Psychiatria Danubina, 2021; Vol. 33, Suppl. 11, pp 91-95 *Conference paper*

THE D.A.M.A. PROJECT AT TERNI HOSPITAL, ITALY

Domenico Frondizi[1,8] , Stefano Cappanera[2], Rita Commissari[3], Marsilio Francucci[4], Massimo Rizzo[5], Donatella Perugini[6], Lorella Angeli[7] & Sandro Elisei[8,9]

[1]*Clinical Neurophysiology Division, Neuroscience Department, St. Maria Hospital, Terni, Italy*
[2]*Infectious Diseases Clinic, Department of Medicine, St. Maria Hospital, Terni, Italy*
[3]*Intensive Care Medicine, Department of Critical Care Medicine and Anesthesiology, St. Maria Hospital, Terni, Italy*
[4]*Department of General and Oncologic Surgery, St. Maria Hospital, Terni, Italy*
[5]*Presidium Medical Management, St. Maria Hospital, Terni, Italy*
[6]*Nursing Department Nurse Chief, St. Maria Hospital, Terni, Italy*
[7]*DAMA Centre Nurse, St. Maria Hospital, Terni, Italy*
[8]*Serafico Institute, Assisi, Perugia, Italy*
[9]*Department of Philosophy, Social and Human Sciences and Education, University of Perugia, Perugia, Italy*

SUMMARY

Experience shows how difficult it is for a person with disabilities to cope with the reality of a hospital, especially if he or she has an intellectual disability. The difficulty in carrying out even simple diagnostic and therapeutic manoeuvres, the complexity of the pathologies, the difficulty in relating to the patient all make it a real risk that many medical problems of patients with disabilities are overlooked or denied altogether. The person with a disability has the right to all care, not only that related to his or her particular pathology, but also that required for other specialist or general pathologies. The UN Convention clearly states the rights of persons with disabilities. The Italian Republic has implemented the UN's declaration with Law 18/2009. The rights enshrined in Article 25 of the UN Convention are also concretely applied in the European Charter of Patients' Rights. The right of people with disabilities to be treated on an equal and non-discriminatory basis is also recalled by His Holiness Pope Francis in his latest encyclical. The DAMA (Disabled Advanced Medical Assistance) Hospital project was created to guarantee the right to health and care of people with disabilities, always, by remodelling its diagnostic and care procedures. The CAD/DAMA Service of the Terni Hospital since 2018 has adopted the DAMA project and also since 2018 has been collaborating with the Seraficio Institute of Assisi. The aim of the CAD/DAMA Service is also to promote and implement research in this area of care and training for healthcare professionals on disability and related issues.

Key words: *disability - intellectual disability - autism spectrum disorders - medical assistence in disability - diagnosis in disability*

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INTRODUCTION

> *"The fundamental point is to realise that there are no special rights or special needs; people with disabilities have the same rights and needs as healthy people. It is rather the responses to their needs that must be different and extraordinary".*
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> *Adriano Pessina*

The anthropological and philosophical assumption of all science is that all people have the right to a dignified life. The United Nations (UN) Convention indicates the instruments that must be used in political and administrative choices to guarantee the rights of persons with disabilities on an equal basis with others (Art. 25 UN Convention on the Rights of Persons, 2006, ratified by the Italian Republic with the law of 3 March 2009). It is therefore a duty of justice on the part of society to enable people with disabilities to be treated on an equal and non-discriminatory basis. Article 1 of the Charter of Fundamental Rights of the European Union (2016) states that "human dignity is inviolable. It must be respected and protected." It also states in Article 21 that any discrimination on the grounds of disability is prohibited and in Article 26 that "the Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community". The right to health and care is also guaranteed by Article 32 of the Italian Constitution. The right of persons with disabilities to be cared for on a basis of equality and non-discrimination is referred to by His Holiness Pope Francis who in his latest encyclical (2020) refers to the "inalienable dignity of every human person". People with disabilities do not have special rights, they have the same rights as everyone else, but they need special tools to make use of these rights (ASMeD & SIE 2020). Article 1 of the United Nations Convention on the Rights of Persons with Disabilities (2006) defines persons with disabilities as "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others". A useful tool for assessing the disability phenomenon is the European Health and Social Integration Survey (EHSIS). According to the EHSIS (2012) there is a greater presence of disability among women (19.9%) than men (15.1%). In Italy, according to estimates by CENSIS (Centro Studi Investimenti Sociali), there are more than four million people with disabilities, equal to 6.7% of the population.

SPECIAL TOOLS TO ENJOY THE SAME RIGHTS

"The greatest obstacle is the illusion of having communicated."

