CHAPTER 4

RESULTS

Number and nature of returns

182 case children were identified from the special needs register and their parents were sent the questionnaire. 95 completed and returned it (response rate 52%). There was no statistical difference between responders and non-responders in terms of gender, educational statement, age or Townsend deprivation score.

The 95 case children fell into a number of diagnostic groupings: 15 had cerebral palsy and 15 had autism. 40 had other developmental/behavioural difficulties, including Down's and other syndromes, emotional/behavioural disorder, ADHD and dyspraxia. 25 had other health conditions, including orthopaedic or neuromuscular problems, special sense deficits or severe asthma, diabetes or cardiac disease.

Following the experience of the pilot, two control children were selected for each case child, and parents of control children were approached by school teachers, who received the questionnaires from the research team. It was therefore not possible to look at differences between respondents and non-respondents for the parents of control children, but 364 questionnaires were sent out to the teachers, of which 69 were returned (response rate 19%).

Missing items

Missing answers to questionnaire items were assigned a 0 (no problem) score. One frequently omitted question related to plans for future adaptations to the home, and it is possible that parents found this too speculative. Parents of control children often left out questions around general and specific support and understanding with respect to their child, and it is possible that for parents of non-disabled children this question was meaningless. Overall, the majority of parents answered all the questions.

Case/control comparison

There was no significant difference between cases and controls as regards age, sex and Townsend score.

To test whether the LAQ-G discriminates between cases and controls at item level, results were compared for each of the 53 questionnaire items. Mean rank was higher for cases than controls for all items except the question

probing longer outings during the past week, where controls actually scored higher (although the difference was not significant: p=0.61). For 49 out of the 53 items, cases scored higher, and the difference was significant ($p<0.05$). For the remaining three, although cases still scored higher, the differences were not significant. The relevant questions were about trips to the supermarket (p=0.85), whether parents were satisfied with their child's school (p=0.07) and the need to put off paying bills in order to make ends meet (p=0.08).

Test/re-test reliability

Parents of 16 children agreed to participate in the test/re-test exercise. 32 controls were identified for these 16 children, of whom 8 agreed to participate. Parents completed two questionnaires four to six weeks apart. Responses to all 53 items were compared. For case children, a difference was present in all 53 items; for controls in 30 out of 53. The p values confirmed that none of these were statistically significant.

Inter-reporter error

11 sets of carers agreed to undertake an inter-reporter reliability exercise. 22 controls were identified for these 11 children, of whom 7 agreed to participate. Two parents/carers completed a questionnaire each. They were encouraged to do this simultaneously and independently. One carer was always the mother. The other was the grandmother for one case child. For all others it was the father. Responses to all 53 items were compared. For case children, a difference was present in 51 out of 53 items; for controls 28 out of 53. The p values confirmed that none of these were statistically significant.

Multi-dimensional scaling, creation of domains and internal consistency

As discussed in the methods section, to allow grouping of items into domains, a multi-dimensional scaling (MDS) procedure was applied to data on 95 case children. The best fit configuration offered by MDS on the basis of Dispersion Accounted For (DAF) ordered the 53 questionnaire items in a three-dimensional model. However, the two-dimensional solution provided a model which accounted for only marginally less variation (DAF 0.9788 versus 0.9881). Graphical representations of both models are shown in Figures 1a and 1b below.

Figure 1a:

