



# THE SCREEN TEST

DONNA PAXTON AND HER COLLEAGUES UNCOVER SOME INTERESTING FINDINGS FROM  
A SCREENING PROGRAMME FOR ADULTS WITH DOWN SYNDROME

**I**t is widely acknowledged that individuals with a learning disability may have increased health needs compared to the general population and that these needs are not adequately met (Kerr *et al* 1996). For people with Down Syndrome some of these health needs are known to be associated with the condition and include cardiac problems, thyroid disorders and sensory impairments as well as an increased risk of developing early onset Alzheimer's disease (Hutchinson 1999). Clinical guidelines have been developed which identify the health areas that need to be included when screening children and adults with Down Syndrome (Down Syndrome Medical Interest Group 1999). Unfortunately, early diagnosis of Alzheimer's disease can be difficult, as many of the health problems to which people with Down Syndrome are susceptible – such as those outlined above – can mimic or be superimposed on the decline associated with Alzheimer's disease (Dalton *et al* 1993). Conversely, deterioration that is actually due to treatable causes may be assumed to be as a result of Alzheimer's disease and the client may fail to receive appropriate treatment (Burt *et al* 1998).

A particular difficulty relates to the differential diagnosis of depression and dementia and the Down Syndrome Association Medical Interest Group recommends mandatory health screening to help overcome this difficulty. This includes screening for hypothyroidism and the provision of hearing assessment. Janicki *et al* (1996) also recommend that health services provide the following:

- periodic behavioural, cognitive and health screens to help identify early signs of decline
- identification and treatment of medical conditions which may mimic the decline associated with Alzheimer's disease
- appropriate care management that develops interventions and supports which are appropriate for each stage of the disease.

Routine screening is a regular occurrence in childhood. However, when the young person transfers to adult services, this may not occur systematically. Parents voice concerns about the lack of services on offer once their child has transferred to adult services (McKenzie *et al* 2001). At this time, the responsibility for meeting the health care needs of the young adult is transferred to the primary health care team.

Many studies have shown, however, that the teams may lack the training, experience and knowledge adequately to meet the health care needs of people with a learning disability (Kerr *et al* 1996, McKenzie *et al* 1999). Similarly, primary care services may view the provision of this health care as the responsibility of learning disability teams (McKenzie *et al* 1999). As a result, it is at this traditional time that young adults may fall through the service net and may fail to receive the recommended screening.

A further barrier is that social care staff may also lack knowledge about both Alzheimer's disease and the broader health needs of people with Down Syndrome (Koenig 1995).



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**The big screen: clinical guidelines have been developed which identify the health areas that need to be included when screening children and adults with Down Syndrome**

This can ultimately impact on the client's quality of life, as many conditions may go unnoticed or untreated. While there is wide agreement that the provision of health screening to adults with Down syndrome is important, both in respect of identifying and treating general health problems and specifically in relation to the differential diagnosis of Alzheimer's disease, such screening does not appear to be provided routinely.

McKenzie *et al* (2000) report on the development of a care pathway for people with Down Syndrome which as health screening as an integral part. The present study reports on the outcome of the health screening component of the pathway which offered a cognitive and health screen to adults with Down Syndrome aged over 30.

#### METHOD

Thirty-one clients participated in the health screen as part of the wider pathway approach (McKenzie *et al* 2000). Of these, 14 were male and 17 were female. Eight of the clients had been found to show sustained behavioural and cognitive decline consistent with a diagnosis of 'probable Alzheimer's disease'.

All participants in the pathway were offered a health screen. They were asked to bring any relevant information with them to the appointment, such as immunisation status, and to be accompanied by a relative or carer, if appropriate, to help answer any questions about their health. A letter was also sent to every GP in the area informing them of the project and

requesting their permission to take blood sample from their patients. The health checks were carried out in the clients' homes or resource centres. The checks included the following: a measurement of blood pressure, pulse and urinalysis. Ears were checked for any obvious signs of infection and/or hard wax. A blood sample was taken and the carer was asked to provide information about past health issues, in particular mental health disorders.

