Psychiatria Danubina, 2021; Vol. 33, Suppl. 11, pp 96-99
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Conference paper

IMPROVING HEALTH CARE ACCESSIBILITY FOR PEOPLE WITH COMPLEX DISABILITIES

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SUMMARY

For many people with disabilities in health care even the simplest actions such as performing an examination or a test can be extremely difficult, just as a hospitalization or an access to the emergency room can be complex experiences. The issue of access to health services is felt to be particularly critical and unresolved by users, families and operators, who still report significant difficulties. The solutions to the problems of accessibility to care cannot be sought only at the clinical and professional level, but must rely on organizational and managerial innovations. The Seraphic Institute has promoted a project to ensure a better response to the health needs of people with complex disabilities to adapt the health care offer to the needs of people with disabilities, activating a proximity service aimed at reducing the inconvenience and costs related to the fragmentation of services and to improve and extend access to care of people with complex disabilities through the activation of a regional reference pole and a network of specialized multicenter and multidisciplinary assistance (Hub & Spoke model)

Key words: *accessibility - disability - caring*

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INTRODUCTION

The term "complex disability" identifies a condition of chronic or permanent need of people with problems that relate to the three macro areas of disability: area of mobility (physical and motor disorders), area of sensory disorders (blindness, deafness), area of cognitive, behavioral and relational disorders (psychiatric and neurodevelopmental disorders) that often present in comorbidity (Cardin et al. 2010).

Among the problems identified, difficulties in communication and collaboration are particularly relevant. Talking about people with disabilities in a logic of complexity does not only mean treating the disease, but also considering other factors. In the structuring of interventions, in fact, many players come into play (family members, caregivers, operators, institutions) with different roles and responsibilities that involve and require integrated and not separate responses.

It is necessary to combine equity and personalization of interventions without identifying the person with his disease, but, above all, it is essential to overcome the logic of performance, it is essential to overcome the logic that focuses attention only on medical services, often linked to standard paths, and provide solutions with a holistic approach (Visentin 2009, Cardin et al. 2010, 2011).

EPIDEMIOLOGY OF DISABILITY AND COMPLEX DISABILITY

According to a survey promoted by the World Health Organization, more than one billion people, about 15% of the world's population, live with some form of disability. At least one-fifth of these, approximately 110-190 million individuals, face "very significant" difficulties in their daily lives (WHO 2011).

In Italy people with severe limitations are about 3 million and 100 thousand (5.2% of the population); the "geography of disability" sees Umbria the regions in which the phenomenon is more widespread with 8.7% of the population and Sardegna with 7.3%.

The elderly are the most affected: almost 1.5 million people over the age of 75 (more than 20% of the population) are in a condition of disability, of which 990,000 are women. This survey does not include persons with disabilities who live in social-assistance residences and children under the age of 6. In the school population, however, we know that about 2.3% are currently certified to have a disability for the purpose of teaching (ISTAT 2019).

Data on people with complex disabilities are very scarce at the international level and even more so at the Italian level and, in any case, the phenomenon can be identified as at least 1% of the general population (Vecchiato 2011).

CRITICAL ISSUES IN ACCESS TO HEALTH CARE

In general, people with complex disabilities present different needs and use the health service mainly for these issues:

- health problems independent of the disability condition;
- health problems that may be a consequence of the disability;
- problems directly related to the disability.

A recent analysis by the World Health Survey reveals that people with disabilities are twice as likely to access health facilities that provide medical care that is inadequate for their needs, three times as likely to be denied care, and four times as likely to be treated inappropriately *(Model Disability Survey)* (WHO).

Critical issues are often documented and reported as if they were a "foretold fate" to be endured rather than a challenge to be faced.

In Italy, a research study of the National Center for Disease Prevention and Control (CCM) promoted in 2012 by the Ministry of Health revealed many critical issues concerning the management of access, diagnosis and interventions. The study highlighted inadequate ways of collecting information, standardized and not personalized treatment pathways, protocols technically incapable of getting to the bottom of the complexity of the problems (CCM 2012).

