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articoli

Inclusion processes for persons with intellectual disability through multiple negotiation networks

Processi di inclusione per persone con disabilità intellettiva attraverso le reti negoziali multiple

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Abstract

This article explores multiple aspects of the inclusion processes related to the CRPD (Convention on the Rights of persons with disabilities) implementation process carried out in Asti (NW Italy) between 2016 and 2020. For the purpose of this article, data have been collected regarding the work of social work professionals, who supported individuals and families following the methodology of “enabling co-design”. The results show the necessity to allow interventions that create a support network to achieve full and equal citizenship, rethinking the transition to adult life through new epistemological categories that make it possible to overcome, both in theory and in practice, what is currently defined as a special adulthood. This goal may be achieved by adopting approaches that are more coherent with the scenario defined by the approval of the CRPD for the rights of persons with disabilities.

Keywords: intellectual disability; inclusion; networks; rights based model; participation; citizenship.

Sintesi

Questo articolo esplora molteplici aspetti dei processi di inclusione relativi al percorso di attuazione della CRPD svolto ad Asti tra il 2016 e il 2020. Ai fini del presente articolo sono stati raccolti dati relativi al lavoro degli operatori che hanno sostenuto persone con disabilità e famiglie seguendo l’approccio della coprogettazione capacitante. I risultati mostrano la necessità di promuovere interventi che creino una rete di supporto per raggiungere una cittadinanza piena e paritaria, ripensando il passaggio alla vita adulta attraverso nuove categorie epistemologiche che permettano di superare, sia in teoria che in pratica, ciò che è attualmente definito come un adulto speciale. Questo obiettivo può essere raggiunto adottando approcci più coerenti con lo scenario definito dall'approvazione della CRPD per i diritti delle persone con disabilità.

Parole chiave: disabilità intellettiva; inclusione; reti; modello dei diritti; partecipazione; cittadinanza.

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1. Background

This article explores the processes involved in the implementation of the Convention on the Rights of Persons with Disabilities (CRPD) as part of a project carried out in Asti (North West of Italy) between 2016 and 2020. The CRPD was first opened for signature in 2007. Out of 193 UN Member States which took part in its drafting, as of today 158 have signed the document and 151 have *ratified* it. As far as Italy is concerned, this happened in 2009, through the law no. 18/09: ratifying the CRPD meant committing to adapting the existing legislation and support systems to what is stated in the document (Griffo, 2019). The CRPD simply tells us this: since we cannot establish a hierarchy of desirable life outcomes for people without disabilities, the condition of disability cannot justify establishing them. If from the psycho-pedagogical point of view, therefore, it is not possible to determine desirable individual outcomes for the life paths of persons with disabilities, from the point of view of the research methodology this operation is even more cumbersome.

Ratification and implementation have therefore become the main subject of the works published between 2006 and 2019. Among these, the majority focus on a specific country of the European Union (Lawson & Priestley, 2013) or in the United States (often observing the delay in ratification of this country) (Chaffin, 2005), while others address this topic by focusing on countries with significant criticalities regarding the issue of human rights (Barnes & Sheldon, 2010).

Despite the different views that necessarily coexist in such an interdisciplinary literature, scholars give mostly unambiguous indications on implementation: implementing the CRPD does not mean guaranteeing one of the rights listed in the document in an occasional or disconnected way with respect to the system, but rather implies a radical change that affects the basic structures of society (Goggin, 2017). This change, also called a *paradigm shift*, affects the way we see disability and, consequently, the way we deal with it (Barbieri, 2019).

Therefore, the implementation of the CRPD always calls into question complex social, organisational, and psycho-pedagogical processes (Grue, 2019). Over time, widespread experiments aimed at exploring this change have begun to develop locally at both national and European level (Curto & Marchisio, 2020). With regards to the transition to adulthood for people with intellectual disabilities, the main framework in the Italian context is the so called *after us* scenario. The concept of *after us* was introduced in the early 1980s when the parents of persons with disabilities began to wonder, no longer just privately, who would take care of their child when they would no longer be there (namely: after *us*) (Colleoni, 2016). They lived in a world where disability services as we know them today – day care facilities, residential facilities – were just taking shape, where school inclusion was in its infancy (the first inclusion law in Italy was issued in 1977 and Law n. 104, which is currently the norm, was issued in 1992) and for disabled persons families were for the vast majority the only form of daily support and contact with the world (Medeghini, 2016). In this historical and cultural scenario, the loss of one’s parents was at the same time the loss of the possibility of being cared for and of living with them, but also the loss of the element of contact with one’s relational and everyday world. The *after us* idea, therefore, takes on a multitude of meanings for the adulthood of persons with disabilities, structured around the event of a great loss: not only the loss of parents but the simultaneous loss of a lifestyle, modalities, habits, and relationships often painstakingly built over the years.

This work refers to an experience with a wider scope, carried out between 2011 and 2020 by the research group called Studies Centre for Rights and Living Independently of the

University of Turin, whose primary aim is to put this growing need for implementation into practice.

