



*Towards a better quality of life:*  
**The rights of ageing people  
with autism**



**Autism-Europe is an international association whose objective is to advance the rights of people with autism spectrum disorders (autism, ASD) 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 autism. 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)

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# Contents

<b>Introduction</b>	5
<b>1. Autism and the ageing population</b>	7
What is autism?	
The prevalence of autism among older people	
<b>2. Challenges faced by ageing people with autism and their families</b>	11
Health issues specific to ageing people with autism	
Ageing triggers an even higher risk of social exclusion for people with autism	
When a person has autism, the whole family experiences discrimination	
Who will care?	
<b>3. Examples of support for ageing people with autism spectrum disorders</b>	19
Wales: National strategy for autism	
Denmark: Hinnerup Kollegiet	
France: Sésame Village	
France: l'Abri Montagnard	
<b>4. The rights of ageing people with autism - Principles for action towards a better quality of life</b>	29
The right to an independent life and self-determination	
The right to maintain or improve the quality of health	
The right to maintain and improve communication and social interaction	
The right to appropriate intervention	
The right to have services to provide a good quality of life	
The right to leisure	
The right to education and lifelong learning	
The right to housing facilities	
Training of professional staff	
The right to realistic and adequate financial support	
Encourage further research and data collection	
<b>Conclusion</b>	34
<b>Bibliography</b>	35



## 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.<sup>1</sup> People are living longer and in better health conditions. Similar trends are also true for people with autism, although their life expectancy remains somewhat shorter.<sup>2</sup>

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.<sup>3</sup>



Most of the available research on autism is focused on children and young adults and little is known about the effects of ageing on older people with autism. During the past few years, however, the issue of ageing in relation to people with autism has become more pressing across Europe and various studies have been launched. These studies highlight the fact that people with autism and their families face numerous barriers and discrimination that tend to worsen with age. Largely due to a lack of public support, adults with autism often remain quite dependent on their families for the support that they require for their condition, ranging from support in understanding complex information and communications to housing, financial support and 24 hour assistance. 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 challenging issue of autism and ageing and outlines the needs of older people with autism that must be addressed at the policy level, without delay. A list of recommendations is provided herein and addressed to policy makers, who are urged to respond. The recommendations take into account the United Nations Convention

- 1 Directorate-General for Economic and Financial Affairs of the European Commission (2011) *The 2012 Ageing Report: Underlying Assumptions and Projection Methodologies*, European Economy, 4. Brussels: European Commission. [Internet] <[http://ec.europa.eu/economy\\_finance/publications/european\\_economy/2011/pdf/ee-2011-4\\_en.pdf](http://ec.europa.eu/economy_finance/publications/european_economy/2011/pdf/ee-2011-4_en.pdf)> [Accessed 1 February 2013]
- 2 Am J, Berkman KA & Perkins EA (2012). ‘Intellect Dev Disabil’, *Into the unknown: aging with autism spectrum disorders* 117(6)
- 3 Barthélémy C, Fuentes, J, Howlin, P & Van der Gaag, R (2009), *Persons with Autism Spectrum Disorders: Identification, Understanding, Intervention*. Brussels: Autism-Europe. [Internet] <<http://www.autismeurope.org/files/files/persons-with-autism-spectrum-disorders-identification-understanding-intervention.pdf>> [Accessed 1 February 2013]



An older woman with autism, who requires a high level of support, in the living room of her individual home in Sweden.

on the Rights of Persons with Disabilities (UNCRPD) ratified by the European Union and most of its Member States. They also echo the Recommendation of the Council of Europe on ageing and disability in the 21st century.<sup>4</sup> The latter foresees that with due regard for their own national, regional or local structures and respective responsibilities, the Member States of the Council of Europe 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 these will inspire relevant stakeholders and policy makers to adopt similar approaches to autism and ageing throughout Europe.

4 Council of Europe (2009) Recommendation CM/Rec(2009)6 of the Committee of Ministers to member states on ageing and disability in the 21st century: sustainable frameworks to enable greater quality of life in an inclusive society. Strasbourg: Council of Europe. [Internet] <[http://www.coe.int/t/e/social\\_cohesion/soc-sp/integration/05\\_recommendations\\_and\\_resolutions/presentation.asp](http://www.coe.int/t/e/social_cohesion/soc-sp/integration/05_recommendations_and_resolutions/presentation.asp)>.[Accessed 1 February 2013]

## 1. Autism and the ageing population

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.

### What is autism?

Each individual with autism is unique, however, all people with autism spectrum disorders (autism, ASD) present clinical features in three domains.<sup>5</sup>

- ***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 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

<sup>5</sup> Barthélémy C, Fuentes, J, Howlin, P & Van der Gaag, R (2009), Persons with Autism Spectrum Disorders: Identification, Understanding, Intervention. Brussels: Autism-Europe. [Internet] <<http://www.autismeurope.org/files/files/persons-with-autism-spectrum-disorders-identification-understanding-intervention.pdf>> [Accessed 1 February 2013]



Timothy Baron, an adult with autism, working on a puzzle.

and represent the 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 people with autism, particularly those with higher intellectual ability, develop specific interests or preoccupations with unusual topics.

- **Other important aspects of autism**

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 that sometimes result 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 autism 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 percent of individuals), 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 autism. 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 evolving 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).<sup>6</sup>

### The prevalence of autism among older people

In January 2010, the population of the European Union stood at an estimated 501.1 million people; of these some 87.1 million were aged 65 or over.<sup>7</sup> At this point in time very little statistical data on ageing people with autism is available.



Photo courtesy of Swedish Autism Society

An older woman with autism, living in Sweden.

