Re-thinking inclusion for adult people with disability: Residential centers from makeshift solution to educational resource for the community

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Abstract

The culture of rights and the inclusive processes that promote the participation of people with disabilities in the community context has grown significantly in recent years, partly as a result of changes in demographic development at national and international level. The progressive ageing of the population and the increase in life expectancy represent a very significant challenge for both people with disabilities and their families This is a social and cultural challenge we have to face not only to guarantee inclusion and participation rights, but also to implement organizational and managerial practices and processes that make them possible. It is therefore increasingly necessary to promote reflections, to develop project ideas and practical experiments aimed at building the adult identity of people with disabilities. The creation of an adult identity is the most important prerequisite for being able to relate to and to perceive oneself as such. On the basis of these considerations, this paper presents some elements derived from a research/action aimed at the realization of a service for people with disabilities in a city area of Lombardy, in order to respond, in a logic of innovation and sustainability, to the different needs of the users who will be welcomed.

Keywords: adult people with disabilities; ageing population; social challenge; disabled people service; innovation and sustainability

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1. Services for adult disability in Italy: the state of the art

The concept of disability has radically changed over the years. Scientific cultural evolution has profoundly changed the approach to disability, no longer described as an individual condition of the person but as a "relationship between a person with a disability and the environmental and behavioral barriers that prevent their full development and participation in life social"¹. The reality of a disability runs through all stages of life. A permanent or temporary disability can be acquired at any time. However, the experimentation of disability is given by coping with barriers of various kinds, which can prevent or limit the full and effective participation of the person in society. The Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) – ratified in Italy with Law 18 of March 3, 2009 – recognizes the right of all people with disabilities to choose their home residence, where and with whom to live. However, it is also necessary to consider how in the Italian history of disability services the evolution of the Day Center represents an element of great importance. Established in the 1970s, it has undergone constant changes and updates. The plurality of words used (socio-therapeutic center; socio-educational center; socio-rehabilitation center; daytime center) shows the variety of projects that, over time, have developed for the realization of these services. The history and the evolution of CDDs show that the development of the offer of day-care centers for people with disabilities begins when special schools are closed (in Italy formally with Law 517/1977), with the consequent and consistent need to offer young children with severe disabilities an alternative to early institutionalization.

In the session of March 3, 2009, the Lombardy regional council approved a motion that commits the president and the regional council to verify that the CRPD's principles are implemented. Specifically, this motion requires the planning and scheduling of interventions for people with disabilities, following the principles of social inclusion, equal treatment, equal opportunities, non-discrimination and independent life.

The Lombardy region has adopted the framework law regional law 12/3/2008 which assigns to the regional council the task of identifying the social offer network and that of social and health services. Part of the supply unit system is made up of the Social Supply Units, that is, the housing communities and socio-educational centers, as well as training services for autonomy. The other part of the offer system consists of services that fall within the social and health area, that is, day centers for people with disabilities

¹ Law 3 March 2009, n. 18 "Ratification and execution of the United Nations Convention on the rights of persons with disabilities".

(CDD), Health Residences for the Disabled (RSD), and Social Healthcare Housing Communities (CSS). CDDs currently represent, in quantitative terms, the largest part of offered daytime services: they are semi-residential services that ensure social and health services and welcome people with disabilities over the age of 18 and usually up to 64. The adult life of people with severe disabilities in Lombardy includes a long-lasting stay in their family, a job placement or attendance in a daytime service with a different degree of protection. The daytime social services system in Lombardy, while not explicitly providing for it, has progressively shaped itself mainly on the characteristics of people with intellectual and relational disabilities, in some cases of people with complex neuromotor disabilities. The adult life of people with severe disabilities is outlined as a long unicum that begins from admission into a service, generally between the ages of 16 and 25 up to the age of 65, or when the family is no longer able to support independently their personal assistance.

Over the years, also to cope with a generalized growth in requests from families and their organizations, new centers called "socio-educational centers" have been gradually established. These centers mainly welcome people with severe intellectual or neurological disabilities, that can participate in specific activities aimed at developing and maintaining their personal autonomy. The Social-Educational Centers (in Italian, CSE) therefore have gradually become hosting places for those who show significant impairment of the autonomy of elementary functions, with the need for specific and continuous assistance. The connection with the community and with the territory represents one of the main objectives of the CSE, while it is hard for CDDs to do so. In both cases, all the activities are oriented towards the well-being of the person with disabilities, even if the day centers are often located far from the community social context. In these services rehabilitation, educational and health care needs are mainly and primarily considered.

