The Rights of Ageing People with Autism
Towards a better quality of life

Image: One of the older residents on Hinnerup Kollegiet (Denmark) who works every day at a local school, bringing milk to the students. The students love and care for her. She, in turn, loves her job and becomes irritated whenever there is a school holiday.
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Autism-Europe is an international association whose objective is to advance the rights of people with Autism Spectrum Disorders (ASDs) and their families, to help them improve their quality of life.

This is achieved through:
- Representing people with autism before all European Union institutions;
- Promoting awareness of appropriate care, education and well-being for people with autism;
- Promoting the exchange of information, good practices and experience in the field of autism.

Autism-Europe is the umbrella organisation for a network of approximately 80 associations of parents of people with autism across 30 European countries. Autism-Europe has established a structured dialogue with the institutions of the European Union and the World Health Organisation, to advocate for the rights of people with ASDs. To maximise its impact on European Union policies, Autism-Europe also works in strategic alliances with other relevant organisations, including the European Disability Forum and the Platform of European Social NGOs.

More information: [www.autismeurope.org](http://www.autismeurope.org)

AGE Platform Europe is a European network of more than 165 organisations of and for people aged 50+ representing directly over 30 million older people in Europe.

The purpose of its work is to voice and promote the interests of the 150 million inhabitants aged 50+ in the European Union and to raise awareness of the issues that concern them most. AGE seeks to give a voice to older and retired people in the EU policy debates, through the active participation of their representative organisations at EU, national, regional and local levels, and provides a European platform for the exchange of experience and best practices. It also aims to inform older people on their rights as EU citizen or resident and on EU policy making processes and recent EU policy development.

More information: [http://www.age-platform.eu](http://www.age-platform.eu)

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Introduction

The ageing of the global population is a challenging phenomenon, especially in Europe. The percentage of the population who are aged 65 years or over is expected to increase from 18 percent in 2010 to 30 percent by 2060\(^1\). People are living longer and in better health conditions. Similar trends are also true for people with autism. Autism spectrum disorders (ASD) are severe lifelong neurodevelopmental disorders, with considerable functional and financial impact on the individual and the family. Very little statistical data is currently available concerning the adult population with autism, however, studies have shown that the prevalence rate is fairly consistent across all age groups, thus 1 in 150 older people is likely to be affected by autism\(^2\).

Research has until recently mainly focused on autism in children and young adults, and little is known about the effects of ageing on older people with autism. However, during the past few years, the issue of ageing of people with autism has become more pressing across Europe and various studies have been launched. They highlight the fact that people with autism and their families face numerous barriers and discrimination, that tend to worsen with age. They are extremely vulnerable to social exclusion and the overarching concern for these people revolves around the question: “Who will care for people with autism who need a high level of support when their families are not able to cope anymore?” As people with autism and their carers grow older, the difficulties they face are set to multiply.

This report offers insight into the issue of ageing and autism and outlines the challenges that need to be addressed. A list of recommendations is addressed to policy makers who are urged to respond to the urgent needs of older people with autism. The recommendations take into account the United Nations Convention on the Rights of People with Disabilities (UNCRPD) ratified by the European Union and most of its Members States. They also echo the *Recommendations of the Council of Europe on ageing and disability in the 21\(^{st}\) century*. The latter foresees that with due regard for their own national, regional or local structures and respective responsibilities, the Council of Europe Member States should contribute to the creation of sustainable frameworks to enable greater quality of life in an inclusive society for ageing people with disabilities.

In this report, positive examples from various countries that pave the way forward for improving the lives of millions of older people with autism are also highlighted and we hope that they will inspire relevant stakeholders and policy-makers to adopt similar approaches to autism and ageing throughout Europe.

1. Autism and the ageing population

1.1 What is autism?

Autism was first referred to scientifically in the 1940s (Leo Kanner in 1943, Asperger in 1944) and the first children studied at that time are now adults, many of them in their sixties. Autism is a *lifelong disability* affecting the functioning of the brain. The world is therefore faced with the challenges brought on by the ageing process of people with autism.

Each individual with autism is unique, however all people with autism present clinical features in three domains\(^3\):

- **Disturbances in the development of reciprocal social interaction**

In some individuals there is significant social aloofness; others are passive in social interactions, with only very limited or fleeting interest in others. Some individuals may be very active in their attempts to engage in

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social interactions but do so in an odd, one-sided and or intrusive manner, without full consideration of others’ reactions. All have in common a limited capacity for empathy – although, again the extent of deficit is very variable – but most are able to show affection on their own terms.

**Impairment of verbal and non-verbal communication**

The development of language in individuals with ASD is extremely variable. Some individuals never acquire speech. Others begin to speak, but then, (often around the age of 18 months to 2 years) there may be a period of regression. Other individuals appear to have superficially good language but have difficulties with understanding – especially understanding of more abstract concepts. In those who do learn to use language, both receptive and expressive difficulties are common. All individuals with autism show some degree of difficulty in reciprocal, to-and-fro interactions with others. In both form and content, language tends to be unusual, and abnormal features include echolalia, pronoun reversal and invention of words. Emotional reactions to verbal and non-verbal approaches by others are also impaired, and are often characterised by gaze avoidance, inability to understand facial expressions or the messages conveyed by others’ body postures or gestures.

