

Parental satisfaction with health services provided to children with Down syndrome in north-west England: an ENT perspective

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Abstract

Aims: To evaluate parents' satisfaction with medical and allied health services provided to children with Down syndrome in north-west England, comparing ENT and its allied services with other areas of health service provision.

Methods: A questionnaire survey of parents attending a north-west England Down syndrome association conference. Demographic data, departments visited, satisfaction with each service (scored one to five), waiting times for each service (scored one to five), service need (scored one to three) and accessibility (scored one to three) were recorded.

Results: Otolaryngology had been used by 50 per cent of children, with a satisfaction of 2.63 (the second worst score). Speech and language therapy was used by 90 per cent of the children, with a satisfaction of 3.26 (the worst score). The service felt to be most needed and also most difficult to access was speech and language therapy.

Conclusion: Otorhinolaryngology departments should assess how they can improve their service to this population with specific ENT needs. Speech and language services for children with Down syndrome should be expanded.

Key words: Down Syndrome; Down's Syndrome; Parents; Otolaryngology; Speech Therapy; Allied Health Personnel

Introduction

Down syndrome is the most common congenital chromosome abnormality, affecting approximately 1 in 1000 live births,¹ representing a sizeable population. Recent advances in social care and medical care have increased the life expectancy of those with Down syndrome, from an average of 25 years in 1983 to an average of 49 years in 1997.¹

Social acceptance of those with Down syndrome has improved over the last few decades. The care of the patient with Down syndrome has been de-institutionalized; today, parents are the primary carers for these children. More resources have been made available to help these children to achieve their full developmental potential, to integrate into society and, ultimately, to lead fulfilled, productive, independent lives.

Down syndrome is associated with multiple medical conditions which influence quality of life and life expectancy. Improvement in these conditions involves early identification of expected pathology, treatment of specific associated disorders and

regular monitoring of the development of these patients.¹ This intensive medical input, from a very young age, is only possible with numerous, regular out-patient visits to diverse medical disciplines and, in some cases, multiple hospital admissions.

In an attempt to understand patients' and parents' experience of these multiple hospital visits and to identify satisfaction with current medical and allied health services provided in the region, parents attending a north-west England Down syndrome association conference in 2005 were surveyed. Their responses allowed us to evaluate their overall impression of the regional health services provided, and to compare their experience of diverse medical and allied health units with the service offered by ENT departments.

Method

All parents attending the north west of England Down syndrome association conference were personally invited to complete a survey questionnaire designed to evaluate their satisfaction with the

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service provided by the regional health departments. The survey was composed of choice questions (using tick-box replies) and quality questions (using visual analogue scale scores), with a final free text answer.

The questionnaire covered the following: age of the child and town or city of residence; medical services and allied health services currently or previously used (general practice, community or hospital paediatrics, Down syndrome clinics, cardiology, general surgery, ophthalmology, otolaryngology, genetics, physiotherapy, occupational therapy, speech therapy, health visiting, audiology, dietics and orthotics). Dividing the services provided into medical specialities and allied health services, respondents were questioned regarding their overall satisfaction with each service (ranked from one (very satisfied) to five (very unsatisfied)) and the waiting time they had experienced for first and follow-up appointments for each service (ranked from one (excellent) to five (very poor)). Dividing the services provided into medical specialities, physiotherapy, occupational therapy, speech and language therapy, and health visiting, respondents were questioned regarding their subjective impression of need for those services (ranked from one (not needed) to three (very needed)) and their difficulty in accessing those services (ranked from one (not difficult) to three (very difficult)). Finally, parents were asked to rank the top three services they considered most needed for their child, in order of importance, from all the available medical, allied health, educational and social services (this was a free text field).

Results

Forty-eight of the 130 parents attending the conference responded to the questionnaire. The response rate was difficult to establish accurately because, in many cases, both parents attended the meeting but only one was invited to complete the questionnaire. The response rate was between 36.9 and 73.8 per cent. The average age of the children concerned was 5.5 years (range 0.5–15 years, standard deviation four years).

Medical specialities

The numbers of children currently and previously attending each medical speciality are displayed in Table I. At the time of the survey, the mean number of medical specialities currently treating these children was 3.2 (range 0–7), with a mean of 5.4 specialities (range 2–9) involved in current and previous care. The specialities more frequently involved were: hospital paediatrics (91.6 per cent), general practice (87.5 per cent), ophthalmology (77 per cent), cardiology (72.9 per cent), community paediatrics (66.6 per cent) and otolaryngology (50 per cent).

