), but the same cannot be said for the other two abilities, where the maximum score increasingly narrows in favour of a larger medium-positive score, both in terms of cognitive ability allowing for effortless interaction with other residents (14.3% very present, 62.9% quite present), and in the level of emotional competence allowing for effortless interaction with other residents (5.7% very present, 48.6% quite present).

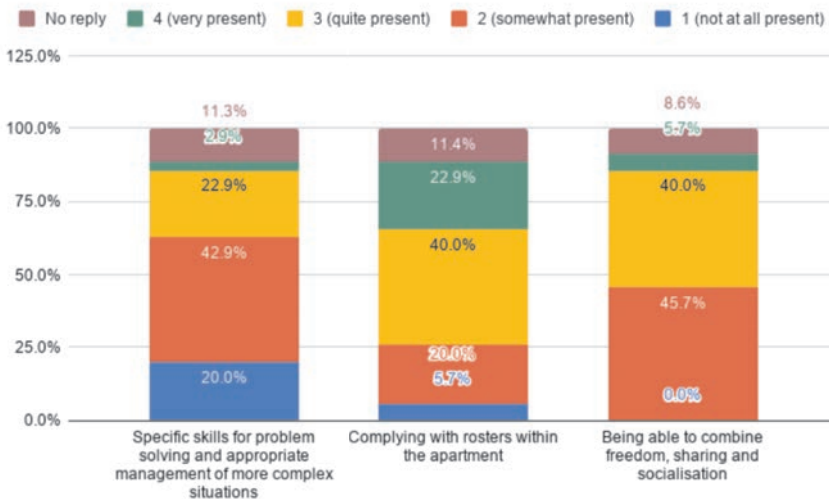
The representation of other, more general social and transverse abilities differs (see Graph 2).





**Graph 2: Abilities and social skills for interaction with other residents**

Specific skills for problem solving and appropriate management of more complex situations were not present in significant levels (22.9% somewhat present, 42.9% not very present), and for some this was too complex (20.0% not at all present), while complying with rosters within the apartment showed a more balanced presence (22.9% very present, 40.0% quite present, 20.0% not very present), although a small group were given a negative assessment (5.7% not at all present), while being able to combine freedom, sharing and socialisation was more complex (40.0% quite present, 45.7% not very present), even though it is within the reach of all (see Graph 3).

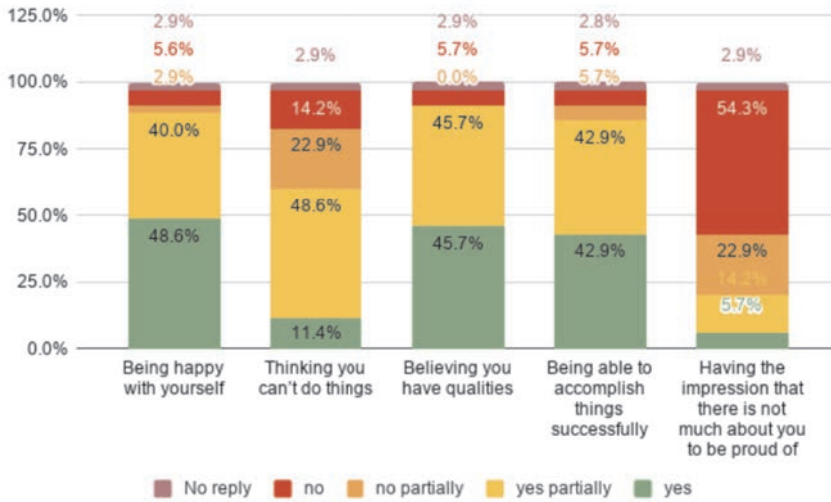


**Graph 3: General social and transverse skills**

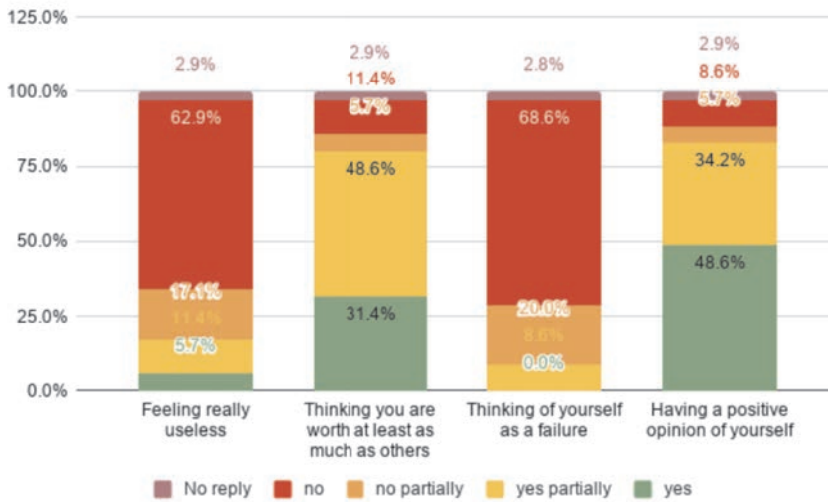
A series of indicators was also examined in order to measure self perception and perception of personal well-being, in this case using a scale indicating whether these are present, absent or partial and tending more towards the present or the absent (see Graph 4 and Graph 5):

- Being happy with yourself;
- Thinking you can't do things;
- Believing you have qualities;
- Being able to accomplish things successfully;
- Having the impression that there is not much about you to be proud of;
- Feeling really useless;
- Thinking you are worth at least as much as others;
- Thinking of yourself as a failure;
- Having a positive opinion of yourself.

