

## ADULT INTELLECTIVE DISABILITY, COMMUNITY AND INCLUSION

### DISABILITÀ INTELLETTIVA NELL' ADULTO, COMUNITÀ E INCLUSIONE

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#### **Abstract**

In the world of the Third Sector, including the associations of families of people with disabilities and the cooperatives that were born from these associations to manage services for adults with intellectual disabilities, a rethinking of inclusion is needed also in relation to the "After Us", To the possibility of being able to give a new first home to people with intellectual disabilities, an educational host community where they can live their lives peacefully and planning their lives. The special pedagogy, to concretize, methodologically makes available the tools of pedagogical planning.

Nel mondo del Terzo Settore, comprese le associazioni di famiglie di persone con disabilità e le cooperative che da queste sono nate per la gestione dei servizi per gli adulti con disabilità intellettiva, è necessario un ripensamento dell'inclusione anche in relazione al "Dopo di noi", Alla possibilità di poter dare una nuova prima casa alle persone con disabilità intellettiva, una comunità educativa ospitante dove vivere serenamente la propria vita e programmare la propria vita La pedagogia speciale, per concretizzare, mette metodologicamente a disposizione gli strumenti della progettazione pedagogica .

**Key Words:** inclusion, disability, adult intellectual disability, health, pandemic, community, family, educational relationship, didactics, special pedagogy, learning, teaching, third sector, pedagogy, inclusive approach, inclusive methodologies.

**Parole chiave:** inclusione, disabilità, disabilità intellettiva dell'adulto, salute, pandemia, comunità, famiglia, relazione educativa, didattica, pedagogia speciale, apprendimento, insegnamento, terzo settore, pedagogia, approccio inclusivo, metodologie inclusive.

#### **1-Problems related to the pandemic period**

The events and, above all, the regulations related to the pandemic have put the inclusive model in a deep crisis, especially for adults with intellectual disabilities living in the community. These realities have been considered alike residences for the non self-sufficient elderly, although they are

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obviously different. The danger of death connected to the coronavirus has mainly concerned very elderly people with multiple pathologies, several of them are placed in special residences where many people died from the virus, especially in the initial phase when no one was prepared to face the invasive disease. People with multiple pathologies and people with intellectual disabilities have been both considered as weak people and even distinguishing between the two types in the health list, they have all been put on the same level in the interventions, improperly standardizing.

People with intellectual disabilities are not sick, if not some with pathologies, like other human beings and therefore should have been considered as other humans who are not sick and therefore not particularly at risk. Instead, they have been locked away in communities for too long, as if they were hospitals and nursing homes. Relations with family members were also interrupted or greatly reduced. The educational alliance has failed, the idea of a new home for adults with intellectual disabilities has not in fact been realized, while sanitization prevailed. This is certainly not the answer to the "Dopo di Noi" (After Us) and the application, the implementation of the law on "Dopo di Noi" of 2016. The inclusion of people with intellectual disabilities has been voided. This is not the answer to the "Durante noi" (During us) and "Dopo di Noi" of family members. The vast world of the Third Sector, made up in the broadest sense of Associations, Cooperatives, Foundations, Religious Bodies, with its many services for people with disabilities, was unable to take a stand and suffered the regulations of the pandemic. What to do to face these problems? What proposals? For what inclusion? Is a change possible?

## **2-Adult intellectual disability and community**

In the world of the Third Sector, including the associations of families of people with disabilities and the cooperatives that were born from these associations to manage services for adults with intellectual disabilities, it is required a new concept of inclusion, also in relation to the "After Us ", The possibility of being able to give a new first home to people with intellectual disabilities, a host community where they can actually live their lives in fullness and serenity.