In summary, there are deficits in all the behaviours required to engage in and regulate reciprocal social interaction. There are often marked difficulties in identifying, understanding and sharing others’ emotions; the individual’s own repertoire of expression and regulation of emotions is also affected.

**Restricted repertoire of interest and behaviours**

Imaginative skills are almost always impaired to some degree. As children, most individuals fail to develop normal pretend play and this, in turn, limits their capacity to understand and represent intentions and emotions of others. In some cases imaginative activity may be present, indeed even excessive, but this does not lead to improved functional adaptation or participation in social play with peers. The failure to develop an inner representation of others’ minds also affects the capacity both for anticipating what may happen in the future and for coping with past events.

Behavioural patterns are often repetitive and ritualised. These may include attachments to unusual and bizarre objects. Stereotyped, repetitive movements are also common.

There is often a strong resistance to change and insistence on sameness. Even minor changes in the environment can cause profound distress. Many children with autism, particularly those with higher intellectual ability, develop specific interests or preoccupations with unusual topics.

**Other important aspects to be taken into consideration**

Many individuals show hyper- or hypo-sensitivities to tactile, auditory, and visual stimuli; they may also demonstrate unusual responses to heat and cold and or pain.

Other commonly associated, non-specific features include high levels of anxiety, sleep problems, abnormal feeding patterns, sometimes resulting in gastrointestinal disturbances (although these appear to be associated more with developmental delay than to autism per se), severe tantrums and self-injurious behaviour.

Many individuals with ASD are affected by other behavioural and psychiatric problems. These are referred to as ‘co-morbidities’ and include psychiatric disorders such as anxiety disorders (in up to 60%), depression and other affective disorders, attention deficit hyperactivity disorder, obsessive-compulsive disorder, tics, catatonia and also, although more rarely, substance abuse and psychotic breakdown.

A thorough assessment of these features is essential. Many such problems (for example, depression or anxiety) may reflect the fact that the environment is inappropriate, or the treatment plan inadequate for someone with ASD. In these cases co-morbidities should be considered as ‘complications’, requiring careful reappraisal of the intervention programme. In other cases, the associated disorders will need treatment in their own right.

Despite the uncertainty of the future diagnostic criteria for autism spectrum disorders, which will have a key role in establishing future prevalence rates of these disorders, there is now converging evidence that, using current diagnostic criteria, many more individuals, in many different countries are being diagnosed with ASD. Rigorous surveys from North America found that about 1 in 150 8-year-old children in multiple areas of the
United States had an ASD. Epidemiological studies from Europe point to a similar figure among children (0.9 per 150, or 60 per 10,000).

1.2 The prevalence of autism is equivalent in the older age groups

In January 2010, the EU-27 population stood at an estimated 501.1 million people; of these some 87.1 million were aged 65 or over. Very few data and statistics on ageing people with autism are available yet. In March 2012, the National Autistic Society (NAS) commissioned one of the largest surveys into autism ever conducted. The survey was completed by 2,938 people with autism and 5,535 carers. 355 of those with autism were over the age of 45 and 120 of these were over 55. Among the over 55s, only a quarter were diagnosed before the age of 40. A further quarter still do not have a formal diagnosis, meaning that it is likely that they are finding it harder to access any help that may need. This situation is far from being an exception in Europe, where the issue of older people with autism is becoming more and more pressing.

The most relevant research that is available indicates that autism spectrum disorders are just as prevalent in older people as they are in younger age groups, thus around 1 in 150 older people is likely to be affected by autism. According to a household survey in the United Kingdom, which was updated in 2012, the prevalence of autism was 1.1 percent. The prevalence of autism was higher in men (2.0 per cent) than women (0.3 per cent).

According to various surveys, individuals with learning disabilities have a reduced life expectancy, however, as for the general population, the life expectancy for this group is increasing. These studies are also indicative of increased life expectancy for people with autism, who can have different ‘degrees’ of learning disability, which can affect all aspects of their life, from studying in school to learning how to wash themselves or make a meal. Some people will be able to live fairly independently – although they may need a degree of support to achieve this – while others may require lifelong, specialist support.

2. Challenges faced by ageing people with autism and their families

General chronological and biological age do not always coincide when people age. Their health status, capacities, level of social interaction, etc., vary widely even within the same age group. Thus the heterogeneity of older people should be taken into account when determining the age-specific care should be available. It is important to reflect on the definition of ‘elderly’ or ‘old age’ when applied to people with autism, who may need specific attention in relation to ageing at an earlier age than the general population.