Graphical representation of initial three-dimensional model

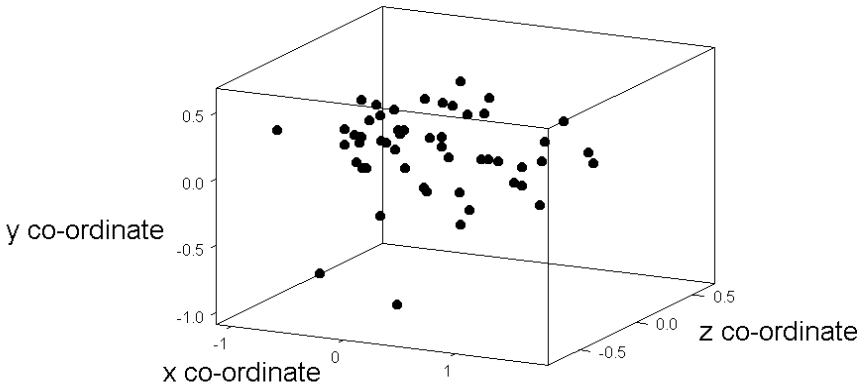
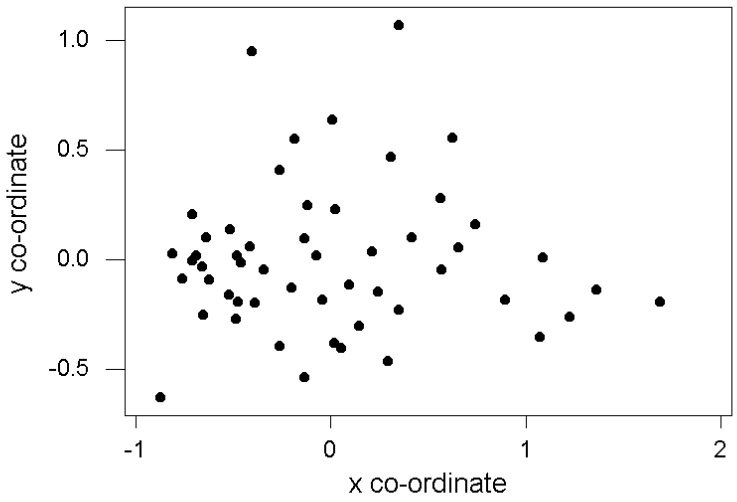


Figure 1b:

Graphical representation of initial two-dimensional model

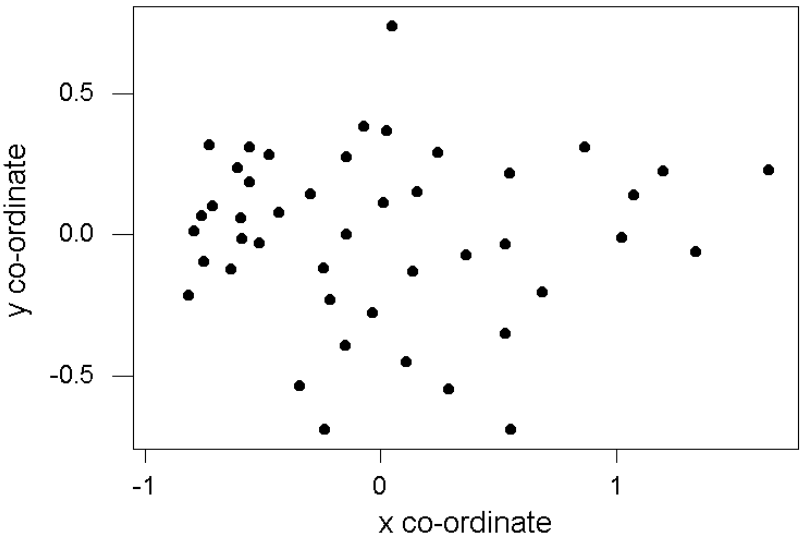


As the two models were virtually identical in terms of DAF, the two-dimensional solution was preferred, as it was easier to visualise. Items were then grouped according to their clustering within the two-dimensional solution and on the basis of their conceptual relationships.

Difficulties were encountered in the allocation of eight items. They were subsequently excluded, and a two-dimensional solution was derived for the remaining 45 items. This final model accounted for 98.0% of the variation within the data (DAF 0.9801), and was reached after twenty iterations, with tolerance again set at <0.001. A graphical representation of the final two-dimensional model is shown in Figure 2.

Figure 2:

Graphical representation of final two-dimensional model



Each dot on the above graph represents a single item. The dot's co-ordinates (i.e. its position within the graph) were statistically determined (by MDS) depending on how the parents answered that question, and Figure 2 is therefore a direct graphical representation of parental responses.

