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Equal Treatment

Supporting Access of People with Intellectual disabilities
to Secondary and Tertiary Healthcare Services

Collection of good practices



Institutions participating in the project:



European Platform for Rehabilitation, Belgium; **Kaunas College**, Lithuania; **EEA Margarita**, Greece; **Research Center of Biopolitics of Panteion University**, Greece; **Girona Biomedical Research Institute**, Spain; **Arnau d'Escala Campus Foundation**, Spain; **Tampere University of Applied Sciences**, Finland

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Abstract (aim, findings, conclusions)

This document is a collection of good practices gathered as part of the analysis activities carried out by the Equal Treatment project's partners (refer to document's cover for institutions participating in the project) aiming at bringing to light the main issues and barriers to equal treatment of people with intellectual disabilities in secondary and tertiary healthcare.

The methodology followed to proceed gathering these good practices and their analysis is detailed in the document together with the main findings. Relevant barriers identified include a lack of effective policies in place in hospitals to ensure reasonable adjustments, issues in communication between healthcare staff and patients with intellectual disabilities and a lack of training of healthcare staff in the field of intellectual disability. The conclusions include a first set of policy recommendations which will serve as a basis to develop the final policy recommendations to be included in the final report.

Introduction

Equal Treatment is an ERASMUS+ funded project with the aim to improve the access of people with intellectual disabilities to secondary and tertiary health care through inclusive European policies in healthcare services; training of healthcare staff on interacting with patients with intellectual disabilities and; stronger collaboration between healthcare staff and professional supporters.

The project started in 2022 and will end in 2024. The project focuses on one main objective: **supported rights and access of people with intellectual disabilities (people with intellectual disabilities) to secondary and tertiary healthcare services.**

Results

1. More effective policies on people with intellectual disabilities inclusion in Health Care services
2. Lower barriers for people with intellectual disabilities to access Health Care services

3. More effective training of Health Care Staff to interact with people with intellectual disabilities
4. Stronger and better collaboration between Health Care Staff and other professional supporters

Target Groups and project beneficiaries: Doctors, Nurses, Administrative staff in secondary and tertiary Health Care services; Educators, Psychologists, Social workers, etc. supporting people with intellectual disabilities (Professional Supporters); People with intellectual disability.

Research methodology

A questionnaire was created to collect good practices in equal treatment of people with intellectual disabilities in secondary and tertiary healthcare. Partners provided relevant feedback to improve it and the last version was approved and later transposed into a Google form in order to circulate it.

During the planning phase, the Equal Treatment Project consortium identified four areas of good practice in the equal treatment of people with intellectual disabilities in secondary and tertiary healthcare. Therefore, the questions for the collection of good practices were divided into these four sections with a fifth section focused on impact evaluation and transferability:

- 1) Good practices of effective policies on people with intellectual disabilities inclusion in Health Care services;
- 2) Lower barriers for people with intellectual disabilities to access HealthCare services;
- 3) More effective training of Health Care Staff to interact with people with intellectual disabilities;
- 4) Stronger and better collaboration between Health Care Staff and other professional supporters.
- 5) The impact evaluation and the transferability of the good practices illustrated in the questionnaire.

In the framework of the Equal Treatment project, a “good practice” is a successful process or methodology that has been proven to work well and with good results, which can be replicable also in other settings¹.

The Google form was circulated among partners, EPR members and the wider network of organisations representing people with disabilities, in compliance with the rules on privacy data. The form was also circulated to 36 members of the European Hospital and Healthcare Federation (HOPE), a European non-profit organisation, that covers almost 80% of hospital care and is also active in the healthcare and social fields. In parallel to the collection of good practices through the form, EPR also carried out a desk research to identify particularly interesting cases to support the collection.

A number of 13 responses were collected and analysed by the EPR Secretariat.

Results

1) Good practices of effective policies on people with intellectual disabilities inclusion in Health Care services

The forms collected showed that when policies are in place, they are often the result of a project run by the hospital or adopted at local or regional level. The protocols or guidelines in place are rarely introduced at national level: only one good practice exemplifies this case, that is the training requirements of the 2022 Health and Care Act in the UK².

Most of these policies are organisational models and protocols which define steps to be taken to provide specific pathways of healthcare, simplify procedures, facilitate access to all hospital services for people with intellectual disabilities and ensure that they receive care of equal quality to that of other patients. Other examples of policies focus instead on the training of healthcare professionals.