A number of recent studies have suggested that many of the typical issues of age-related decline are also relevant for individuals with intellectual disabilities, including people with autism. Some studies have suggested that such individuals may demonstrate age-related cognitive decline/dementia at earlier ages or more rapidly than the general population. However, further studies would be needed to know whether people with autism have increase prevalence rates of dementia as in Down Syndrome.

Importantly, many of the factors that seem to influence cognitive decline are not related to intellectual level, but to other factors linked to autism, including epilepsy, obesity, pain, falls, hypertension, diabetes, sedentary lifestyle as well as hearing and vision issues.

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The consequences of ageing on people's health and well-being

The needs of ageing people with autism are the same as those of other ageing people (economic, social, affective and environmental), however, their needs are exacerbated by the neurological, physiological and psychological factors linked to their specific condition.

People with autism can also suffer from health problems due to associated diseases and conditions, that can severely affect their life outcomes and life expectancy\(^1\). In particular, much higher rates of depression and anxiety are present among older people with ASD than among the general population. People who are aware of their condition generally report extreme frustration at their lack of close relationships and concerns that their problems are not being understood by others and often dismissed\(^2\).

The secondary effects of medical drugs should also be considered, since many people with autism have been prescribed anti-psychotic drugs for an extended period of time and medication is unlikely to be reduced by doctors after this form of treatment has begun. Many parents and carers have reported that heavy medication has some negative effects on adults with autism, however, further research is needed in this area.\(^3\)

Older people with ASD also have to deal with a range of general health problems (including gastrointestinal problems, insomnia, epilepsy, autoimmune problems and mitochondrial diseases).

It has been demonstrated that those living in large institutions also have reduced life expectancy. In this instance, the main cause of death is respiratory failure (50 percent). People with intellectual disabilities also have proportionally higher rates of gastrointestinal cancer than the general population (48 to 58.5 percent vs 25 percent of cancer deaths) (Cooke, 1997; Duff et al., 2001; Jancar, 1990). Many authors suggest that in individuals with intellectual disabilities, an emphasis on physical health and independence may be beneficial and lead to healthier ageing. This is also likely to prove relevant for people with autism.\(^4\)

Mencap, a charity supporting people with a learning disability and their families and carers in the United Kingdom, has reported continuing poorer health outcomes and access to services for those with a learning disability. According to a survey conducted in 2010 in the United Kingdom\(^5\), almost half of doctors (45 percent) and a third of nurses (33 percent) also admitted that they had personally witnessed a patient with a learning disability being treated with neglect or a lack of dignity or receiving poor quality care. Nearly four out of ten doctors (39 percent) and a third of nurses (34 percent) went as far as saying that people with a learning disability are discriminated against in the NHS.\(^6\)

Ageing triggers an even higher risk of social exclusion for people with autism

Older people are more at risk of social exclusion than the general population.\(^7\) In that context, ageing people with disabilities face an even higher risk of social exclusion, and of those, people in need of a high level of support or having problems of communication have a double vulnerability and face an extremely high risk of social exclusion. People with autism are included in the latter group. By definition, the communication and interaction problems affecting people with autism can lead to isolation. People with autism also sometimes display behavioural problems that may arise from, or are aggravated by, their communication and interaction difficulties, which in turn reinforce their isolation. Their difficulties of communication are

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\(^6\) Francesca Happé, Rebecca A. Charlton, ibid

\(^7\) ICM Research surveyed a sample of 1084 doctors and nurses online between 25.05.10 and 07.06.10

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exacerbated by the lack of appropriately trained staff in various settings: health and residential services, etc.

Sometimes, people with autism are simply not provided with any kind of support. According to the survey of the National Autistic Society conducted in 2012, with regard to adults with autism who have a diagnosis, 71% of the over-45s who responded to the survey have not been assessed, meaning their needs have not been recognised by their local authority, let alone met. In addition, as previously indicated, many individuals who were born prior to the original definition of Asperger syndrome or Autism, have largely had no contact with specialist services. Importantly, they may also be receiving inappropriate treatment due to misdiagnoses in later life.21

The lack of support can have dramatic consequences; it is very revealing that people with ASD are significantly more likely to experience homelessness than the general population. This is evidenced by research conducted in 2010 involving entrenched ‘rough sleepers’ in an English county which identified that 9 out of 14 rough sleepers were assessed as being on the autistic spectrum.22 This situation is likely to worsen when people with autism get older and lose the support of their family members.

Older people with autism face the problems resulting from both their disability and the ageing process. These difficulties are worsened by the consequences of the financial crisis, reducing financial support and decreasing the resources available in the social and the healthcare sectors necessary to meet the growing, and as yet largely unknown, needs of older people with ASD. These difficulties are coupled with considerable ignorance about the actualities of ageing in autism.

People with disabilities have amongst the hardest hit by the financial crisis as evidenced by research commissioned by the European Foundation Center which assessed the impact of European governments’ austerity plans on the rights of people with disabilities. The main findings were that 1 out of 5 persons with disabilities (21.1%) are at risk of poverty in the EU compared to people without disabilities (14.9%).