In general, many disability services are still influenced today by the culture centered on the problems of disability, often managed with an emergency logic, and struggle to adopt correct practices for planning inclusive programs centered on people.

Starting from these considerations, it appears increasingly necessary to promote reflections, develop design ideas and initiate practical experiments with a view to building the adult identity of the person with disabilities.

2. Ageing and disability: new challenges for new scenarios

The progressive ageing of population has long been a social phenomenon known to all, experts and non-expert people. This is a trend that affects, albeit

with geographical differences, the entire world population, according to the most recent socio-demographic reports (UN World Population Prospect 2019; UN World Population Ageing 2020). This statement means that not only people worldwide are living longer but also that the proportion of older people will continue to grow in the coming years, showing a significant gap in numbers compared to children under the age of 5. Specifically, the WHO document Ageing and Health specifies that "by 2030, 1 in 6 people in the world will be aged 60 years or over. At this time the share of the population aged 60 years and over will increase from 1 billion in 2020 to 1.4 billion. By 2050, the world's population of people aged 60 years or older is expected to triple between 2020 and 2050 to reach 426 million". It is therefore interesting to note that this trend now affects the majority of countries and no longer just the "usual knowns". On the contrary, many traditionally young countries are ageing at a rate that will challenge their adaptability and finances².

Within this general framework, we should specifically mention the Italian situation, where the ageing of the population has been one of the fastest among the most developed countries over the last 50 years³.

The increase in life expectancy (LE) at birth is the result of scientific progress, as well as a social and cultural milestone of absolute value and an indication of the increasing improvement in living and sanitarian conditions. At the same time, however, we must also consider the consequences of these changes and the related critical issues that seem to emerge clearly at different levels: the economic, the social and the political one.

Several elements can be pointed out in this respect. These include: the socioeconomic burden of care, assistance and social security costs for the elderly- a condition defined as "*longevity shock*" that is the prolongation of the lives of those who enjoy a life annuity beyond the average LE attributed to them; the possible increase in degenerative diseases and conditions linked to the presence of a disability (physical, sensory and cognitive conditions).

In addition to what has just been said about the care needs of a growing elderly population, there is also the fact that the ageing process also directly involves people who experience a disability during their lifetime. We could consider, for instance, that nowadays people with intellectual disabilities can hope to live much longer than in the last century and, consequently, for the first time, they can experience old age. Specifically, some international research⁴

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² Robotti O. (2020). Longevità bifronte tra minacce e opportunità. *Tendenze*, 1.

³ Galluzzo L., Gandin C., Ghirini S., Scafato E. (2012). L'invecchiamento della popolazione: Opportunità o sfida. Not Ist Super Sanità, 25.

⁴ Dolan E., Lane J., Hillis G., Delanty N. (2021). Changing trends in life expectancy in intellectual disability over time. *Irish Medical Journal*, 112(9): 1006; Coyle C. E., Kramer J.,

highlighted the increasing LE in people with intellectual disability across almost all Western societies in recent decades, although these rates remain lower than those of general population without disabilities. The LE of people with intellectual disabilities and neurodevelopmental disorders has increased thanks to a very wide range of factors. As for the general population, improved social and health conditions, nutritional improvements, medical and scientific progress have also contributed significantly to better living conditions. With special regard to the condition of disability, we must also consider the processes of deinstitutionalization and the quality of social integration that promoted the achievement of important goals in terms of skills acquired, quality of life and autonomy for these people. The social inclusion of adults with disabilities is one of the most demanding challenges that many families and operators have been facing in the last few years. It is a scenario that every country will have to face more and more through targeted political attention, adequate investments and planning actions that are able to combine criteria of sustainability, innovation and promotion of rights and quality of life of people with fragility⁵.

It is a challenging issue that involves a plurality of actors: families, services, institutions, social resources of the territories.

