

MANIFESTO DI MILANO

Anffas's Vision

"Where, after all, do universal human rights begin? In small places, close to home—so close and so small that they cannot be seen on any maps of the world. Yet they are the world of the individual person; the neighbourhood he lives in; the school or college he attends; the factory, farm, or office where he works.

Such are the places where every man, woman, and child seeks equal justice, equal opportunity, equal dignity without discrimination.

Unless these rights have meaning there, they have little meaning anywhere. Without concerted citizen action to uphold them close to home, we shall look in vain for progress in the larger world.

We believe that the destiny of human rights is in the hands of all our citizens in all our communities"

— Eleanor Roosevelt, "In Your Hands" (1958 speech delivered on the 10th anniversary of the Universal Declaration of Human Rights)

THE NEW VISION AND THE EFFECT ON OUR COLLECTIVE MISSION

CONTENTS

- **associative participation and the participation of persons with disabilities:** To overcome the concept of being an association of parents and family members of persons with disabilities who alone do not know or cannot represent themselves, to become an association of parents, family members and persons with disabilities who together seek and claim respect for human rights, also through appropriate support and counselling for their best expression, participation and quality of life;
- **the overcoming of the "family-centric" Association towards an "person-centric" association:** in the respect of the rights of self-determination of those that Anffas represents, the contents of the document "The heart and the reason" has been shared to represent the modernization and to give continuity and new lymph to the associative thought;
- **the inclusive policies:** The required step is to overcome the concept of an exclusive and therefore closed Association, to move to an Association of community utility and therefore necessarily open to the world and on the world;
- **Relaunching membership and associative representation:** through the analysis of the mechanisms that have led to the progressive deresponsibilization of members and to counter the growing phenomenon of the socio-user of services;
- **Open up to social marketing:** using innovative tools to increase notoriety, strengthen the image of Anffas and attractiveness to "Anffas products";



- **a common language between code of families and code of professionalism:** Families and operators need to collaborate effectively and with the same language in a strong alliance on issues such as individual project, quality of life, services, inclusiveness;

- **training "Do not be unprepared!":** training remains the main tool for achieving this aim;

- **associative alliances and the overcoming of self-referentiality:** We must open ourselves to contamination with other realities that deal with health and social protection, but not only;

- **an association that works at all levels:** It is necessary to strengthen the role of all levels associative fully and actively involving also the autonomous institutions branded Anffas to the associative life.

The provisions of the new Vision can/ must re-orient at every level the Mission of Anffas starting from the revision of the statute and regulation and the code of ethics of National Anffas and cascade of all levels associative.

THE ASSOCIATIVE LINE

Premise

The frame of reference for the construction of the new Anffas Onlus's vision, can only be indisputably the UN Convention on the rights of persons with disabilities. The entry into force of the Convention, in fact, introduces a real cultural revolution, accepting the idea of disability as a social relationship and not as a subjective and passive condition of the person. It is therefore a question of creating a genuine re-evolution of the **concepts of health and disability**. The person with disability and its family, can no longer be seen as **passive objects of interventions, but as active subjects and protagonists aware** of the planning of resources adapted to their real needs both in the design of territorial service and in the case of individual and customized projects. All in the perspective of improving the quality of life. In this context, the **family itself needs to be adequately supported throughout its life cycle and in its different specificities**. Therefore, the Association's task is to **accompany people to know, understand, request, collaborate and plan**, also through the support and mediation of appropriate professional figures.

The associative line assumes, therefore, a **crucial** character for the life of ANFFAS and in particular you will have to assume full awareness of the fact that:

A. putting the disabled person at the centre of their work as a causal agent of their lives forces the levels of associations and management to review their way of thinking and doing: the priorities must be implemented and updated, the instruments, modalities of communicating and of taking decisions;

B. aiming to contribute to the inclusive development of communities - to protect the most discriminated groups - represents an enrichment of its work, but also an increase in difficulties and of unknown. ANFFAS should be able to keep its specificity alive and active - to promote and protect the rights of persons with disabilities and their families - and, at the same time, open up and make yourself available for comparison and joint work with other community realities that share the same purpose (e.g. people discriminated against by gender, economic conditions, racial affiliation, etc.).

It follows that the process of implementation of the associative line must also reflect coherently the extraordinary and crucial nature of the new goals.

The commitments

A. The rights of persons with disabilities shall be always (time), wherever (place) and in any case (context) respected and guaranteed

Persons with disabilities have the same human, civil, social and economic rights as any other human being.