The partial or complete closure of social services was reported in Bulgaria, Greece, Hungary, Ireland, Portugal and Romania. Mergers and the re-organisation of services were also reported. Services include day care centres, home care services, vocational training, rehabilitation, specialised nurseries and schools.

AGE Platform Europe also reports that in countries where residential care is partly or fully financed by families, many older people have been withdrawn from residential care and moved into informal care at home or transferred to less costly homes (municipal homes), with an inherent risk of lack of proper assessment of their care needs. Also, currently in Greece, effective withdrawal of the right to free or subsidised medication, means that older people with chronic conditions are being forced to abandon essential treatment regimes, or stop taking expensive drugs, or rely on the availability of voluntary free drug programmes run by philanthropic organisations, thus negating the achievements of the past 30 years in ensuring that all population groups have access to health care and treatment. In many other countries every year the list of non-reimbursed drugs gets longer.

- **When a person has autism, the whole family experiences discrimination.**

In all EU countries, informal family care is the main form of long-term care for older people, this is reinforced by the cutbacks in the provision of health and social care due to the financial crisis. Older people with autism also suffer from a lack of resources and trained staff to respond to their needs. Therefore family members, due to the pressure they experience to care for and support their relative while maintaining a living, often experience “associated discrimination”. The fight against discrimination should therefore include the discrimination a person experiences through his or her association with another person who is discriminated against. In addition, in the UK the cost of supporting people with autism and the opportunity costs of lost productivity were estimated in 2009 at £28 billion per year.25

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20 Source, Carol Povey, National Autistic Society, 2012


22 *Autistic Spectrum Disorder, A Guide for Homelessness Practitioners and Housing Advice Workers*:

23 AGE’s report on the impact of the crisis will be published as a contribution to the European Year 2012. This publication builds on the work in the field of social inclusion and social protection carried out by AGE Platform Europe and its member organisations since the beginning of the financial crisis in 2008. The document also presents recommendations from the seminar AGE co-organised with the Committee of the Regions on the impact of the crisis on older people on 19 June 2012 in Brussels.

24 Coleman Case Coleman v Attridge Law & Stephen Law - C-303/06

Ageing people with autism have older parents or relatives (like siblings) who are also in a situation of vulnerability because they do not get enough support to respond to the needs of their family member with autism. In addition, older parents have to face also the consequences of their own age and may themselves need support and adaptations. As the resources for care are diminishing and the responsibility to provide care goes at the individual level, families (informal carers) should receive sufficient support in order to provide help to the persons with disability in their families.

Parents of adults with autism also have to face their own health and age-related issues.

Marc, an 86 year-old father of an adult son with autism, has experienced the difficulties of becoming an elderly carer. When Marc’s beloved wife became ill and died in 2012, Marc became the remaining carer for their middle aged son. The process of his wife’s rapid decline into dementia and a number of other age-related conditions, led Marc to believe that in finding solutions for adults with autism and their ageing parents “the incidence of dementia in the older population should not be neglected since it affects about 20 percent of people who are over 80 years of age. This risk is underplayed. When a carer quickly develops dementia, they are not only unable to consistently provide care for a person with autism, but they may also be unable to seek other care solutions. If they are a sole carer, this could have dramatic consequences for the person with autism. This issue should also be looked into for people with autism, because little is known about the prevalence of dementia in the autism population.”

• **Who will care?**

Most older adults with disabilities no longer have their parents to take care of them and voice their needs. This raises an essential question: what will happen to 3.3 million older people who have autism when their parents are no longer able to care for them or have passed away?

‘Who will support him when I’m gone?’

A Belgian mother of a 36 year old man who has autism and epilepsy is sick and has been a widow for several years. Her son’s siblings are not providing support and in the face of a 10 year waiting list for supported housing facilities, she is concerned about what will happen when she is longer able to support her son.

“There is currently no place in Brussels [for supported housing facilities]. I visited 20 care homes, all of them are full. My child is very withdrawn, anxious and depressed. Who will support him when I’m gone?”

(excerpt from Autirecherche 2006 - Enquête sur les besoins de la population bruxelloise, francophone, adulte avec autisme, Inforautisme asbl)

One of the biggest concerns for the families of adults with autism is who will care for them when their parents are no longer able to do so. 96% of parents surveyed by the National Autistic Society in a study conducted in 2012 are worried about their son/daughter’s future when they are no longer able to support them.

• 68% describe themselves as very worried
• 28% say they are quite worried

35% have made some plans for what will happen if they are no longer able to support their son/daughter, but only 4% say they have planned a lot. This leaves a large number of people worried about what will happen to their son or daughter when they are unable to support them, but very few having made plans for them.