The projectual activity of the territorial services sometimes risks of being reduced, in some institutional planning offices, to a simple definition of "where" to place the person, without considering "what" (what opportunities to provide, what objectives to foresee) and "how" (types of support and interventions) to do in order to promote quality proposals for the person's life. In order to avoid this risk and to act according to an investment and foresighted approach, some services are also orienting themselves by carrying out research/action projects aimed at understanding the needs, resources and areas of implementation linked to the specificities of the local territory. This is the aim of the project presented in this paper.

Through the involvement of various local realities engaged in the structuring and implementation of effective practices for taking charge of the adult person

Mutchler J. E. (2014). Aging together: Sibling carers of adults with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 11(4), 302-312; Dykens E. M. (2013). Aging in rare intellectual disability syndromes. *Developmental Disabilities Research Reviews*, 18(1), 75-83.

⁵ Cfr. Doukas C., Metsis V., Becker E., Le Z., Makedon F., Maglogiannis I. (2011). Digital cities of the future: Extending@ home assistive technologies for the elderly and the disabled, *Telematics and Informatics*, 28(3): 176-190; Lin J. D., Lin L. P., Hsu S. W. (2016). Aging people with intellectual disabilities: Current challenges and effective interventions. *Review Journal of Autism and Developmental Disorders*, *3*(3): 266-272; Orellana K., Manthorpe J., Tinker A. (2020). Day centres for older people: a systematically conducted scoping review of literature about their benefits, purposes and how they are perceived. *Ageing & Society*, *40*(1): 73-104.

with disabilities, in accordance with national and territorial social policies, some key elements for the creation of a new service have been identified.

3. During and after us: what balance between legislation and sustainability?

In recent years, the words "after us", used to consider the period in which people with disabilities' parents can no longer help or care for them, has been joined by the expression "during us". There are several reasons for this language shift. These include: the aforementioned phenomenon of the increasing life expectancy, which includes people with and without disabilities; the recognized need to promote the accompaniment of people with disabilities to an adult identity, beyond an emergency care approach; closely related to last one, the importance of promoting quality of life design models that involve the family system at an appropriate time.

Building pathways to adulthood for young people with disabilities is considered essential today for a real quality of life. We are referring to forms of educational support that do not stop where working autonomy is not achievable, but aim at developing social, relational, and personal skills through continuous training, the structuring of empowerment contexts, the creation of orientation paths in order to build a "future", conceived not as a distant project but as a concrete succession of evolving steps.

In Italy, with Law no. 112/2016 (*Provisions on assistance in favour of severely disabled persons without family support*), a new way of understanding the "after us" is being defined. We are starting, in small steps, to think about the person with a disability as an individual, to whom, like everyone else, we must recognize and allow the implementation of a right: the right to live one's own life as a continuous journey, without interruptions or drastic changes just because emergencies or conditions related to the impossibility of assistance occur. It is a law that is strongly linked to the 2016 UN Convention and, in particular, to the issue of independent living, which is fully described in Article 19.

As the reference literature points out, among the most pressing needs to be met from an educational perspective we must consider the reduced systematic planning of the transition phases, the lack of projects for the management of the "after us" phase, organized in due time, and the limited services for the social inclusion of young adults with disabilities⁶.

⁶ Giaconi C., Socci C., Fidanza B., Del Bianco N., d'Angelo I., Capellini S. A. (2020). Il Dopo di Noi: nuove alleanze tra pedagogia speciale ed economia per nuovi spazi di Qualità di Vita. *MeTis-Mondi educativi. Temi indagini suggestioni*, 10(2): 274-291.

Law 112, which has had a long parliamentary process in which the representative associations have played a decisive role, is certainly an important point of no return. The law is in fact an attempt to respond to an important and urgent challenge, even if with a delay, compared to the legitimate expectations of the families involved: trying to find innovative answers to the needs of people with severe disabilities. This is an issue that involves the destiny of tens of thousands of people.

The law sets out two important lines of action: the provision of a series of assistance, care and protection measures for people with severe disabilities who do not have family support; the provision of tools to encourage the provision of assistance by private bodies, even in the presence of the family context.

On the one hand, it is necessary to consider this law as a legislative effort, within the framework of public policies for disability, towards the recognition of methods of taking charge of persons with disabilities aimed at ensuring them not only the essential services, but also rights of participation and self-determination. But not only. This law responds, at least on a formal level, to the need to deal with the issue of the "after us" right from the start. when families are still able to take care of their children with disabilities and, above all, are still able to plan and share with their children the most suitable choices that respect their dignity and needs⁷.