Parents' satisfaction levels for each medical service, alongside the waiting time for first and subsequent appointments, are included in Table I. Mean overall satisfaction with the medical services was 2.17 (range 1.67–3.5). The specialities with

better satisfaction results were Down syndrome clinics (1.67, $n = 3$) and cardiology (1.76, $n = 35$). The specialities with worse scores were genetics (3.5, $n = 7$) and otolaryngology (2.63, $n = 24$).

Allied health services

The numbers of children currently and previously attending each allied health speciality are shown in Table II. The average number of allied health services presently used was 2.9 (range 0–7), with an overall past and present use of 4.4 (range 2–8). The more used departments were: audiology (91 per cent), speech and language therapy (90 per cent) and physiotherapy (77 per cent); the least used was dietics (21 per cent).

The average level of satisfaction for allied services was 2.51 (range 2.17–3.26). The best satisfaction scores were recorded by orthodontics (2.17), dietics (2.18) and audiology (2.21). The worst scored service was speech and language therapy (3.26).

Level of need and ease of access to services

To assess parents' subjective impressions of need for and availability of the different services provided, parents were asked to score the following services: medical services, physiotherapy, occupational therapy, speech and language therapy, and health visiting. The results of this questionnaire are included in Figure 1. The service felt to be most needed was speech and language therapy (2.83). This was also felt to be the service most difficult to access (2.12). The service felt to be least needed was health visiting (1.52); this was also felt to be the least difficult to access (1.14).

In the last part of the questionnaire, we asked the parents to rank the different services according to what was the single most required service for their child. The service ranked as most needed, above all others, was speech and language therapy (ranked first by 46 per cent and in the top three by 69 per cent). The next most needed services were educational support, medical services and physiotherapy (ranked in the top three by 46, 25 and 23 per cent, respectively). Those results are shown in Figure 2.

Discussion

Down syndrome affects approximately 1 in 1000 live births.¹ All children with Down syndrome undergo screening for cardiac, ophthalmology and hearing disorders. Furthermore, those children have a higher incidence of diverse pathology than the general population, and, therefore, they are also referred to many other medical specialities (average number of services used: 5.4) and health allied services (average number of services used: 4.4). In an effort to help this 'high attender' population and to minimize and rationalize the use of hospital services, we attempted to gain a greater understanding of these children's parents' individual and comparative impressions of the different health services provided. As an ENT department, most of our resultant efforts have initially been concentrated on improvement of

TABLE I
MEDICAL SPECIALITIES INVOLVED IN CARE OF DS CHILDREN: USAGE AND SATISFACTION

Specialty	Users (<i>n</i>)			Satisfaction score		
	Current	Previous	Total (<i>n</i> (%))	Overall	For time to 1st appt	For time to follow-up appt
DS clinic	2	1	3 (6)	1.67	2.33	1.5
Cardiology	14	21	35 (73)	1.76	1.67	2.11
GP	27	15	42 (88)	1.85	1.59	1.71
Surgery	5	11	16 (33)	1.86	2.25	2.44
Ophthalmology	28	9	37 (77)	2.03	2.39	2.68
Orthopaedics	7	7	14 (29)	2.08	2.22	2.6
Community paediatrics	26	6	32 (67)	2.1	2.38	2.5
Hospital paediatrics	23	21	44 (92)	2.2	2.13	2.19
ENT	14	10	24 (50)	2.63	2.47	2.94
Genetics	7	7	14 (29)	3.5	3.2	3.5
Average	3.2	2.3	5.4	2.17	2.26	2.42

DS = Down syndrome; appt = appointment; GP = general practice

ENT services; from here, we will seek to integrate our services with those of other hospital departments.

Ear, nose and throat disorders are found more frequently in children with Down syndrome than in the general population (Table III).¹⁻⁸ Otorhinolaryngology departments are used by 50 per cent of Down syndrome children. The average satisfaction with the service provided by ENT was 2.63 (average to satisfactory). This result is the second worst of all the medical specialities, only exceeded by genetics (3.5, only used by seven patients). Audiology services should assess all children with Down syndrome as part of a routine screening programme. Of the children relevant to this series, 92 per cent had used this service, with an average parental satisfaction level of 2.21 (the average satisfaction with allied health services was 2.51).

There are several potential reasons for reduced parental satisfaction with ENT services compared with satisfaction with other medical specialities. The questionnaire did not specifically address parents' reasons for dissatisfaction, so the following is the authors' interpretation of the results of the survey, and also findings from personal experience.