The project described in this article arises from the collaboration between an organisation of family members of persons with intellectual disabilities and the Studies Centre for Rights and Living Independently of the Turin University. Also, thanks to the contribution of the CRPD, in the last few years one of the key concepts of the debate on disability has been the transition to adulthood (Flynn, 2020). On the one hand, thanks to the combination of medical progress and deinstitutionalisation, people with disabilities have in fact progressively achieved a life expectancy that reaches – and in most cases exceeds – adult life (Trollor et al., 2017). If we look at people without disabilities, early adulthood (the 18-25 age group) is characterized by a variety of experiences, identity exploration and increased risk-taking (Mitra & Arnett, 2019). It is during this time, for example, that many young people move away – albeit often temporarily – from the family home (let's think of programmes intended for this purpose: Erasmus, study trips, volunteer experiences abroad, etc.). Always around this stage, young adults experiment with different lifestyles, search for an education that matches their interests and ambitions, form meaningful sentimental or emotional relationships outside the family, often look for their first job and start to become financially independent (Schwartz et al., 2020). Although the transition of each individual towards adulthood occurs in different ways and at different times, it is common knowledge that it is precisely this variety of experiences that contributes to the transition to adult life (Kealy et al., 2020) and allows them to face the intricate development of the relationship between opportunity and freedom that characterizes adulthood. It is also known how the broadening of experience recursively influences the development of the drive to seek self-determination, that is, to periodically choose the course of one's existence (Clark & Williamson, 2016) according to the range of socially available options.

If all of this happens regularly for young persons without disabilities between 18 and 25 years of age, by looking at the same period of life, however, for young persons with disabilities – especially intellectual ones – it is easy to observe how opportunities tend to shrink (Canevaro, 2013). In Italy, in particular, thanks to inclusive education, children with disabilities in the vast majority of cases experience childhood and a large part of adolescence in the real world. At the end of school, just when their classmates see existential opportunities open up, children with disabilities see their opportunities shrink, even drastically, and turn decisively towards special, protected, and dedicated contexts.

This mechanism often generates a vicious circle in which young adults with intellectual disabilities are not encouraged and supported to undertake different experiences but are pushed to take part in *special* projects in which others define what is best for them, sometimes (still) on the basis of diagnoses or assessments of severity, or in which they are encumbered by the burden of proving that they are skilled enough (Logeswaran et al., 2019).

The new paradigm introduced by the CRPD, thus, highlights the need to overcome this mechanism and build transition to adulthood as a support system, so that all people – regardless of their condition and not on the basis of it – may have full access to society.

2. Context, materials and methods

The *19 Pari* project experiments with a global way of planning and supporting the transition to adulthood for persons with intellectual disabilities and their families, developing innovative practices that then are meant to be transferred to the public service. Transition to adulthood takes place through *enabling co-planning* (Marchisio, 2019), a planning methodology used by professionals, the person with disabilities in charge of the independent living project and their family, aimed at identifying objectives, strategies and actions to support the unravelling of each of the areas of life in the real world, in full compliance with individual rights and on the basis of equality of rights with other citizens (Marchisio, 2019). The idea behind this concept is not to propose special projects for people with intellectual disabilities, but to support them, with the help each of them may need, along diversified, co-designed and self-determined paths. To this end, the personalised projects of independent living will provide for the activation of both formal (professional and non-professional) and informal forms of assistance that support the living project in the ways and times deemed appropriate by the individual and their family, integrating the dimension of employment, social roles, adult identity and free and self-determined living (that is, living with people and in places chosen for themselves, without this right being subordinate to skills).

The data collected for the purposes of this article concern the work of the tutors for independent living – who are the professionals in charge for the life project case management- who accompanied individuals and families in the customised co-designed projects (for the methodology see: Curto, 2021; Marchisio, 2019).

The independent living tutor, therefore, always works in an authentic situation by taking into consideration, context by context, the real-life contexts of the family unit s/he supports and acting in a timely manner in these contexts, through an articulated mapping of the support network.

Starting from the desires, dreams, and preferences of the individual and the family in question, tutors build an articulated and flexible personalised support system rooted in the individual's living environment. This is achieved by working within contexts with integrated training, material, educational and mediation actions.

The ultimate goal is always to allow each individual to live in the real world, within the community to which they choose to belong, on the basis of equality with others, regardless of their characteristics.

Tutors, thus, work primarily not to increase the individual's abilities, but to broaden the field of possibilities available to them. This *field of possibilities* is both a tool for supporting (and, if necessary, *recovering*) the processes underlying the construction of adulthood, and an element to be developed as a harbinger of meaning in people's lives, as it is itself part of the definition of adult life.

The core of this project is, therefore, the mapping of people's life contexts, always carried out through enabling tools: this mapping, which the data partially confirms, includes both the identification of each significant context, and the qualification of each context according to two main axes: relationships and choice.

The data reported here have been collected with the primary aim of being used for ongoing monitoring, and have been aggregated for the purposes of this analysis.