¹ <https://europa.eu/capacity4dev/rom/documents/rom-handbook-v6-annexes-january-2020>

² <https://www.legislation.gov.uk/ukpga/2022/31/contents/enacted>

The good practices consist of forms of individualised services for people with intellectual disabilities. Some of the most common interventions include priority access in emergency (in one practice implemented in a paediatric hospital in Italy, children with intellectual disability skip the triage at the emergency room regardless of the severity of their condition), reduced waiting time, quick dismissals, waiting in a dedicated and well-equipped space, access of caregivers, longer reception times and double appointments, coordination of medical appointments and examinations. A common adaptation in place is the provision of a dedicated space for the patient with intellectual disability. This helps to create spaces within the hospital which look more familiar than medical and where the people with intellectual disabilities can wait for their turn in a quiet environment.

Two questionnaires also mentioned the use of sedation or anaesthesia for procedures which might be potentially painful for the patient (people with intellectual disabilities often have a lower threshold for pain compared to the general population and might experience more discomfort and anxiety during examinations³), in order to combine exams and reduce the duration of their stay or the number of accesses to the hospital. In another two questionnaires, professionals pay particular attention to the evaluation of pain of people with intellectual disabilities, since it is often a symptom difficult to interpret and manage. In the hospital of Fuenlabrada (Spain), for instance, visual support can be used to better define the level of pain of the patient with intellectual disability⁴.

All good practices include a way to codify information about patients with intellectual disability to flag them. This, together with an initial interview with the patient, is a general first step in any set of interventions. The most common procedure involves a specific form or a questionnaire that is filled in by the patients, their caregiver or family relative, or the general practitioner. According to the practice, the forms include different types of information, ranging from the patient's clinical history and allergies to disability-related information such as communication skills (including how

³ <https://www.burlo.trieste.it/bambini-disabilit-cognitive-sperimentano-dolore-ansia-paura-maniera-pi-intensa>

⁴ <https://autismomadrid.es/noticias/teayudamos-proyecto/>

the patient expresses pain, anxiety and discomfort) and comprehension barriers, mobility, collaboration and behaviour (for examples how to approach the patient in term of physical touch, distance and eye contact).

In the UK and Ireland the National health Services call this document a “hospital passport”⁵ (also called “health passport” in Ireland⁶) and invite all patients with intellectual disabilities and their carers to download it from the website and bring it with them at hospital visits. This practice has been introduced in Finland as well, where the NGO Tukipiiri (a Support Circle for people with intellectual disabilities) has created a hospital passport jointly with the Lapland’s hospital district, following the British format⁷. The hospital passport is a good practice which enables doctors, nurses and therapists to know how to deal with the patient on a case by case basis and to provide reasonable adjustments before any examination or treatment. It also helps family carers to communicate to the hospital staff crucial information about their relative in a safe way, as they sometimes might forget to mention everything due to stress.

The information and data collected from the questionnaires and admission forms and later integrated through an interview between the professional and the patients and/or caregiver, is always saved in an online hospital database, so that:

- 1) all professionals and staff are informed about the patient’s needs and can make adaptations accordingly;
- 2) it is easier to flag the patient with intellectual disability on future occasions.

The initial interview is usually conducted by a professional or a member of the project team who act as a facilitator in order to verify the information in the questionnaire to obtain better knowledge of the patient outside of an emergency situation and increase their familiarity with the hospital and procedures. If the patient doesn’t tolerate being in the hospital, the interview is carried out by phone.

⁵ <https://www.mencap.org.uk/advice-and-support/health-coronavirus/health-guides#:~:text=A%20hospital%20passport%20tells%20the,an%20easier%20to%20understand%20way.>

⁶ <https://www.hse.ie/eng/services/list/4/disability/health-passport-intellectual-disabilities/>

⁷ <https://www.tukipiiri.fi/uutiset/sairaalapassi/>

2) Lower barriers for people with intellectual disabilities to access Health Care services

All policies and practices collected have some recommendations to facilitate and ensure effective communication with people with intellectual disabilities. The most common tools used to support communication include visual aids, pictograms, social narrative and easy-to-read information. Moreover, some hospitals have dedicated signage in place to help patients with intellectual disability to find their way in the building. Two hospitals support families in preparing the patient to access the hospital and to provide them information about the medical procedures through books, videos and other materials. Some also have a website dedicated to disability with videos and easy-to-use information about the project or programme in place for people with intellectual disabilities. In the questionnaire about the project “TEAjudamos” of the hospital of Fuenlabrada, for instance, it is explained that the pictograms can be found and downloaded from the website of the project⁸, while families can also borrow medical tools like encephalogram helmets and bring them home to help the patient with intellectual disability to familiarise with them ahead of the examination.