On the other hand, it is also necessary to underline its limits: we refer not only to insufficient appropriations to meet the many needs of Italian families, but also to the many territorial differences whereby each region acts in a completely different way, providing different answers to the same needs.

However, it should also be considered that the "After us" is part of a social context characterized by a deep complexity, both as regards the existing services on the territory and as regards the referents and managers of these services (between health and social assistance, between State, Regions, Provinces, Municipalities) and of the scarce commonality between the institutional actors that should give concreteness to what is provided by Law 112⁸.

A few years later, there is a need to review and implement this legislation through significant corrective actions. More specifically, it has become necessary to consider the "after us" program as a pathway on which innovative and sustainable forms of planning must be promoted, involving local authorities and third sector actors⁹. For example, co-planned and participatory models that

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⁷ Verga M. (2021). Il Dopo di noi e il durante noi: brevi riflessioni a cinque anni dall'approvazione della Legge 112/2016. *Sociologia del Diritto*, 2.

⁸ Verga M. Il Dopo di noi e il durante noi. Op. Cit., p.151-152

⁹ Vivaldi E. (2021). L'assistenza alle persone con disabilità (grave) prive del sostegno familiare. *Forum dei Quaderni Costituzionali*, 1: 563-575.

encourage the proximity of responses to specific needs: the person lives in a territory, in a community, and it is there that sustainable responses are shared and built. Constructing the "after us" during the "us", designing different ways of taking care of adults with complex disabilities does not mean in the final analysis satisfying only residential or care needs, but it means making full use of a context in which networks of relationships can be developed.

4. Between the needs of users and the needs of professionals working in CDDs

The promotion of pathways to adult life for people with disabilities and the construction of innovative project models aimed at responding to the needs of people with complex disabilities should start from a clear understanding of their needs and of the professionals who work in the services provided. The possibility of giving a direct voice to users means to be in accordance with the most recent cultural guidelines which pay special attention to the participation dimension of people with disabilities (principles of self-advocacy; capability approach). In addition to the well-known construct of self-determination, which plays an essential role in the process of designing realities, activities for people with disabilities, there is also a dimension of self-representation, linked to the possibility for everyone to offer his or her own personal perspective in the construction of social, cultural, and collective images connected to the world of disability.

The Convention on the Rights of Persons with Disabilities (UN, 2006) highlights how a lacking or reduced participation of persons with disabilities in decision-making processes on issues related to their lives constitutes not only an obstacle to the construction of inclusive processes, but also a significant limitation to the recognition of human rights.

The principles, values and meanings of a real inclusive perspective, towards which today's society is increasingly moving, clearly highlight the need to think and to act in such a way as to ensure that each and every person has the opportunity to express themselves as fully as possible. In a design process aimed at creating a daytime service capable of responding, in a logic of innovation and sustainability, to the different needs of the users who will be received within it, it becomes necessary to try to understand the words, perceptions, and proposals coming from those who will be directly involved. There are clear references to the expression 'Nothing about us, without us', first uttered in 1980 by Ron Chandran-Dudley, a blind activist and the first President of Disabled Peoples' International (DPI), with which disabled people have long claimed the right to represent themselves, to have a say in the political, social, and cultural decisions that directly affect their condition.

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Alongside the possibility of investigating these needs, using appropriate survey tools that take into account the difficulties of the people involved, we must also consider the importance of giving a voice to other protagonists in the life of people with severe disabilities. On the one hand, we are referring to the family, which in recent decades has been increasingly recognized as an active player in the processes aimed at promoting the life's quality of the vulnerable person. Understanding the family's functions, needs and possible contributions means, therefore, overcoming a caring vision that for a long time dominated the field of interventions promoted, in order to highlight instead qualities and competences, sometimes not immediately visible. On the other hand, it refers to the professionals who support people with complex disabilities on a daily basis in the services provided. More specifically, it is very important, in a project design aimed at building services for adult disability, to promote actions that enhance the value of the educational figures working in these structures. In this sense, it may be appropriate to design interventions aimed at promoting the working wellbeing of the staff involved. It is well known that the role of wellbeing in work contexts has gained increasing and appropriate attention in recent decades. This is especially true for those who work in contexts of care and taking care of human frailty: health, care, educational care.