Firstly, the relationship context was analysed considering a series of items on a checklist investigating how and in what way each context supported or opposed adulthood. Qualitative checklists were chosen, whose meaning had been discussed and shared with the tutors/researchers who worked with the individuals involved, in order to avoid this *double handling* of data collection that may have introduced a significant distortion.

The second context we considered is that of choice, which was divided into two macro-dimensions: whether or not the person had chosen to take part in that specific environment (which means that they had alternative opportunities at the same economic, social, and relational cost) and the context of proactive support to decision-making, while the individual in question participates in that environment.

Each context is then assigned a score, which is obviously a qualitative value, defined in numerical form only to allow graphical representation. The main items were then integrated by secondary items, such as the detection of adaptations, modifications and all the contextual elements employed to guarantee the right to participate.

For the purposes of data collection, the nodes of the network have been classified and grouped in certain typologies due to the multiplicity of these contexts. The places called *open without the need for affiliation* are all those contexts, commercial or services to the citizens, which can be accessed directly, without the need to take preliminary steps (for example all shops, bars, post offices, banks, etc.); the places denominated *open with affiliation* are all those city contexts which require some form of registration before being able to participate in the planned activities (for example library, scout groups, sports groups, gyms, etc.). Then there are the nodes of the network that are not places, but people (or their houses), who are in turn divided into *nodes with emotional ties* (friends, partners, etc.) and *places with family ties* (e.g., grandparents, etc.). Then, finally, there are places where a professional relationship is established, that is, those in which people come into contact with the person with disabilities because that is their job (for example psychologist, social worker, etc.) and workplaces (where the PwD, in fact, works).

It is important to keep in mind that the fragmented representation (context by context) that emerges if we look at the data as we do in this analysis produces a distorting effect due to the method of detection itself, whereas the work carried out with the enabling co-design approach is an articulated and harmonious project, built and personalised with each individual and their family and not limited to a mere list of participation in one or the other context.

The data were collected over a period of 12 months by 4 tutor-researchers on 6 followed projects. The contexts/subjects involved in the mapping were 336. For each context, different surveys were conducted, one for each contact that the tutor had. The measurements were carried out through an application downloaded on the tutors' smartphone, who managed to record the data in real time, thus minimizing bias. The purpose of the data analysis is to show the different phases of the process, highlighting its peculiar aspects with respect to the traditional transition paths to adulthood.

3. Results

A first general observation that can be made by looking at the data concerns the type of project design, which, as said above, is customised and co-designed. Each project, therefore, provides the individual with a tailor-made support system combining both formal and informal networks. This means that there are neither pre-packaged services listed in a catalogue, nor standardised hourly packages. On the contrary, each action is tailored to suit the individual, their desires and life contexts. In terms of dedicated time, this type of customisation is expected to lead to a more efficient distribution of hours compared to a standardized distribution.

	Actual	Standardized	Difference
a	23.4%	16%	+7.4%
b	17.1%	16%	-1.1%
c	13.1%	16%	-2.9%
d	29.7%	16%	+13.7%
e	9.5%	16%	-6.5%
f	7.2%	16%	-8.8%

Figure 1. Actual hours compared to standardized hours.

As we can see from Figure 1, the resources dedicated to each individual in terms of hours are also quite distant (both greater and lesser) from what would be expected in a standardized service. It should also be noted that in this working model the resources are not distributed on the basis of the intensity of the impairment but is achieved by integrating all aspects of the individual's existence, their family, and their context. Already the VelA project (Marchisio & Curto, 2017), in fact, had shown that the analysis of the support networks made it possible to obtain more predictive data relating to the intensity of intervention, compared to what could be done by classifying the impairment based on degrees of *severity*. The 19 Pari project confirms these data showing that the monitoring of support networks needs to be systematically integrated into the co-design framework for the entire duration of the programme.

When it comes to analysing the support network, not only in the context of this analysis of course, it becomes more pertinent to define *what is being done* during those hours.