The first potential reason for dissatisfaction becomes apparent on analysing overall satisfaction and waiting times for appointments. Analysing Table I, it was easy to find a correlation between scores for satisfaction and those for 'waiting time

for the first and follow-up appointments'. Ear, nose and throat services scored second worst for waiting time (2.47 for first appointment and 2.94 for follow-up appointment) and also had one of the lowest overall satisfaction scores. It may be that it is simply the waiting time that has the greatest impact on parents' satisfaction, and considerable effort has been made to reduce waiting times throughout the NHS, presumably because of this effect on customer satisfaction.

The nature of the diseases seen in each clinic and the available treatment options for each speciality should also be considered. For example, a parent is likely to be more satisfied with a single, complex, life-saving cardiac surgical procedure, followed by discharge from follow-up because of cure, than with multiple attendances and admissions for recurrent otitis media with effusion, with hearing loss and multiple ventilation tube insertions, or the rejection of hearing aids despite their heroic efforts to achieve compliance. Cardiac and surgical clinics are the only services that have discharged more patients from their care than they are currently seeing (60 per cent of cardiac clinic and 69 per cent of surgical clinic attendees are previous users). Both these clinics scored better than the mean for all medical specialities (1.76 and 1.86, respectively; mean = 2.17).

We must also consider that other specialities may provide clinics specifically for children with special

TABLE II
ALLIED HEALTH SPECIALITIES INVOLVED IN CARE OF DS CHILDREN: USAGE AND SATISFACTION

Specialty	Users (<i>n</i>)			Satisfaction score		
	Current	Previous	Total (<i>n</i> (%))	Overall	For time to 1st appt	For time to follow-up appt
Orthotics	18	5	23 (48)	2.17	2.29	2.38
Dietics	6	4	10 (21)	2.18	2.88	2.6
Audiology	33	11	44 (92)	2.21	2.45	2.3
Health visiting	14	18	32 (67)	2.36	2.2	2.32
Physiotherapy	17	20	37 (77)	2.43	2.54	2.36
OT	11	11	22 (46)	2.94	2.94	2.73
SLT	38	5	43 (90)	3.26	3.41	3.41
Average	2.9	1.5	4.4	2.51	2.67	2.59

DS = Down syndrome; appt = appointment; OT = occupational therapy; SLT = speech and language therapy

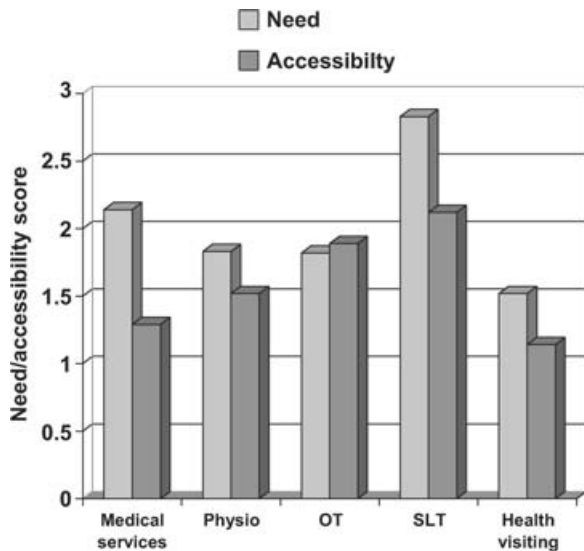


FIG. 1

Selected services scored on need (1 = not needed, 2 = needed, 3 = very needed) and difficulty of access (1 = not difficult, 2 = quite difficult, 3 = very difficult). Physio = physiotherapy; OT = occupational therapy; SLT = speech and language therapy

needs, or even specifically for children with Down syndrome, in order to allow adequate consultation time and to gather a knowledgeable multidisciplinary team. If ENT clinics have not made such allowances, and children with Down syndrome are thus seen in routine ENT clinics without any distinction or extra time for consultation, it could be difficult to provide a satisfactory consultation.

With new technological advances and simpler access to medical information, we found many parents to be extremely knowledgeable and up-to-date regarding medical problems related to Down syndrome. They expect a similar level of

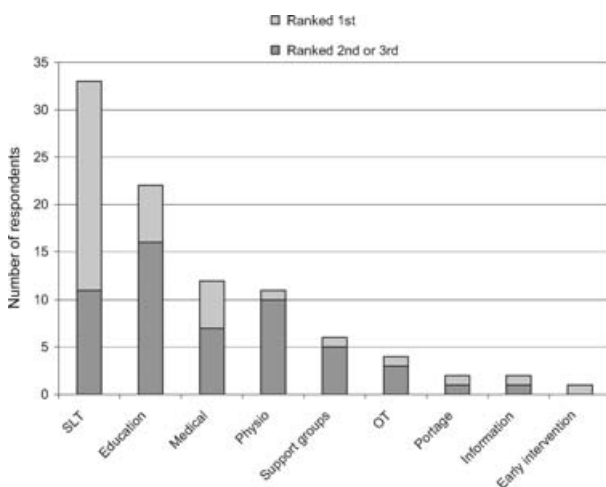


FIG. 2

Respondents' ranking of the single most important service for their child (and the number of respondents ranking these services within their top three). SLT = speech and language therapy, Physio = physiotherapy, OT = occupational therapy