- <sup>6</sup> For more information on Autistic Spectrum Disorders, please see Autism-Europe’s full document: Barthélemy C, Fuentes, J, Howlin, P & Van der Gaag, R (2008), Persons with Autism Spectrum Disorders Identification, Understanding, Intervention. Belgium: Autism-Europe. [Internet] <<http://www.autismeurope.org/about-autism/definition-of-autism/>> [Accessed 1 February 2013]
- <sup>7</sup> Eurostat Statistical books (2011) Active ageing and solidarity between generations. A statistical portrait of the European Union 2012, 2012 Edition. Belgium: European Union. [Internet] <[http://epp.eurostat.ec.europa.eu/cache/ITY\\_OFFPUB/KS-EP-11-001/EN/KS-EP-11-001-EN.PDF](http://epp.eurostat.ec.europa.eu/cache/ITY_OFFPUB/KS-EP-11-001/EN/KS-EP-11-001-EN.PDF)> [Accessed 1 February 2013]

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.<sup>8</sup> According to a household survey in the United Kingdom in 2012, the prevalence of autism among the general population was 1.1 percent. The prevalence of autism was higher in men (2.0 percent) than women (0.3 percent).<sup>9</sup>

In March 2012, the National Autistic Society (NAS) commissioned one of the largest surveys ever conducted on autism. The survey was completed by 2,938 people with autism and 5,535 carers. Among those with autism, 355 were over the age of 45 years and 120 of these were over the age of 55 years. 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 they 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.

- 8 Bankart, Baron-Cohen S, Brugha T, McManus, S, Meltzer, H, Purdon, S, Scott, F, Smith J & Wheelwright, S (2009) Autism Spectrum Disorders in Adults Living in Households Throughout England - 2007, Report from the Adult Psychiatric Morbidity Survey. United Kingdom: NHS The Information Centre for health and social care. [Internet] <<http://www.ic.nhs.uk/pubs/asdpsychiatricmorbidity07>> [Accessed 1 February 2013]
- 9 Brugha T, Cooper SA, McManus S, Purdon S, Scott FJ, Smith J, Spiers N, Tyrer F (2012) Estimating the Prevalence of Autism Spectrum Conditions in Adults - Extending the 2007 Adult Psychiatric Morbidity Survey. United Kingdom: NHS The Information Centre for health and social care. [Internet] <<http://www.ic.nhs.uk/pubs/autism11>> [Accessed 1 February 2013]

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

It is important to reflect on the definition of ‘elderly’ or ‘old age’ when applied to people with autism. General chronological and biological age do not always coincide when people age, thus it is difficult to define ‘old age’ by a specific age range. The health status, capacities, level of social interaction, etc., of people with autism can 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 that should be available and some people with autism may need specific attention in relation to ageing at an earlier stage than the general population.

While the overall life expectancy of people with autism remains lower than for other individuals, their life expectancy is increasing along with the general population.<sup>10</sup> 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.<sup>11</sup> These studies are also indicative of increased life expectancy for people with autism, who can have different ‘degrees’ of learning disability.<sup>12</sup>

### Health issues specific to ageing people with autism

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 suffer from health problems due to associated diseases and conditions, that can severely affect their life outcomes and life expectancy.<sup>13</sup> Older people with autism also have to deal with a range of general health problems (including gastrointestinal problems, insomnia, epilepsy, autoimmune problems and mitochondrial diseases).

Some studies have suggested that individuals with intellectual disabilities, including people with autism, may experience age-related cognitive decline/dementia at an earlier age or more rapidly than the general population.<sup>14</sup> However, further studies would be required to know whether people with autism have increased prevalence rates of dementia as found among people who have Down syndrome. Importantly, many of the factors that seem to influence cognitive decline among people with autism 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.

10 Am J, Berkman KA & Perkins EA (2012). ‘Intellect Dev Disabil’, *Into the unknown: aging with autism spectrum disorders* 117(6)

11 Holland T Kidd, JM? (2008) *Mental Capital and Wellbeing: Making the most of ourselves in the 21st century*. London: Government Office for Science. [Internet] <[http://www.bis.gov.uk/assets/foresight/docs/mental-capital/sr-c10\\_mcw.pdf](http://www.bis.gov.uk/assets/foresight/docs/mental-capital/sr-c10_mcw.pdf)>. [Accessed 1 February 2013]

12 The National Autistic Society (2013) What are learning disabilities?. [Internet] <<http://www.autism.org.uk/about-autism/related-conditions/learning-disabilities.aspx>> [Accessed 1 February 2013]

13 Billstedt E, Gillberg C, Gillberg IC (2005) ‘Autism after adolescence: population-based 13–t o–22, follow-up study of 120 individuals with Autism diagnosed in childhood’. *Journal of Autism and Development Disorders* (35),3

14 Charlton RA, Happé F (2010) Aging in Autism Spectrum Disorders: A Mini-Review, [Internet] <<http://www.karger.com/Article/Pdf/329720>> [Accessed 1 February 2013]

Much higher rates of depression and anxiety are also present among older people with autism than among the general population. People with autism 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.<sup>15</sup>

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.<sup>16</sup> 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.<sup>17</sup>

It has been demonstrated that people 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).<sup>18</sup> Many authors suggest that among 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.<sup>19</sup>

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<sup>20</sup>, almost half of doctors (45 percent) and a third of nurses (33 percent)