While the recommendations developed by the Down Syndrome Medical Interest Group (1999) also cover cervical spine instability, the present study was unable to screen for this because of the more specialised resources needed, for example neck x-rays. It was also recommended that the growth of children was monitored. As this was not possible, because our population consisted of adults, Body Mass Index was calculated as an alternative indicator. This information was recorded and collated on a health assessment form. Following the assessment, a summary was written for the GP providing baseline information and the original blood results. Letters were sent to the clients thanking them for their participation and reminding them of any follow-up appointments.

All health problems that were detected were reported to the GP for treatment, further investigation or reported on to other community learning disability team members as appropriate. It was suggested that some clients should be referred to psychiatric or dietetic departments, for example.

## RESULTS

Table 1 illustrates the number and percentage of clients with each type of health problem. This is shown for the total group and separately for the clients who did and did not show deterioration consistent with Alzheimer's disease.

**Table 1** No. and percentage of referrals to other professions as a result of the health screen

Profession	Number	Percentage
Dietician	12	39
Speech & Language Therapist	6	19
Community Nursing	6	19
Clinical psychology	6	19
Psychiatry	6	19
Occupational therapy	2	6
Physiotherapy	2	6
GP	13	42
Haematology	1	3

Table 2 illustrates the number and percentage of referrals to other professions as a result of the health screen.

**Table 2** Number and percentage of clients with each type of health problem

**Area of identified health need (number of participants who complied with each aspect of screening)**

	Total group		Deteriorating clients		Non-deteriorating clients	
	Number	%	Number	%	Number	%
Cardiac (31)	15	48	4	50	11	48
Blood abnormalities (22)	18	82	5	71	13	87
Thyroid (22)	5	23	2	28	3	20
Vision (31)	21	68	5	63	16	70
Hearing (31)	12	39	4	50	8	35
Ear wax (31)	25	81	8	100	17	74
Mental health (31)	8	26	2	25	6	26
Depression	4	13	1	12	5	22
Mood disorder	4	13	1	12	5	22
Urinalysis (27)	9	36	1	12	8	47
Body mass index >19 overweight 26-30	1	3	0	0	1	4
grade II obese 31-40	9	29	0	0	9	39
very obese – grade III 40+	14	45	2	25	12	52
Bowel problems (31)	15	48	1	12	14	61

## DISCUSSION

The present study indicates that the participants had a range of health needs which had not been previously detected or reported to the clients' GP. These ranged from serious problems such as cardiac and thyroid abnormalities, to problems that were easily treated, for example ear wax. All of the total group screened had at least one undetected health problem which was known to mimic the decline associated with Alzheimer's disease, such

as thyroid, sensory, cardiac and mental health problems. Overall, the group who were found to show decline consistent with Alzheimer's disease did not differ significantly from the non-deteriorating group in terms of having increased health problems, with the exception of hearing problems, which were mainly the result of ear wax and therefore easily treated.

In a number of cases a higher percentage of the non-deteriorating group were found to have particular health problems than the deteriorating group. The diagnosis of Alzheimer's disease involves the exclusion of alternative causes, in particular other health problems. The results of this present study suggest that the decline of the deteriorating group cannot be attributed to other treatable causes.

The study has a number of implications. Firstly, it would suggest that, despite a large body of literature highlighting the health needs of people with learning disabilities in general (Martin et al 1997) and people with Down syndrome in particular (Lennox and Kerr 1997), many health problems remain undetected. There may be a number of reasons for this.

Barker and Howells (1991) and McKenzie et al (1999) observe that GPs may believe that it is the responsibility of community learning disability team members to meet the clients' health care needs despite a number of reports which have identified primary health care teams as responsible for meeting these needs (Department of Health 1995). This uncertainty may contribute to health needs being unmet and indicates a clear need for collaboration between two services. The Royal College of Nursing (1998) advocates that there should be a named learning disability nurse attached to every GP practice to help facilitate better care. The present study suggests that one obvious role of the learning disability nurse working in this context is the provision of health screening.

Secondly, previous studies have suggested that one important factor is the reliance on staff to detect accurately and report the health needs of clients (Paxton and Taylor 1999).

