

# Diagnosis of autism in adulthood: what can we learn?

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## Editorial comment

The Specialist Autism Adult Assessment and Resource Centre (SPARC) was set up in 2013 in Birmingham to make a diagnostic assessment of adults living in the West Midlands who were thought to be on the autism spectrum. This paper presents data on 30 adults who were assessed by the SPARC team in key areas of their lives (ie education, relationships, employment and living situation). Literature on autism in adulthood can be depressing but the experiences reported here show that although these adults experienced failure and frustration, many were also successful.

Many individuals have shown remarkable resilience in the face of difficulties and are keen to change their lives. Many could be more successful if adjustments were made to schools, colleges and the working environment and if adults were allowed to do things differently, in the workplace and/or within their family. Gainful employment would make the most difference to many individuals' lives, providing this suits their profile, social preferences and sensory challenges. Without employment, there is often little to do during the day, sleep patterns become disrupted, finances are limited, social contact is reduced and medication is often used to address the anxiety and depression that can result and benefits and allowances replace wages and salaries. Tailoring education to future adult lives and being supported into work is likely to make a significant and positive difference.

## Introduction

A specialist autism diagnostic service known as SPARC (Specialist Autism Adult Assessment and Resource Centre) was set up within the West Midlands in 2013 in response to the Autism Act (2010). The Act stated that specialist diagnostic assessment teams should be available to adults living in every local authority in England. At that time, a few of the 14 local authorities in the West Midlands had a specific team, but others did not. SPARC operates from within the headquarters of Autism West Midlands but is a separate charity with its own governance and processes (see [www.sparcautism.org](http://www.sparcautism.org) for more information).

Adults who think they might be on the autism spectrum or professionals and relatives who think this may be the case, can be referred to SPARC via their GP, with

the consent of the person concerned. There needs to be evidence that the person is struggling with aspects of their everyday lives (eg employment; relationships; leaving the house and accessing services). The commissioner for the local authority has to consider the evidence for such an assessment and agree the funding. It was assumed that those referred would be in the above average or average range of intellectual ability, given that any adult with a learning disability is likely to be referred to their local team for learning disability. This has proven to be the case, with the majority of adults referred to SPARC not having a learning disability.

This paper considers the information gained during the diagnostic assessment of 30 adults ranging in age from 18 to 56 years, who were given a diagnosis of autism

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at SPARC during the period 2013 to 2015. It presents data on their age at referral, gender, level of education, employment status, current living arrangements and marital status, and discusses the key areas of their lives where differences or difficulties were identified. Recommendations on how to enhance identification earlier in their lives and on how to support autistic people in adulthood are made.

**Note on terminology used at SPARC**

The use of the term Asperger syndrome has been debated in the UK and US and the most recent version of the Diagnostic and Statistical Manual (DSM-5) no longer has Asperger syndrome as a diagnostic category, and instead uses the umbrella term of autism spectrum disorder for all forms of autism. The rationale for this is that it is very hard to distinguish between those with Asperger syndrome and people with autism who are of average ability or above. However, as there are still many useful books, resources and websites which refer to Asperger syndrome, the SPARC team directs individuals to these.

**Details of the sample**

The age at the time of assessment and the gender of the sample are given in *Table 1*. For the purposes of this paper, an equal number of males and females was selected and a similar age range across gender. In the experience of SPARC to date, an almost equal number of males and females have been referred which contrasts with the findings of previous literature on gender and prevalence in autism. It might be the case that in childhood, there are more autistic girls missed than boys so there is a greater number of women seeking diagnosis in adulthood. It is certainly the case that most of the women assessed at SPARC were quiet and passive at school and relatively high achievers and so would not have called attention to themselves and not been easily identifiable by staff as having specific needs. The majority of people referred to SPARC are in the age range from 20 to 40 years.

**Table 1: Age and gender of the 30 adults selected for this paper**

Age	Female	Male	Total
18	2	2	4
20-29	5	5	10
30-39	3	3	6
40-49	3	3	6
50-60	2	2	4
<b>Total</b>	<b>15</b>	<b>15</b>	<b>30</b>

**Person or agency who suggested the referral to SPARC**

Two of the women were referred at the request of their parents as they had concerns about their daughter’s anxiety and behaviour. One of these families had a son diagnosed with autism and ADHD and felt that their daughter’s needs and functioning had been overlooked as much attention had focused on the needs and well-being of their son. A third woman was referred at the suggestion of her husband who has a sister with autism. His wife had had a very traumatic childhood and he felt that other professionals had perhaps thought this trauma explained her unusual behaviours. Four women referred themselves to SPARC, two because their child had been diagnosed with autism and they began to think they also had features. In the third case, the support worker for the person’s son diagnosed with autism suggested she sought a diagnostic assessment. Seven women were referred by other professionals (including an eating disorder clinic; an employment support worker; a mental health team; counsellor and clinical psychologist).