- 15 Felce D, Griffith G, Hastings RP, Kerr M, Nash, S, Stuart-Hamilton I, Totsika V (2009) The circumstances and support needs of older people with Autism. Cardiff: Welsh Assembly Government. [Internet] <<http://wales.gov.uk/topics/health/publications/socialcare/reports/Olderpeopleautism/?lang=en>> [Accessed 10 September 2012]
- 16 Howlin P, Goode S, Hutton J, Rutter M (2004) Adult outcome for children with autism. London: JChild Psychol Psychiatry (45) 212–229
- 17 De la Cuesta GG, Mills R, Povey C (2011) Autism and ageing: issues for the future. Clin Pract, 230–232; <<http://www.gerimed.co.uk/archive/detail?id=410> INVALID LINK>
- 18 Baines S, Emerson E (2010) Health Inequalities & People with Learning Disabilities in the UK: 2010. United Kingdom: Learning Disabilities Observatory. [Internet] <[http://www.improvinghealthandlives.org.uk/uploads/doc/vid\\_7479\\_IHaL2010-3HealthInequality2010.pdf](http://www.improvinghealthandlives.org.uk/uploads/doc/vid_7479_IHaL2010-3HealthInequality2010.pdf)> [Accessed 1 February 2013]
- 19 Charlton RA, Happé F (2010) Aging in Autism Spectrum Disorders: A Mini-Review, [Internet] <<http://www.karger.com/Article/Pdf/329720>> [Accessed 1 February 2013]
- 20 ICM Research Survey (2010), A sample of 1084 doctors and nurses online between 25.05.10 and 07.06.10

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 within the National Health Service.<sup>21</sup> This discriminatory approach triggers anxiety among older people with autism and their families related to the care they may receive.

In addition, issues surrounding palliative care, terminal illness and the right to a painless death also need to be examined alongside issues of capacity to decide, informed consent, relevant laws and medical practices, cultural attitudes and religious beliefs of parents and children.

### 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. In that context, ageing people with disabilities face an even higher risk of social exclusion and among them, people in need of a high level of support and or experiencing difficulties in 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.

The difficulties in communication that people with autism face are exacerbated by the lack of appropriately trained staff in various settings including health and residential services. Research commissioned by the Welsh government in 2008 demonstrated that the difficulties experienced by people with autism in everyday life do not appreciably diminish in later life. Middle aged people with Asperger syndrome, who are ‘high functioning’ and hold well-paid and prestigious jobs, had health problems at three times the national average; mainly stress-related. Their ability to form close relationships was impaired, and although some people were in well-paid posts, overall, unemployment was significantly higher than the national average. Detailed interviews with older people with Asperger syndrome revealed a lifetime of being misunderstood and isolated because of the lack of understanding and flexibility in the system. Health professionals’ ignorance of the condition was particularly noted as a problem area.<sup>22</sup>

Sometimes, people with autism are simply not provided with any kind of support. A survey that was conducted by the National Autistic Society in 2012 showed that among the respondents who had received a diagnosis of autism, 71 percent of those aged 45 years and over have not been ‘assessed’, meaning their needs have not been recognised by their local authority, let alone met.<sup>23</sup> 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

21 Mencap The voice of learning disability (2010) Doctors say patients with a learning disability receive poorer care [Internet] <<http://www.mencap.org.uk/news/article/doctors-say-patients-learning-disability-receive-poorer-care>> [Accessed 1 February 2013]

22 Felce D, Griffith G, Hastings RP, Kerr M, Nash, S, Stuart-Hamilton I, Totsika V (2009) The circumstances and support needs of older people with Autism. Cardiff: Welsh Assembly Government. [Internet] <<http://wales.gov.uk/topics/health/publications/socialcare/reports/Olderpeopleautism/?lang=en>> [Accessed 10 September 2012]

23 Bancroft K. et al (2012) Autism: the way we are. London: The National Autistic Society, NAS survey. [Internet] <<http://www.autism.org.uk/get-involved/50th-birthday/survey-report.aspx>> [Accessed 1 February 2013]

services. Importantly, they may also be receiving inappropriate treatment due to misdiagnosis of their condition.<sup>24</sup>

The lack of support can sometimes have dramatic consequences; it is very revealing that people with autism 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.<sup>25</sup> This situation is likely to worsen when people with autism get older and lose the support of their family members.

The lack of support for adults with autism has been worsened by the austerity measures adopted across Europe following the financial crisis. Austerity measures have led to reduced financial support and resources available in the social and the healthcare sectors to meet the growing, and as yet largely unknown, needs of ageing people with autism.

People with disabilities have been amongst the hardest hit by the financial crisis, as evidenced by research commissioned by the European Foundation Center<sup>26</sup> which assessed the impact of European governments’ austerity plans on the rights of people with disabilities. The main findings were that 21.1 percent of people with disabilities in the EU are at risk of poverty, compared to 14.9 percent of people without disabilities. 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<sup>27</sup> 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 in the family home or transferred to less costly 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 everyone has access to health care and treatment. In many other European countries the list of drugs no longer reimbursed by governments gets longer every year.

People with autism face problems resulting from both their disability and the ageing process. These difficulties are coupled with considerable ignorance about the actualities of ageing in autism, as well as reduced social support following austerity measures in response to the financial crisis.

24 Briel R, James IA, Mukaetova-Ladinska E, Reichelt FK, Scully A (2006) ‘Diagnosing Aspergers syndrome in the elderly: a series of case presentations’. *Int J Geriatr Psychiatry* (21), 951–960.