Recently in France, a 49 year-old man with a mental disability (who had been left without support after the death of his mother last year) died alone in their apartment. The man’s body was found, months later, mummified. This case involving a man with a mental disability illustrates the same problem that people who have autism face: a severe lack of services that leave people alone and vulnerable.

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26 Names have been changed for privacy reasons
Tom, a middle-aged man from the United Kingdom who has Asperger syndrome, explains his concerns about the future and the lack of support available for when his elderly father passes away:

“I live in a block of flats. I’m not happy where I live. It’s a very violent area. There’s drugs, prostitution, noisy parties, that sort of thing. So I don’t feel safe there. But it’s the only place the council have available at the moment, within easy reach of various facilities.

My Mother died of cancer back in 1991. Now I have to rely upon my friends and my father. He’s very kindly doing it. Obviously I love him to bits and trust him, but he is 80 now, and I worry about what’s going to happen when he’s not able to do that anymore.

I’m not very good financially. Despite my masters degree, filling out a tax form – that’s beyond me. I most often understand what the questions are saying, but I don’t know what the right answer is, or where to find it. I get a feeling of dread. If I could go to someone I trust and they go through it that would be easy.

Having somebody into my home can be very traumatic for me. I worry they could have touched any electrical switch that I wouldn’t know about. I don’t cook, because I’ve got a great fear of there being a house fire. I always eat out. So in the end, what I’m almost doing is avoiding things that cause me stress.

I used to have support from the rehab service, but they started introducing charges that would have meant me paying thousands of pounds a year. I just couldn’t afford it. They keep cutting back in local government. I get a bit of financial support, but they’re asking for way too much – I hardly have anything left.”

This was also reflected in another survey conducted in 2012 by the NAS with siblings, many of whom reported that they were concerned about how they would support their adult brothers and sisters as their parents become less able to cope. 111 siblings of people over 40 were contacted to ascertain their views on taking on supporting the needs of their sister or brother with autism, and their own support needs; once parents are no longer able to provide the support they once did.

The siblings of adults with autism have their own lives, with jobs, families and other responsibilities. Many want to provide help and support for their brothers and sister with autism. They may not be able to provide a home, or financial support, although some can and do. The help that siblings can offer is both emotional and practical, but with their own busy lives, they need information and support.

Similar anxieties about who will care for people with autism when a primary carer passes away are experienced by partners of people with autism, who are often providing a large amount of informal support.

Paul, a 65 year-old man from the Netherlands who was recently diagnosed with Asperger syndrome after many years of misdiagnoses, explains that: “If my wife were to pass away, it would be extremely difficult for me to cope emotionally and to manage on my own. We have been married for many years and my wife provides me with the support I need in my everyday life. If my wife would not be able to care for me anymore, I would probably have to be sent to a care home, where I fear that I would not receive adequate support.”

The informal caregiving for older persons is predominantly provided by women. Thus it enhances short and long-term risks of poverty and increases carers’ own risks of developing physical and mental health problems, notably depression.

The concerns of parents and relatives in the United Kingdom – where autism services are some of the best in Europe – are echoed by families across the rest of Europe. Nowadays, people with autism and their families are confronted by a lack of realistic and appropriate services and financial support in most countries. They often feel let down by authorities who have little information on vulnerable individuals and carers.

### 3. Examples of the support for ageing people with autism spectrum disorders

While the need for support among ageing people with autism across Europe is severe and urgently needs to be addressed, the current levels of support provided are also diverse across Europe. In some parts of Europe, some very good examples of support for the needs of older people have been in operation for some years now, and continue to develop and evolve as new knowledge about autism emerges.
In this section, two comprehensive residential support centres that provide examples in the support of ageing people with autism are profiled.

**Denmark: Growing up and growing old at Hinnerup**

Hinnerup Kollegiet in Denmark is home to 167 adults with autism, providing a supportive and adapted environment from early adulthood through to old age.

In Denmark, diagnosis of children with autism began in the 1960s and Autism Denmark began operating specialised housing facilities for adults with autism in 1975. Hinnerup Kollegiet is one of Autism Denmark’s specialised housing facilities in which adults with autism live and work. Hinnerup started as a housing and working community in 1982, when ten young adults with autism moved in. The place was established by a strong parent group who thought of Hinnerup, as their grown-up children’s new home. The young people had the possibility of learning to cope with ordinary practical things, as well as making friends and learning crafts in Hinnerup’s own workshop.

As time passed, both employees and parents gained more knowledge of autism, and the pedagogical approaches developed. Parents and staff understood that autism was a lifelong condition and that Hinnerup in time would become a permanent residence for adults with autism. Therefore, Hinnerup built two specialised departments for older people where individual care, self-determination and development were seen as keywords for good life quality.

**Philosophy**

Hinnerup Kollegiet works on the basis of the fundamental approach that people are different and have different needs - even when they have autism in common. All decisions are based on the individual person’s needs and desires and their decisions are met with respect. Goals for improved life quality are set together with the residents and the staff work with the residents to achieve their goals. The residents are not placed under any pressure; they are supported and encouraged to achieve their goals.