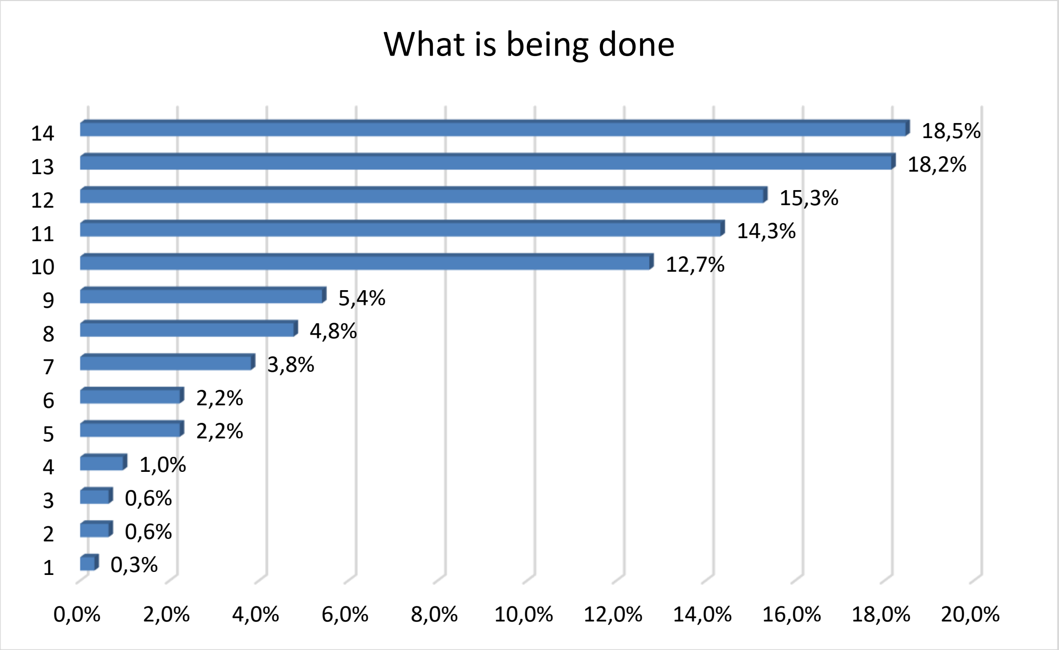

Figure 2. What do you do with a tutor?

First of all, we can notice a significant inversion in comparison to usual independent living programmes: the dimension of domestic economy, usually prevalent in standardized transition to adulthood projects based on skills, only covers 0.3% of the meetings in projects that are co-designed and based on equal rights (Contardi, 2016). As can be seen from the data, the prevailing dimension of transition to adulthood projects is that of access: access to local public services (from a community-based perspective) and access to work together cover 36.7% of the tutor's time/working hours.

In the data shown in Figure 1, two further elements appear relevant. First of all, the strong presence of co-design should be noted, which lasts for the entire duration of the project, covering 15% of the tutor's working time. In this sense, co-design becomes pivotal in the struggle for the right to self-determination. The tutor, in fact, uses it as a tool for self-determination when facing life's crossroads, allowing the individual and their family to have the last word on the direction to take in all the choices, from the small ones (such as which gym to attend) to the big ones (such as whether to live alone or with a friend). In enabling co-design, we proceed without pre-defined paths, but we are always able to detail the motivations, objectives, and actions of the intervention in a timely manner.

Working without pre-defined paths is both an instrument and an end to the project. As shown by the data in Figure 2.64% of the time the tutor met the PwD, the meeting place was chosen by the individual with disability or a family member.

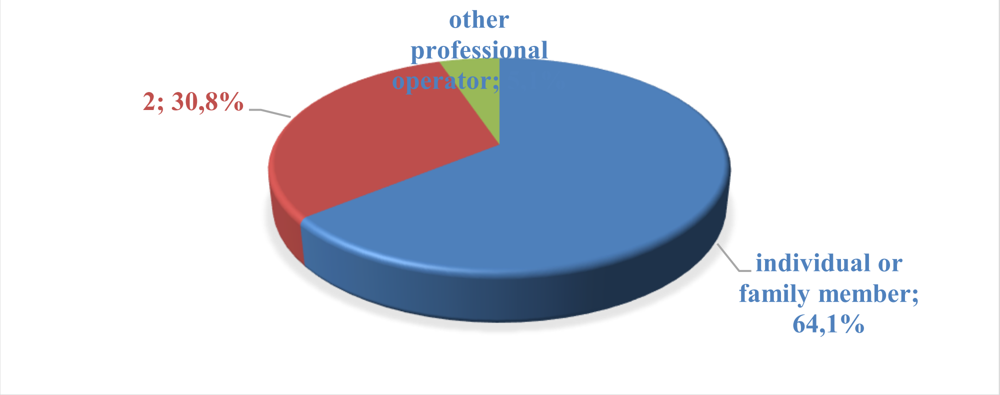

Figure 3. Who chooses the meeting places?

This choice, as said before, is at the same time a means and an end: self-determination pervades the entire project, and is carefully integrated in each phase, up to the point of covering the smallest decisions, such as the choice of where to meet. In this sense, again, the flexibility of the model helps: the professional operator is free to follow what the person chooses, without having to adhere to rigid procedures and without having pre-established places, e.g., the day centre, where they are expected to work.