25 Welsh Assembly Government (2011) *Autistic Spectrum Disorder, A Guide for Homelessness Practitioners and Housing Advice Workers* Cardiff: Welsh Assembly Government. [Internet] <<http://wales.gov.uk/docs/dhss/publications/110324asdhomelesspracen.pdf>> [Accessed 1 February 2013]

26 European Foundation Center (2012) *Assessing the impact of European governments’ austerity plans on the rights of people with disabilities*. Brussels: European Foundation Center. [Internet] <[http://www.efc.be/programmes\\_services/resources/Documents/Austerity2012.PDF](http://www.efc.be/programmes_services/resources/Documents/Austerity2012.PDF)> [Accessed 1 February 2013]

27 Age Platform Europe (2012) *Older people also suffer because of the crisis*, Age Platform Europe. Brussels: Age Platform Europe. [Internet] <<http://www.age-platform.eu/images/stories/EN/olderpeoplealsosufferbcofthecrisis-en.pdf>> [Accessed 1 February 2013]

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

In all EU countries, informal family care remains the main form of long-term care for older people with autism. This situation is reinforced by the cuts to the budgets for health and social care that have been made by governments across Europe in response to the financial crisis. Due to the lack of resources available for adults with autism, family members who are under pressure to care for and support their relative while also trying to meet their own needs often experience ‘associated discrimination’.<sup>28</sup> In the United Kingdom the cost of supporting people with autism and the opportunity costs of lost productivity were estimated in 2009 at £28 billion per year.<sup>29</sup> 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, older parents also have to face the consequences of their own ageing and may themselves need support and adaptations. As the resources for care are diminishing and the responsibility to provide care is shifted to the individual level, families (informal carers) should receive sufficient support in order to provide help to the person with a disability in their family.

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

Michael Baron, an 86 year-old father of an adult son with autism, has experienced the difficulties of becoming an elderly carer. When Michael’s beloved wife became ill and died in 2012, Michael 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 Michael 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 support them to 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?

<sup>28</sup> The Employment Tribunal (2000) Case C-303/06 S. Coleman v Attridge Law and Steve Law- C-303/06 [Internet] <<http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:62006J0303:EN:HTM>> [Accessed 1 February 2013]

<sup>29</sup> Beecham J, Knapp M, Romeo R (2009) ‘Economic cost of autism in the UK’. *Autism* 13(3), 317–36



Michael Baron (right), 86 year-old father of Timothy (left), an adult with autism, experienced the difficulties of becoming an elderly carer when his beloved wife died in 2012.

### **‘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 no 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?”<sup>30</sup>

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. The results of a survey conducted by the National Autistic Society in 2012 showed that 96 percent of parents who responded are worried about their son/daughter’s future when they are no longer able to support them. Of these, 68 percent described themselves as ‘very worried’, and 28 percent said they are ‘quite worried’.

Among the survey respondents, 35 percent had made some plans for what will happen if they are no longer able to support their son/daughter, but only 4 percent said they had 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 who have made plans for them.

Recently in France, a 49 year-old man with a mental disability (who had been left without

<sup>30</sup> Inforautisme asbl (2006) Autirecherche - Enquête sur les besoins de la population bruxelloise, francophone, adulte avec autisme [Internet] <[http://www.inforautisme.be/01qui/activites\\_enquetes.htm](http://www.inforautisme.be/01qui/activites_enquetes.htm)>.[Accessed 1 February 2013]

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.

### Adults with autism worry about the future without their parents' support

Tom, a middle-aged man from the United Kingdom who has Asperger syndrome, explains his concerns about the future including 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 has available at the moment, within easy reach of various facilities.

My mother died of cancer back in 1991. Now I have to rely on my friends and my father. 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 in my home can be very traumatic for me. I worry they could have touched an 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, I'm almost 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."

These concerns were also reflected in another survey conducted in 2012 by the National Autistic Society<sup>31</sup> with siblings of people who have autism, many of whom reported that they were worried about how they would support their adult brothers and sisters with autism as their parents become less able to cope. For this survey, 111 siblings of people with autism who are aged over 40 years were contacted to ascertain their views on taking on the role of supporting the needs of their sister or brother with autism once their parents are no longer able to provide the support they once did. The survey results showed that 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 sisters with autism. They may not

<sup>31</sup> Michael C, Gomez de la Cuesta G (2012) We Exist Too, Valuing the Contribution of the Siblings. United Kingdom: The National Autistic Society. [Internet] <<http://www.autism.org.uk/-/media/NAS/Documents/Living-with-autism/Autism-in-Maturity/We%20exist%20too.ashx>> [Accessed 1 February 2013]

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.

### Partners can also play a crucial supporting role

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 people is predominantly provided by women. The pressure to provide care – in the absence of necessary support measures – increases the short and long-term risk of poverty among people with autism and their carers, and increases the 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, in most countries people with autism and their families are confronted by a lack of realistic and appropriate services and financial support. They often feel let down by authorities who have little knowledge of, or support for, vulnerable individuals and carers.

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

Across Europe, the level of support provided for older adults with autism is currently quite diverse. In some parts of Europe, some good examples of support have been in operation for some years now, and continue to develop and evolve as new knowledge about autism emerges. In this section, good models for the support of ageing people with autism at local and national levels are profiled.

#### Wales: National strategy for autism meets the needs of older people

Over the past few years, cooperation between the Welsh government and Autism Cymru has led Wales to take a proactive approach to addressing the needs of older adults with autism. This has included undertaking some early research on adults with autism in Wales and then taking measures to improve identification, diagnosis, public awareness and provision of support for older adults with autism. This has involved significant leadership and financial support from the Welsh Government.

In October 2012, the Welsh Government launched the All-Wales Diagnostic and Pre/Post Counselling Network for Adults with ASD. The Network will bring into play for the first time a genuinely national approach to diagnosis for adults with autism. Thus it will make it far easier for adults with autism, especially those of middle to older age, to access local diagnostic services and to be referred to the support services they may require.