Pierre Martineau

People with disabilities often do not have the opportunity to participate fully in social and economic life due to behavioral and environmental barriers. The poverty rate for people with disabilities is 70% higher than the average, partly because of limited access to employment and partly because families with at least one disabled person have to bear significantly higher expenses due to this condition (IFL MAH 2002). However, the difficulty of access to care for people with disabilities does not derive from their economic condition alone. A survey carried out by Spes contra Spem and the National Observatory on Health (2016) revealed that hospitals themselves are often unable to manage or accommodate this type of patient. A further obstacle to access to treatment is represented by ideological aspects and the inadequate training of health personnel. The lack of ability of doctors to interact with people with disabilities is often the cause of misdiagnosis or low quality of care provided (Lecomte & Mercier 2008). The lack of adequate education in this regard makes it difficult, if not impossible, to manage patients with disabilities, especially those with intellectual disabilities (Piccirilli 2014). Intellectual disability is defined as a condition in which general intellectual functioning is significantly below average (IQ of 70 or below) and is associated with deficits in adaptive behaviour and manifests itself in developmental age, i.e. before the age of 18 years. The reported prevalence is very variable, ranging from 1 to 3% of the population, the incidence around 1.8%. Intellectual disability can be caused by any condition that impedes normal brain development before, during, after birth or in childhood. It is caused by genetic aetiological factors (monogenetic, polygenetic, chromosomal aberrations) or by acquired factors that can be gestational, perinatal and postnatal. Fifty per cent of cases do not have an etiopathogenetic explanation. A characteristic of intellectual disability is the relational difficulty of varying intensity, the main element of which is represented by communication deficits, due to lack of communication tools or ideational deficits, which explains the poor or non-existent cooperation found by health professionals. In the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, 2014) the term 'mental retardation' has been replaced by 'intellectual disability': the term 'intellectual disability' is the equivalent of 'disorder of intellectual development', adopted in the first draft of the International Classification of Diseases (ICD-11) (Bertelli et al. 2016). The new terms of the DSM-5 refer to a developmental disorder that includes intellectual and adaptive deficits in the areas of conceptualisation, socialisation and practical skills. In order to make the diagnosis of intellectual disability, according to the DSM, the following 3 criteria must be met:

- **A:** deficits in intellectual functions, such as reasoning, problem solving, planning, abstract thinking, judgment, school learning or learning from experience, confirmed by both clinical assessment and individualised and standardised intelligence testing.
- **B:** deficits in adaptive functioning manifested in failure to meet developmental and socio-cultural standards for personal independence and social responsibility. Without ongoing support, adaptive deficits limit functioning in one or more activities of daily living, such as communication, social participation and independent living, in multiple domains such as home, school, work and community.
- **C:** onset of intellectual and adaptive deficits in developmental age. Epidemiological studies show that people with intellectual disabilities are at least twice as likely to develop physical illnesses and disorders, with Down's syndrome, for example, being much more prone to heart, gastrointestinal and eye diseases and age-related disorders. It is therefore clear that these patients need assistance and medical check-ups more frequently than the rest of the population (Bertelli et al. 2016). The average life expectancy of people with disabilities is lower than that of the general population. The approach to the intellectually disabled patient must also take into account related behavioural problems that often fall within the autistic spectrum such as: -self-harm -stereotypes and rituals -self-stimulation -severe aggression -destructiveness -anxiety -crises of agitation and panic -fears and phobias -hyperactivity -affectivity disorders -difficulties in learning autonomy skills -difficulties in acquiring daily life skills -communication and relationship difficulties -limited and stereotyped interests (Bertelli 2019). A disturbance of sensory perception can certainly contribute to or be the cause of self-harm (hypoalgesia) or, on the contrary, aggressive, destructive, agitational crises can be favored or triggered by hypersensitivity to sounds, especially if sudden, intense lights and olfactory stimuli (De Knegt & Scherder 2010; McGuire & Kennedy 2013). Approaching a patient with intellectual disabilities therefore means adopting a non-verbal communication method, paying attention to the appropriate modulation of the sources of environmental sensory stimulation. Before approaching a patient with intellectual disability it would be appropriate to ask oneself some questions: is the route and the spatial reality (sounds, lights, smells) in which the patient is assessed suitable?, is the usual clothing of the health care team, the tone and prosody of verbal language adequate? Is there sufficient knowledge of the methods of non-verbal communication in its various forms (gestures, mimicry, gaze, breathing, use of space or proxemics)

(Piccirilli, 2006). Sedation should be postponed to a later stage when a diagnostic strategy has been defined with the dual aim of improving patient compliance and reducing the dynamics of psychological conditioning. The lack of a correct approach can make it difficult or impossible to clinically assess a patient with intellectual disability by misunderstanding the possibility of other concomitant pathologies; such a condition leads to repeated visits with possible aggravation of the subject's condition up to possible death (Berliri & Panocchia 2014).