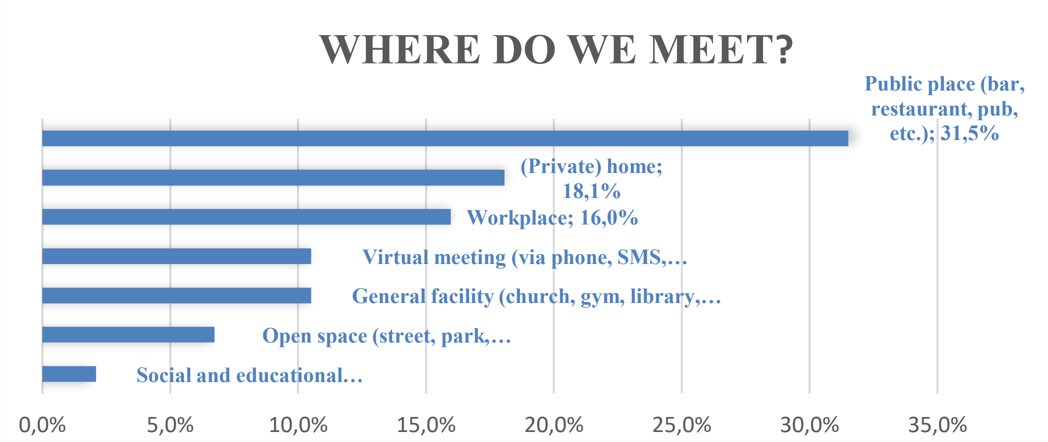

Figure 4. Where do we meet?

When individuals are the ones that choose, only 2% of the meetings take place in educational facilities or specially designed places.

Only 18% of the meetings take place at home (considering that co-designed ones are also included) while 49% of the meetings occur in public places, open to everyone. Often, however, a distorted image spreads, according to which the alternative to spending time in special places dedicated to people with disabilities would be to remain confined to one's house.

The data clearly show why the projects stresses so much on accessibility, on ensuring participation in community life, equal access and opportunity to use the services and facilities without there being any minimum requirements to do so. It can therefore be deduced that the focus of the intervention is building the support network. The broadening of the network, together with the field of experience, constitute, in fact, more than 15% of the time spent with the tutor; the meaning of this with respect to the model of multiple negotiation networks will be discussed in the conclusions (Saraceno, 2017).

The picture portrayed by the data regarding the building of the network shows that projects designed for 6 individuals that took place over the course of 6 months involved 336 subjects. In this context, *subjects of the network* are intended as non-specific subjects, not the professionals appointed to take care of the individuals. We mean all those places, contexts, spaces but also all those bonds, relationships, encounters that are part of the daily life of an adult who lives within their community of belonging.

The mapped network nodes are those where the tutor has performed at least an access facilitation intervention (that is, a modification of the requirements in order to allow equal access opportunities to the person in question compared to other citizens). For most of the nodes in the network, it was necessary to divide the intervention into more than one meeting (60%), while for 40% of the nodes only one meeting was sufficient.

In those meetings the tutor worked in the different contexts with two main purposes. The first was to make them accessible, in particular from the relational and communicational point of view. The second was to make the person's experience in that context authentic and self-determined, that is, functional to supporting their transition to adult life. This aspect will be discussed below, analysing the data relating to the choice.

Dwelling on the choice of places for a moment, it is interesting to observe what happens to the data if we cross-check the contexts in which the person's daily life develops and who suggested/indicated the meeting place, as does Figure 4.

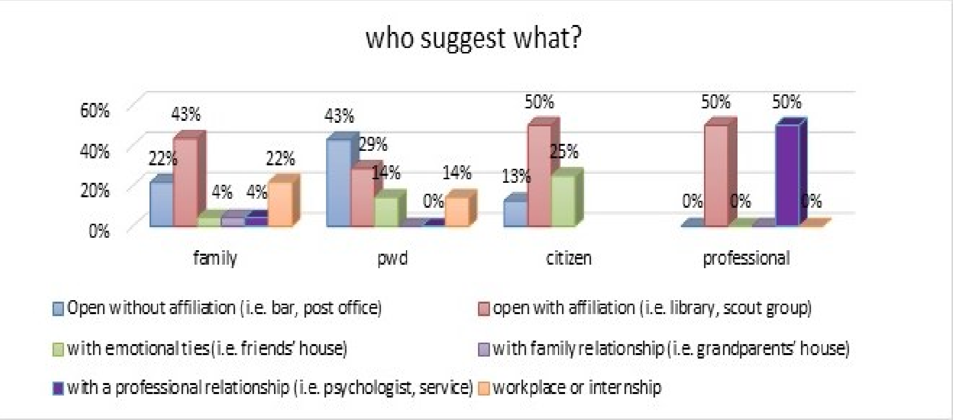

Figure 5. Who suggests what?

As can be seen (Fig.5) among the contexts proposed by the family and by the individual, open places in the real world – with or without affiliation – prevail, making up 65% of the contexts proposed by families and 72% of the nodes proposed by the individual. Conversely, among the places proposed by other professional operators (not the tutor), places in the real world drop to 50% and these suggestions end up only involving places with affiliation. Above all, it should be noted that if we look at the contexts proposed by the professional operators, those with professional relationships rise to 50%, compared to 14% of the contexts proposed by the PwD. Professional operators show a tendency to dismiss places in the real world as possible contexts for carrying out daily tasks, revealing perhaps a deep-rooted habit of imagining people with disabilities where they have always seen them, that is, in special services.

When it comes to what happens in each context, the first area analysed is that of questions and answers asked to the person with disabilities. Here, the main data detected is the behaviour of those interacting with the person with disabilities in each context analysed, focusing on the fact that there is a realistic expectation of receiving a reply (for example, waiting for it before acting) and of adjusting the action according to that reply (without the need for further validation from a person without disability).