These actions have been undertaken by the Welsh Government in the framework of a 10 year Autism Spectrum Disorders Strategic Action Plan launched in 2008. Wales is the first government in the world to deliver a national strategic policy for autism and over these past three years has supported its implementation with 7.1 million pounds of funding specifically for autism.

As a result of this strategy, Wales now has a formal infrastructure for autism. Each of the 22 local authorities in Wales has a lead ASD officer and an ASD stakeholder group consisting of people with autism, family members, autism-related charities and professionals in the field of autism (totalling over 400 members across Wales). There is also a national stakeholder group operated by the Welsh Government. Each of the 22 local authority areas has a local ASD action plan, based upon the national plan. During 2009/-2010 alone, 22 new collaborative projects for people with autism, their families and those who work with them were developed as a result of local ASD action plans and funded via the Welsh Government funding for autism. Wales also now has a national web resource for practice and learning in the field of autism and a learning improvement network led by a national coordinator.<sup>32</sup>



<sup>32</sup> Morgan H & Stuart-Hamilton I (2011) 'What happens to people with autism spectrum disorders in middle age and beyond?'. *Report of a preliminary on-line study. Advances in Mental Health and Learning Disabilities* (5), 22-28



*Ann is working at the local school for some hours every day. She takes care of the teachers, makes coffee, cleans the kitchen, waters the plants and receives a lot appreciation from the teachers. She likes it when the teachers make her laugh, so they do that a lot.*

### Denmark: Growing up and growing old at Hinnerup Kollegiet

Hinnerup Kollegiet in Denmark is home to 16 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 as part of the local community. Hinnerup started in 1982, when ten young adults with autism moved in. The place was established by a strong group of parents who thought of Hinnerup as their grown-up children's new home. The young residents were given the opportunity of learning to cope with ordinary practical things, as well as making friends and learning crafts in Hinnerup's workshop.

As time passed, both employees and parents gained more knowledge about autism, and Hinnerup's pedagogical approaches developed. Parents and staff understood that autism was a lifelong condition and that Hinnerup would, in time, 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 quality of life.

- **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. The staff work together with the residents to set and achieve goals for improved quality of life. The residents are not placed under any pressure; they are supported and encouraged to achieve their goals. The staff at Hinnerup also work continuously with the residents to promote communication and understanding through visual communication methods and structured frameworks for understanding important concepts in everyday living and social interaction.

- **Education and ethics**

The pedagogy at Hinnerup focuses on assisting the residents to develop their cognitive skills in understanding and interacting with the world around them. The residents at Hinnerup need a lot of support in simple everyday tasks, but all efforts are aimed at facilitating greater autonomy, according to individual capabilities and competencies. The staff, in turn, take a positive approach to the residents based on appreciation of their unique qualities. Basically, the concept is simple: you must respect people with autism, their thoughts and their way of being.

- **Support in the transition to retirement**

Most of the residents at Hinnerup work close to home in the related day care services, and some work at the local school. All of the residents engage in a wide range of common leisure activities organised by the staff and in the local community.

For some of the older residents, working life is coming to an end and their daily routines will need to change. Therefore, Hinnerup works to ensure a slow and careful transition to retirement for its residents. 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.



One of the residents at Hinnerup Kollegiet (right) who works every day bringing milk to the students in a local school. The students love and care for her and she, in turn, loves her job and becomes irritated whenever there is a school holiday.