The law 22 June 2016 n. 112 tried to introduce new proposals for people with even severe disabilities aimed, as much as at autonomy, well-being and social inclusion (Gazzi, 2017). The founding principles of this legislation can be found in the Constitution itself and are as follows: art. 2 which guarantees the inviolable rights of man both as an individual and in social compositions; art. 3 which establishes the principle of equality; art. 30 which provides for the right and duty of parents to support their children, with the intervention of the law in case of parents' difficulties; art. 32 which protects the right to health; art. 38 which provides for the assistance of disabled citizens in connection with work. The law essentially aims to offer (art.1) assistance, care and protection to people with severe disabilities, referring to law 104/1992, and without family support. It offers assistance with the establishment of a Fund and with the encouragement of the establishment of trusts, that is, of destination restrictions. The purpose of the Fund is to promote and implement domiciliation in homes or apartment groups (co-housing) to avoid institutionalization and allow the highest possible level of autonomy for people with severe disabilities without family support. Beyond the legal details and the complexity of the legislation itself, this clearly fits into what various bodies promoting personal services and families have always wished: de-institutionalization and, consequently, inclusion.

It is therefore an additional and better possibility for the families of people with intellectual disabilities and for the related associations, in order to give an answer to the "Dopo Noi"(After Us), that is the priority concern about what will happen to their children when the parents will no longer be there or in any case they will not be able to join them on the journey of life. Law 112 is certainly important because it identifies "home" as the optimal existential dimension to carry out the path and the life plan of the person with disabilities when their parents will pass away or when they will no longer be able to assist their children. So the law supports the right for each of us, including our family members with disabilities, to live well at home rather than in a special service (Bollani, 2017). And it is also very important because "the structure of the law was meant to improve private and public resources and to try to activate a several investments for the benefit of life projects for the After US, through a mix of new instruments, legal such as the Trust, fiscal such as tax concessions, but also of social service such as the life project, the case manager and the project budget.

In our associations, our dictum has always been 'when a child with a disability is born, one family is not enough'. Therefore, this law favors both the aggregation of families by encouraging them to join associations "with tested experience", and the possibilità of allocating bequests and resources for the cause of the After Us (Bollani, 2017).

In other words this encourages the orientation of individual families and various associations of families of people with disabilities towards a supported and competent plan for the creation of new housing solutions that respond to the idea of home in the best sense of the family.

The State and the Regions could and should encourage these innovative and inclusive paths, despite bureaucracy, rigidity, standardization and above all an excessively sanitary approach to services. Home must be "the reflection of the uniqueness of each person, of their freedom and of their significant relationships which make them so". We ask the world of the third Sector of and good social cooperation to continue to support people with disabilities and their parents by taking the challenge and the possibility of opening new alternative support paths to residential structures, also aimed at promoting quality of life and social inclusion "(Bollani, 2017). Significant experiences already in progress, contextualized territorially, seem to confirm these solutions and views (Bollani 2017).

There are also some critical notes on the law, notes that must question family associations and other third sector entities engaged in services for people with intellectual disabilities.

First of all, it is not explained who are the carers of the disabled in the apartments, an important detail in defining the approach of the proposal. Could it be just a welfare proposal? Are personal assistants or social health workers enough to guarantee the house, to reproduce the family style or do you want to propose something else? We know very well that parents cannot be reduced to welfare or care tasks, but that first and foremost they are educators. So it would take educators to accompany. "The human being is much more than an object to be washed, dressed and fed. "The adult human being with intellectual disabilities is a person, with own personality, own peculiar way of being and personal own way to get in relations even and especially emotionally, of communicating and acting"(Mariani, 2017).

The educational relationship is needed, even in the adult stage of life. "The helping educational relationship allows, according to a community thought, a planning welcome: the dynamic planning of welcoming contexts in which the person can feel welcomed. This works for the integral promotion of the person, the gradual development and progressive realization of the global potential, and therefore of the improvement of their possibilities (Mariani, 2017). Each person is

unique and unrepeatable and cannot be accompanied through an organization with standard timetables and standard approaches for all residents.

In order to better understand people and situations, rather than to contrast the value and identification of everybody, it is necessary to keep in mind the difficulties that may arise: of conceptual elaboration and long-term planning beyond everyday life; of deconditioning from external stimuli, of understanding, of the use of languages and therefore of understanding and making oneself understood.<sup>3</sup> There is the risk of bringing the care approach to communities and apartments that want to be a home and of being reduced just to the satisfaction of basic needs, such as nutrition, hygiene, health protection, protection, rest. The service would be limited to the provision of assistance services.