On the one hand, often, the time required for the individual to provide the answer (or the way the question is formulated) does not allow the person with disabilities a real opportunity to exercise the right to self-determination in a concrete situation. On the other hand, the choices made by persons with disabilities are often not treated on a par with those made by people without disabilities (Fig.6). The preferences of persons with intellectual and relational disabilities are often subjected to validation by professional operators or people without disabilities. This fact reveals that the rhetorical capital concerning persons with intellectual and relational disabilities still needs a lot of improvement, and that this lack has profound consequences in terms of discrimination (Melancon, 2014).

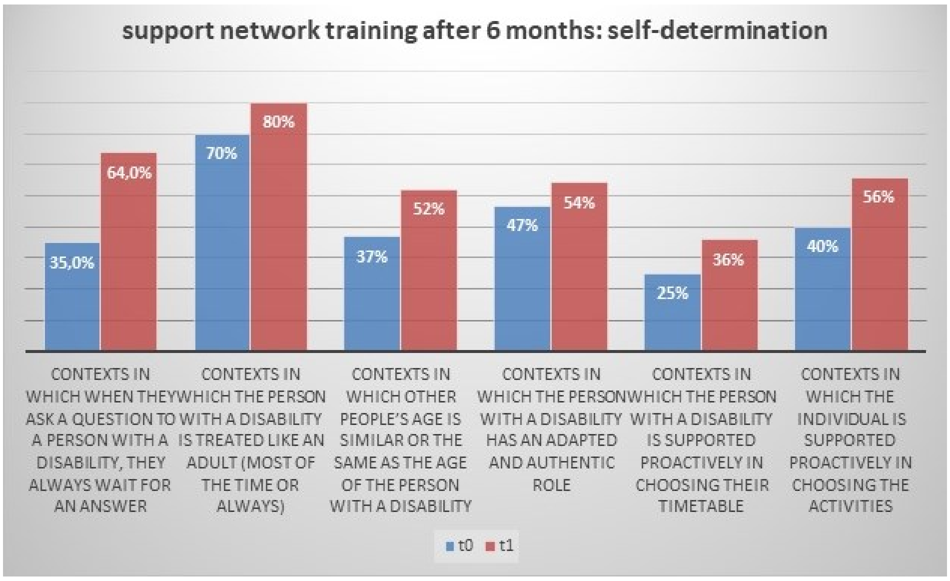

Figure 6. Support network training after six months: self-determination.

With regard to these data the contexts in which people addressed questions directly to the person with disabilities and waited for an answer rose from 35% to 64% of those frequented.

The second area concerns the role that the person with disabilities takes on in the various contexts they attend. Often, in fact, the interactions of people with disabilities – especially intellectual and relational ones – with other citizens still appear to be characterized by mechanisms of commiseration, infantilization and condescension. As a consequence, often the role of the person with disabilities is different from that other citizen have in that same place.

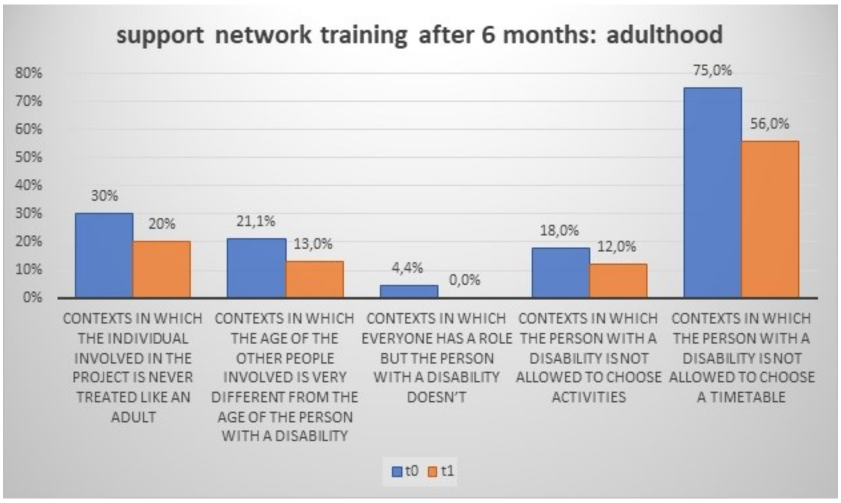

Figure 7. Support training after six months: adulthood.

In this area, we have therefore found the work of tutors quite effective in varying the number of contexts that treat the individual like an adult. These contexts increase from 70 to 80% of those frequented (Fig.7). We can notice that the variation is lower than that relating to the opportunity to choose in different contexts. A possible explanation for this difference is that the paternalistic attitude and the recognition of an adult role are fewer conscious acts than simply asking a question or waiting for an answer, which are explicit acts.