The continuous aim of Hinnerup’s staff is to promote communication and understanding through visualisation and concrete, structured frameworks.

**Education and Ethics**

The pedagogy at Hinnerup is cognitive and focuses on the positive and appreciative in human resources. Basically, the concept is simple: you must respect people with autism, their thoughts and their way of being. The residents at Hinnerup need a lot of support in simple everyday tasks, but all efforts are aimed at facilitating greater autonomy, organised according to individual capabilities and competencies.

**Support in the transition to retirement**

Most of the residents at Hinnerup work close to home in the related day care services, and engage in a wide range of common leisure activities organised by the staff and in the local community. Some residents also work at the local school for example. For some of the older residents, working life is coming to an end and their daily routines are about to be changed. Therefore, Hinnerup works to ensure a slow and careful transition to retirement for its residents. A retirement at the Hinnerup Kollegiet will consist of many small daily chores and a number of social and creative activities according to the needs and desires of each individual resident.

**Health and wellbeing**

The process of ageing brings many changes in relation to health and wellbeing that can be challenging for people with autism.

In order to prevent age-related diseases and to accustom residents to doctor visits, all residents of Hinnerup have scheduled appointments at the doctor to get a health check at least once a year.

At Hinnerup, when a change is required staff communicate changes to residents by both verbal and visual methods to ensure that the meaning of, and reason for, the change is clear to the resident and is not intended as a punishment, even if it may feel that way until the resident adjusts to the change. Often, where a change implies some loss (of routine, of an object, or loss of any kind) to the resident, then the resident is given the opportunity to choose something else to replace what was lost. When a lifestyle change is required for health reasons, Hinnerup uses a doctor to convey this to the resident and in this way the staff can maintain a good relationship with the resident and support them in the lifestyle amendment. People with
autism do not always have the same experience of pain and do not express pain in the way the rest of us would. Older people with autism sometimes change behaviour if they feel bad, maybe their mood is changing, they become aggressive or they are more passive than they were before. Some older people use much effort to act exactly as usual if something is wrong, they do not understand the change and may be afraid of it, they are trying to hide it as long as they can.

Throughout their adult lives, the residents at Hinnerup have been motivated with sweets or food after they have fulfilled a task. Edible rewards are effective because food affects the senses and releases positive signals in the brain. When people with autism grow older, however, they become less mobile and do not burn as many calories. Therefore at Hinnerup, other types of rewards are sought so that weight gain does not become a problem for residents.

Building a framework for ageing well
Buildings are nothing without good appreciative pedagogy, care and ethics. Buildings can, however, be important in relation to creating optimum conditions for ageing well. Hinnerup's two special homes for the elderly each contain eight apartments and are built in the shape of the letter H (when viewed from above). Each building has four separate entrances at the extremities of the building to enable residents to have access to their own apartments without going through common premises, and an element of privacy, while at the same time maintaining easy access to the whole Hinnerup community and contact with staff.

Hinnerup hosts some of the oldest people diagnosed with autism in Europe, some of whom have lived at Hinnerup for 30 years. As this group grows older some unforeseen issues have begun to require attention. For example, while the apartments are built specifically for people with autism, provisions have not been made for other forms of disability. There are currently no lifts in the bathrooms to assist less mobile people with showering and not enough space in bedrooms for wheelchair access. In the current situation, if it should happen that a resident develops a need for a much higher level of care, it would be necessary for the resident to move to a nursing home or a hospital. Hinnerup wants to avoid that stress factor, hence it has been decided that four new homes will be built in 2013 to accommodate these needs. The homes are being designed in collaboration with leading architects, who will follow good practices in design for people with autism to reduce the stress, sensory issues and anxiety that follows most people with autism throughout their lives.

France: From a youth spent in institutions to old age at Sésame Village
Sésame Village in France provides an alternative way of life for adults with autism who have lived most of their lives in large institutions.

The Sésame Autisme Rhône-Alpes parents association established Sésame Village, the first residential care facility specifically for adults with autism in the Rhone region in 1987.

Some years later, the parents recognised that the needs of older people with autism were not adequately accommodated elsewhere, Sésame Village was specifically designed to meet the needs of adults with autism as they grow into old age. Sésame Village provides places for 36 people, including 32 permanent residents and 4 places for temporary or emergency care of older people with autism as an alternative to hospitalisation or living at home for a period of time.

Situated in the centre of Messimy, within the local community, the village is comprised of five buildings totalling 2,017m2. There are four individual houses and an administrative centre, as well as orchards and greenhouses for gardening activities with residents. Each house contains a kitchen, dining room and living room, and between eight and ten individual bedrooms of 20m2 with individual bathrooms. The houses’ interiors are identical with colour reference points and characteristic decoration to make them individual.

A village atmosphere is created by a square with a sheltered area, kiosk and seating and the area is opened to the public on special occasions (markets, celebrations, cultural exhibitions, etc).

