

Aging with a disability: a European perspective

- Key concepts
 - Lessons learned
 - Recommendations
- from the E-Dignities Project

1. Key concepts

Over the last decades the life-expectancy of people with intellectual disabilities¹ in Europe has increased to come close to the medium of the total population. This is good news!

Ageing is a process of change that affects many aspects of life. In order to reduce the risk that changing conditions lead to a lower quality of life, all actors involved – the disabled persons themselves, their families as well as professionals – need to **know how to deal with change.**

Self-advocates and representative organizations, backed up by the UN Convention on the **Rights of People with Disabilities** (UNCRPD) (2006)² and the European Charter of Fundamental rights (2000)³, stress the importance of the right to enjoy a good quality of life in all phases of life. **Matching rights and expectations with available resources** is an important challenge for policy makers, administrators and service providing organizations.

E-Dignities* - The Project

The project (2010–2012) has explored life conditions of people with intellectual disabilities across different European countries and challenges related to their aging process. Also strategies for improving these conditions and future perspectives have been examined and discussed. Service providers from France, Italy, Portugal, Belgium, United Kingdom, Austria and Luxemburg were involved in the reciprocal learning process and have participated with staff, service users (self-advocates) and administrators. The perspectives of all participants were valuable and essential in understanding the issues, challenges and areas of risk.

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¹ Although the project has focussed on the experience of people with intellectual disabilities, many of the concepts outlined below are relevant for a wider audience of people with disabilities, family members and carers.

² <http://www.un.org/disabilities/convention/conventionfull.shtml> (retrieved 4/6/2012)

³ http://www.europarl.europa.eu/charter/pdf/text_en.pdf (retrieved 4/6/2012)

Many of these challenges have been already formulated in the Graz Declaration (2006)⁴ which has been widely disseminated in Europe.

Quality of life relates to subjective and objective criteria that define well being in various domains: health, living conditions, occupation, social relations and networks. In all these domains lessons were learned in the E-dignities project.

The “citizenship model” of disability offers an important framework to address issues related to the ageing of people with disabilities. It is a relatively new model, compared to the “medical model” and the “social model” of disability and it is related to the “rights-based” approach to disability. It considers people with disabilities first of all as citizens with rights and duties, just like anyone else. In this model people are involved and make informed choices about all aspects of their own life, including they way they would like to live, their occupation, their relationships.

Although a positive approach, that definitely enhances people’s freedom, and freedom to make choices, there are some problems with its implementation: many people with intellectual disabilities that are seniors now were never taught to understand and access their rights and were never taught to make important decisions. The way vulnerable people are treated in life, influences their preparation for old age and the life conditions in this complex phase of life. It is therefore not possible to reflect on **the transition phase** towards eldership, without taking in consideration the life experience of people.

Other issues became central in our thinking while listening to the people with intellectual disabilities (self-advocates) involved in the project: **fair treatment and equal opportunities**. Having access to opportunities that all people have in life, as well as living integrated in the community, very likely increase the possibilities of aging in dignity and autonomy and with a good quality of life.

Maximum space for self-determination and hooking decision-making on participation, are effective approaches to ensure attentive and respectful planning processes able to guarantee good quality of life of service users as well as meaningful work for the staff. It requires an individualised approach and an effective support to people in realizing their goals and their life projects. It further requires changes in policies, in public intervention, in the funding of services, as well as in their organization.

Aware that these issues are easier said than done, special attention in the project was dedicated to exploring **the gap between theoretical objectives and everyday practice** as reflected in the experience of the people and the local services that were visited. This “bottom up – top down” approach provided us with important insights in critical issues, areas of possible improvement and lessons learned.

Some simple questions that has given us guidance:

Is there a difference between aging with an intellectual disability and aging in general?

⁴ <http://www.easpd.eu/LinkClick.aspx?fileticket=eDUBIDI0HSU%3D&tabid=3531> (retrieved 4/6/2012)

What is good for me, in general terms, when I get older? Why should that be different for people with intellectual disability?

It is helpful to understand the issues at stake - i.e. aging and what will happen with you -, as issues that affect everybody, including **ourselves**, and not only “**the others**” and to avoid the trap of automatically thinking in terms of “specialized care” because the UNCRPD requires us to respect specific rights.