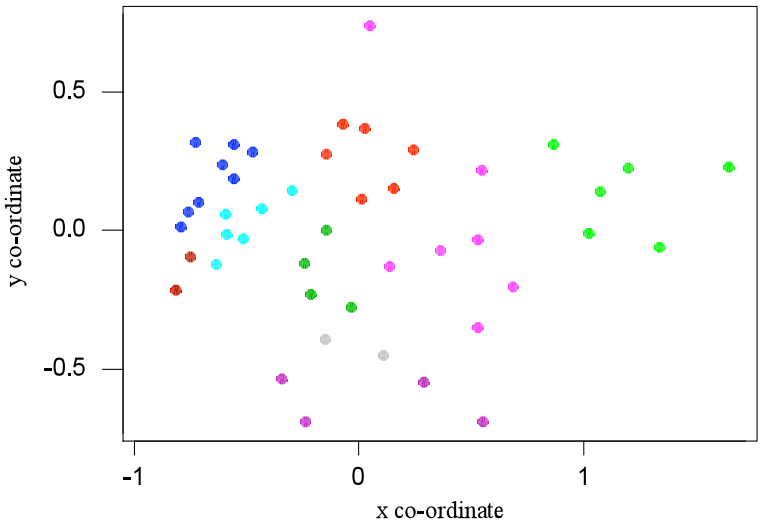
Groupings of items into domains depended on their spatial relationship and their proximity to other items (or dots), and their conceptually relationship. The model allowed nine groupings to be identified, and inclusion within each grouping was then analysed using Cronbach's α.

The nine groupings identified by MDS were stronger conceptually and yielded better α values if condensed into six domains, two with sub-sections. Domains were named to reflect some of the categories in the Activities and Participation dimension of the ICF: *communication, mobility, self care, domestic life, interpersonal interactions and relationships* and *community and social life* [WHO, 2001 #160].

A graphical representation, including colour coding of domains and their sub-sections, is shown in Figure 3. Table 1 shows allocation of specific items to domains, and their respective α values.

Figure 3:

Graphical representation of final domain structure



Nine groupings into six domains:

1) Communication
2) Mobility
3) Self care
4) Domestic life
5) Interpersonal interactions and relationships:
   - general interactions
   - particular relationships
6) Community and social life:
   - family participation
   - child's social life
   - child's civic life

Table 1:

Domain structure with alpha values

Questionnaire item	Domain		Cronbach's alpha
Use of communication Ease of communication	Communication		0.71
Getting out of bed Picking something off floor Adaptations to the home Future adaptations needed Rooms in house entered Items of equipment in home Lifting child Rooms entered unassisted	Mobility		0.88
Washing hands Putting on vest/T-shirt Getting out of the bath Going to the toilet Getting in and out of a car Carrying drink across room	Self care		0.91
Eating a bowl of cereal Giving medication Days missed off school Financial problems Home visits Telephoning professionals	Domestic life		0.66
Doing up buttons/buckles Contact with friends outside Leaving home alone Longer outings Furthest distance unassisted Out of school activities	General interactions	Interpersonal interactions and relationships	0.69
Assistance needed at night Behaviour Making a noise Stress on siblings	Particular relationships		
Time spent on play activities Time spent unsupervised Change of employment Organising family holidays Restrictions on social life Stress on parents Support in general	Family participation	Community and social life	0.84
Relationships with children Help in getting care for child Support in the area Ability to get a break	Child's social life		
Time to travel to school Satisfaction with school	Child's civic life		