Transition to a new way of life
Many of the residents of Sésame Village today are adults who have lived the majority of their lives in large institutions following the ageing or death of their parents. In these large institutions, they did not receive adapted care and adequate support to develop their skills within their capacity. Therefore, their level of need for support remains very high and the transition to a new way of life brings new challenges.
Some adults now aged between 40 and 50 have already spend 20 years of their lives in the same institution, the same facility and in the company of the same residents. They have their habits. It is only possible for them to change their place of residence and get used to a new human environment without triggering too much anguish if the changes have been well prepared and if the person still has the capacity to adapt.

An environment adapted to the needs of older people
The possible worsening of an individual’s health or increased dependency needs can be the catalyst for a hurried and very destabilising move into Sésame Village. The needs and difficulties of older people with autism are into account and a medical staff is able to take care of them even when their health deteriorates. No upper age limit is foreseen and they can remain at Sésame Village for the rest of their lives, with the only exception being particular cases in which Sésame Village is unable to meet an individual’s specific support needs.

While most older adults require a reduced pace in life, ageing adults with autism, especially those who have spent many years in large institutions, often have a particular predisposition to fatigue and often suffer from the side effects of heavy medications. Therefore, an adapted pace of life is required. The village environment fosters as harmonious a life as possible for each person in relation to him or herself and others, and each resident has a personalised plan for their care and wellbeing.

Maintaining relationships with family
The family members of people aged over 40 years is often reduced to siblings due to the old age or loss of one or both parents. Sésame Village is a place where residents' relatives can spend a day with them, share a meal with them in the living rooms specifically conceived for that purpose or go for a walk in the village (activities that are not always possible for individuals with autism who are living in large institutions).

Therapy and skills development
A multidisciplinary team at Sésame Village provides a therapeutic function in close liaison with medical services. Residents are also supported to maintain, and continue developing, their skills in a range of areas to facilitate the person’s well-being, preserve their capacities and facilitate cultural openness.

Social life
In order to enhance the social inclusion of residents to the greatest extent possible, social activities are organised in conjunction with nearby organisations for people who live with similar conditions.

4. The rights of ageing people with autism - Plan for action towards a better quality of life

In recent years, the European Union has undertaken remarkable steps to enforce equal rights for citizens with disabilities. The EU has ratified the United Nations Convention on the Rights of Persons with Disabilities in December 2010, and to date most of its Member States have also ratified it. The Convention on the Rights of Persons with Disabilities is an international human rights instrument intended to protect the rights and dignity of persons with disabilities. Parties to the Convention are required to promote, protect, and ensure the full enjoyment of human rights by persons with disabilities on an equal basis with others. There are eight guiding principles that underlie the Convention and each one of its specific articles:

a. Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons
b. Non-discrimination
c. Full and effective participation and inclusion in society
d. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
e. Equality of opportunity
f. Accessibility
g. Equality between men and women
h. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

In this context, the rights of ageing people with disabilities should not be forgotten. People with autism, their families or representatives, and relevant organisations must take stock of the situation and governments must fulfil their obligations related to the UNCRPD.

It is also important to address the implementation gap as the intersection of age and disability is not taken into account by EU and member states legislators and policymakers in the implementation of the UN CRPD. People with disabilities have to face a normative gap, since there is a distinction on the treatment of people with disabilities depending on their age. For instance, under the current French system – a country which ratified the Convention on the Rights of Persons with Disabilities – people are better off if they become incapacitated before the age of 60, because at 60 years old and a day, one is considered just an older person and not a human being with rights equal to others. The targeted allowance is considerably reduced and older people have to contribute to their long-term care costs up to 90%.


The Council of Europe indicates that ageing of people with disabilities, particularly of those requiring more intensive support, compels Member States to adopt innovative approaches. In this regard, the Council of Europe notes that “the quantity and quality of community-based and residential support services in this field have been unsatisfactory, especially for people with learning disabilities. Older people with disabilities have suffered a double disadvantage, as seen in their relatively low priority in health- and social-care policies and provision.”

With due regard for their own national, regional or local structures and respective responsibilities, the Council of Europe member states should contribute to the creation of sustainable frameworks to enable greater quality of life in an inclusive society for ageing people with disabilities.

Recommendations to policymakers

The following recommendations formulated by Autism-Europe in collaboration with AGE Platform Europe take into account the United Nations Convention on the Rights of Persons with Disabilities, the articles 25 and 26 on the rights of the elderly and people with disabilities of the Charter of Fundamental Rights of the European Union as well as the Recommendations of the Council of Europe on ageing and disability in the 21st century. They are also based on Autism-Europe position paper published in 2003 on ageing. They are addressed to policy-makers to give them guidance to fulfill their obligations towards older people with autism.

The right to an independent life and self-determination (art. 19 of the UNCRPD)

Ageing people with autism and with other types of disabilities requiring a high level of support have the right to decide their future and to ask for the respect of the provisions of the UN Convention on the Rights of People with Disabilities.