Other hospitals provide recommendations to staff on how to interact with people with intellectual disabilities. The hospital Río Hortega of Valladolid, which has a programme called “ASI”⁹, encourages staff to address the patient normally, using clear and simple language, a soft tone of voice, and avoiding excessive medical jargon when explaining procedures. In the UK, the Health and Care Act 2022¹⁰ requires training for healthcare staff so that they can learn how to interact appropriately with people with intellectual disabilities at a level appropriate to their role.

In order to enable family supporters to better communicate with clinicians, a series of hospitals identified a professional who acts as a point of reference for families. It can be called “coordinator” or “case manager”, and has the task to stay in touch with

⁸ <https://www.teayudamos.eu/teayudamos.php>

⁹ https://www.plenainclusion.org/sites/default/files/v.12.30_humanizando_la_salud_dulce.pdf

¹⁰ <https://www.legislation.gov.uk/ukpga/2022/31/contents/enacted>

relatives and the family doctor of the patient and provide support and advice during hospitalisation and emergencies. Communication tools and a contact point for families have both the ultimate aim of enabling the patient with intellectual disability to obtain, process and understand information related to their health, condition and upcoming examinations.

Another common element to lower barriers for people with intellectual disabilities to access healthcare services is the presence of professionals or nurses specialised in intellectual disability. It can be the project team made of specialised nurses and doctors, the aforementioned “case manager”, or a “nurse coach” (this figure was introduced in the region of Tuscany during Covid-19 to provide advice via phone calls on possible healthcare services and procedures available). The Disability Program of the University Hospital of Geneva has led to the introduction of referent nurses and intellectual disability-physicians who are present in care units and in the outpatient clinic for people with intellectual disabilities and accompany the patient in each specialised consultation¹¹. They are now permanent positions in the hospital.

Nurses assisting people with intellectual disabilities are often involved in the care of all the other patients, which means that patients with intellectual disability are supported during their pathways to healthcare but end up receiving the same treatment and services of other patients, in the same framework of care. One of the good practices collected (the D.A.M.A. project in Italy¹²) included also the provision of further support to the patient and the caregivers in the hospital by a volunteer who is trained and often a parent of a person with severe disability. This person can help medical staff to better understand the needs of the patient, including sometimes the need for psychological support in the family.

Only one of the good practices analysed proposes practical adaptations of technology that is easy to use for people with intellectual disabilities. Only a respondent mentioned the use of an online portal to make appointments. Most of them mention only the codification and standardisation of patient data in the

¹¹ <https://www.hug.ch/programme-handicap>

¹² <http://www.fmc-onlus.org/dama/>; <https://hrcak.srce.hr/file/391844>

electronic system of the hospital in order to identify them more easily. In Ireland, the Health Passport is available on a free app¹³.

3) More effective training of Health Care Staff to interact with people with intellectual disabilities

All the good practices collected have some measures in place to promote more effective training of healthcare staff on how to interact with people with intellectual disabilities. Usually specific training is provided to the doctors and nurses who make up the team in charge of the project or programme. Training courses for hospital staff are developed as part of the project deliverables during the implementation phase which are more or less comprehensive. For example, the Disability Programme in the University Hospital of Geneva designed a training program with three levels of awareness for specific categories of professionals¹⁴:

- Flash training for doctors and senior nurses;
- A two-hour session for emergency health care professionals and professionals in sensitive environments (ICU etc.) and;
- A five-day training programme for health care professionals and hospital staff.

The training is done with the participation of a disabled person as a co-trainer and expert, as well as the use of a disability simulator, and it covers topics from communication to rights and consent.

The PASS programme in Tuscany includes a training course for health care professionals based on three modules covering the rights of people with intellectual disabilities, the interaction with the patient and the caregiver during access to the hospital services and visits and specific information about diagnosis and therapy for people with intellectual disabilities¹⁵.