Research suggests, however, that staff may not always have the knowledge or skills to do this adequately (Kinell 1987). Staff may fail to realise the significance of a particular health condition for the client. In the present study, two clients who were deteriorating did not receive a health screen because staff repeatedly failed to attend the appointment despite letters being sent to the service manager reminding him of the importance of excluding treatable causes for the client's decline. This suggests that staff may benefit from some basic training in this area. A

number of training packs have been developed for this purpose (Earnshaw and Donnelly 2000).

A third reason for the health problems of people with Down syndrome continuing to go undetected may be that the Down Syndrome Medical Interest Group (1999) recommendations were only published and are targeted at children with Down syndrome. This may mean that resources are also being targeted at children and adults are seen as less of a priority.

Overall, the study would suggest the importance of having a screening programme as part of a pathway for clients at risk of developing Alzheimer's disease. As noted above, Alzheimer's disease is diagnosed by the exclusion of other factors which may be causing decline (Aylward et al 1995). Such factors clearly include other health problems. It cannot yet be assumed that all clients are having their health needs reported and met routinely. An established health screening programme would therefore appear to be a crucial component of any pathway that hopes to promote better services for this client group.

The development of such a screening programme does, however, have resource implications, not only for the nursing services but also for other professions in the learning disability

team. The present project resulted in a number of referrals to other team members, including psychology, psychiatry, speech therapy and, in particular, dietetics. Twenty-six of the participants were overweight to some degree. It is often assumed that weight gain is characteristic of people with Down syndrome, despite the Down Syndrome Medical Interest Group (1999) indicating that the weight gain is no greater than that in the general population. To develop and run a care pathway for clients with Down syndrome relies on a service having an appropriate professional composition and being resourced to an adequate level (McKenzie et al 2000). A failure to do so may result in basic health needs continuing to be undetected and untreated.

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## REFERENCES

- Aylward CH et al (1995) *Diagnosis of dementia in individuals with intellectual disability*. Washington. American Association on Mental Retardation.
- Barker K, Howells G (1991) The medical needs of adults. In *Primary Care of People with a Mental Handicap*. London, Royal College of General Practitioners.
- Burt DB et al (1998) Dementia in adults with Down syndrome: diagnostic challenges. *American Journal on Mental Retardation*. 103(2), 130-145.
- Dalton et al (1993) Association between Alzheimer's disease and Down syndrome: clinical observations. In Borg JM et al (eds) *Alzheimer's disease, Down syndrome and their relationship*. Oxford. Oxford University Press.
- Department of Health (1995) *The health of the nation: a strategy for people with learning disabilities*.
- London. Department of Health.
- Down Syndrome Medical Interest Group (1999) *Basic medical surveillance essentials for people with Down syndrome*. Oxford, DSMIG.
- Earnshaw K, Donnelly V (2000) *Down syndrome and Alzheimer's disease: a training pack for carers and staff working with individuals who have dementia*. Bradford. Bradford Community Health NHS Trust.
- Hutchinson NJ (1999) Association between Down syndrome and Alzheimer's disease: a review of the literature. *Journal of Learning Disabilities for Nursing, Health and Social Care*. 3(4), 194-203.
- Janicki MP et al (1996) Practice guidelines for the clinical assessment and care management of Alzheimer's disease and other dementia among adults with intellectual disability. *Journal of Intellectual Disability Research*. 41(5), 365-372.
- Martin DM et al (1997) health gain through health checks: improving access to primary health care for people with intellectual disability. *Journal of Intellectual Disability Research*. 41(5), 401-408.
- McKenzie K et al (1999) Learning disability services: a survey of general practitioners. *Scottish Medicine*. 15(5), 4-6.
- McKenzie et al (2000) Professional Composition of Community Learning Disability Teams in Scotland: implications for service provision. *Health Bulletin*. 58(3), 192-197.
- McKenzie et al (2000) Pathways to Success. *Learning Disability Practice*. 3(1), 16-19.
- McKenzie et al (2001) An evaluation of community learning disability services for children with a learning disability. *Health Bulletin*. 59(2), 91-96.
- Paxton D, Taylor SD (1998) Access to primary care for adults with a learning disability. *Health Bulletin*. 56(3), 686-693.
- Royal College of Nursing (1998) *Two per cent of the nation: a health strategy for people with a learning disability in Scotland*. Falkirk, Royal College of Nursing.