One parent said, about her daughter:

*“For her, the world is a confusing, busy, noisy place which causes her a lot of anxiety to the point of being a barrier to her living life outside of her home. She wants and aspires to those things she sees for her older siblings but does not have the resources or support to help her achieve her potential.*

A husband said about his wife:

*"She is a deeply feeling, deeply caring and polite and humble person but feels clumsy with people."*

For the men assessed, six referred themselves as they were seeking to understand themselves better; six were referred at the suggestion of a professional they had met (eg clinical psychologist; university assessor; mental health team); and two were referred at the request of a relative who worked in the health sector. One man was referred at the suggestion of his wife, as their son had recently received a diagnosis of autism.

### **Who attended the assessment?**

Almost all came with a partner or family member or professional worker, showing that the majority did have support of some kind. Two women came alone to the assessment and were confident to do so; three came with their partner or husband; five came with one or both of their parents; and four came with a support worker. One woman was visited at home by the SPARC team as she rarely left the house. She lived with her parents and her three children.

For the men, three attended with their wives, three with their partners, eight with one or both of their parents or with a brother or aunt. Only one person in his fifties came on his own. He lived a very isolated life and said his family had disowned him as they thought his difficult behaviours were deliberate. Getting the diagnosis was a huge relief to him as a result. He was a man of above average intelligence whose life had been seriously affected by his autism, rejection by his family and lack of understanding and support.

### **Number of those referred who reported a relative with a diagnosis on the autism spectrum**

Those seen were asked whether other members of the family had autism or another developmental difficulty or mental health disorder. Clearly, the SPARC team was not able to verify this information so caution is needed in interpreting the data. Seven of the 30 people seen said they had a close relative with a confirmed

diagnosis on the autism spectrum. In some cases, this was the trigger for seeking a diagnosis themselves. A further eight of the referrals said they had relatives with similar characteristics to themselves, often described as socially awkward or avoidant of social encounters, very dogmatic and hard to relate to or very unusual in their dress or routines or great collectors and hoarders.

Two of the men referred had either one or two children with autism. One of these men felt his own mother had autistic traits. One man, aged 31 had a younger brother with a diagnosis of OCD. Another man felt both his brother and father had autistic traits.

Five of the women had a close relative with a diagnosis of autism (ie child or sibling). One woman had two children with a diagnosis of autism. Two other women had a son with Asperger syndrome and in one case the granddaughter was due to be assessed for autism. Another mother had a 26 year old daughter awaiting assessment for autism and another had a brother with autism and learning difficulties. A further six said their father had autistic traits. Four women said that one or both of their parents was thought to have mental illness or alcoholism. So, the mothers in the sample were more likely than the men to have had added demands on their time, often social demands, as they had to attend meetings to discuss their children's needs. All were determined to do their best by their children and it was heartening to hear how well they dealt with the demands of raising their own family.

### **Additional difficulties or diagnoses reported**

A quarter of the 30 referrals reported having literacy issues or dyslexia (two females and five males) and three others said they had been diagnosed with Attention Deficit Hyperactivity Disorder (ADHD). A high percentage (75 per cent) had been treated for depression or anxiety and two fifths of the sample reported long term physical health issues (eg irritable bowel syndrome; chronic pain; asthma). These factors are going to have a significant bearing on their ability to function in everyday life in addition to their autism. One 53 year old man had a sister with a diagnosis of schizophrenia and his father was an alcoholic. Another had a sister with

a diagnosis of dyslexia. A 27 year old man had a half sibling who was an in-patient in a psychiatric unit. There is a possibility that a diagnosis of autism might explain challenges that were attributed to mental illness or that the mental health issues were secondary to autism.