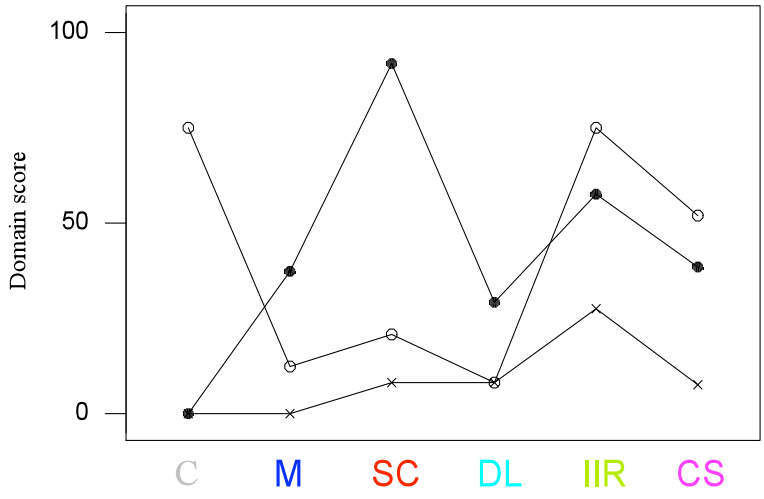
Creation of descriptive profiles

For each of the questionnaire items, a simple scoring system was developed by assigning a score for each point on the response set, with possible scores ranging from 0 to 4 for each item. From these item scores, a score for each domain was derived by summating the scores for the items relating to that domain. Scores were then scaled to a maximum of 100 by using an appropriate constant, to allow 100 as the top anchor point on each scale. The appropriate constants for each of the six domains are listed in the Scoring procedure.

Six domain scores could therefore be calculated for each child. These domain scores could then be used to describe children with different disabilities, using a descriptive profile. Examples of descriptive profiles for three children (one with cerebral palsy, one with autism, and a control child) can be seen in Figure 4.

Figure 4:

Descriptive profiles of three children



C	Communication	● child with cerebral palsy
M	Mobility	○ child with autism
SC	Self care	× control child
DL	Domestic life	
IIR	Interpersonal interactions and relationships	
CS	Community and social life	

A higher score reflects more severe impact of disability and therefore a greater restriction in participation (i.e. *a child with a higher score participates less*).

As expected, the child with autism had high scores in the *communication* and in the *interpersonal interactions and relationships* domains, whereas the child with cerebral palsy scored higher in *mobility* and *self care*. The control child showed lower scores than the two disabled children in all but the *domestic life* domain.

Face validity

Parents were invited to make comments about the questionnaire, and a number of both case and control parents offered constructive remarks. These comments are not listed in detail here, but overall they suggest that the questions made sense to parents. Some parents of non-disabled children said that a few questions were inappropriate for them and their child. Overall, the face validity of the LAQ-G appeared reasonable.

Construct validity

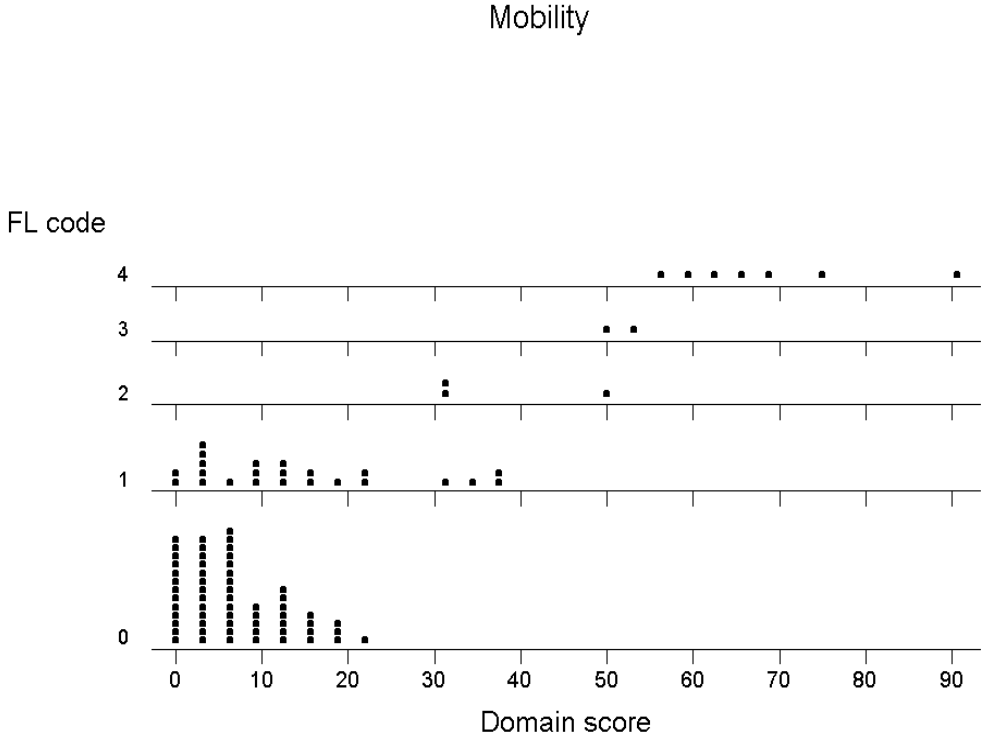
Association with a measure of functional limitation