Specifically for disability services and the design of innovative paths and models of the services provided, attention to the dimension of the wellbeing of professionals is a topic of significant interest. What has been stated leads us to reflect, for instance, on the need to rethink the profession of the educator overcoming the cultural prejudice that reduces this role to the pure performance of "one-way" services. This prejudice was reinforced by the idea of care as a mechanical response to primary needs and as such considered to be easy to satisfy and lacking, for the educator involved, of additional emotional loads. It is therefore important to conceptualize this profession, grasping the intertwining of actions, thoughts, and emotions that find space not only outside, but also and above all within each person, be it the receiver or promoter of care practices and gestures.

5. An innovative project proposal in Lombardy (Italy)

One of the greatest difficulties in building services for adults with disabilities is generated by the cultural barrier that makes it difficult to think of the person with a disability as an adult, who has adult needs. Based on these considerations, CeDisMa – Centro Studi e Ricerche sulla Disabilità e la Marginalità, Università Cattolica del Sacro Cuore – has carried out a research project aimed at investigating, identifying and defining, through the

involvement of various realities engaged in the implementation of effective practices in the care of people with disability, the pedagogical, architectural, organisational key elements at the basis of a scientifically founded, innovative and sustainable design of day services for adults with disabilities. More specifically, the research was developed within two epistemic macro-areas, each structured in different phases:

- 1. THE STATE OF THE ART
 - 1.1 Study of the target audience;
 - 1.2 Bibliographic and documentary research on the excellent realities on the national and European territory;
 - 1.3 Documentary research on policies aimed at adult disability, both national and of the territory involved in the research/action;
 - 1.4 Bibliographic research on innovative pedagogical approaches addressed to medium-severe adult disability.
- 2. STUDY IN DEPTH
 - 2.1 The main pedagogical indications that must support the new design of the service;
 - 2.2 The structural attentions that guarantee the absence of architectural barriers and the creation of adequate spaces to enhance the skills of potential service users;
 - 2.3 The new needs of people with disabilities, families, operators and general guidelines for new services.

In the light of the general aims of the research and of the specific objectives, the working group adopted a methodology that respected, on the one hand, the complexity of the topic and, on the other, the need to acquire all the elements considered fundamental for the structuring of innovative proposals, carefully calibrated on the specificities and needs of the territory.

Proposing an Inclusive and Innovative Service requires combining the aspects of care, treatment, and health care with those aimed at defining operations and procedures capable of enhancing the human capital of the people included within the Service. The project proposal starts from the Bibliographical Research divided into four areas:

- 1. State of the art;
- 2. Normative and Reference regulations;
- 3. Pedagogical Orientations;
- 4. Innovation and sustainability.

The Bibliographical Research, conducted like a Narrative Systematic Review¹⁰, was based on the following steps:

- definition of criteria for inclusion/exclusion in the review of documentary resources;
- identification and selection of documents/resources to be included in the review;
- definition of typologies to distinguish resources/documents of a different nature; and
- determination of reference areas to better categorize resources;
- a creation of a concise abstract to summarize the contents of the resource and highlight the focus;
- construction of the collection/archive file in Excel format with respective filters to facilitate actions on the document;
- a subdivision of the excel file into multiple worksheets;
- writing of the report for guided reading of the revision realized.

A total of 124 documentary resources were included in the review and analyzed from an educational point of view, including:

- n. 15 documental resources for the Normative reference;
- 22 documents for the State of the art;
- 58 documents for the Pedagogical Approach;
- n. 29 documentary resources for the Innovative Proposals.

The analysis of the documents and resources included in the Narrative Systematic Review is to be understood to guide the reader in an in-depth study of the main areas considered for the project purpose.