**Childhood experiences**

Nine of the 30 people seen had had very difficult childhoods due to separation, loss, parents’ mental health and relationship issues. These clearly added to their difficulties and could have confused the diagnostic picture and affected professionals’ ability to identify their autism in the past. Differential diagnosis for those who have had a number of adverse events in their lives can be difficult and very good history taking is very important. An issue for the older adults seen is that parents may not be able to provide a detailed history of events and the person’s early development.

**Current living situation**

Table 2 shows the current living situation for the 30 people referred. Of the women, five of the 15 lived at home with their parents, one of whom was away at university, and all were under the age of 25 years. Three women lived alone and were happy to do so. One had bought her own house (aged 27), another lived in a rented flat (aged 30) and the third lived in a flat close to her parents who continued to provide support (aged 47). There were no plans in place for who might replace this support when the parents were no longer able to do so. Four lived with their children without a partner, and in one case the 18 year daughter was the carer for her mother (aged 50). This is in contrast to the men, only one of whom was living with his two children. The other men were in child-free homes.

**Table 2: Current living situation**

Living situation	Alone	With a partner	With their children	With a partner and children	With their parents
Female	3	2	4	1	5*
Male	1	5	0	1	8*
<b>Total</b>	<b>4</b>	<b>7</b>	<b>4</b>	<b>2</b>	<b>13</b>

One of these adults was away at university.

Eight men lived with their parents, one of whom aged 44 years, was the carer to his father. Another young man commuted 120 miles to and from university from his parents home each day. Only one man lived on his own. This is contrary to much of the literature which speaks of social isolation. Two people struggled to live on their own and felt very isolated and lonely and were anxious about their neighbours. Others on low wages or benefits were depressed that they were not able to live in better housing or to afford to buy their own place. Many are very sensitive to noise and would have preferred to have lived in a quieter area.

**Children born to those in the sample**

Of the 30 adults in the sample, 21 had no children and an almost equal number of males (four) and females (five) had children, but the women had more children and were more likely to remain in contact with them (see Table 3). Two of the fathers had one or two children diagnosed with autism. The two other fathers no longer had any contact with their children. All of the women had more than one child, two having four children and another having five children. Three of these mothers said that one of their children had a diagnosis of autism (two) or was in the process of being assessed for autism (one). Given how demanding children are and how many autistic individuals find children unpredictable and their social demands difficult to manage, these women were living with and caring for their children successfully.

**Table 3: Details of those in the sample who had children**

Age group	Number of children	Men	Women
18-30	0	7	8
31-40	0	2	-
40-49	0	1	1
50+	0	1	1
39-40	1	2	-
40-50	2	2	1
37	3	-	1
39-49	4	-	2
45	5	-	1
<b>Total</b>	<b>-</b>	<b>15</b>	<b>15</b>

### Educational support and level of education achieved

Those attending SPARC were asked to bring along any reports written about them, including school reports. Very few had kept these, so robust information on their school years and the support given was lacking and relied on their memory and recall. A few had been given specific support for aspects of the curriculum such as literacy and extra time in exams. A number of adults had started to skip school in the later secondary years, often unknown to the parents and the staff, in some cases. The majority of those seen at SPARC found school difficult, particularly the social aspects and friendships and many reported being teased or bullied and rarely reported this to parents or staff.

Most of the people seen were of average ability or above, given the level of qualifications achieved. Only two of the 30 spent some time in a special school. The rest were educated within mainstream schools for their entire school career. Almost without exception, the adults seen at SPARC were passive and quiet at

school and did not act out. When asked whether any staff noticed their anxieties or lack of social inclusion, their response was invariably, 'no'. Although this is their perception and perspective and not backed up by other evidence from schools, this was a common view. Work is needed to enable staff to look out for and identify children who find school traumatic and who need support, particularly in the social aspects of school.

### Experiences of some of the women in education

One woman went to college after school and did Business Studies but did not gain a job connected to this. She worked in a coffee shop and as a data input assistant. She then went to university to train to do a degree which involved practical work. She was fine on the theory but failed the practical and so was not able to find work afterwards when she had gained her degree. Another woman of well above average intelligence found mainstream secondary school very hard and left early with just three GCSEs. She then did some online courses and Open University modules and job-hopped for 18 years. She went on to Disability Benefit for several years and is now unemployed. A third woman (aged 37) had excellent A level grades, despite having anorexia for much of her adolescence and started to attend a university local to home, but could not cope with the course and so stopped attending. She now does low level administrative jobs.