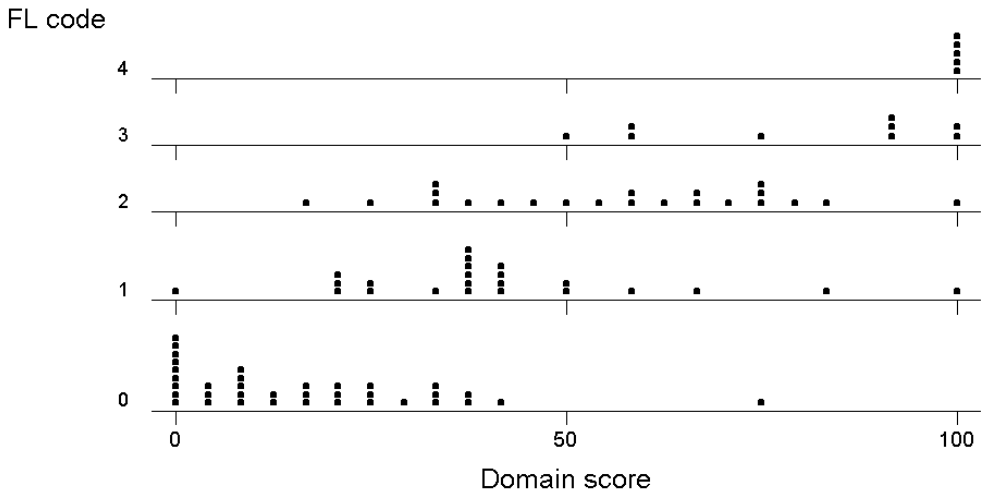
Information on the Northumberland special needs register included codes for functional limitation FL in eight areas, registered on a four point scale (mild, moderate, severe and profound) almost identical to the disability classification recommended by the British Association for Community Child Health [BACCH Working Group on Definitions of Disability in Childhood, 1994 #4]. FL codes are assigned to every child by a clinician who knows the child. We expected a higher FL code to be associated with a higher domain score where the two were comparable.

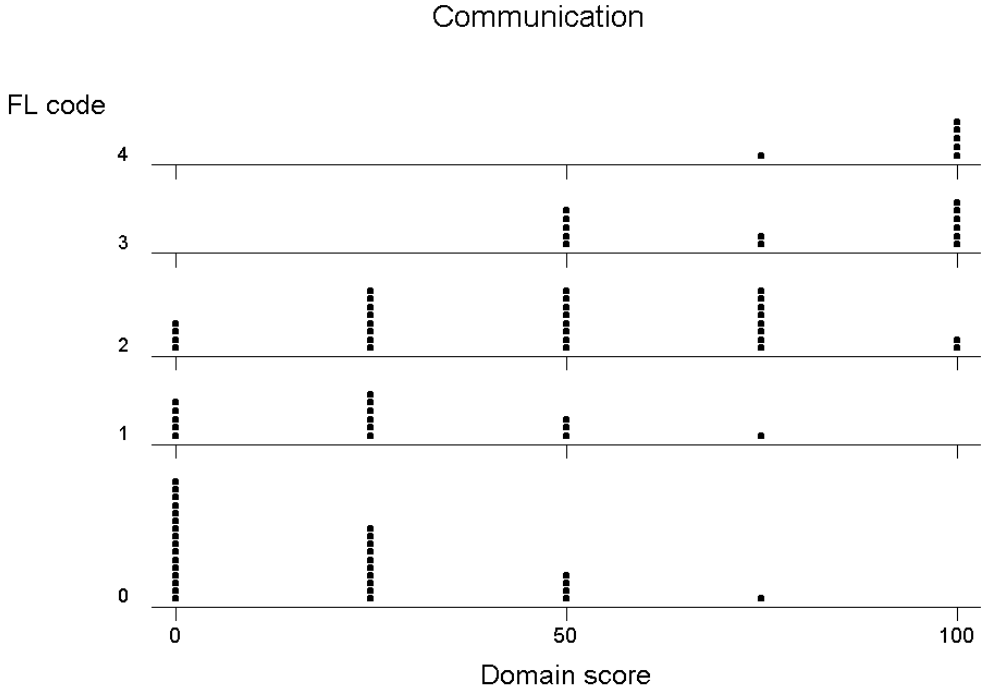
Three FL codes were comparable to three health domains identified by the generic Lifestyle Assessment Questionnaire LAQ-G: children's FL codes in mobility, personal care and communication were compared to domain scores mobility, self-care and communication. The results are shown as dot-plots in Figure 5.