Furthermore, the objective of letting the person with a disability make their own choices had a greater impact (the contexts in which the person with a disability is never treated like an adult dropped from 30% to 20% of those attended) while it was less easy to obtain a constant behaviour in this regard from every subject of the network. Even considering roles, the variation in contexts in which the person with disabilities takes on a coherent, adult role tailored on their characteristics and preferences (therefore authentic) was + 7%: from 47% to 54%. Also, this field displays a limited variation, yet there is a clear indication as to which direction we should take so that the work can accompany the individual's entire life project and allow them a wider field of social possibilities than before.

About this, we should add that the individuals involved in the project were already adults at the time of joining, and therefore their interlocutors had already set up, and often perpetuated, infantilizing relationships and communication models before the start of the project. It can reasonably be assumed that a greater variation in these parameters may be obtained by educating those working in certain contexts not to adopt this conduct from the start, rather than trying to change already established behaviours.

4. Discussion

4.1. Escaping the trap of individual outcomes

As you will have noticed, the data collected for monitoring of the 19 Pari project does not consider individual outcomes. This was the only possible choice, dictated by the paradigm introduced by the CRPD. When, in fact, we are dealing with a project of transition to adulthood on the basis of equality with other citizens, it is not possible to determine a priori what the desirable outcomes are in existential terms.

It depends on the person, on their preferences, on the opportunities allowed by the context in which they live, on their own and their family's value system, on their priorities, on the cultural and material needs they were raised with.

First of all, when we want to *measure* individual existential outcomes – and then classify them as desirable or not – we need to carry out two operations of dubious epistemological legitimacy. The first is to assume that there are individual existential outcomes, which reflects a vision of the human being as an entity detached from contexts and relationships. This vision is not supported by epistemological or psychosocial scenarios or any other disciplinary field: no sociologist, psychologist, or economist would vouch for the legitimacy of this concept.

Moreover, these pre-chosen and standardized areas of life are further burdened by the addition of artificial objectives. Life goals – even assuming they can be operationalized – are nominal variables, which therefore cannot be ordered.

When CRPD become our normative and cultural reference, we as professionals need a more complex model, which allows non-linear causality and does not need to represent existential outcomes in individual terms. In this sense, the model of multiple negotiation networks is very helpful, in that it also includes the dimension of living framed in a more complex reasoning that will be further elaborated in the conclusions.

4.2. From the *After Us* idea to full citizenship

As anticipated in the background, the *after us* concept has been part of our culture and our languages for several years and today contributes to shaping the shared view of adulthood of persons with disabilities: it is both a framework within which the transition is possible and an a priori structurally special path. For people without disabilities, in fact, adult life does not have a different connotation depending on the presence of one's parents. It is an expression that defines a space and an image reserved for persons with disabilities, to which we are so addicted today that we perceive it as neutral, while it actually contains two simple but radical a priori assumptions.

The first assumption lies in the meaning of that *us*. The *after us* idea takes for granted the hypothesis that, at the time of the loss of one's parents, the entire material, emotional, daily, and relational world of each person with disabilities is limited to the small family unit. The second assumption lies in the implicit completion of the sentence: *who will take care of them after us*? It is therefore assumed that the main theme relating to the adulthood of persons with disabilities can still be tackled by simply answering the question *who takes care of them?*.

These assumptions are legitimately rooted in the experiences of parents thirty or forty years ago, who lived in a very different world from ours and who throughout their life had been substantially called to respond to each of their child's human needs: the need for relationships, leisure, having a meaningful social role, economic needs, personal assistance and so on (Beach & Schulz, 2017).

To date, however, this framework allows persons with disabilities to see the transition to adulthood as a process that happens under fundamentally different conditions and in ways that are radically different from other people, a process that can take place, for example, without having to deal with the age of the person (but with the age of the parents), with the intrinsic and social evolutionary drives, with the relationships and roles that that specific person has within the community to which they belong (Overmars Marx et al., 2019). This widespread idea ends up having a crystallizing effect on the relational modalities that are available to the young adult with disabilities. In fact, since the *after us* cultural model always answers the implicit question *who will take care of them?*, we often define all the relationships that the young adult gradually builds by modelling them on the parental one.

The scenario where adulthood revolves around the question *who will take care of them?* does not urge us to ask ourselves how to support persons with disabilities to become colleagues, neighbours, partners, friends. The *after us* epistemological framework basically imagines replacing the parent with another individual or institution, with an adequate place, a group of professional operators but it does not allow us to imagine modifying the *childlike* role that the person holds.

For the young persons without disabilities communities build the opportunity, since adolescence, to begin to structure that variety of relationships that are not modelled after the parental one. The new relationships that gradually develop combine dimensions such as strangeness/confidence, care/risk, freedom/control, expectations, gratuity, hospitality, and many other aspects to varying degrees (Goble, 2004). The fact that the adult life of people with disabilities develops within the *after us* framework, on the other hand, means that what shapes the networks that are built around the young person is the search for a series of parental substitutes.

The future and adult life for typically developing persons is a multiple combination of places, relationships, people, roles, experiences, while for persons with disabilities adult life becomes imaginable only in the form of one or two services or individuals who basically perform the same function: they take care of them.