Some of the projects are run in partnership with local universities and authorities. Regarding universities, the aim is to encourage the introduction of the topic of disability in university curricula and improve the skills of professionals. This is the

¹³ <https://www.hse.ie/eng/services/list/4/disability/health-passport-intellectual-disabilities/>

¹⁴ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6423855/pdf/12939_2019_Article_948.pdf

¹⁵ https://www.formas.toscana.it/images/Programma_PASS_generico.pdf;
https://www.formas.toscana.it/images/Decreto_Formazione_PASS_1625_2018_ALLEGATO_A.pdf

case of the D.A.M.A. project in Italy developed with the University of Milan¹⁶ and the Disability Program of the University Hospital of Geneva which has developed a specific course for student nurses together with the University of Applied Sciences and Arts of Western Switzerland¹⁷. The good practice involved specialist organisations to provide education and orientation to new workers. In the case of Burlo Garofolo hospital in Italy, professional training on how to deal with emergencies of people with intellectual disabilities and some forms of comorbidity (e.g. psychic issues and drug addiction) is promoted by the hospital together with regional authorities¹⁸.

The good practice from the UK is the only example of a national-level measure to improve training of health care professionals. The Health and Care Act 2022 requires that all registered health and social care providers must ensure that their staff receives training in intellectual disability and autism in order to interact appropriately with those patients¹⁹. The Care Quality Commission sets out training requirements which will have to be met, but they don't specify a training package.

4) Stronger and better collaboration between Healthcare Staff and other professional supporters

The good practices offer various examples of collaboration between health care staff and other supporters. Intellectual disability-nurses or teams usually cooperate with other units dealing with people with intellectual disabilities. The teams themselves have a multidisciplinary nature and bring together professionals from different disciplines (nurses, doctors, social workers, sometimes also representative of families). Cooperation takes place also between health care professionals and professional supporters of the patient with intellectual disability or support persons with personal experience in dealing with people with intellectual disabilities, as in the case of volunteers in the D.A.M.A. project mentioned in Paragraph 2. Volunteers have to complete a period of training as well, which is led by the project team

¹⁶ <http://www.fmc-onlus.org/dama/>

¹⁷ <https://www.hug.ch/programme-handicap;>

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6423855/pdf/12939_2019_Article_948.pdf

¹⁸ http://mtom.regione.fvg.it/storage//2017_434/Allegato%201%20alla%20Delibera%20434-2017.pdf

¹⁹ <https://www.legislation.gov.uk/ukpga/2022/31/section/181/enacted>

together with other trained volunteers and colleagues from other healthcare bodies working with people with intellectual disabilities²⁰.

Most of the initiatives analysed involve to some extent other health services, local and regional authorities, universities and organisations representing people with intellectual disabilities. The P.A.S.S. programme in Tuscany for instance was developed in collaboration with local health authorities and university hospitals, as well as associations representing people with intellectual disabilities²¹. The Burlo Garofolo Hospital in Trieste, Italy, established an Office for Continuity of Care with the objective to enable the continuous care of children with intellectual disability and other special needs based on the coordination between the hospital and other social and health services active on the territory²². The Office works thanks to a multidisciplinary team that acts as contact point between the various entities. The programme “ASI” of the Río Hortega Hospital in Valladolid was launched by a work commission in 2016 which brought together hospital staff, social services providers and members of the Foundation of people with autism of Valladolid²³. The Foundation was also responsible for developing training courses for staff. The Hospital stays regularly in touch with associations to improve the project through a feedback system.

5) Impact evaluation and the transferability of the good practices

Some of the projects analysed in this report proved particularly successful and were further disseminated on their local and regional areas. The D.A.M.A. programme for example has been adopted as an effective good practice by other 19 hospitals across Italy since its launch in San Paolo Hospital in Milan in 2000²⁴, while the “ASI” programme has been disseminated in the Eastern area of Valladolid.