Figure 5:

Dot-plots comparing functional limitation code with domain score





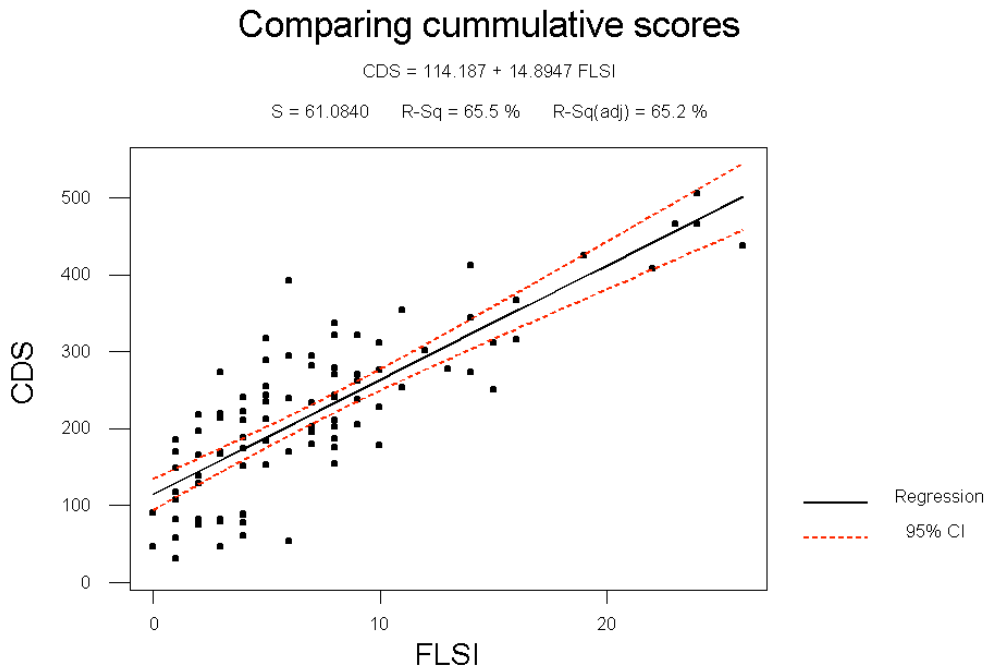

Communication
FL code
4
3
2
1
0
0
50
100
Domain score

FL codes have previously been summated into a severity index (FLSI) as a means of identifying children at the more severe end of the disability spectrum [Colver, 2000 #26].

A child's six domain scores can also be summated into a cumulative domain score, and we looked at whether overall the restriction in a child's participation (expressed as cumulative domain score CDS) was comparable to cumulative limitation of function (expressed as Functional Limitation Severity Index FLSI) for the purposes of validation.

Broadly speaking, a child's FLSI should predict the CDS. This was assessed by using simple linear regression as shown in Figure 6.