People with disabilities and their families have the same human and citizens’ rights as anyone else. The challenge is to respond to the special needs of people with intellectual disability in the framework of a general rights based approach. In other words, whatever is good and accessible for any person should be guaranteed to persons with intellectual disability. When we are speaking about aging this normally comes down to “**autonomy**”, “**respect**”, “**dignity**” and “**freedom of choice**”.

Very often we heard during the project: “Do not forget to put the user always in the centre”. This is a very positive approach but it has important implications if it has to be more than a slogan. It touches upon **the power balance** in all care homes and social services. **Being object of care dehumanizes!** It is a general challenge that “service users” of all kinds become subjects of their own care. This is also about being involved in and **to be in control** of decisions made about one’s life. In general this simply means that we must respect and value the views of persons with disabilities and remember the slogan “nothing about us without us” in all aspects of service planning and delivery.

In terms of inclusion in the community “being in control” means: being able to participate in all aspects of community life – i.e. to learn, to work, to get about and meet people, to be part of social networks, to get access to all public services, to have a personal support and to be able to choose.



Person Centred Planning is an appropriate methodology that puts the person in the centre of any care plan. It involves a process of continual listening and learning, focused on what is important to someone now and for the future. In this approach the care team works in alliance with the disabled person, his/her family and with a supporting circle. But this has to broaden up into a general human and community centred approach thus becoming a personhood concept in which the status is bestowed upon one human being in the contexts of meaningful social relationships. This concept of personhood implies recognition, respect and trust.

Person centred-ness is not only important in thinking about services for people with disabilities. All social interventions should first of all value the person as an individual with his/her potential, abilities, social and affective resources. This will reduce the risk of discrimination on the basis of age, gender, social or ethnic group, disability etc.; social constructs that in many cases correspond with group labels based on stereotyping.

In the situation of **communication** or interaction with the disabled or elders, this means creating space for mutual **listening**. The experience of many participants was that very often professional carers are eager and ready to act immediately. But being listened to is sometimes more important than being “assisted”! Every action undertaken to help should start with a period of listening and then being followed by acting “together” instead of acting “for”.

Adopting a person centred approach it becomes “natural” to see the person included in community life and to organise care as to make this possible. Care should be organised, as long as possible, in the person’s habitual living environment and integrated in the community. Nevertheless specialized services should be available to be activated, not automatically, but on an as-needs-basis.

2. Lessons learned from the E-Dignities Project

As a sort of mind map, and to facilitate the data gathering, we have focussed on four domains of life where change happens when people get older: health, living conditions, occupation and social relationships. As most of the partners are service delivery organisations, we have reflected on the implications of change and changing needs related to four aspects of our intervention:

- user involvement
- the development of services
- the preparation of staff
- the furthering of social cohesion

What follows is an overview of lessons learned during the study visits in Austria, France, Italy, Portugal, Belgium and the UK.

2.1. User involvement

User involvement should be expressed in user-centred processes. As a consequence this means the development of person centred services which have the person and his/her interests as a starting point and not the structural or administrative conditions of the service.

User involvement does not only mean involving people in choices. Moreover it is about giving people the ownership of their own life and goals!

Instead of making decisions for the person, intervention should aim at assisting the persons with disabilities in their own decision making process.

An example from daily life: the question is not serving carrots or potatoes, but creating opportunities to be involved in the preparation of meals!

We do not protect people by taking decisions for them, but by allowing time and by providing space and assistance for people to take as much as possible their own decisions. This challenges the power balance. It involves tolerating the frustration of not being able to decide yet or to tolerate the frustration to accept decisions that you consider not the best possible decision.

Decisions made are not always communicated verbally to others, or do not necessarily correspond to the staff's logic. On the contrary "user involvement" in the sense of "user centredness" means to allow that things go differently than you have planned or expected them to go.

Listening is key! Authentic "listening" requires attentiveness to verbal and non verbal communication.

User involvement involves a change in the dialogical structures between the staff and the families, turning it into a dialogue that involves service users, families and staff in communication, planning and decision making. Working in partnership is the right approach.

Health issues

It is important that people are fully informed about their health conditions, health risks and health prevention, and that people with disabilities have full access to health prevention programs as well as to medical services. Information has to be provided in "easy to read" and understandable language. It is important that health care professionals are trained to communicate with people with disabilities.

Living conditions

We all need a place that we can call our home. Many people with disabilities across Europe live in public or private residential services. A leading principle in the care plan should be that the service user has the right to consider the structure and in particular his/her private room as his/her "home". If this awareness is not widespread, consequently the carer will easily "invade" the privacy of service users.