Furthermore, State investments for this innovation are low and most of the residential services for disability continue with a primarily health approach, which got spread especially with the new millennium, replacing education that was a priority up to then and decisive for the quality of services aimed at the quality of life of people with disabilities.

As result of these critical notes there is a persistent concern of family members, especially parents, about the destiny of their relatives with disabilities, located in residences, large or small, but without family style, with an exponentially growing discomfort and with the further danger, as a consequence, of behaviors affected by anxiety, nervousness, aggression and the daily use of psychotropic drugs.

On the contrary, "education" allows planning, personalization, enhancement, beyond the common classifications, performing demands, welfare, hypocritical pietism. Education should not be restricted but has to incorporate autonomy, skills, competences, participation, self-determination as means, not as targets (it would even be dangerous if they were) and therefore to be brought into the helping educational relationship. The helping educational relationship is always promotional and transforming. It is based on the assumption of allowing oneself to be destabilized, provoked, changed by the other, also changing the organization of the service that must be made available to the person and not vice versa" (Mariani, 2017).

In this historical period, therefore, the different realities of the so-called Third Sector must not only take part into different contexts to respond to emerging needs for help, but clearly think about the quality of the help to be offered.

We could also say that the quality of services must be added to the quantity of services. And the quality of services requires starting again from the essential, from the home, from the community. "everybody needs a 'refuge' where to live, where to put their precious things, where to express themselves not in solitude, but with someone to dialogue and to share with, to whom to express friendship and affection.(Alberti, 2017)" Perhaps "the family of origin is irreplaceable, the parents are irreplaceable, but the Family Home tries to reconstruct, even if imperfectly, the family environment, respecting the principles and values that are the basis of a family: love, affection, sharing, sincerity and honesty (Alberti, 2017). The educational community is therefore the best housing solution for people with intellectual disabilities, the inclusive response. The educational community is "a union of people" who live their lives together, share important daily moments share their goods, not so much the material ones, but the deepest ones of the human soul. They love each other, they communicate with each other not only verbally, but above all gesturally and with

smiles and looks. Deep relationships are created between fellows and with educators who share their difficult life and try to make it peaceful.

The community is the favourite place of relationships it is a space in which to elaborate one's own experiences, it is the refuge in which joys and failures, victories and defeats can be placed, it is the ideal place where you can live a life project and share it with others, where you can develop your own attitudes towards autonomy, collaboration, interaction (Alberti, 2017).

### **3-Inclusion Methodology in services for people with intellectual disabilities**

In the last forty years exponents of Special Pedagogy in Italy have laid the foundations of educational accompaniment in services for people with intellectual disabilities for true inclusion, favoring the gradual and progressive transition from integration to inclusion, both on the theoretical recognition of existential originality, of the right to inclusion, of the quality of life (Vico, 1984; Canevaro, 2006; Cairo, Mariani, Zoni Confalonieri, 2010), both on a methodological and practical level, of good practices, of use of the tools of pedagogical planning and of adaptable environments on a personal scale, with innovative proposals and concrete issues related to the quality of services for the quality of personal life (d'Alonzo, 1997; Mariani, 1998; Mariani, 1999). The pedagogists have made it possible to place oneself in front and to the side of the person with intellectual disabilities with the pedagogical gaze.

First of all, for a concrete inclusion in personal services, including residential ones, a pedagogical point of view is necessary.

The pedagogical gaze recognizes the uniqueness of the person and mainly his qualities, that is, his beautiful gifts; in the alternative also the endogenous difficulties, that is, deriving from his deficient condition, but always taking into consideration that they can be greatly intensified by the so-called exogenous causes, the ones deriving from the environmental and relational context. Change the observation. It is no longer an detached observation aimed at filing, quantifying, categorizing, but an observation in action to understand how to best accompany what to offer. Education is permanent, it continues even in the adult phase of existence and is truly reliable, through the personalized educational project, to be updated periodically, of the dynamic life plan of the person in full respect of his dignity and his becoming.

