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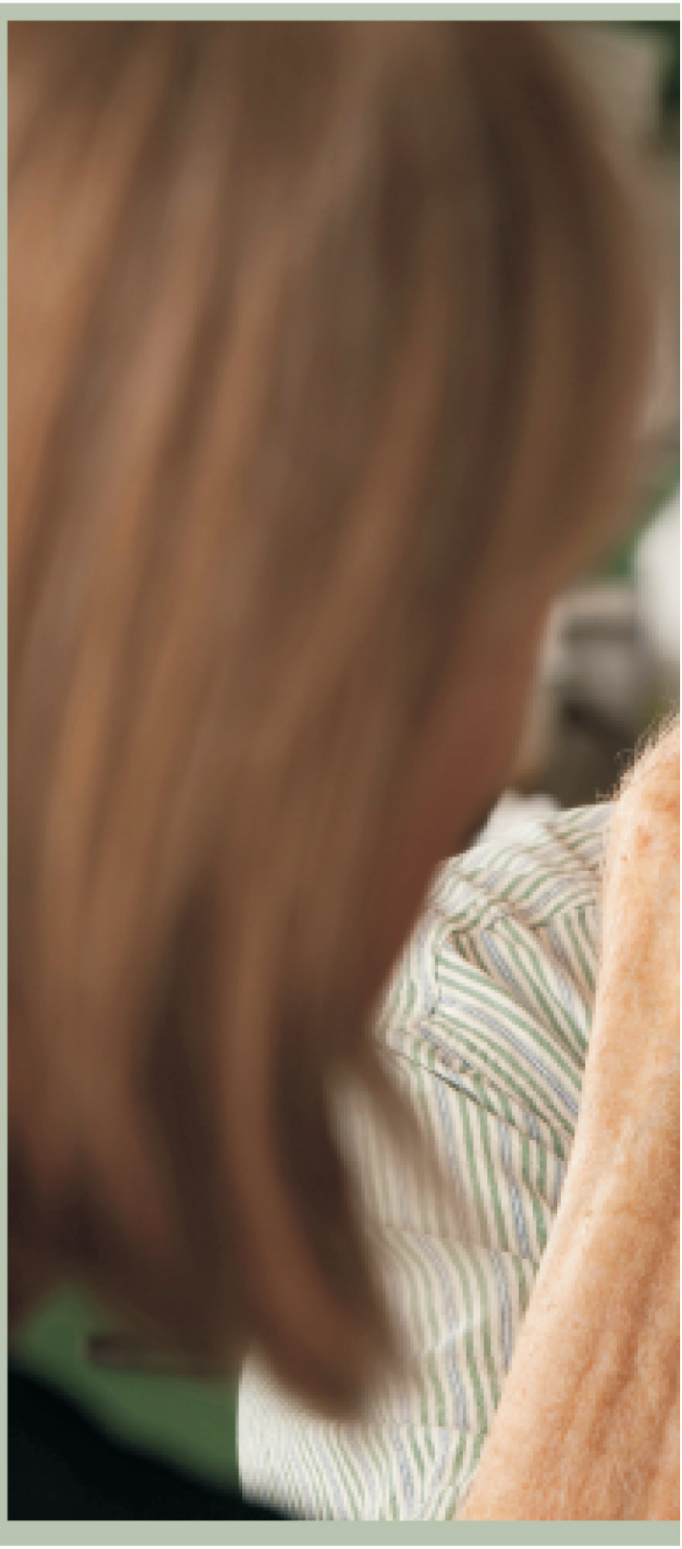
GROWING OLDER WITH AUTISM



There are a host of challenges for people growing older with autism. Shekhar Mukherji highlights a lack of diagnoses to detect the condition and explains what measures can be taken to address the growing problems and needs associated with supporting older people with autism.

Various studies have shown that ASD affects between 0.6 per cent and 1.2 per cent of the population. Because of a strong genetic component in ASD, it is considered to be among the most heritable of developmental disorders. This is borne out anecdotally by stories of undiagnosed fathers exclaiming that they have similar symptoms when their children have been diagnosed with Asperger's syndrome.

As we start making serious inroads into the 21st century, the curtain is rising on new needs and emerging opportunities. Among the more prominent of these needs are those of people with autism spectrum disorders (ASD) now advancing into old age.

THE LOST GENERATION

Though we know of this emerging problem, it remains difficult to clearly define. While autism was first identified in the 1940's, the category of autism was introduced in the diagnostic manuals only in 1980 and proper identification of autism spectrum disorders has only been truly established in the UK since the late 1980's.

As a result, there are a host of individuals with autism spectrum disorders who are not known to services and not listed on any registers. In a seminal report, *The circumstances and support needs of older people with autism*, published in September 2009, Stuart–Hamilton reports that of an estimated 8300 Welsh adults with ASD aged 40 years or over, only some 100 of these individuals have been formally diagnosed. Clearly, there is a lost generation of people with ASD, perhaps with associated mental health and cognitive problems, who are living unsupported in the community or with ageing parents. We really do not know the extent of their needs as only 1.2 per cent of a projected population has been identified.

Pan European figures estimate that eight million people with ASD live in Europe of which 20 per cent are older than 65 years, most of whom are undiagnosed.

THE NEW GENERATION

Though the diagnosis of ASD has only properly been set into practice for just over the last two decades, there has been a continuing and increasing diagnosis of children with ASD over the last 50 years. As a result, many of these individuals, with a formal diagnosis of ASD, are now progressing into older adulthood or old age.