Service users in residential care are more than "users" or even "clients". A place to live is a right, and thus they have to be considered tenants with full rights!

This awareness impacts on the role of carers, of the personalisation and adaptation of environments to cope with the changing conditions of the aging person.

Occupation

The challenge for policy makers and service providers is to provide choice in occupational situations for seniors with disabilities. This might consist in gradually reducing workloads and hours, retirement and opportunities for active aging in the social context. Important in this context is a flexible transition phase from the full time occupation to meaningful activities in other contexts. This might involve the collaborative design of activities by mainstream services for elderly and specialised service providers.

Social relationships

Value and aim of inclusion is that the person with intellectual disability is capable of developing and maintaining social relationships. But here the reality is very often that users say that the only persons they know are their immediate family or their carers in the centre. Therefore the bridging from the service provider into the social networks of the community, the development of cultural programs with the involvement of partner organizations and volunteers are an important tool to improve the social networks of people with intellectual disabilities. Social networks mediate social functioning and having such a network in place may be regarded as the height of social inclusion.

2.2. Service development

It is important to rethink or to assess the impact on the way services are organised in response to the challenges of ageing, in response to the challenge of person centred approaches and in the sense of community based perspectives that open up the services and their structures.

Service users and their families should be involved at relevant levels of decision making concerning the design and development of new services or in the adaptation of services to changing needs.

It is important to **support family members** during the process of growth and aging of the disabled:

- help them to accept and process the change of role and status of the disabled family member (a disabled senior citizen is first of all an adult who deserves the same respect as any older adult and infantilisation should be avoided);
- help them accept and process the inevitable separation and the idea of death;
- help them find information and tools needed to create a solid legal protection for the last phase of life of their joint.

Health

It makes sense to provide people with intellectual disabilities specialised and appropriate health care for age related pathologies. To a certain extend mainstream services can have a role, although specialised competence should be available. The experience of the partners is that mainstream health care centres often cannot guarantee appropriate support to the very specific needs and demands and biographies of ageing persons with intellectual disability. Service development and staff training should take into account the good management of triangle: Health - prevention - sickness.

Living conditions

Living conditions is a very complex domain of life that includes the housing situation and the context where the home is placed.

Regarding housing, in times of unfavorable economic conditions, is important to be able to find **new and creative solutions** that, at low cost, can provide the best conditions of life.

A key element is to involve users in planning possible solutions about housing; the **user needs are varied and the answers should be variegate.**

Co-designing solutions will lead to better living conditions and will increase the person's participation, also financially, if possible.

Designing a good housing situation means also helping to achieve a good living condition. In order to find the best possible solution for specific groups of users, where possible, mixed design teams should be activated in which different players collaborate: users, families, policy makers, experts and managers of services.

The **community**, if invited properly, can be an **active player** in the improvement of living conditions of persons with disabilities; this might mean the involvement of volunteers (with appropriate responsibilities), parents' associations or other resources in the neighborhood. A productive dialogue involving all stakeholders will lead to new possibilities.

Housing solution could be designed to be as “**permeable**” as possible, enhancing individual freedom and facilitating the interaction between the service users and community members. Interaction can be envisaged with other resources of the quarter, such as social and leisure centres,

It should be avoided that people are moved from one place to the other for different reasons than their wishes or needs. “Aging in place”, in other words, in a familiar environment, is a general human desire, so why shouldn't it be a key objective for service providers.

Occupation

It is important that services are prepared to cope with people wanting to leave their occupation. As each person is different with different needs, preferences and opportunities, flexibility is required in identifying and supporting personalized transition tracks from work/occupation to retirement. It should be avoided that decisions are taken “automatically” or too hastily: time is needed to observe, to understand the needs and to build custom responses.

Social relationships

Supporting people in building up or keeping up significant social relationships should be a high priority for service delivering organisations. This might involve relationships within or outside the service. Service users should have the choice to join social activities or not, and if they prefer to have their own networks of friends they should be facilitated to express their affective needs and resources as naturally as possible. Sexuality is still a taboo in many services, but appropriate and reasonable adjustments should be made to make sure that service users without conditioning can develop also this part of their identity.

Many people with disabilities make proficient use of web 2.0 social networks. In various countries there are examples of specific networks that offer a higher level of protection against abuse in case the user is a person with an intellectual disability. Services should facilitate social networking though establishing a policy for the protection of their users.