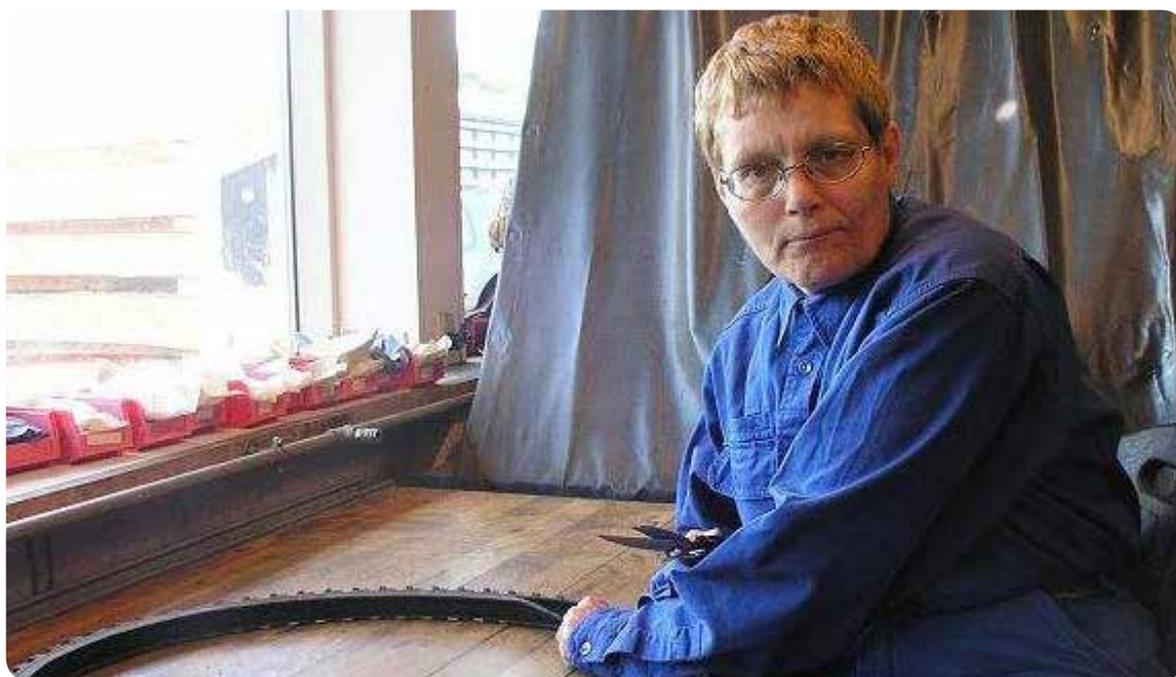
- **Health and well-being**

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

In order to prevent age-related diseases and to accustom residents to visits to doctors, all residents of Hinnerup have scheduled health checks with a doctor 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. It is important for residents to understand that changes are 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 of any kind) for 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. By doing so, 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 or express pain in the same way as the rest of us. Older people with autism sometimes change their behaviour if they aren't feeling good. Their mood may change or they may become more passive or more aggressive than they were before. Alternately, some older people with autism make a lot of effort to act exactly as usual when something is wrong, because they do not understand the change or may be afraid of it, so they are trying to hide it as long as they can.

Throughout their adult lives, the residents at Hinnerup have been rewarded 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.



*Ulla is working at the workshop at Hinnerup Kollegiet, Ulla's mother was one of the parents fighting to establish Hinnerup Kollegiet more than 30 years ago, when Ulla was a young woman.*



One of the workshops at Hinnerup Kollegiet where residents make gift articles. Hinnerup has a gift shop in the nearby city where the gift items from the workshop are sold.

- **Building a framework for ageing well**

Buildings can 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, including the 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 residents with showering and not enough space in bedrooms for wheelchair access. In the current situation, if 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 follow 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.

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

Some years later, the parents recognised that the needs of older people with autism were not adequately accommodated in the residential facility or elsewhere in the local community. So, they decided to create Sésame Village, a place specifically designed to meet the needs of adults with autism as they grow into old age.

Sésame Village opened in 2010 and 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 the local community of Messimy, Sésame Village is comprised of five buildings totalling 2,017m<sup>2</sup>. 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 20m<sup>2</sup> with individual bathrooms. The houses are identical inside, with colour reference points and characteristic decorations 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).



Activities for adults at Sésame Village.



One of the residents at Sésame Village (left).

- **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 individual capacities. Therefore, their level of need for support remains very high and the transition to a new way of life brings new challenges.

Some of the residents at Sésame Village who are now aged between 40 and 50 years had previously spent 20 years of their lives in the same institution, the same facility and in the company of the same residents. After this length of time, these people have formed strong habits. It is only possible for them to change their place of residence and get used to a new 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 need for support can be the catalyst for a hurried and very destabilising move into Sésame Village. The needs and difficulties of older people with autism are accommodated and medical staff are able to take care of them even when their health deteriorates. There is no upper age limit for residents 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 medical 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 well-being.

- ***Maintaining relationships with family***

The family members of people aged over 40 years is often reduced to their 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***

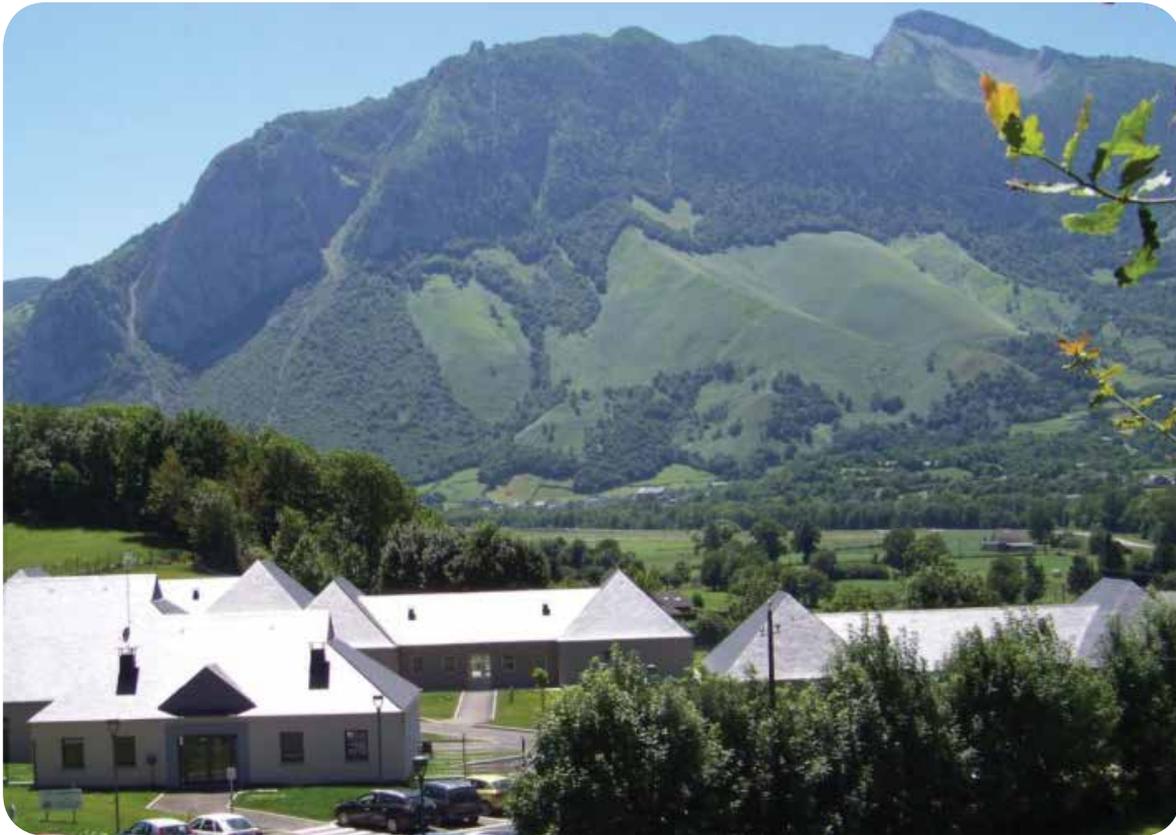
The multidisciplinary team at Sésame Village provides a therapeutic function in close liaison with medical services. Residents are also supported to maintain, and continue developing, their skills in a range of areas to facilitate the person's well-being, preserve their capacities and facilitate cultural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



Leisure activity for adults with autism at Sésame Village.