Hospital pathways for people with complex disabilities also present numerous criticalities.

A recent survey reveals that:

- only in slightly more than a third of facilities (36.0%) is there a priority flow for patients with disabilities who need to perform hospital services;
- only 16.8% of facilities have a single reception point for people with disabilities;
- no facility has relief maps for blind people, while only 10.6% of facilities have tactile pathways;
- light displays are present in 57.8% of hospitals;
- only 12.4% of facilities have rooms or paths suitable for visiting patients with intellectual disabilities;
- 21.7% have dedicated spaces within the hospital for the care of people with intellectual/cognitive disabilities (Spes contra Spem 2012).

In June 2021, the Serafico Institute has conducted a nationwide survey using an online questionnaire to highlight the main critical issues experienced by people with disabilities, their families and caregivers. The survey showed the following data:

- 84% of people believe that the answers provided by the National Health Service are inadequate;
- 78.5% believe that healthcare personnel are not adequately trained to respond to needs;
- 49.8% highlight the absence of priority access pathways;
- 37.3% consider that staff are not able to manage behavioral issues;
- 63.3% highlight the fragmentation of visits and health migration.

All studies and surveys point to an underuse of health services and a lack of equity of access to care and, ultimately, an impairment of the right to health of people with disabilities (Boyd et al. 2010, Parekh et al. 2010, Vecchiato 2011, Emerson et al. 2012).

Inequalities are greater in the most severe and complex situations, because the person has more difficulty in expressing his or her needs and asserting his or her rights to medical care.

Difficulties in accessing care make those who are entitled to timely care more unequal (Alborz et al. 2005).

However, solutions to the problem cannot be sought only at the clinical and professional level. In order to improve accessibility to care, changes and innovations are also needed in the organization of health services, in the definition of resources and responsibilities, but, above all, it is essential to improve the management of accessibility to health care.

Attention and facilitated pathways for people with special needs are not a privilege, but an absolute necessity to provide fair and effective care (Vecchiato 2011).

THE ROAD TO THE PROJECT

For 150 years the Serafico Institute has been taking care of people with disabilities. Over the years, it has always adapted to new pathologies, new emerging needs, changes and new healthcare requirements. Along this path, we have opened up over time to serious complex disabilities, neuropsychiatric and neurodevelopmental disorders. An important step was also the opening of the “InVita” Research Center that was created with the aim of meeting the clinical aspects, problems and needs of these people with the recent acquisitions of neuroscience.

The people with complex disabilities have very limited levels of cooperation and find very difficult to be seen according to routine health care protocols and to benefit from specialist services offered by traditional delivery centers, where they often find little response to their health needs.

In order to best guarantee the necessary services and a better accessibility to care, the Serafico Institute has already provided a concrete response: for two years our Center has opened a multispecialist outpatient clinic, with activities carried out in environments tailored to people with disabilities, with easily accessible spaces and medical instruments adapted to their specific physical and psychological needs.

Thinking about the " health function" of settings, all spaces are equipped with comfortable furnishings and reassuring objects.

The current health services are: dentistry, ophthalmology, EEG and evoked potentials, spirometry.

The integrated outpatient activity, however, represented only the beginning of a larger project aimed at ensuring equal accessibility to healthcare services and a better quality of care and life of people with special needs, their families and caregivers.

In fact, from the positive experience of having concentrated many outpatient services within a single path, from the listening to the requests and suggestions of families and caregivers (often forced to real "journeys of hope" to perform even a simple visit) was born an ambitious project to improve the response to the health needs of people with complex disabilities.

THE PROJECT

The project is to create a regional reference pole and a network of specialized multicenter and multidisciplinary assistance according to the Hub & Spoke model, in order to adapt the healthcare offer to the health needs of people with complex disabilities.

The Serafico Institute will be the regional reference pole for disability (Hub) that will organize a network of different health facilities and services (Spoke) chosen according to criteria of quality, safety, equity, specialization and economic sustainability.