Some programmes include the measurement of service experience on an annual basis or some form of evaluation based on voluntary feedback from the patients. The

²⁰ <http://www.fmc-onlus.org/dama/>; <https://hrcak.srce.hr/file/391844>

²¹

http://www301.regione.toscana.it/bancadati/atti/Contenuto.xml?id=5150748&nomeFile=Delibera_n.666_del_19-06-2017-Allegato-B

²² <https://www.burlo.trieste.it/sites/default/files/generali/PROTOCOLLO.pdf>

²³ https://www.plenainclusion.org/sites/default/files/v.12.30_humanizando_la_salud_dulce.pdf

²⁴ <http://www.fmc-onlus.org/chi-siamo/rete-nazionale-dama/>

University Hospital of Geneva, for example, has a satisfaction questionnaire to assess the efficiency of its services, which can be filled on a voluntary basis by the people with intellectual disabilities, when possible, or by the caregiver or support professional²⁵. A hospital evaluated its services through verbal and written comments from the patients, their carers or colleagues.

Among the main obstacles to the implementation and transferability of the good practices are stigma, a lack of data on barriers met by people with intellectual disabilities, a lack of professional training and knowledge of intellectual disability among health care professionals, the disproportionate ratio in number of patients with intellectual disability and of staff, infrastructure barriers of the hospital and a general rigidity of the health system where changes to procedures are initially hard to implement. Additionally, it is a well-known fact that staff retention and numbers are an issue in many healthcare services which impacts on the quality of care provided specifically, to harder to reach groups such as people with intellectual disabilities.

Regarding the impact of the Covid-19 pandemic on the adaptation of services to people with intellectual disabilities, among the key consequences highlighted were the postponement of appointments and in general a poorer treatment of patients with disabilities and the elderly, especially in terms of isolation and lack of communication. Also the training of professionals was affected, as it was provided online while some sessions with people with intellectual disabilities had to be postponed. The use of masks was a particular obstacle in the communication with people with intellectual disabilities. An example of adaptation to the needs of people with intellectual disabilities during the pandemic was given by the PASS in Tuscany, which established a helpline where patients could receive disability-related information from professionals and introduced the role of nurse coach to provide advice via phone calls on possible services and procedures available and facilitate remote follow-up²⁶.

²⁵ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6423855/pdf/12939_2019_Article_948.pdf

²⁶ <https://toscana-accessibile.it/-/pass-percorsi-assistenziali-per-i-soggetti-con-bisogni-speciali>

Discussion

The analysis of good practices showed that several successful programmes exist in different parts of Europe and contribute to improving the experience of people with intellectual disabilities in secondary and tertiary healthcare. The practices focus particularly on the training of health care professionals at all levels, which is a key element to ensure equal treatment of people with intellectual disabilities in healthcare services, especially given the lack of experience and knowledge on intellectual disability that is still too often observed among staff.

It is important to have permanent staff who know the clients and can provide continuous support; intellectual disability-nurses or physicians, nurse coaches or case managers all play a key role in supporting the patients and families, but also other hospital professionals. When staff changes, education and orientation are needed. Involving people with intellectual disabilities and associations representing them and their families is equally important. People with intellectual disabilities and their families and caregivers are experts by experience and can contribute greatly to the design of training programmes for health care professionals and for clearer communication between hospital staff and patients.

There is no standardised system in place to identify and flag patients with intellectual disability and to possibly share this data among hospitals in the region or at national level. Moreover, there might be ethical issues related to data protection regulations. The hospital passport used in the UK, Ireland and in a part of Finland is a valid alternative that could be easily adopted in other countries, however it is still not widely known. Some ethical issues can arise also during the initial interviews with the patient. In some of these countries there are strong legislation and regulations, but unfortunately these are not visible enough in practice and compliance is not enforced enough. Advocacy work is difficult and slow and the health system can be quite rigid when it comes to introducing new procedures that change the way of working. As explained by one responder, changes are initially blocked by professionals and accepted only once their positive impact is evident. In some other cases, there are policies in place for patients with “special needs” but not for people with intellectual disabilities specifically.

Technology is still not fully used to support the equal access of people with intellectual disabilities in secondary and tertiary healthcare services. One responder observed that artificial intelligence could be useful to provide speech recognition, for example. Mobile and digital services could be used more, for example in some home services. On the other hand, in this case, people with intellectual disabilities may remain hidden in homes and thus the feeling of isolation can grow.