L'Abri Montagnard in France

### France: An individual and multidisciplinary approach to improving quality of life in old age at l'Abri Montagnard

The staff of l'Abri Montagnard, a residential facility for adults with autism in France, observed the changing needs of their ageing residents and developed a systematic approach to accommodating these needs as they evolve.

L'Abri Montagnard is located in Saint-Bethoumieu in the south of France and houses adults with autism who live in single storey homes in groups of eight people.

- **Observing changes due to ageing**

The staff of l'Abri Montagnard began to notice changes among the residents (65 percent of whom are now aged over 45 years) including increased behavioural problems, a generally slower pace of life, and new diseases, psychiatric conditions and disabilities. These changes due to ageing were occurring earlier among these residents who have autism than in the general population; starting from around 45 years of age. They observed that people with autism are more vulnerable to the process of ageing than other people.

- **Developing a multidisciplinary approach**

As people with autism have individual symptoms and needs, it was clear that these people have an even greater multitude of special needs as they grow older. The team at l'Abri Montagnard therefore developed a multidisciplinary system of therapeutic, educational and social support. The approach aims to avoid overmedicating people with autism (as

can be common practice elsewhere), instead focusing on developing individuals skills in communication and interaction. In the process of ageing, the ability to express pain and interact with health care professionals becomes even more important. By providing a high quality of care for each individual, the staff aims to ensure the best conditions for the residents to continue developing their skills. The multidisciplinary approach also brings together relevant professionals to ensure continuity of care for the residents.

- ***Developing tools and processes to evaluate individual skills and progress***

The staff at l'Abri Montagnard have developed tools and processes to evaluate residents' needs and skills upon admission to the residences, and changes to their needs and skills as they age. These include regular reports and 'evaluation grids'. The evaluation grids aim to record, as precisely as possible, each resident's sensori-motor and cognitive skills, their physical, personal and domestic autonomy, their expression and communication skills, their capacity to adapt to changes, their hygiene skills, their sensory difficulties and their specific behaviours. On the basis of these observations, the staff can make adaptations to the environment, teaching methods, visual aids and routines according to each person's individual needs. In addition, the quality of care that individuals are receiving is also monitored by this system.

- ***Ongoing research and ethics***

The monitoring and evaluation of individual residents is part of ongoing research conducted at l'Abri Montagnard that aims to contribute to evolving knowledge about how to develop and maintain the highest quality of support for people with autism throughout the process of ageing. L'Abri Montagnard also aims to foster collaboration with relevant professionals on this research, including medical and paramedical practitioners and geriatric and psychiatric departments of hospitals.

L'Abri Montagnard also has an ethics committee to deal with any situation raising ethical issues or with any event likely to affect de quality of care. The committee makes recommendations to the staff on how to address these situations and monitors the implementation of the recommendations.



Visual supports at Abri Montagnard

## 4. The rights of ageing people with autism - Principles 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 (UNCRPD) is an international human rights instrument intended to protect the rights and dignity of people with disabilities. Parties to the Convention are required to promote, protect, and ensure the full enjoyment of human rights by people with disabilities on an equal basis with others.<sup>33</sup> There are eight guiding principles that underlie the Convention and each one of its specific articles:

1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
2. Non-discrimination;
3. Full and effective participation and inclusion in society;
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
5. Equality of opportunity;
6. Accessibility;
7. Equality between men and women;
8. 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 gain a strong understanding of their rights and governments must fulfil their obligations under the UNCRPD.

The intersection of age and disability has not yet been taken into account by the European Union and its Member States' legislators and policy makers in the context of implementing the UNCRPD. Across Europe, people with disabilities currently face a gap between policy and practice, for example, in France – a country which has ratified the UNCRPD – a person over the age of 60 years is no longer considered a person with a disability in relation to welfare payments. Instead, a person aged over 60 years is simply considered an older person, regardless of their disability and individual needs. In this case, government allowances are significantly lower and the individual may be required to pay up to 90 percent of their long-term care costs. Therefore, in France, older people have an interest in becoming incapacitated before the age of 60 years.<sup>34</sup> This gap in understanding and addressing the needs of older people with disabilities must be addressed as part of the implementation of the UNCRPD.

Taking due account of the United Nations Convention on the Rights of Persons with Disabilities, the Council of Europe has adopted the *Recommendation on ageing and disability*

33 United Nations Enable (2008) Convention on the Rights of Persons with Disabilities [Internet] <<http://www.un.org/disabilities/default.asp?id=150>> [Accessed 1 February 2013]

34 Age Platform Europe (2013) [Internet] <<http://www.age-platform.eu/en/>> [Accessed 1 February 2013]

in the 21<sup>st</sup> century<sup>35</sup> in 2009. In its recommendation, the Council of Europe indicates that the 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.<sup>36</sup>

The following recommendations formulated by Autism-Europe take into account the United Nations Convention on the Rights of Persons with Disabilities, the articles 25 and 26 of the Charter of Fundamental Rights of the European Union (on the rights of the elderly and people with disabilities), as well as the Recommendation of the Council of Europe on ageing and disability in the 21st century. They are also based on Autism-Europe’s position paper on ageing that was published in 2003. These recommendations are addressed to policy makers as guidance in fulfilling their obligations to older people with autism.