The organization and implementation of an inclusive, innovative and flexible Service for Adults with Disabilities cannot transcend the regulations al laws that guide the legislative accreditation process and operatively. Inclusion needs the pedagogical approach to propose a service to promote an effective valorization of adult people with disabilities to avoid lapsing into welfare and aim at de-utilization and the person-centered approach to their needs. The scientific literature proposes inclusive methodologies and strategies for making services capable of promoting the quality of life of people with disabilities, outlining operational guides for the definition of a life project capable of

¹⁰ Khan K.S., Ter Riet G., Glanville J., Sowden A.J., Kleijnen J., editors for the NHS Centre for Reviews and Dissemination (CRD). Undertaking Systematic Reviews of Research on Effectiveness. CRD's Guidance for Carrying Out or Commissioning Reviews. 2nd ed. New York: NHS Centre for Reviews and Dissemination, University of York, 2000.[CRD Report No. 4]. Available from: http://www.york.ac.uk/ inst/cdr/report4.htm.

accommodating the process of change inevitably generated at each stage of the journey towards adulthood.

Alongside a design process capable of going beyond the application of regulations as a response to duty, over the years the legislative/regulatory support has not been limited to the mere structural aspect but has contributed to the promotion of the centrality of the individual.

Autonomy is a need that goes far beyond independence and self-sufficiency; it is a requirement conditioned by many factors; it is susceptible to constant variations and any environmental or social event can intervene to modify its conditions.

During the drafting of the research project all the people involved, with different roles, in the future service for people with disabilities were interviewed: the municipal administration, the supplier that will provide the service, social workers, operators (educators but also all the other care figures present in a center for people with disabilities) and last, but not least, a group of people with disabilities who belong to a center for people with disabilities in the area where this new service will be entered.

The sample identified, though small, is significant for the Lombardy area where the new service will be created. Eleven people were involved, mostly male (54%) and aged between 56 and 65 (45%); followed by the group of people aged between 46 and 55 (36%). No respondents were under 30 or over 65. This is an innovative as well as a fundamental aspect: knowing the voice of those who will use the proposed new service. It emerged, from all those involved, that is important that the new service allows people with disabilities to be linked with the territory, and families and users, both, to maintain contact with the local reality, avoiding becoming a parallel space that never meets "the world outside the window".

6. Educational horizons and new perspectives for innovative inclusive approaches: designing environments and places

The research made it possible to focus on all the details necessary to obtain a picture of the state of the art, not only in theoretical terms or emerging from a single point of view.

The first aspect of great innovation in the project is linked, in fact, to the multidisciplinary and multidimensionality with which it was conducted: pedagogical, technological, and architectural aspects met and intertwined the needs of the territory, operators and experts, families, and, even more importantly, those of the users.

Designing spaces to meet the needs of people with disabilities is certainly not a simple task. The person with disabilities lives his or her evolution towards adulthood often without finding "adult" answers to the mature needs that emerge in daily life. To include means never to replace, but to build bridges for effective participation to express ourselves according to the philosophy of the bio-psycho-social model.

The demographic analysis carried out in the little canton of Cantù (in Lombardy, Italy) highlighted very clearly how the typical users of CDDs in the area are relatively young. The average age is around 40 years. The index of "life expectancy at birth", more commonly known as "life expectancy" is estimated, according to ISTAT data for 2020 in the area of research, at 81.7 years. This is a figure that gives us pause for thought and opens up wide-ranging ideas.

It is a question of planning services that will be "home" for a long time for these people. It's fundamental to think about the quality of life.

The work carried out has allowed us to put down deep roots around some nodes that seemed to us central:

- the sharing of a documentary and bibliographic research to lead back to the centrality of the person, to respond with pedagogical competence to the needs of the person with disabilities;
- the identification of innovative aspects necessary to promote a context-free of architectural barriers, "nurtured" by facilitators who promote autonomy;
- the framing of those demographic aspects that make it possible to plan in response to the needs of the moment but with an open and attentive eye to future projections;
- the survey of the voices of those who "live" within the Services can offer a careful look at the critical aspects but also at the positive aspects to be recognized and consolidated;
- the definition of the salient points for the design and implementation of a truly innovative and inclusive CDDs.

The objective is high and goes far beyond the building. It concerns the pedagogical foundations on which the center will stand in all its various aspects. Wanting to define a primary objective, the basis of all others, we could trace it to the promotion of growth and improvement of forms of participation and individual and collective responsibility that would allow, certainly, to overcome inequalities and discrimination.