What is the purpose? The aim is freedom, freedom actually meant as giving the possibility of life that is always new, renewing, revitalizing, beyond routine and its dreariness. Thus we discover that freedom is not theory, an empty word, just declaration of utopian intentions, it is instead reality! It opens up to hope, going beyond the terrible aspect of everyday life, also through an appropriate use of the different expressive and communicative languages.

The integration was aimed at allowing people with intellectual disabilities to adapt to the context they belong to, giving the possibility of being able to express their human potential in the community that has decided to take charge of the person taking into great consideration their difficulties and its existential problematicity. We have examples of good integration by services their teams of truly motivated, generous, empathic operators, with the daily commitment to allow possible participation in community life in certain contexts, with proposals for adequate activities and related teaching and methods.

We cannot hide that, from a limited point of view sometimes applied in several personal services, integration has unfortunately made in a coercive adaptation of people to the contexts to which they belong. Organization and rigid and pre-packaged activities have prevailed as model of adaptation.

Individualized Educational Projects have been reduced to the predominant programming of the service, with teaching methods and methods for insertion and adaptation. Organization prevailed over people. The same teams of operators have adapted passively, but with uneasiness and perplexity shown by some, especially educators.

Many people, including family members and related associations, have complained and still today they even speak of segregation, but we must understand that complaining is not enough, we need to find the path of change with reason and courage, then follow it.

About inclusive services for people with intellectual disabilities, the questions change in order to accompany and guarantee a Personalized Educational Project for inclusion.

We move from questions for integration to questions for inclusion.

The questions for integration are generally the following.

- What is the condition of the person who needs to be taken care?
- What are their deficits, any pathologies, psychic weakness, behaviors considered as problematic?
- How can they be included in the personal service?
- What are they able to do (autonomy, skills, competences)?
- What assistance do they require? What therapies are considered necessary? What rehabilitation?
- What self-determination as a choice?
- What social participation is possible?

From an Integration point of view these are questions that can be regarded as important.

The questions of inclusion, which do not want to exclude but which relativize those of integration by overcoming them, are the following.

- How can we enter into a relationship with the person who needs to be taken care?
- And in the emotional and bodily relationship? What understandable words can we combine with gestures?
- What are the communication channels, the possibilities of understanding and making oneself understood?
- How to discover with wonder and then how to dynamically enhance the potential for the integral promotion of the person?
- How to allow them to express themselves?
- How to read and understand uneasy moments and how to contain them?
- How to really personalize the environment?

The questions are corresponded with the use of pedagogical planning tools.

The Personalized Educational Project is the fundamental tool, it allows a dynamic, motivating, engaging, unitary accompaniment. Methodologically it cannot be reduced to objectives and activities to be carried out, but, on the basis of careful and continuous observation in the concreteness of everyday life, an observation that cannot be reduced to individual behavior but also

to the environment and interpersonal relationships, while taking into account the diagnosis, but without being reduced to it, allows to define:

- the purposes,
- the methods of accompaniment and the activities to implement them.

The methods of accompaniment by all the operators must be strict in order not to fragment and disorient the person with different styles and methods.

The Personalized Educational Projects better than Individualized Educational Projects: the Personalized illuminates the consideration of the person as being naturally and culturally related.

It must be worked out in a team and basically is aimed to seek the unity of the proposal to the person with disabilities. Not everyone must do the same things in the same way in the accompaniment, but everyone must agree on what they want to do. It is very important to give time to deepen in community, to discuss and, finally, to be able to find, through the necessary mediations, the meeting points, common methods considered effective for substantial serenity and possible freedom of the accompanied person. This method of meeting and teamwork can allow for a fairly unitary accompaniment, being able to face even complex situations of people with disabilities even with significant behavioral problems and which are unmanageable in care facilities, if not with massive drug use. In an educational reality, aggression, self-aggression and other behaviors considered extremely problematic, often caused by fear, anxiety, tensions, abuses, frustrations, conflicts, are faced by searching with perspicacity and with serenity the external causes and, consequently, proposing appropriate educational interventions, above all through community prevention in a context characterized by calm, cheerfulness, reassurance, rules (Mariani, 2015).

In synergic connection to the Personalized Educational Project there are the tools of community pedagogical planning: the Project of the Service to the Person and its variations in course, the Programming.