### Experiences of some of the men in education

Of the 15 men, 13 were of at least average intelligence and gained some passes at GCSE level, albeit in only a few subjects in some cases. Two of the men appeared to be of low average ability and did not achieve any passes in school. Despite some serious issues at times and problems in other areas of their lives, five of the men succeeded in gaining a university place and completed their degree. Two had issues while at university and dropped out for a year but then continued and were awarded their degrees. One young man was now studying on a Masters programme. These degrees were in Music, Social Sciences, Research Methods and Conservation. There is evidence that support for students in Further Education and at university is improving but there is still much work to be done in this area.

### Mental health: self report

Over three quarters of the sample had been treated or were being treated for depression or anxiety (see *Table 4*). These individuals had a history of depression, social anxiety and generalised anxiety. Two women had had a serious eating disorder and one person had experienced a psychotic episode while at university. There is evidence that autistic individuals are more at risk of developing an eating disorder and that women with anorexia have more autistic traits than typical females (Tchanturia et al, 2013). In studies by Nilsson et al (1994) and Wentz et al (2009), it was found that about a fifth of those with anorexia at the age of 15 years, were also on the autism spectrum. It is important that those working with anorexic patients know the link with autism as the reasons for the eating disorder may be different and adjustments are likely to be necessary to the treatment offered. One anorexic woman diagnosed with autism told the SPARC clinicians that she felt that her food intake was the only aspect of her life over which she had control. She found the regime within the inpatient unit extremely difficult, particularly the group sessions.

One man in his 20s had made a serious attempt to harm himself when he was traumatised at work. One has to consider whether medication was the only or most effective means to address the issues presented. Increasingly, Cognitive Behaviour Therapy (CBT) and mindfulness are being offered and there is evidence that if CBT is modified for use with autistic individuals, it can be very effective (Attwood and Garnett, 2016). One also needs to consider how the everyday lives of people might be changed to lessen their anxiety and depression (eg by finding gainful employment, having more contact with people with whom they share an interest, taking exercise).

### Employment experiences

*Table 5* gives details of the employment status of the adults in the sample.

#### Women and work

Of the women, six had been employed at some point in their lives but were not employed at the time of the assessment, one of these through choice as she was caring for her children full-time. Just three women had never been employed (aged 18; 20 and 28).

**Table 4: Number of people who had received treatment for mental health or eating disorders**

Mental health issue	Males (15)	Females (15)	Total
Depression	6	7	13
Anxiety and depression	2	4	6
Eating disorder	0	2	2
Psychotic episode	1	0	1
<b>Total</b>	<b>9</b>	<b>13</b>	<b>22</b>

**Table 5: Employment details of those in the sample**

Employment status	Never been employed	Not employed at present	Employed	At university
Female	3	6	4	2
Male	2	9	2*	2
<b>Total</b>	<b>5</b>	<b>15</b>	<b>6</b>	<b>4</b>

\*self employed

Generally speaking, the type of jobs in which they were employed were those which did not require a high level of skill and it is likely that they were working below their intellectual ability. There were two women in a role which matched their intellectual level, one being a teacher and the other working in a high level diagnostic role within a hospital. She had attended university and gained her degree, but took a year out as she found university very stressful. She enjoys living alone but finds public transport difficult and travels either very early or late at night to avoid the worst of the crowds.



Some women had had a number of different jobs and had found it hard to manage the social situations and encounters required. The types of job included working in a shoe shop, cleaning, care home duties, administration and security work. One woman was promoted to the checkouts from shelf stacking but hated this as she was reprimanded for not smiling at customers and being rude. One woman with three children found work a less chaotic space than her home life and had a partner who provided the child care and domestic tasks.

### Men and work

Two of the men were self employed, one mending lap tops and the other had developed his own online business. Ten of the 15 men were currently not working and of these, two had never had a job (aged 18 and 27). The rest had generally been in part-time, low skilled jobs. Very few appeared to have received good advice or support on trying to work out what they might be suited to. There had been incidents of teasing and bullying at work which had led to unemployment and some had been dismissed as a result of issues that occurred at work. One of the men had been a sales assistant but found it hard to lie about the product and another shop worker was told he did not try hard enough to sell the items of jewellery.

There was often a common story for all who had been in work which involved not being able to tell lies, to socialise, to engage in small talk, to eat in front of others and having difficulties in handling teasing and understanding office politics. Many also told of finding open plan and noisy environments difficult to work in and coping when other employees did not appear to follow the rules, which made them doubt their own knowledge of these and led to anxiety.