2.3. Preparation of staff

Being able to deal with change and the changing conditions of the service users is an important prerequisite for people working in the care sector. Also having adopted a personalized approach in responding to people's needs is an important learning outcome for those that at all levels are involved in providing care to people with disabilities. It is further important that care workers and their supervisors aim at the empowerment of people and situations and not merely limit their intervention to

assistance and conservation. This principle, aiming at actual and meaningful citizenship, is fully in line with the UN Convention on the Rights of People with Disabilities is not age specific. Finally it is important that professional care workers continue to develop their skills and are actively involved in lifelong learning activities. This will prevent negative stress leading to the burnout syndrome.

Some resources are available, like the European Care Certificate (www.eccertificate.eu), but more education, training and accessible learning materials should be developed to support the professional development of care workers.

Health

Staff should be trained to understand the specific health related problems associated to aging with an intellectual disability.

It might be necessary that, at some level in the care system, professionals develop specific care skills related to health issues in case of aging with a disability.

It is further a good idea to engage staff in health promotion and prevention programmes.

Living conditions

A person centred approach is key in defining living environments. Not all care workers have adopted a person centred perspective yet, based on the recognition of principles such as liberty, rights, choice.

Staff could further be trained to support people in identifying what they can do themselves to improve their living conditions.

Occupation

Supporting the transition of people from work to retirement is a delicate job and staff should be aware of the various issues that might emerge.

Important learning outcomes in this area could be related to the understanding and skills needed to support people in changing their situation. Also being able to assess the meaningfulness of activities and being able to suggest changes are important competences for care professionals.

Social relationships

There are various aspects to consider when preparing staff to support the development or maintenance of social relationships of individuals with disabilities. Research shows that for many clients of residential services the care staff is considered a very consistent part of the social network. Nevertheless a trust relationship with carers should not be given for granted. Further these relations cannot substitute authentic contacts with peers and other friends. It is important that staff members are aware of the affective needs of people with a higher risks of exclusion due to barriers in their environment, lack of transportation, lack of personal support, lack of opportunities.

Another important issues is that staff members work in team and have shared goals and approaches in addressing the needs and requests of the service users.

2.4. Social cohesion

Independent living and community based services facilitate social cohesion. Disabled people should have greater choice of the support they need to go about their daily lives in the community. Further mobility and support where needed, should be provided in order to avoid the formation of ghetto's.

The sense of belonging, of recognition and of ability is central for social cohesion and the living included in the community.

At a more societal level it remains important to educate the general audience on diversity issues. This will break down barriers between people and favour the integration of all groups in society.

Equality between men and women should be enhanced.

Local authorities should enhancing good practice in social cohesion to further the development of an inclusive society.

Health

It is good practice that health care is as much as possible and as long as possible provided in mainstream/community health services.

Living conditions

People with disabilities should live as much as possible in supportive environments that prioritise social participation. This should include supported mobility, technological solutions that enhance independence, opportunities to meet other people though safeguarding the freedom of choice in meeting some people and others not.

Occupation

There should be flexibility in occupational activities to favour interaction in and with mainstream settings.

It is a good idea to suggest people with disabilities to get involved in voluntary work. People with disabilities are not only „objects“ of voluntary work, but can do precious work themselves and express in this way participation and integration in the community.

Social relationships

It is a helpful exercise to map the resources in the social space/context of the person and the organisation.

Social media offer important opportunities for people with a reduced mobility to feel connected.

3. Recommendations

- To obtain change action needed at different and separate levels
 - personal
 - service delivery
 - policy making
- It is important that each stakeholder is aware of its role and responsibilities and that of the other stakeholders.

Service providers

- Service providers and their organizations should promote **international benchmarking** and develop a genuine interest in the key concepts expressed above, reflecting on their significance and application in all aspects of the service delivery..
- Specific attention has to be paid to the development of **user centred services** and **person centred approaches**: To put the person in the very centre of attention means to take her/him serious as citizen with full participation in public life, as self-determined actor in civil society as well as customer with freedom of choice and control over her/his choices in the sphere of services.
- User centred services will be able to better cope with the changing conditions of their service users. **Age specific challenges** need to be properly identified and addressed. The highest possible level of quality of life and self determination of the person need to be the driver of any intervention within the limits of the available resources.
- The **workforces** across services are given the appropriate support and training to equip them with the values, skills and knowledge to deliver person centred care for people with disabilities of all ages. This also includes “the duty of care”.
- To be a resource in the landscape of needs, policy and solutions, you have to know the policy context in which your organisation operates and the external constraints. Identify appropriate policy making levels to address issues.