The Personal Service Project, which can last several years and from which the most concise Service Charter can be derived, contains:

- identity and historical background of the Organization promoting the service;
- type of people accepted;
- purpose of the service;
- facilities and means available;
- main organizational lines: staff, related team work and organizational plan; setting up everyday life; pedagogical planning tools and methods of their use; methods of selecting operators; methods of admission and discharge of people who use the service; economic resources available for maintenance with related procurement methods.

The planning variations in the medium term, for example annual, half-yearly, quarterly, are the Schedules. These, for example in a residential community for people with intellectual disabilities, contain the detailed setting and organization of the period taken into consideration: typical day of the residents and hours of activities, schedules with shifts of carers, methods of handover, times and methods of team meetings, and collect the activity sheets and various initiatives, not only daytime occupational and stimulation activities, but also the daily moments such as getting up and

going to bed, hygiene, meals, free time, and also various outings and external activities in the area, holidays, inclusive with for each:

- name of the business,
- contents,
- targets,
- methods of carrying out,
- accompanied people involved,
- operators involved and reference,
- place /s,
- structures and vehicles,
- times.

And therefore, even the so-called welfare activities become educational, they are characterized by an educational approach, which is also planning, personalized, enhancing. Specialized health support activities, such as those of nurses and physiotherapists, must also be included in the Programming with specific cards.

It must be very clear that the Programs must be developed in close connection with the Personalized Educational Projects and therefore be very dynamic, in relation to changes in people and with the possible arrival of new residents. The organization can only be extremely flexible. The care assistants allow themselves to be continually destabilized by renewing conditions and newcomers.

On the basis of the medium-term Schedules, very detailed short-term Schedules, the weekly ones, can be set.

Thus the programming from static and common documentation is turned into dynamic and inclusive documentation.

Through the tools of pedagogical planning we get to the pedagogical antinomy person-community: the person lives in community, the community suits to the person and the person is called to participate in the life of the community, always looking to the harmony.

Through the tools of pedagogical planning, the planning becomes a peculiar characteristic of the human being, of human communities. Planning by the community that joins the person on the journey of life allows us not to be at the mercy of events. The choice to destabilize is the choice that makes authentic living to help out beyond mere and sometimes empty declarations of being close to the so-called least. It certainly requires commitment, effort, sometimes sacrifice, but, for those who are aware of the value of planning, also the certainty of growing in humanity, ingenuity, creativity, wonder, joy. Planning therefore is clarity of purpose in order to be able to offer routes of meaning; it makes us to think continuously, thus allowing us to go beyond any pragmatic conclusion. There is awareness of the imperative need for a dynamic project welcome and we finally go beyond the common dangers in the assistance services of spontaneity, instinct, improvisation that have nothing to do with a project accompaniment of people who need to be accepted and to be accompanied permanently, partially or even in some total situation, on the journey of life.



Pedagogical view and the tools of pedagogical planning allow us to enter into the logic of education. We intend education in its full meaning to plan welcoming contexts in which the person can feel welcomed, thus dynamically promoting the personal global potential and thus being truly inclusive.

As a result the central and priority operators of a residential community for adults with intellectual disabilities are qualified educators at the university level, experts in planning and in the educational relationship. Educators according to a pedagogical point of view, develop the potential of the person for own integral promotion, define and implement the methods of accompaniment, are mediators with concrete and planning reality, support and sometimes even, when needed, make choices for them. Parents certainly also carry out caring tasks, but they are and always remain first and foremost educators. Consequently, and necessarily in the educational communities that replace the family, those who are in charge of replacing them and supporting them in the journey of life are educators who know how to combine empathic sensitivity and paternal and maternal affection with pedagogical skills, with the self-control that characterizes a professional of the 'project accompaniment (d'Alonzo, Mariani, Zampieri, Maggiolini, 2012). This pedagogical approach to services for adults with intellectual disabilities would finally lead to consequences for a desirable change in management standards within services for people with intellectual disabilities: the main carers, both numerically and for project responsibilities, should be educators. by profession, with the coordination and advice of their point of reference, the pedagogue, for personalized and community pedagogical planning. There could be assistance support figures, such as social and health workers, but they would be subordinate figures, well directed in their work by educators. Other health professionals could also be external support if needed, such as a family: physiotherapist, nurse, doctor; but outside the health and welfare logic of the community.