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

People with autism and other types of disabilities requiring a high level of support have the right to make decisions for their own future, and to ask for the provisions of the UN Convention on the Rights of Persons with Disabilities to be respected.

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

People with autism should be provided with the necessary means to ensure:

- Prevention of health problems related to ageing, notably through regular check-ups and screenings;
- Accurate diagnosis and accurate information on their specific health condition;
- Prevention of problems related to their specific health conditions (e.g. osteoarthritis due to stereotypy);
- Treatment of individual health conditions.

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

Older people with autism should be provided with access to adapted/alternative means of communication and visual information.

35 Council of Europe (2009) Recommendation CM/Rec(2009)6 of the Committee of Ministers to member states on ageing and disability in the 21st century: sustainable frameworks to enable greater quality of life in an inclusive society. Strasbourg: Council of Europe. [Internet] <[http://www.coe.int/t/e/social\\_cohesion/soc-sp/integration/05\\_recommendations\\_and\\_resolutions/presentation.asp](http://www.coe.int/t/e/social_cohesion/soc-sp/integration/05_recommendations_and_resolutions/presentation.asp)> [Accessed 1 February 2013]

36 Friedel E (2009) LINK 52

Where possible, inter-generational dialogue involving older people with autism should be fostered by:

- Participation in cultural events and other leisure or sports activities with younger people in the broader community;
- Facilitation of contact 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 should be provided for people with autism throughout their lifespan, including during 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.

Individualised support plans for people with autism should be designed and put into practice with the main objectives of:

- Improving and maintaining skills for autonomy 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 that aim to meet their needs. Families, care providers and friends should also be involved in these processes, as appropriate services should be the result of a dialogue between relevant stakeholders. A diversity of accredited services must also be available.

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

In order to achieve these goals, services should provide specific, qualified interventions consequent to contemporary knowledge in the field of autism. Services should also have 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.

These measures will enable family and staff members to identify the individual needs of people with autism. These measures will also provide a way of reducing the risk of isolation and exclusion.



Leisure activity for adults with autism at Sésame Village.

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

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

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

Relevant 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 be supported to remain in their own homes as long as they can, 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 aids, housekeeping, adaptation of the environment, etc) must be provided;

- Support for ageing family members who care for older people 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. If that is not possible 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 that is required.
- **Living in a special residence for ageing people with disabilities**
  - Across Europe, special residences should be established for ageing people with autism who require a high level of support and medical care;
  - Older people with autism should have the possibility to maintain contact with their relatives and friends. 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 the results of research from various 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 people with disabilities who are in need of a high level of support 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 well-being;
- 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, with the aim to offer adequate responses to these needs. For example, research should be undertaken on the effects of long-term medications for people with autism as well as on finding ways to avoid these side effects.

## Conclusion

The ageing population is a phenomenon that is challenging policy makers around the world. With around 1 in 150 people currently being diagnosed with an autism spectrum disorder, this means there is a large – and growing – number of ageing adults with autism whose needs have not yet been considered in most countries.

Older people are at higher risk of social exclusion than the general population. When this is coupled with the communication and social interaction problems affecting all people with autism, older people with autism face an extremely high risk of social exclusion.

One of the most fundamental issues to consider in relation to adults with autism is the fact that so many have never received a formal diagnosis. Many individuals who were born prior to widespread knowledge of autism among the medical profession – or even prior to the original definitions of autism and Asperger syndrome – have not received a diagnosis or been in contact with specialists at all. Yet, studies show that the prevalence rate of autism is likely to be the same for adults as it is for children who are diagnosed with autism in Europe today – around 1 in 150 people. Without a diagnosis, or awareness of one's condition, it can be impossible to access appropriate services. In addition, some older individuals with autism have received incorrect diagnoses in the past and continue to receive inappropriate treatments.

Whether an individual has received a diagnosis or not, lack of support is widespread among adults with autism. This lack of support can have dramatic consequences, leading people with autism to be at higher risk of poverty and more likely to become homeless than the general population.

In the positive cases where older people with autism are in contact with relevant services, there is often a lack of appropriately trained staff that can address their needs. In addition, around Europe, services for people with disabilities have been hit very hard by the ongoing financial crisis, with social services being forced to close down in some countries.

As the minimal resources available for people with autism have been further reduced, the responsibility to provide care has fallen onto families. In fact, throughout the European Union informal family care is the main form of long-term care for older people with autism. Therefore, the greatest concern for most families of adults with autism is who will care for them when the parents are no longer able to do so. Older parents and siblings often need support and adaptations for themselves as they also undergo the process of ageing, and caring for a person with autism during their own old age is not always possible. Families and informal carers rarely receive sufficient support for their role, and are often disadvantaged as a result.

In recent years, the European Union has undertaken remarkable steps to enforce equal rights for citizens with disabilities and foster their social inclusion. The EU has ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in December 2010, and to date most of its Member States have also ratified it. The Convention alone does not ensure the respect of fundamental rights of people with disabilities. The States Parties (countries and regional integration organisations, such as the EU, that have signed and or ratified the Convention) must ensure its implementation in cooperation with the representative organisations of people with disabilities. In this process, the specific needs of older people with disabilities, including people with autism and those who require more intensive support, should be adequately considered and their rights enforced, in all areas of life.

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