Almost all the issues reported related directly to the differences associated with autism, and without a diagnosis, the individuals themselves lacked an explanation for why they were criticised and their line managers failed to understand their reactions and responses. As a result, the autistic adults became very self critical and described themselves as useless, low skilled, and lacking in ability and despite their best efforts to do the job as instructed, often did not meet the standards required. Without an understanding of

their social and sensory issues and their problems in executive functioning, their employers were not able to make adjustments to enable them to succeed.

Several books have now been written to support both autistic adults in employment and their employers and following ideas and guidance would increase their chances of maintaining employment and succeeding in work (eg Edmunds and Beardon, 2008; Hendickx, 2008; Kirby, 2014; Lara and Osborne, 2017; Meyer, 2001; and Scheiner et al, 2017).

### Recommendations on employment

From the 30 adults discussed in this paper and the larger group of people assessed at SPARC, it seems very clear that not enough work has been done to prepare young people for work and very little guidance is offered as to which college courses might be appropriate and which job opportunities might be available. Even without knowing their diagnosis of autism, taking a detailed account of their current functioning and interests should enable advisers to make better selections than appear to be the case. Most have to rely on parents or their own efforts to find a job. As a result, the jobs taken are often a poor match to their profile and problems then result.

In relation to enhancing the employment opportunities for autistic adults, there is a need for good assessment methods to:

- identify an adult's profile of skills and interests
- identify areas which might pose difficulties
- provide work experience to develop basic work-related skills,
- offer support in finding appropriate employment
- ascertain the support needs once employed
- put in the support and adjustments that are likely to be required

Having a mentor at work who can problem solve with the adult and/or line manager would be useful in many cases. The Department for Work and Pensions scheme, Access to Work, can be very effective and serves to support and maintain the employment of autistic adults.

Several books have been written giving advice on the issues autistic students might experience and the type of adjustments which would enable them to succeed at college and university (eg Freedman, 2010; Kirby, 2013; Muggleton, 2013). A European funded project on autistic students at university has also produced a number of resources (see [www.autism-uni.org](http://www.autism-uni.org)).

### Sexuality and relationships

An issue reported in the general literature on autism which was borne out by parents' comments is that autistic individuals often find it hard to judge others and may fall into difficult and abusive relationships. They may stay in these relationships as they have no guide or yardstick on which to gauge whether this is OK or because they have few or no other social connections. For women who have children, they may have to stay for financial reasons or to share the child care and so may stay for longer than they would wish. *Table 6* shows the current relationship status of adults in the sample.

**Table 6: Relationship status of adults in the sample**

Relationship experience	Women	Men	Age
Never had a sexual relationship	6	4	18 - 30
Never had a sexual relationship	-	2	31 and 44
One relationship long ago	1	1	47 and 51
Has a girlfriend/boyfriend	-	2	23 and 26
Lives with partner, was married	1	1	37 and 39
Lives with partner	-	2	18 and 53
Married	2	3	28 - 56
Separated	5	-	39 - 50
<b>TOTAL</b>	<b>15</b>	<b>15</b>	

Six women had had no experience of being in an intimate relationship with anyone. Two were aged 18, three were in their 20s and one woman was 30. Two were married and one lived with her partner. One of the married women said she had very few friends now but did write to several pen pals. She had met her husband on an

online dating site and found they had both attended the same school in the past which served as a positive link to begin the relationship. Her husband explained, "We fell into mutual weirdness and called it love".

Three men were married and their marriages were considered quite stable. Three others lived with their partners, one of these in a same sex relationship. Another had been married and had a child but divorced two years after the marriage. Six of the men had had no intimate relationships, one saying that he had thought this was not possible if you had Asperger syndrome. Another man said he would like a relationship but was very unsure how to make this happen. The literature on sexuality and relationships and autism has grown over recent years and there are some counsellors who specialise in working with autistic adults. These are suggested to those who attend SPARC who are keen to explore relationships or to enhance their current situation (Aston, 2001; Hendrickx, 2008; Slater-Walker, 2007).