Within the residential projects involved in this investigation, people with disabilities tended to be happy with themselves (48.6% yes, 40.0% yes, partially), consider that they have qualities (45.7% yes, 42.9% yes, partially), are able to accomplish things successfully (42.9% yes, 42.9% yes, partially), think that they are worth at least as much as others (31.4% yes, 48.6% yes, partially) and have an overall positive opinion of themselves (48.6% yes, 34.2% yes, partially). On the contrary, the questions based on a negative reading of oneself had generally negative responses: in the projects involved in this investigation, people with disabilities did not feel useless (62.9% responded no, 17.1% no, partially), did not have the impression that there is not much about them to be proud of (54.3% no, 22.9% no, partially), and did not think they were failures (68.6% no, 20.0% no, partially). More neutral responses were given on the ability to be or do something: only in this case did the responses tend towards the median (48.6% yes, partially, 22.9% no, partially), thus highlighting a problematic area in terms of self esteem regarding the ability to be or do things.



Graph 4: Self perception and perception of personal well-being (first series)



Graph 5: Self perception and perception of personal well-being (second series)

Finally, examining self awareness and discovery for the people with disabilities involved in this study, for more than half of them we can talk about paths of self awareness (57.1%), while for the remainder (42.9%) involved it was not considered possible to talk about paths of self discovery and awareness or, if they were present, it was not considered that they had produced positive results.

## 4. Analysis and prospects

The goal of residential services aimed at people with disabilities is to make people, regardless of their deficit, “individuals able to live in independence (total or partial) and to also make use of the opportunities offered by the community” (Cottini, 2009, p. 121). In the investigations presented here, the goal was to measure how experimentation with high-quality independent living models can influence forms of independence on the personal and social level through the strengthening of basic relational, emotional and cognitive skills<sup>2</sup> (life skills), as well as communication and the search for personal well-being in more general perception.

The investigation outlines independent living experiences structured on the basis of residential services, experiences which are very different from the institutionalised situations of the past and clearly oriented to recognise people with disabilities as adults with their own needs, desires, aspirations and responsibilities. The data of the investigation highlight how this orientation is not, however, homogeneous. Below we make reference to the classification contained in the International Classification of functioning, disability and health (WHO, 2001), specifically some sub-groups of the “Activity and Participation” component which covers the full range of individual and social areas of life. Through this we can see that, while independence goals linked to “Domestic life” (d6) or out-of-home “Mobility” (d4) are generally acquired, others are less certain, such as those linked to “Social, civil and community life” (d9), for example the ability to organise free time (d920), a very wide category which includes games, sport, art and culture, crafts, hobbies and socialisation. Some have never developed this component. Added to this are other difficulties, such as being willing to experiment with new requirements/situations.

The uncertainty present in these components lends itself to different readings (there could be some resistance in play, or else difficulties in identifying, seeking out and organising personal interests in an independent manner), but even before this it highlights a lacuna in terms of educational activities which are not sufficiently oriented to developing the independence of those components. It is, indeed, possible that due in part to the social value given to these areas in the lives of people with disabilities, it is necessary to invest greater time and planning to identify paths and activities able to bring people together with unknown interests and facilitate them getting involved in new situations, opening up possibilities even where the utility is not immediately clear. The *inclusive perspective*, which these data show to be fully acquired, able

- 2 These abilities and life skills, as well as being countless, differ between cultures and contexts. In any case, the WHO (1993) has attempted to define some which recur in personal formative contexts, for the promotion of health and well-being: the decision-making process, problem solving, creative thinking, critical thinking (cognitive skills), stress management, handling emotions, self consciousness or self-awareness (emotional skills), empathy, effective communication, interpersonal relational skills (relational abilities).

to face up to the development and consolidation of relational and communicative skills, cannot in any case neglect those areas not directly involved in the living, working and community integration processes, which imply further investigation of knowledge of oneself and one's inclinations, skills and abilities obtained through time spent outside obligations from work, the domestic environment or linked to the response to needs required for survival.

Other life skills to be reinforced are those linked to problem solving and the appropriate management of more complex situations: in this case too, deficiencies emerge which would ideally require specific educational intervention, able to strengthen all operations of analysing, solving and managing problems – identifying the problem, generating possible solutions, assessing the solutions in terms of advantages and disadvantages, choosing the solution most appropriate at that time and with which resources, planning the actions and verifying the results (Marmocchi et al., 2004) – starting out from the best-known environments in which controlled routine-breaking events can be induced and domestic simulations put on. Actions of this type could contribute to also sustaining the development of self esteem and feeling able to be or do things, in these cases being able to solve problems or manage complex situations, the only one of the self-perception indicators which highlighted some problematic aspects in terms of self esteem.

Each person has their own representation of disability, which influences their way of relating to it and which, as a secondary effect, influences behaviour and the way of looking at others (Caldin, Scollo, 2018). The inclusive point of view does not, therefore, see the need for change only in others, but also in oneself and in the context. Starting out from a right, that of living independently and being included in the community, as laid out in Article 19 (2) of the *UN Convention on the Rights of Persons with Disabilities* (UN, 2006), it is possible to put into action processes of change which certainly act on people with disabilities, increasing the possibility of them being recognised as adults and themselves feeling adult, responsible and emancipated. In any case, this is a path of awareness in the direction of adult life in which the healthcare workers, educator or case manager involved will inevitably find themselves up against the choice of putting their own representations of disability up for discussion in order to make space for the human condition of the possible, and thus increase each person's level of empowerment with their actions.

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