About the innovative aspects, we can briefly list:

- the opening to the territory (INBook Service, Electric Car Recharge, Amazon HUB, We Make Place¹¹);
- the definition of barrier-free and flexible spaces (open space, movable walls);
- the use of "accessible" home automation, technology to promote autonomy, make simple some complex procedures, which avoids adding other complexities;
- the attention to the Quality of Life¹² and the WELL-BEING, no one excluded;
- the creation of a common thread that keeps together the needs of the person with disabilities, those of families, operators, and experts who take care of them, the territory that opens to become a smart city not only for the technological aspects but also for the culture of inclusion and promotion of the welfare of all and everyone.

From the voices of experts, operators, users, and families, we highlight:

- the importance of adequate, ample, and flexible spaces;
- the attention paid to caregivers, also in order to "support" the emotional aspects linked to their role;
- the value of the open connection with families who remain the best "teachers" and allies to better respond to users in full respect of the value of family ties and the importance they play in the construction of one's social identity;
- the need to be open to the territory with trips, visits that make the stay at the Services an opportunity for social participation and not an obstacle;
- coexistence as an opportunity to build a truly inclusive society.

From the ICF perspective, we have learned that disability exists only to the extent that the characteristics of an individual encounter a barrier context.

The first major barrier is cultural: a "closed" service for the disabled that does not open up to the community is equivalent to a parallel reality that never

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 $^{^{11}}$ A we make place is a center for the collection of recycled material (that could be obtained from the companies of the Canturino area – e.g. textile companies, furniture companies, or carpentries) to be transformed to give new life to the material, promote the pedagogy of making and encourage creativity.

¹² Cfr. Doukas C., Metsis V., Becker E., Le Z., Makedon F., Maglogiannis I. (2011). Digital cities of the future: Extending@ home assistive technologies for the elderly and the disabled. *Telematics and Informatics*, 28(3): 176-190; Orellana K., Manthorpe J., Tinker A. (2020). Day centres for older people: a systematically conducted scoping review of literature about their benefits, purposes and how they are perceived. *Ageing & Society*, 40(1): 73-104.

meets the community, an area in which there is no exchange and no growth, no encounter.

All the innovations identified in this work are not only strictly related to digital aspects but, rather, to the image of a Service well inserted in the territory that allows forms of active participation and becomes "educational". The positive aspects of this innovation have repercussions not only for the users who will benefit from this perspective but for the entire community that, borrowing the words of Pope Francesco: «in the relationship with the most fragile experience the profound meaning of making community».

References

- Coyle C. E., Kramer J., Mutchler J. E. (2014). Aging together: Sibling carers of adults with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 11(4): 302-312.
- Dykens E. M. (2013). Aging in rare intellectual disability syndromes. Developmental Disabilities Research Reviews, 18(1): 75-83.
- Dolan E., Lane J., Hillis G., Delanty N. (2021). Changing trends in life expectancy in intellectual disability over time. *Irish Medical Journal*, 112(9):1006.
- Doukas C., Metsis V., Becker E., Le Z., Makedon F., Maglogiannis I. (2011). Digital cities of the future: Extending@ home assistive technologies for the elderly and the disabled. *Telematics and Informatics*, 28(3): 176-190.
- Galluzzo L., Gandin C., Ghirini S., Scafato E. (2012). L'invecchiamento della popolazione: Opportunità o sfida. *Not Ist Super Sanità*, 25.
- Giaconi C., Socci C., Fidanza B., Del Bianco N., d'Angelo I., Capellini S. A. (2020). Il Dopo di Noi: nuove alleanze tra pedagogia speciale ed economia per nuovi spazi di Qualità di Vita. *MeTis-Mondi educativi. Temi indagini suggestioni*, 10(2): 274-291.
- Orellana K., Manthorpe J., Tinker A. (2020). Day centres for older people: a systematically conducted scoping review of literature about their benefits, purposes and how they are perceived. *Ageing & Society*, 40(1): 73-104.
- Robotti O. (2020). Longevità bifronte tra minacce e opportunità. Tendenze, 1.
- Verga M. (2021). Il Dopo di noi e il durante noi: brevi riflessioni a cinque anni dall'approvazione della Legge 112/2016. Sociologia del Diritto, 2.
- Vivaldi E. (2021). L'assistenza alle persone con disabilità (grave) prive del sostegno familiare. *Forum dei Quaderni Costituzionali*, 1: 563-575.

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