Figure 6:



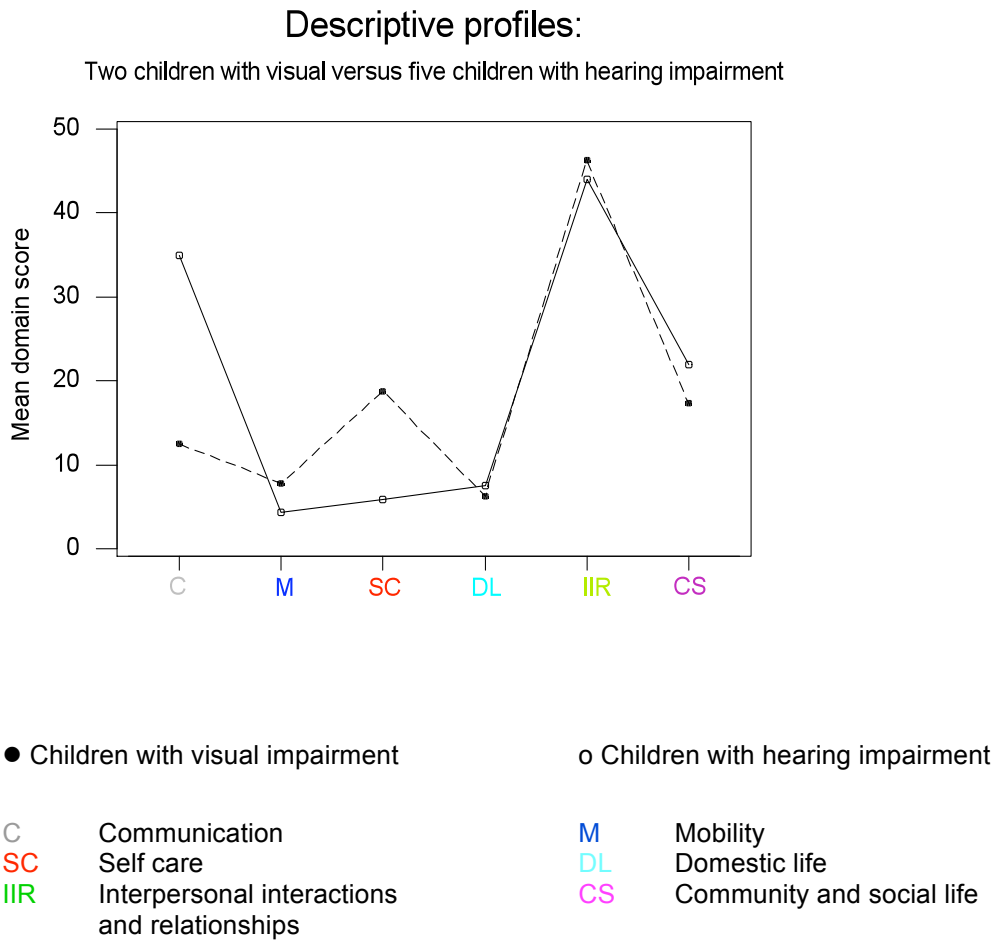
CDS = Cummulative domain score, calculated by summating the six domain scores
FLSI = Functional limitation severity index,
calculated by summating individual functional limitation codes

The four exercises summarised in figures 5 and 6 suggested a good degree of construct validity.

Descriptive profiles for children with different diagnoses

Children from different diagnostic groupings could be expected to show certain predictable differences in terms of the descriptive profile of their difficulties. For example, children with visual problems would predictably have difficulties with interpersonal relationships, community and social life, as would children with hearing problems. However, the latter could also be expected to have problems with communication. This was confirmed when the mean domain scores of two children with visual problems and five children with hearing difficulties were plotted as shown in Figure 7.

Figure 7:



Another example involved comparing children with arthritis to children with neuromuscular problems. Both could be expected to have problems with mobility, but the children with neuromuscular disorders could be expected to have additional difficulties with communication. This was confirmed when the mean domain scores of five children with orthopaedic problems and four children with neuromuscular problems were plotted as shown in Figure 9.

Figure 8