The National Autistic Society reported in 2009 that 34 per cent of the people with autism it surveyed were over the age of 40 years, with 30 per cent between the ages of 40-64 years, and 60 per cent of them were single, living alone and with no support. Parents of people with ASD are equally concerned regarding their children's future as they and their children age.

GOVERNMENT REPORTS AND GUIDANCE

In the wider context of energetic activity in the autism sphere, there has been a lack of attention by government agencies in the United Kingdom to the growing problems and needs associated with supporting older people with ASD.

The Autism Act (2009) was the first piece of legislation designed to address the needs of one specific impairment group while providing a legislative umbrella for adults with autism in England and Wales. The Act, however, does not specify any support or guidance for older people with the condition. Similarly, the *National Audit Office report (2009)* on *Supporting adults with autism through adulthood* does not address, even in passing, the needs of older persons with autism.

Fulfilling and rewarding lives was the strategy for adults with autism in England which evolved out of such reports and was published by the Department of Health in 2010. Again, this important document does not make a distinction between adults of working age and older adults. Similarly, the *National Dementia Strategy* does not provide any guidance for the management of dementia in people with developmental disabilities including ASD.

In contrast, the Danish *National plan for Autism (2008)* has a prominent section on 'Life after 60' and residential developments and support extended to the older age group reflect this attention.

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DIAGNOSING AUTISM IN OLDER ADULTS

There is a scarcity of adequate and validated screening tools to detect autism and ASD in older adults who have never previously been evaluated for the condition. *The Autism Diagnostic Observation Schedule (ADOS)* has been adapted and used for diagnosing ASD in older people. Similarly, the *Diagnostic Interview for Social and Communication Disorders (DISCO)* is non-specific and though in use in older people with ASD, remains unvalidated. The Department of Health used a modification of the *Autism Quotient* self reporting questionnaire in a survey in 2007.

However, these measures are clearly insufficient. There is a need for new diagnostic instruments or the modification and proper adaptation of other standard clinical screening tools used to diagnose ASD in childhood for use in first time diagnosis in older people.

SOCIAL ISOLATION

Though the literature does describe some areas of opportunity, in the main it paints a picture of social isolation and mental health problems, particularly among more able people with ASD. Depression and anxiety disorders appear to be rife, unrecognised and untreated.

Social isolation remains a concern and there is some evidence of differential outcomes for people with ASD based on their intellectual ability. Research from a hospital cohort shows that people who are intellectually more able achieved better outcomes, such as living independently. However, this indicator may be hypocritical, where living independently leads to loneliness in the absence of consistent and well-structured support. Some studies have indeed shown those living independently may become more socially isolated compared to people leaving in group homes. On the other hand, varying degrees of social isolation may be preferred by people with ASD, in keeping with their core areas of difficulty. In preferring to limit social contacts, the loss of loved ones may have a greater impact in the absence of a significant number of friendships and family relationships. Isolation needs to be distinguished from loneliness, which may lead to depression and anxiety and will require support.

As people with ASD age, health concerns such as epilepsy, pain, sensory issues, diabetes and obesity become increasingly important. It is therefore essential to gather a health history from families so that a health risk profile for people with ASD can be developed as they age.

Interestingly, some things tend to improve with age. For instance, restrictive and repetitive behaviour of all types diminish as people get older while social communication and intelligence appear to improve. There is also anecdotal evidence that learning and skills development can continue throughout adulthood leading to richer and more fulfilling lives.

QUALITY OF LIFE ISSUES AND FUTURE NEEDS

In the United Kingdom, we now need both a national and local focus on the quality of life of this group of people, spanning both their physical environment and their health, social and emotional needs.

Small personalised residential facilities – group homes and supported housing – which take into account the environmental needs of older people with ASD are generally lacking and the UK has tended to lag behind developments in Europe, particularly in Denmark and France. Services providing day opportunities are caught in the cusp between autism specific, learning disability and older people's services, with practically no choice of an inclusive service.

Training modules for health and social care staff need to be broadened to help them diagnose and support ageing people with ASD. This training needs to take place both locally and nationally at the primary health care level and within social care organisations. A survey carried out by the National Audit office in 2008 found that General Practioners provide a poor standard of care for their patients with ASD, including older people.

Similarly, along with ongoing research, quality of life measures and new assessment tools need to be developed to make valid, evidenced based judgements of a person's life situation and outcomes related to any improvements and opportunities put in place.

In the minds of most people, autism has been identified as a childhood disorder. It is only when we start to consider the effects of the condition over the entire lifespan of an individual that perhaps our focus and priorities will start to change. **CMM**

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In the three recognised deficit areas in neurocognitive functioning there are variable outcomes with age. Social cognition and related behaviours may improve with age. Executive function, which includes planning, generativity and cognitive set shifting, tends to deteriorate with age. Local global processing, the inability to extrapolate local interpretation into a global coherence, along with certain memory functions also tends to deteriorate with the same pattern as in people without ASD; however, there is practically no research on the patterns and prevalence of dementia in ASD as people age. Brain changes seen in adults with ASD through recent neuroimaging studies indicate the possibility of higher rates of cognitive deterioration and depression developing with age. Another variable which has not been properly assessed is the effect of long term drug therapy on the autistic brain.