### Aspects of daily living in which problems were reported

Adults who attend for a SPARC assessment are asked to complete a Concerns Questionnaire developed by a Consultant Clinical Psychologist, Rachel Golding, specifically for use in SPARC assessments (see [www.autism-id.co.uk](http://www.autism-id.co.uk)). This covers 37 areas of everyday living such as sleep, diet, time management, travel and friendships. They are asked to rate the level of concern they have on each of these, if any. A rating of 2 signifies great concern and a rating of 1, some concern. This is a self rating schedule and as such is prone to the usual limitations of a self rating instrument. Nevertheless, the difficulties described by those attending SPARC show great similarity in terms of the nature of the issues reported and their impact on everyday functioning.

The areas most commonly given a rating of great concern, are issues with flexibility, concentration, decision making, sleep, time management and anger management, emotional recognition and mental health, doing domestic household tasks and self esteem. The areas where fewer concerns were noted were gender and sexual orientation, housing, compliance with the law, finance, and movement and coordination (see *Table 7*).



**Table 7: Ratings given by adults to signify the degree of concern, if any, in relation to 37 areas of everyday life (in order of frequency)**

	<b>Area of life</b>	<b>Number of adults expressing great concern</b>	<b>Number of adults expressing some concern</b>	<b>Total adults noting an issue</b>
1	Flexibility	26	4	30
2	Concentration	18	10	28
3	Decision making	12	16	28
4	Sleep	21	5	26
5	Time management	14	12	26
6	Anger management	18	8	26
7	Emotion recognition and expression	12	14	26
8	Mental health	16	10	26
9	Domestic (cleaning)	16	10	26
10	Self esteem	20	6	26
11	Activity levels	12	13	25
12	Hearing	10	14	24
13	Memory	14	10	24
14	Friendships	18	6	24
15	Physical health	10	13	23
16	Anxiety management	14	8	22
17	Mood regulation	18	4	22
18	Employment	18	4	22
19	safety	10	12	22
20	Social understanding	18	4	22
21	Diet	13	8	21
22	Interests and hobbies	10	10	20
23	Travel	12	8	20
24	Domestic ( food preparation)	8	12	20
25	Personal hygiene	10	10	20
26	Personal appearance	12	8	20
27	Movement and coordination	8	10	18
28	Language	8	10	18
29	Finance	10	8	18
30	Vision	4	13	17
31	Speech and voice	8	8	16
32	Marriage, civil partnership and long term relationships	12	4	16
33	Relationship with family	6	10	16
34	Pain perception	3	9	12
35	Compliance with law	6	6	12
36	Housing	4	4	8
37	Gender identity and sexual orientation	0	0	0

Concentration was a huge area of difficulty and many had been told they were daydreaming and not paying attention, both at work and school. One woman said:

*“I have problems with daydreaming and if I’m not interested my mind will wander. If I’m engrossed in what I am doing I don’t like to be interrupted.”*

Social and emotional understanding (knowing what to say and do) is an area which causes significant anxiety and stress. Many avoid or fear social situations. Autistic adults often over analyse and ruminate on what was said worrying whether it was OK or not. They are often criticised for what they have said and done. One woman said:

*“People often think I dislike them because of the way I look at them. I sometimes don’t understand why people are upset or angry.”*

There are now very many books written by autistic adults which describe their experiences and successes and which make suggestions on what might help others. These are invaluable for those new to the diagnosis and to family members and professionals (eg Grant, 2015; Hendrickx, 2015; Lawson, 2011; Muggleton, 2014; Simone, 2010; Steward, 2014). Websites and forums and Youtube videos also continue to develop which show the diversity within the autism spectrum and provide opportunities to share ideas in an accessible and safe environment.

**Sensory issues**

It is only in the last ten or so years that awareness of the problems which are presented by different sensory perception and processing in autism have become apparent and acted upon. The two areas where almost all 30 adults expressed concerns were with vision and hearing (see *Table 8*). Bright lights and sunlight were a difficulty for 14 adults and sudden or loud noises and background noise was very upsetting or distracting for 22 of the adults seen. Other sensory issues reported related to the feel of clothing (12), feeling uncomfortable when touched or hugged by others (16) and two adults said they were very sensitive to changes in temperature.

These issues often have a major effect in the workplace, but also in living with their families and accessing services and facilities in the community.