The data presented in this work, instead, show a different path that brings the transition to adult life of persons with disabilities closer to what this means for a person without disabilities: on the basis of equality with others, as the CRPD states.

It becomes therefore necessary, in order to enable interventions that activate the support network as a place of citizenship and not of custody and protection, to rethink the transition to adult life through new epistemological categories that make it possible to overcome, both in conceptualizations and in practices, what is currently defined as a special adulthood.

4.3. Self-determination

The data showed how the analysis of the support networks allow us to highlight substantial differences between the opportunities for access and citizenship that are offered to young people with disabilities compared to their peers. The combination of these barriers generates, for many people, an insurmountable obstacle to access adult life. A fundamental and much debated aspect of this access concerns the concrete opportunity to make decisions that influence the course of one's existence: the so-called self-determination.

Thinking about people without disabilities it's clear that the decision-making processes that form the scaffolding of adult life are usually interdependent processes, where the participation of other people is required (in multiple forms: from the informal advice of a friend to the official advice of a lawyer), where options are discussed and sometimes partially modified, where one negotiates, changes their mind and finally reaches a decision, with a sort of continuous assistance provided informally by family and friends, and strengthened by the choices made in previous experiences: self-determination is a multilevel and complicated process.

For people with disabilities, instead, the representation of self-determination as a skill that lies entirely within the person, as a personal skill, which they must demonstrate before being allowed to use it in authentic and meaningful contexts, is currently widespread.

For people with intellectual disabilities, however, particularly where the impairment is significant, usually the people in charge of helping to decide are also those who may have the power to make that decision for you, therefore decision making loses its authenticity. Secondly, for professional operators in informal contexts to become able to support the decision without making it, they need to be trained because it is not something that happens spontaneously (as the data show, it is a highly specialised job). This generates a basic disparity of context, according to which persons with disabilities have little motivation and opportunity to decide, and in turn those working in the various contexts see their uncertainty and effort, so they tend to take their place, thus generating a vicious cycle.

Moreover, a whole series of contexts *withdraw* almost automatically from the field of opportunity of persons with disabilities, in the absence of adequate support to help them maintain their role of meaningful contexts.

All this generates an intense need to work, in order to enhance self-determination, primarily on widening the field of opportunity, by allowing the various contexts that are part of each existence to relate to that person as a citizen.

5. Conclusion: towards multiple negotiation networks

Practice modifies the epistemology of a phenomenon. The research is dominated by clinical-empirical epistemology, which tends to measure unilateral effects and to represent phenomena as linear. Life, however, is more complex.

In the context of this article, we have worked with items and numbers, there is nothing to prevent us from doing so. But to apply the CRPD, we do not need new grids: we need a new perspective.

What allows deinstitutionalized life is not, as we have said, the concept of housing or home economics skills, but what Benedetto Saraceno (2017) calls negotiation: the active exercise of exchanging material and symbolic opportunities with your community.

The data analysed in this article, albeit partial, show some of the dimensions through which this *negotiation* can be built, promoted, practiced, and made accessible in the life of persons with intellectual and relational disabilities, without any prior selection based on individual characteristics. Within the paradigm of the CRPD, the objective of our work as professional operators is in fact no longer the evaluation, planning and structuring of interventions appropriate to a certain type of situation, but the creation and multiplication of exchanges in a negotiation network, which includes the material, emotional, symbolic, identity and cultural dimensions.

This model, called multiple negotiation networks, helps us rethink a framework that allows the implementation of practices according to which rights are not an abstract reference but "a necessity of both process and result" (Saraceno, 2017, p. 163). The question that enabling co-design tries to answer in methodological terms is "asking how a weak individual can enter into negotiations" (ibidem). Since the CRPD have been ratified, in fact, we professionals are no longer allowed to ask themselves if, but they should ask themselves how. In terms of power, there is a radical difference.

On the one hand, in fact, we have processes centred on objectives of autonomy, which are based on the idea that social inclusion stems from the "improvement of the damaged skills" of the person (ivi, p. 164) therefore on progressive acquisitions that allow, in the end, those who manage to live on the basis of equality with others. However, this framework is incompatible with the CRPD since, as we have seen, the Convention affirms that disability cannot be used as a motivation for the limitation of rights; if we are faced with the limitation of a right, not managing is not a sufficient justification.

As a result, we need models that, in order to function properly, do not base their practices in the distinction between those who manage and those who do not. The multiple negotiation networks model, of which the data presented give us a cross-section in operational terms, comes to our aid since it does not focus on autonomy but on participation, an authentic participation of citizens, not a misrepresentation of the term that becomes synonymous with *free time*. The goal is no longer to ensure that the weak cease to be weak in order to be able to share the stage with the strong but, as Saraceno (2019) states, to change the rules of the game, to build a scene, networks, communities to which everyone can belong, and where each citizen is allowed continuous, situated and rooted exchanges regardless of their own characteristics.

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