The right to maintain or improve the quality of health (art. 25 of the UNCRPD)

- Prevention of health problems related with ageing
- Accurate diagnosis and accurate information on their specific health condition
- Prevention of problems related to their specific health conditions
- Treatment of individual health conditions

The right to maintain and improve communication and social interaction (art 9 and art 26 of the UNCRPD)

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30 Evelyne Friedel, LINK 52, Dec. 2009
Older people with ASD should be provided with access to adapted alternative means of communication and visual information.

As far as possible, foster inter-generational dialogue by:

- Involving young people through their participation in cultural events and other games or sports activities with older people with autism in the community
- Facilitate contacts between schools, youth organisations and structures for older people with autism.

**The right to appropriate intervention (art 26 of the UNCRPD)**

Multidisciplinary assessment and co-ordination of interventions throughout the lifespan of the person with autism, including during the old age, while taking into account:

- The functional abilities of the older person.
- The interests and wishes of the older person and his/her family

Design and put into practice an individualised support plan with the main objective of:

- Improving and maintaining autonomy skills in the home or residence
- Improving and maintaining social skills in community activities

**The right to have services to provide a good quality of life (art 26 of the UNCRPD)**

Older people with autism should be fully and directly involved throughout the process of designing, implementing and evaluating services. Families, care providers and friends should also be involved in these processes, as appropriate Services should be the result of a dialogue. Diversity of choice of accredited services must be available.

Services users with ASD and their families/representatives must have permanent contact and dialogue with the staff, the opportunity to express their needs, priorities and hopes and to participate fully in the development, monitoring and review of individual plans.

In order to achieve these goals, services should provide specific, qualified intervention consequent to current, updated knowledge as well as a stable and reliable structure that adopts quality standards related to the quality of life of the users and is based on a set of rules defining responsibilities, day-to-day routines and procedures.

This will enable family and staff members to identify the individual needs of the person with autism. It will also be a way of reducing the risk of isolation and consequently exclusion.

**The right to leisure (art 30 of the UNCRPD)**

Older people with ASD also have the right to take part in leisure activities and enjoy cultural life. They should be provided with adequate support according to their needs in order to benefit from culture, entertainment, recreation and sport.

**The right to education and lifelong learning (art 24 of the UNCRPD)**

Services must provide a learning environment and education facilities adapted to older people with autism. For people with autism, throughout their lifespan, education represents a lot more than a basic right. Lifelong education is necessary to compensate for the great difficulties that people with autism have in extracting meaning from simple experiences (something most other people are capable of without specific educational support), and to attain the highest possible degree of self-sufficiency.

**The right to housing facilities (art 19 and 23 of UNCRPD)**

People with autism must remain in their own homes as long as they can and wish, like other ageing people, or live in places where they were accustomed to spending time before retiring from ‘active life’. Preparation for the changes in living arrangements must be carefully planned. New environments must be adapted to the specific needs of each person with autism.
• **Living at home**
  Provision of specific support (medical, technical resources, housekeeping, adaptation of the environment, etc) must be provided. Support for the ageing members of the family who care for the older person with autism must also be provided.

• **Living in supported housing facilities**: People with autism must be supported to live in the home they are accustomed to living in with no age limit. Or, they should be placed in a nearby residence to limit the changes to their daily life. Complementary medical and health support (nurses, other support staff, hospital care, technical aids, accessibility, etc) must be provided at the level of intensity of care that is required.

• **Living in a special residence for ageing people with disabilities**
  Across Europe, new types of special residences with medical care for ageing people with autism in need of a high level of support and of medical care should be provided. Older people with autism should have the possibility to maintain contact with their relatives and friends to enhance their social inclusion and foster intergenerational relations. In that regard, staff should take an active role in preserving relationships by enabling people with autism to visit their parents at home or by making arrangements for the parents to visit the residence.

**Training of professional staff (art 19 and 26 of the UNCRPD)**

  Taking into account research results across European countries, it is urgent to implement:
  - Staff training, co-ordinated and prepared according to a systematic plan and with a holistic approach.
  - Programmes for home assistance for ageing people with autism and their families

**The right to realistic and adequate financial support (art. 28 of the UNCRPD)**

  People with autism and other populations with complex dependency needs should be able to live independently in the country of Europe where they were born or reside and have the right to realistic and appropriate funding:
  - To have access to a good quality of life in terms of physical, emotional, social and material wellbeing;
  - To have an environment that fosters communication and is adapted to the behavioural problems faced by people with autism;
  - To live a healthy and inclusive life in the community;
  - To choose a way of living either at home or in a residential setting with adequate support from health and education services.

**Encourage further research and data collection (art. 31 of the UNCRPD)**

  More research must be conducted to better understand the challenges and needs of ageing people with autism, as well as offer an adequate response to these needs.
Bibliography