**Table 8: Sensory issues reported**

Sensory issues	Males	Females	Total
Noise	10	12	22
Bright lighting	6	8	14
Discomfort when touched or hugged by others	6	10	16
Texture of foods and smells	3	6	16
Sensitivity to clothing	4	8	12

Late or later identification of autism

It is clearly difficult to know how the 30 adults presented as children and whether they could have been identified as autistic earlier in their lives, and if so, whether this would have been beneficial. For some adults seen, the SPARC team feel that an earlier diagnosis would have helped to guide their education and employment choices and helped in their relationships with others. Many of the adults had felt depressed for most of their adult lives and would have liked to have known why they felt different and why they experienced the problems they did. Some had felt rejected by their families for being different and had struggled with employment and generally felt they had under achieved.

For the older group (ie those aged 30 years and above), professionals within education, health and social care would have known less about autism when these adults were children. What is often apparent when the adults talked about school was that they were very unhappy for long periods of time and they felt no one on the staff appeared to know this. Autistic children often keep their heads ‘below the radar’, and do not report their unhappiness to staff. Many of the 30 adults would have appeared quiet and passive at school but were often the subject of bullying and teasing which went unseen.

They often did not have friends, or friendships did not last, so they did not have the protection and support of a peer group. They appeared to suffer in silence at school.

What would have helped them as children (and what would help autistic children at school currently) would be for the form tutor or class teacher to have an individual conversation with each of their pupils at the start of each term, using a structured format (eg the Ideal school template developed by Williams and Hanke, 2007), to identify which aspects of school they are enjoying and where they have issues or are very unhappy. In that way, they would have become visible and had their needs addressed. Many mainstream schools have enhanced their practice a great deal in recent years but there are other schools where staff still need a great deal of advice and guidance. There are other schools where staff still need support and guidance. In recognition of the good practice which exists and the gaps that still exist, the Department for Education in England has produced sets of standards and competency frameworks in autism for the three key phases of education – early years, school and post 16 provision. These are free to download and are being used by many schools now to guide and enhance their autism provision and practice (see [www.autismeducationtrust.org.uk](http://www.autismeducationtrust.org.uk)).

### **Wasted opportunities?**

For the older women assessed in this sample and the wider group, some reflected on their lives and felt they wanted to do better and live differently. With low paid employment they often lived in rented accommodation in poor areas which added to their difficulties in terms of noise and the actions of their neighbours. All people can reflect on the decisions made and the path taken but there is a sense in which some of these women and men could have led more fulfilled lives and those out of work could have been employed if adjustments had been made and/or support given. Many were on medication for depression and anxiety to cope with a life that was lacking in purpose and where they were under employed. Sleep was a major issue mentioned by the majority. This is in part due to the fact that individuals

are under occupied in the day and therefore not physically tired. Some prefer to be awake at night when all is quiet and there are fewer social encounters. Autistic adults often over analyse their interactions and worry about events and do not have strategies to reduce their anxiety. When they wake up, the worry cycle starts again making it hard to return to sleep.

### **Concluding comments**

Overall, the SPARC team has been pleasantly surprised that in many cases the adulthoods of the autistic people they have seen have not been as lonely or difficult as previous literature and case studies suggest. The growing awareness of autism in the workplace and training in diversity generally, may be bearing fruit. Past literature found that autistic adults were often unemployed, lived alone or with their parents and did not have significant relationships. While this was true for some of the 30 adults, there were nine who were employed (seven) or self employed (two) and ten who had been employed. There were eight adults living in stable relationships and four who were separated and others living alone by choice or with parents. There is still much that can be done to enhance the lives of autistic adults as evidenced in the ratings they gave in the Concerns Questionnaire and in terms of education, employment and friendships.

The key areas where good and appropriate advice needs to be given are in relation to their choice of college or university course, employment options which suit their profile, support in making friendships, where desired, and accessing literature which is helpful. Many autistic adults seem to prefer to teach themselves (ie they are autodidacts) rather than attending lectures or counseling and therapy sessions, and the number of online courses and self-help books is growing which should be helpful. Enhancing people's quality of life will lessen the dependency on medication and the support given by family members and parents. The SPARC team is optimistic that as the awareness of autism increases across schools and services and the workforce generally, many more autistic adults will be successful and live the lives they wish to lead.

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Autism Education Trust: [www.autismeducationtrust.org.uk](http://www.autismeducationtrust.org.uk).

Access to Work support once in employment: [www.gov.uk/access-to-work](http://www.gov.uk/access-to-work).

A specialist Adult Autism and Research Centre [www.sparcautism.org](http://www.sparcautism.org)