TABLE III

ENT DISORDERS ASSOCIATED WITH DOWN SYNDROME

<i>Hearing loss</i> (38–78%) ^{6,8}
Conductive ~83%
– OME/infection 60%
– Idiopathic 25%
– Ossicular malformation
Mixed/sensorineural 4–20% ²
External auditory canal stenosis
– 40% at birth, usually resolves by age 2–3 years ²
Ventilation tubes extrude sooner
Multiple sets of ventilation tubes often required ⁴
Glue more tenacious ⁷ – blocks tubes, recurs quicker
More frequent infection of ventilation tubes ⁵
Abnormal eustachian tube cartilage, large adenoids, contracted nasopharynx
Reduced immune function
<i>Chronic rhinorrhoea</i> (almost universal) ²
<i>Obstructive sleep apnoea</i> (63%) ²
Large tonsils, adenoids (true & relative)
Small nasal passages
Micrognathia
Macroglossia (true & relative)
Hypotonia
Obesity
<i>Atlanto-axial instability</i> (15%) ²
2% develop spinal cord compression
<i>Subglottic stenosis, narrow tracheal diameter</i> ²
Tube 2 sizes smaller for intubation

OME = otitis media with effusion

knowledge from their doctors, and their resulting preconceptions about, and high expectations of, a medical appointment can sometimes jeopardize their impression of a satisfactory result from the consultation.

We consider it important to highlight the results for the speech therapy services. These are considered the most important service of all the disciplines (being ranked in the top three most needed services by 69 per cent of respondents); however, they also scored the lowest satisfaction level for any allied health service. Parents also ranked speech therapy services as the most difficult to access (1.18), and they scored the worst of all the medical and allied health services for waiting time for first appointment (3.41). These results stress the importance given by parents to waiting times and accessibility; they are two of the most important factors in satisfaction.

Suggested improvements in ENT services

The survey does not identify the factors involved in parental satisfaction, and further studies are warranted to assess these. However, based on the results showing low parental satisfaction with ENT services, and also based on the senior author's experience as a parent of a child with Down syndrome and as an otolaryngologist with special interest in Down syndrome, we suggest the following potential points of improvement in ENT services for children with Down syndrome: (a) efforts to reduce waiting times; (b) better general knowledge of ENT and associated relevant medical conditions in this population; (c) more (special) clinics for children with special needs, allowing longer

consultation times and rapid access; (d) priority listing for even routine procedures such as ventilation tube insertion and tonsillectomy; (e) expansion of allied health services (especially speech therapy), with rapid access from ENT clinics; (f) consideration of the establishment of subregional or regional Down syndrome clinics, with an ENT specialist in attendance; and (g) specific incorporation into otolaryngology training of the topic of ENT manifestations of Down syndrome, in order to raise awareness of the potential problems encountered and the specific needs of this population.

- **Down syndrome is associated with multiple medical conditions which affect life expectancy and quality of life**
- **Input from several medical and allied health specialities is often required for each child**
- **There is a high incidence of ENT disorders in this population**
- **In north-west England: ENT had the second lowest parental satisfaction level of all medical specialities involved in care for children with Down syndrome; speech therapy has the lowest parental satisfaction level of all allied health services; and parents feel speech therapy is the most needed and most difficult to access of all services provided for children with Down syndrome**

Conclusion

Our survey shows that, of all the medical services provided to children with Down syndrome in north-west England, ENT, despite being utilized by half of this population, is rated second lowest in terms of parents' satisfaction. Further studies are warranted to assess factors influencing parental satisfaction, and ENT surgeons should reassess the service they provide to this population.

Of the allied health services, audiology provided above average parental satisfaction. Speech and language therapy provided the lowest level of

satisfaction. It was felt to be the most difficult service to access, with the longest waiting times, and it was also felt by parents to be the most needed service for their child, of all the medical, allied health, educational and social services. The results of this survey indicate that speech and language therapy services for children with Down syndrome in north-west England should be expanded.

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Mr P Sheehan takes responsibility for the integrity of the content of the paper.

Competing interests: Patrick Sheehan is an ENT consultant with a special interest in Down syndrome who runs the ENT clinic for Children with Down Syndrome at Manchester Children's University Hospital. He is also the parent of a child with Down syndrome.