It will be a single network integrated in functions, with differentiated competencies and management coordinated by the Hub. Equal access opportunities and homogeneous treatment will be guaranteed.

With this organization, the person will be directed to the most appropriate facility to address that type of problem. An integrated management of the person with special needs will be realized, an organic and concrete response to the fragmentation of care, inappropriate treatments and deviations from guidelines.

The Serafico project is relevant to the strategies of the National Plan for Recovery and Resilience (PNRR).

In fact, Italy's PNRR, which is part of the Next Generation EU (NGEU) program, is divided into six missions; Mission 6 concerns "Health" and includes two components: 1) Proximity networks, intermediate structures and telemedicine for territorial health care; 2) Innovation, research and digitalization of the national health service.

Our Project has been inserted in the PNRR projects of Umbria Region, Mission 6 “Health” - Line of action n.45.

SPECIFIC TARGETS

The Serafico project is designed to promote a system of care to:

- Improve the care possibilities of people with complex disabilities;
- Guarantee equal opportunities in access to health services, overcoming inequalities;
- Reduce fragmentation of interventions and health migration of users;
- Minimizing the aggravation of pathologies and the development of possible comorbidities;
- Prevention of avoidable hospitalizations and reduction of hospital days;
- Promoting continuous training of health personnel, family members, caregivers and volunteers;
- Development of clinical research in the specific field of complex disability.

KEY DIRECTIONS

The project has three key directions:

- Building a Clinical Center at Serafico to expand and enhance clinical activity;
- Creation of a regional network of health services;
- Training of staff, family members and caregivers.

Building a Clinical Center at Serafico to expand and enhance clinical activity

The Clinical Center expands and strengthens the clinical, diagnostic-therapeutic and outpatient polyspecialist activities that the multidisciplinary team of the Serafico Institute has already been carrying out for many years.

It shall be designed and built to provide services, service packages and health care pathways adapted to the health needs of the three macro-areas of disability, with a view to promoting global care.

Particular attention will be paid to the management of access, to the ability to welcome and listen to the demand, to the assessment of needs in collaboration with the family for an appropriate and effective management of interventions.

It will be equipped with medical equipment with appropriate features to meet the health care needs of low or non-collaborative users. Facilitated spaces and pathways are provided to improve compliance for person with autism spectrum disorders.

Expected outcomes

- Reducing fragmentation of interventions and the number of hospital admissions;
- Logistical, temporal and spatial concentration of interventions, according to the "all in one time" principle;
- Improvement of treatment compliance.

Organization of an integrated network of health services

This key guideline, aims, first of all, to map the health needs of people with complex disabilities.

Next, the goal will be to map the network of health facilities and services for the health needs of these people.

In the organization of the network, a telemedicine service will be part of the health care pathways.

Expected outcomes

- Definition of clinical paths adapted to the needs and requests for help;
- Implementation of treatment and prevention possibilities;

- Reduction of unnecessary hospitalizations;
- Reduction of discomfort on the part of the user, families and caregivers.

Training for staff, families and caregivers

A crucial element of the project is adequate training for healthcare professionals, families and volunteers. It must address both specific and transversal aspects.

These are health education programs for the transmission of skills to be integrated with the "know-how of families" to better define the care pathway.

Expected outcomes

- Increased empowerment of health personnel, families and caregivers.

CONCLUSIONS

The issue of access to health services is the leading indicator of inequalities of caring.

A change and renewal of cultural and organizational models is required in order to improve accessibility and equity to healthcare and health needs of people with complex disabilities, their families or caregivers. This process requires organizational and technical-professional conditions that do not separate responsibilities and skills, precisely at the crucial moment of access, when it is necessary to indicate the appropriate care, based on clinical and health care continuity, with an integrated multidisciplinary approach.

Acknowledgements: None.

Conflict of interest: None to declare.

Contribution of individual authors:

All authors have worked together and contributed equally to this manuscript.

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