Such rights shall be incompressible and unchangeable and for no reason shall attenuations or adaptations of their value and meaning be permitted, let alone in relation to health and operating conditions requiring increased support.

Promote respect for human rights, ensure respect for the intrinsic dignity of the person in society and services, act to protect against discrimination, act to increase the prominence of persons with disabilities, their self-determination and self-representation to the maximum extent possible, acquire political, design and management skills in compliance with the logic of social inclusion become the land on which to develop the activities of the entities that make up the "ANFFAS system".

For these purposes, ANFFAS Onlus in synergy and harmony with the Regional Bodies as well as with the general structures of the Association is committed to:

- investing in national communication actions to help broaden awareness of the human rights and quality of life approach, the concepts of equality, equal opportunities and reasonable accommodation, in coherence and adherence to the paradigms established by the UN Convention on the Rights of Persons with Disabilities;
- to increase the number of ANFFAS associations entitled to act under Law 67/2006, to coordinate their activities, to train association leaders and services to the "culture" of anti-discrimination, to promote concrete forms of protection against discrimination;
- define, within the minimum levels of operation of ANFFAS branded services, operational practices and tools to protect persons with disabilities from the risks of abuse and ill-treatment;
- investing in training and communication activities on self-determination issues and self-representation of persons with disabilities to the maximum extent possible.

B. Families of persons with disabilities must be supported and protected for the improvement of their Quality of Life

Disability is a dimension of life that belongs to the human condition and largely depends on the community, and is not a problem to be placed at the sole responsibility of the family.

It is indeed the Italian Republic's task to remove economic and social obstacles which, by effectively restricting the freedom and equality of citizens, prevent the full development of the human person and the effective participation of all citizens in political, economic and social organization of the country.

For these purposes, ANFFAS Onlus in synergy and harmony with the Regional Bodies as well as with the general structures of the Association is committed to:

- Keep specific attention on the *SAI? network* and on ways to adequately support the Family of persons with disabilities by prioritizing the goal of supporting it, through a

process of empowerment, (power of knowledge to be able to make informed choices) the enforceability of rights and the strengthening of its role as an irreplaceable resource to promote self-determination, self-representation, participation and social inclusion through the proper construction of a person's life plan;

- This commitment includes, in the context of the life plan of the person with disabilities, the possibility that the territorial association and/or the legal entities, assume the role of legal protection in favour of the same (e.g. legal guardian);
- maintain and increase its active role both in terms of advice and support on the issues of sharing the cost of services, for the respect of dignity and autonomy of the person with disabilities and for combating the processes of impoverishment

C. Social Inclusion = caring for communities to care for people = ANFFAS can no longer act alone

Social inclusion is the scenario of civil coexistence in which people with disabilities can participate, on the basis of equality, in the life of the community to which they belong. The more communities organize, educate and develop by embracing human and cultural diversity, the more likely all people, including those with disabilities, can live their lives with dignity (opportunities for work, housing, social, emotional and sexual relations, etc.).

More and more it is therefore necessary to act by promoting and committing to enter into agreements and alliances with organisations with similar aims to those of ANFFAS.

For these purposes, ANFFAS Onlus in synergy and harmony with the Regional Bodies as well as with the general structures of the Association is committed to:

- promote the maximum possible collaboration between the associative structures, creating and networking from the Anffas organization, in the consideration that the exchange of experiences and good practices is a key element in our being Anffas
- promote partnerships and synergies with civil society entities with which to share actions for the protection of citizenship rights, social equity and to combat discrimination against vulnerable groups, while maintaining its cultural and organizational specificity
- maintain a loyal, critical and proactive relationship within the Networks to which they belong, in consistency with the aims, priorities, modalities and guidelines decided by the Anffas National Assembly.

D. "ANFFAS branded" services are services for enhancing the skills of people with disabilities for their social inclusion

Despite the strong territorial differences (both qualitative and quantitative) the Italian system of services to the person represents an irreplaceable support for people with disabilities and their families.

The entry into force of the UN Convention, however, has sanctioned that it is necessary to overcome any conception that sees the use of a service as the best and exclusive response to which the person can aspire to improve his or her quality of life.

Services are an important part of the response, but they must not and cannot exhaust the ultimate aim of social inclusion.

The project of life (built with the full involvement of the person and his family to ensure maximum freedom of choice) is a means to define the programs, tools, resources and responsibilities necessary to achieve maximum social inclusion.