The DAMA Hospital (Disabled Advanced Medical Assistance) is a hospital in which there are outpatient and inpatient services with diagnostic and therapeutic paths adapted to the needs and characteristics of people with intellectual and/or physical disabilities, who would normally have difficulty in accessing health services designed and organized for the general "normal" population. In this context, the care relationship with the person with special needs makes use of appropriate methods to establish a positive and effective contact with the patient and to identify the best organisational solutions to respond to the emerging health problem (Berliri & Panocchia 2014). The DAMA Project was born at the San Paolo Hospital in Milan in the early 2000s, where a new organisational structure for taking care of people with severe intellectual and motor disabilities was first conceived. However, precisely because of its versatility, this model proved to be effective for different types of individuals with special needs and therefore replicated in many realities not only in Italy. The aim of the project is to create a new organisational model that rationalises the health-social care process, optimising time and resources in the treatment of people with disabilities. The model consists of a number of points that are essential for its effectiveness:

- the creation of a dedicated multidisciplinary team;
- creation of a database for people with disabilities. Having a computerised file containing the main information about the patient would result in a greater readiness to provide adequate responses in emergency situations and to set up dedicated paths for the individual.

This would also make interaction with the patient easier, as one would be aware of predictable behaviour and the outcome of previously adopted pathways.

- the creation of a call centre. The use of a call centre, managed by the health personnel dedicated to the project, becomes the main means of communication between families and caregivers. Through this medium, families can communicate in times of emergency or need. This may also result in a reduction of inappropriate hospitalisation, as families may be given advice on how to solve problems, depending on the situation, without having to go to additional facilities.

THE CAD/DAMA SERVICE OF THE TERNI HOSPITAL

In accordance with the recommendations and directives of the United Nations, Europe, the Italian Constitution and the Umbria Region (2014), the Terni hospital has adopted the DAMA organisational model in the context of the CAD (Centro Accoglienza Disabili) service (Azienda Ospedaliera 'S. Maria' di Terni 2018). Recognising the usefulness of the DAMA pathway, in November 2018 the Serafico Institute of Assisi, which promotes and carries out rehabilitation, psycho-educational and socio-healthcare activities for children and young adults with physical, psychic and sensory disabilities, signed an agreement with the Santa Maria of Terni Hospital to activate a clinical-rehabilitation research protocol.

The multidisciplinary disability team (doctors and nurses) of the Santa Maria of Terni Hospital aims to achieve two objectives in line with the DAMA "philosophy":

- an adequate diagnostic and therapeutic response to the problems faced by patients with disabilities.
- the capitalisation of the experience necessary to define or improve the diagnostic and therapeutic paths that can be adopted so that disabled patients can also fully enjoy the right to health and care.

The care practice of the model, while respecting the specific specialist competences, foresees a holistic approach to the patient, making use of the anamnestic data. It is good practice to promote the dissemination and compilation of formats by the patient's family members/caregivers, which include, for example, answers to questions concerning communication modes, food preferences, susceptibility to environmental stress. Food preferences are useful for the possible intake of oral medication. The knowledge of non-verbal communication techniques in its various forms is of fundamental importance to establish a relationship with the patient with intellectual disability. The experience gained in the management of the individual patient and by extension of patients with similar characteristics makes it possible to give a more clinically satisfactory response to the clinical problems manifested by patients with intellectual disabilities, thus reducing re-entry into the hospital environment and diagnostic errors. As already observed in these patients there is often an "atypical" presentation of organic pathologies especially when accompanied by the symptom pain. In the absence of verbal communication, the intellectually disabled patient may express his distress only through behavioural disorders, or their exacerbation, which may be misinterpreted as primarily psychiatric or epileptic manifestations. In such situations there is a need to carefully consider whether or not to administer sedative drugs, which can further complicate a correct diagnostic process and even irreversibly delay it. Sometimes a

simple painkiller, in appropriate doses, can make the clinical picture more comprehensible and the patient more easily assessable. The approach and the success of the diagnostic and therapeutic process are always the result of the work of the multidisciplinary team. The experience gained can also be capitalised on, given the scarcity of specific data available in the literature, and made usable for specific training courses, which are still lacking. The CAD/DAMA service of the Terni Hospital provides a diagnostic-therapeutic pathway in election and an emergency-urgent pathway.