Lastly, it's interesting to note that one of the 13 responses was a blank form, as the respondent stated that there was no good practice in place for people with intellectual disabilities and people with disabilities in general. This leads to two observations:

- Good practices on equal treatment of people with intellectual disabilities do exist, but are still not a common feature of hospitals across Europe. There are still deep regional and sometimes local differences, with places where indeed there are no programmes, projects or measures in place to improve services for people with intellectual disabilities;
- Even when good practices exist, they might not be well disseminated or professionals might not be aware of them or recognise them. Therefore, it's important to raise awareness of the availability of these programmes and measures among health care professionals through material, meetings or training sessions.

Another point of reflection is the fact that in some cases, respondents had difficulty to answer the questions, either because they address a field that they didn't know much about or, because they didn't have a clear understanding of what was meant by "good practice". Some of them started thinking about existing good practices only after hearing more specific questions about how they usually deal with people with intellectual disabilities. In some cases the good practice existed but still in a very informal way, as something that the professional does regularly out of habit or routine rather than enshrined in a protocol. To be regarded as a good practice, these initiatives require repetition and mainstreaming and must be carried out consciously and consistently. Some of them are perhaps still at an early stage of implementation,

but represent nonetheless promising and meaningful inputs. However, this point stresses the need to better define what is meant by a good practice in the questionnaire to make it clearer for respondents.

Strengths & limitations

The present analysis has both strengths and limitations. The main strength of the questionnaire is its completeness, as it addresses all key areas of access to healthcare services of people with intellectual disabilities in a comprehensive and detailed manner. In this way, the questionnaire enabled the collection of up-to-date information and data on a variety of relevant aspects.

However, at the same time this might have made the form too lengthy. The decision to circulate the questionnaire as a Google form might have been an issue for some people, as well as the division of questions among sections which prevented respondents from having a complete overview of the questions. Another issue was compliance, with a few hospitals unwilling to identify themselves and to provide some data.

Most interestingly, in one case the respondent replied with a blank form because they believed there was no good practice related to the adaptation of services to people with intellectual disabilities. However, the perceived lack of good practice is itself an important result which stresses the need to increase both knowledge about intellectual disability in healthcare settings and awareness of existing programmes and projects which indeed represent good practices that can be further disseminated.

Conclusions and key recommendations:

The analysis of good practice showed that positive examples exist but are not always fully mainstreamed into policies and hospital procedures, while there continues to be a lack of health care professional preparation when working with people with intellectual disabilities.

Developing the competencies of professionals remains a necessary condition for the provision of quality health care services and the performance of effective professional functions, as highlighted also by the literature review. This applies in particular to services for people with intellectual disabilities, which constitute a vulnerable population group in Europe and are potentially more prone to get physical and mental health conditions in midlife and old age compared to the general population, as scientific research has shown.

Some initial recommendations were drawn from this analysis:

- Implement policies that consider people with intellectual disabilities as a separate group with specific needs that can differ from those of other patients with special needs.
- Improve procedures to flag patients with intellectual disability, either through a hospital passport or a form to be filled in. Hospital passports can help information sharing and decision making amongst healthcare staff by providing important information on the person.
- Design and implement adaptations including reasonable adjustments and communication methods to ensure people with intellectual disabilities have access to health services of the same quality as other patients. The lack of effective communication and organisational barriers are among the biggest challenges faced by people with intellectual disabilities and their families.
- Design effective training programmes in collaboration with other actors (universities, local or regional authorities, associations representing people with intellectual disabilities) to improve the knowledge of all health care professionals and hospital staff on intellectual disability and the way they interact with patients. Training opportunities should be continuous, ranging from university curricula to professional development. Capacity building and improving the knowledge of service providers was identified in the literature review as a way of improving access, particularly in relation to improving the quality of services.
- Explore ways in which new technology, including artificial intelligence, can assist people with intellectual disabilities in healthcare services, improve communication and enhance equal treatment.
- Establish the role of intellectual disability-nurses or case managers within the different services of the hospital, defining clear tasks and qualifications needed.

Professionals with specific knowledge of intellectual disability are key to support patients, families or caregivers and other health care professionals, thus improving service experience for all actors involved. Make sure staff dealing more often with people with intellectual disabilities is permanent, so that they know patients better and can establish stable and regular contacts with them.

- Involve families, caregivers and associations representing people with intellectual disabilities in the design of programmes or projects and in the evaluation of procedures in place, through open lines of communication, feedback questionnaires etc. Involve these actors also in the training of professionals.

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