With regard to the activities carried out in the "ANFFAS branded" services, the themes of individualised design and programming must always be based on elements/practices/tools of scientific evidence, through dissemination, the implementation and the progressive application of the "*Matrici ecologiche e dei sostegni*" tool, with particular attention to the correct correlation between supports and increase in the quality of life.

Considering the strategic value of services to the person, as well as ANFFAS's history and appearance, ANFFAS Onlus in synergy and harmony with the Regional Bodies as well as with the generality of the structures Associative commits itself to:

- maintain constant attention to the methods and tools to make effective, practicable and verifiable the synergy between the level of association and management in services "branded ANFFAS" (e.g. the definition of minimum levels of operation and quality of services, procedures for the award of the mark, etc.);
- defining, initiating, promoting and monitoring a specific process of changing "ANFFAS branded" services towards a "generation" of services to counter any form of institutionalisation, the social inclusion and the most independent and interdependent life of persons with intellectual and/or relational disabilities, knowing that such a process of change requires:
 - **Investments** in the research and testing of models and tools to take charge consistent with the associative line, which take into account both the personal variables and the context of life of the person
 - **Training investments** towards households, service providers and management and association managers
 - **Communication activities** to effectively convey the progressive abandonment of the logic of taking charge exclusively health care in favour of those set according to models of quality of life
 - **Institutional reports** aimed at redefining the criteria for accreditation of services, together with the development of actions to ensure the adequacy of the financing necessary for their functioning and the verification of effectiveness based on the evidence between the support granted and the improvement of the domains of quality of life
 - **Devote specific attention** to supporting the local areas where there are (in a single body or in separate bodies) associative activities and management activities, in order to maintain the services in a rut of coherence and belonging to the associative line

E. There is always full respect for the rules and transparency (ANFFAS must be an example for the Communities)

Italian society has for a long time been crossed by an increasing propensity to disregard the "rules" and the lack of consideration for the "Common Good".

A macro-phenomenon of criticality and opacity that also concerns not a few subjects of the so-called "Third Sector" including the field of social assistance, educational interventions, etc. All this makes it even more urgent that such organizations operate not only in full compliance with the "administrative" rules (taxation, management of employment relationships, etc.), but also and above all the ethical rules defined in the documents supporting the activity (service cards, ethical codes, etc.)

ANFFAS is legally and culturally an organization that belongs to the diverse system identified as the Third Sector. ANFFAS is committed to ensuring that its work is consistent with the founding principles of the Third Sector with the distinctive value of being an association that is characterized by advocacy and service management.

ANFFAS = TRANSPARENT HOUSE becomes the commitment that all the organizations that make up the "ANFFAS system" assume towards their associates, collaborators, citizens and institutions.

To this end, each ANFFAS structure undertakes to use the monitoring tools defined by ANFFAS Onlus in respect - first and foremost - of its administrative activity, as well as systematically collecting opinions and assessments from service users, starting with people with disabilities. Each ANFFAS entity also undertakes to conduct specific annual monitoring and verification activities to measure and assess the consistency between what is stated in its quality assurance documents (Charter of Services, Code of Ethics, Social Budget, etc.) and how concretely played out.

The recommendations of the self-representatives

We have read and discussed the document and we have approved it and we invite you to adopt it.

Recommendations:

- 1) Use more easy-to-read language, because it can be more useful to everyone;
- 2) Helping orphans in the "*after us*" and families who are in financial difficulties to access services;
- 3) Helping families throughout life, even as they age;
- 4) We want to be involved in decisions that affect our future (not that of our parents!);
- 5) Provide that in the political decisions that concern us are involved not only families but also our representation or a written document with the requests of the self-representatives;
- 6) Ensure that this document is shared and used to remain united (people with disabilities, families and operators) in mutual respect with common rules and new objectives;
- 7) To help families in distress and in times of great difficulty or suffering;
- 8) Recognize and respect the group of self-representatives of the project "*Io cittadino!*";
- 9) Getting the group of self-representatives into all schools to make culture and teach new things;
- 10) Persons with disabilities who are most in need of help can also make their contribution. The association should enhance it;
- 11) These commitments must be learned... BY HEART!!

Recommendation of the Facilitators Group

The group of facilitators confirms its commitment and is at the service of self-representatives and associations so that this is achieved by recognizing the value and strength of what is expressed by the self-representatives themselves.