Pathway in election

The general practitioner (GP)/pediatrician of free choice (PLS), the family member, the caregiver, who intercepts the health needs of the patient with a disability, contacts the hospital directly by calling the toll-free number of the CAD service. The healthcare staff in charge of this service acts as a filter to identify patients who need access to the DAMA pathway and also, using a special form, collects the patient's preliminary anamnestic data, which is essential for the multidisciplinary team to get to know the patient on an initial basis. The diagnostic and therapeutic procedure, if outpatient, is defined by the doctors in the team and by the referring doctor of the specialist unit needed from time to time. The patient's family or caregiver (whether or not the patient is present) will be informed about the decision-making process, as will the GP/PLS. Adequate spaces (easy and uncrowded entrances, suitable sources of acoustic and visual sensory stimulation, pharmacological aids for possible sedation and support of vital functions) are provided when the patient is admitted. Sedation is performed with oral Midazolam, adjusting the dosage of the drug to the patient's weight and tolerance threshold and is generally facilitated by the use of liquid drinks preferred by the patient. When an acceptable level of sedation has been achieved, venous access can be arranged and then evacuation sedation completed in the presence of the anesthesiologist.

Hospitalisation

If hospitalisation is necessary, it is planned according to clinical urgency by agreement between the doctor(s) of the DAMA team and the doctor(s) responsible for the medical/surgical area identified. It is necessary to identify a dedicated room with a private batharoom in which the patient can be accommodated together with the family/caregiver. The CAD/DAMA staff will provide references and support to the staff of the assigned Operating Unit.

Upon discharge, the GP/PLS must be notified by telephone by the doctor of the DAMA multidisciplinary team of the patient's return home, in order to agree on post-hospitalisation assistance procedures.

Emergency - Urgency pathway

The patient with intellectual disabilities who arrives at the emergency department with a code red, being in danger of dying, follows the "life-saving" channel and procedures like any other patient in the same clinical condition.

For other codes, the patient with intellectual disabilities enters the emergency department through triage, accompanied by a family member or other care-givers. If the patient is a guest in a residential or semi-residential facility, he/she should preferably be accompanied by an operator from the facility in which he/she is staying (after informing the family members), so that he/she can act as a communicative mediator with the health personnel of the PS. Access to the emergency room doctor's assessment is facilitated. The following scenarios are then possible

- resolution of the clinical problem in the outpatient clinic;
- short-term observation:

  1) resolution of the case in observation and maintenance of continuity with GP/PLS.

  2) admission; the CAD/DAMA staff will provide references and support to the staff of the appropriate Operative Unit for the completion of the diagnostic-therapeutic procedure.

  3) activation of the multidisciplinary CAD/DAMA team for the organisation of the diagnostic-therapeutic pathway, which can be completed in an outpatient setting.

The CAD experience from 1 March 2018 to 15 November 2021 concerned 312 patients with disabilities of which 126 with intellectual disabilities.

Case history: 1 March 2018 - 15 November 2021:

- patients with disabilities evaluated: n: 312;
- patients with intellectual disabilities evaluated: n° 126 of which under sedation:

  a) 64 diagnostic examinations

  b) 2 treated in emergency-urgency (1 head trauma; 1 acute respiratory failure in obese and smoker)

  c)15 sent by the Serafico Institute of Assisi - patients with intellectual disabilities scheduled for diagnostic tests under sedation: 10

CONCLUSIONS

The right to health and care is guaranteed by national and international norms and legislation. The right of persons with disabilities to be cared for, on a basis of equality and non-discrimination, is recalled by His Holiness Pope Francis in his latest encyclical "Brothers All" (2020). This is often difficult and of lower quality than the rest of the population. The DAMA Hospital (Disabled Advanced Medical Assistance) is a hospital in which the organisation of multidisciplinary, outpatient

and inpatient services, with diagnostic and therapeutic paths adapted to the needs and characteristics of people with intellectual and/or physical disabilities, has the primary objective of always guaranteeing the right to health and care for these people. This approach is inseparable from a finalized and adequate training process of the health personnel involved. The experience of the CAD/DAMA Service of the Terni Hospital, which has been operating since 2018, was reported. The collaboration with the Serafico Institute of Assisi, proposes, in addition to satisfying the possible clinical-diagnostic needs required by the healthcare staff of the Institute, to promote and implement research in this area of care.

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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Correspondence:
Frondizi Domenico, MD
Clinical Neurophysiology Division, Neuroscience Department, St. Maria Hospital
Terni, Italy
E-mail: d.frondizi@aospterni.it