#### **4-Summary and conclusions**

This is not a mere utopia, something theoretical or not possible to apply. There is an irrepressible need to radically change the fate of communities towards inclusion and we have clearly shown that it is possible.

In the Third Sector, including family associations, there is a need for awareness, courage, planning, decision, educational alliances for inclusion.

It is imperative and imperative to define the meaning, purposes and methodology of inclusion.

First of all, inclusion is recognizing once and for all the true condition of people with intellectual disabilities who are people and like all human beings and must be enabled to be themselves, in the fullness of humanity, that is, in the gradual, progressive, dynamic, natural and cultural passage, never linear and definitive, from egocentrism to gift, as much as it is possible, but without putting any limits a priori.

Inclusion implies the transition from active adaptation to destabilization of the context. Everything changes: it is no longer the person who must adapt, but the community that must change, recognize and therefore to welcome the person. Roles, relational dynamics, organization, environment must necessarily change. It is the community that chooses to let itself be provoked by the person, who questions itself, which must change first of all mentally and consequently concretely in its way of acting, of being, of communicating, of interacting.

Continuous design innovation is required. The necessary step to take is from assistance to education, which translates into project accompaniment, community sharing. "For humanization it

also needs to be and live as a true community. To be truly such a community must be (continuous and never ending tendency to have to be, in dynamism and creativity):

- with witnesses of horizons of meaning and relative values;
- respecting the history and experiences of the people welcomed;
- in the constant openness to dialogue with its aspects (listening, clarity, meekness, trust);
- with affective attention (dedication to the other, body contacts in the paternal, maternal, paternal style in the clarity of relationships and roles);
- with the proposal of community life by promoting active and creative participation, in reciprocity, with responsibility, in the dynamism of rules and roles);
  - always keeping the dynamic integral promotion of the person central with particular attention to education in critical capacity and the progressive maturation of values;
- with the related Personalized Educational Project as a dynamic search for the good and community proposals for liberation itineraries;
- in the awareness of the limits of the proposal, of personal free will and the mystery of the person, of the possibility of failure, beyond the devastating desire for omnipotence with absurd expectations in the claim of perfection;
- and, finally, not in opposition, to the awareness of limits, in the hope that is not naive, allowing oneself to be destabilized, always giving the possibility, beyond the errors, the problems, the stigma, the prejudice, the pathologization de-empowering everyone, accompanying and accompanying people" (Mariani, 2021).

It is therefore necessary to rethink disability policies to restore hope and serenity to parents regarding the future of their children, the "After Us". We need to change the regulations to deinstitutionalize, to desanitarize, to de-bureaucratize. You could even spend less and improve inclusion. It would also be possible to fully implement the Italian framework law on disability (104/1992), for some parts still current and not implemented.

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It is necessary to reverse the trend towards the progressive sanitization of services for adults with intellectual disabilities, which got dramatically worse during the pandemic, so misleading words that should have disappeared as a patient, sick person, mentally retarded etc. have returned to be used in the world of intellectual disability. Even within the residential areas, the protocols for covid have drastically reduced the relationships between accompanied and between carers and accompanied, with serious repercussions on relational and emotional life, while acknowledging the commitment of many generous and prepared educators to try to safeguard a minimum community life. We have returned to full institutionalization. In this phase, the inclusion was voided in the name of the emergency.

The urgent target of the Third Sector realities will be to resume reasoning, projects, educational alliances for inclusion, with the commitment to urge the Policy for a radical change of the laws of the State and Regions regarding services for adults with intellectual disabilities.

The task of Pedagogy and, precisely of Special Pedagogy is to broaden the horizon of adults with intellectual disabilities, their families, starting with educators and pedagogues, of the vast world of the Third Sector. But which Pedagogy? A community pedagogy for the dynamic integral promotion of the person, towards a new humanism (Bianchini, Mariani, 2016).

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