Carers

- Change of professional attitude towards **person-centred approaches** and towards **assisted decision making**. Learn to perceive the person you assist as an authentic citizen with rights and responsibilities, enhance these and consequently respond to “wants” and not only to “needs”.
- Supporting decision making is a responsibility of the carer: The decision making process has to be clear, transparent and realistic about the **choices**.

- The social and affective needs of people with disabilities need to be considered and their resources in this domain need to be valued. **Listening** is key in understanding and respecting people's emotional, affective and sexual life.

People with disabilities

- We ask the users and self-advocates: "Be loud, be heard, be constructive and be creative!"
- Consider this first of all as a problem that affects you personally. Pretend to be involved in decision making.
- Ask, if you wish, to be helped in participating and understanding issue of your concern
- Be loud, but don't feel guilty if you don't feel strong enough.
- We recommend the assistance for the creation of independent councils of self-advocates as well as the construction of participatory and co-decision structures for users in the services.

Authorities (Policy makers)

User involvement

- At all levels of policy making and service development it is good practice to involve people with disabilities actively in making decisions that affect them. Presumed difficulties in communication or understanding is not an excuse to leave them out.
- Time and resources have to be allocated for their involvement in the planning, the design, the implementation and follow up phase.
- Information in Easy to read and other forms of accessible communication has to be provided.

Health

- There is a great need for assessment as well as special attention for the impact of age-related pathologies on the functioning of the persons in his or her environment (social implications of age-related impairments).
- Special assistance for people with intellectual disabilities in prevention, education against health risk behaviour and specialises health units or assistance in public hospitals has to be provided.

Living conditions

- At local level various solutions with different levels of assistance have to be provided. By doing so a greater range of choice can be offered. A single room for all, is a human right.
- Be creative and facilitate flexible and person-centred solutions for all! This means also to be realistic: Inclusive and person-centred settings do not necessarily cost more, but without doubt give higher quality of life and better community structures for all.
- Being person centred requires a change of mentality, of policy and of economic thinking: People should not adapt to structures but structures should be developed to accommodate the changing needs of the individual. It might not be cheaper on the short term, but the Social Return on Investment will be higher!
- Beside services, appropriate financial support should be guaranteed to individuals in order for all people to live in dignity.

Advocacy

- Older people with intellectual disability are increasingly confident in their self-advocacy. But still they are a double minority, being in a doubled social construction: being old and being disabled in and for society. This socially constructed vulnerability has to be taken into account, as well as their changing needs for assistance and care.
- Self-advocates, family members and representatives of services should collaborate and be proactive in the dialogue with public authorities and media.

Policy implementation

- Negating fundamental rights is a form of inflicting violence on people.
- A double risk exists where there is a lack of choice in a situation where resources are available. This enhances the gap between rights, expectations, needs and outcomes.
- An active dialogue between all stakeholders should be furthered, in order to discuss the development of person-centred community based assistance for elderly or ageing people with disability.
- Plan where possible with a long term perspective, providing opportunities for people to choose down the line of their life project.
- Cooperation has to be furthered between stakeholders in the general field of ageing and the field of disability, as the needs of elderly that gradually lose functional autonomy and elderly with a life long disability tend to overlap. A person

centred approach should nevertheless guarantee that people's interests are not overlooked. Solutions should be designed that seek the quality of life of people in meaningful activities.

- Pretend that other stakeholders listen to your arguments and seek their collaboration in defining solutions. This is a far more rewarding strategy than hiding yourself in administrative ditches.
- Choose appropriate communication channels and media to discuss with your target audience. Informative material should be made available in accessible formats.
- Gear as much as possible resources to community based appropriate services that respond to real needs. Access to services should have a low threshold.
- Support the development of technological solutions to facilitate independence and participation. Start early with programmes for the digital education of people with disabilities, in order to avoid the widening of the digital divide.
- The exchange of good practice between all stakeholders at national / European / international level should be enforced.
- More research and information on Aging with a lifelong disability is needed.

E-dignities partnership

- CADIAI, Bologna – Italy (Lead partner)
- University of Northumbria at Newcastle – United Kingdom
- Lebenshilfe Österreich, Vienna - Austria
- FMS, Gerardmer - France
- Fenacerci, Lisbon - Portugal
- AIAS Bologna onlus - Italy
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