CHAPTER 3

METHODS: FIELD TESTING THE GENERIC LAQ

Site

Field-testing was conducted in Northumberland, a district with a population of 72,500 children and young people aged 0 to 19 [1]. Northumberland’s Child Health Service has a special needs register allowing easy identification of children with a range of disabilities [2]. The Northumberland Local Research Ethics Committee granted ethical approval for this project in September 1996.

Sample size

We decided on pragmatic grounds, that a clinically important difference in mean item score between children with disability (cases) and those without (controls) should be no less than 0.5. Therefore, setting alpha at 0.05 and power at 0.9 and using a standard deviation of 0.6 (from the pilot study) the minimum sample size needed to show a difference was 33 case and 33 control children [3].

In order to estimate what sample size was necessary to derive sensible health domains, other studies seeking to validate health status measures specifically for disabled children were consulted. Sample sizes ranged from 32 to 100 [4-7].

In order to be able to make comparisons between four major diagnostic groupings (cerebral palsy, autistic spectrum disorder, other developmental/behavioural difficulties and other health conditions), we wished to recruit around 30 children in each: 120 children.

Allowing for a 66% return rate (achieved in the pilot study) a sample of 200 case children was deemed desirable and would fulfil the above statistical requirements.

Sample recruitment

The sampling frame was children aged 5 to 7 years on the Northumberland special needs register. This age range represents the first two years of schooling in Northumberland, and was chosen for two reasons:

- children are leaving their home for most of the day for the first time, and difficulties are likely to begin impacting differently and more significantly than during the pre-school years; and
• children with difficulties are often being assessed for a statement of special educational need at this time, and completion of the LAQ-G could be linked to obtaining and documenting other information about the child for this purpose.

From 1\textsuperscript{st} January 1999 to 31\textsuperscript{st} December 2000, children with disabilities (cases) were identified from the register in the month of their birthday. The majority of children on the register have a simple learning disability or language delay, and some subjective de-selection was necessary to ensure a balanced quota of various disabilities and health conditions as outlined above. As this was to ensure a reasonable number of children with each of those common disabling conditions found in a typical health district in the UK, the sample does not represent population prevalence. Parents of selected children were sent the LAQ-G for completion.

For every case child, two questionnaires were sent to the head teacher of the mainstream school they were (or would have been) attending, and the head teacher was asked to identify two non-disabled control children, matched for gender and as closely as possible for age and address. The head teacher also undertook to pass the LAQ-G to the children’s parents, although there was no way of ascertaining whether that actually happened.

All copies of the LAQ-G were sent or given to parents together with a covering letter (personalised for parents of case children) and a front-sheet for parents to record details of the child, and explaining how the questionnaire should be filled in. Anonymity was assured, and a stamped addressed envelope provided for return of completed questionnaires. No follow-up letters were sent.

\textbf{Reliability}

Reliability was assessed at item level. Subgroups of parents within the case sample were selected on the basis of the month in which their child was born, and parents of control children recruited via the appropriate school as above. These parents were sent an initial letter, describing the research and inviting them to sign and return a consent slip if they wished to participate. For those parents who agreed, two copies of the LAQ-G were sent out as described below. Anonymity was assured and stamped addressed envelopes were provided. Up to two follow-up letters with additional copies of the questionnaire were sent after two-week intervals to maximise returns.

\textit{Test/re-test reliability}

Stability of the LAQ-G over short periods of time was tested by the same parent being asked to complete a second LAQ-G after four to six weeks.

\textit{Inter-reporter reliability}

Consistency between reporters was tested by asking both parents (or two main carers) to complete the LAQ-G simultaneously and independently.
Data management and statistical analysis

Data were entered into an Access database. Missing items were assigned a 0 score. The data were considered ordinal and therefore analysed using non-parametric and multi-dimensional techniques, with the procedures contained in the SPSS for Windows suite [8].

Cases and controls were considered unpaired samples for case/control validity and analysed using Mann-Whitney U.

Questionnaire completions on the same child (test/re-test and by two reporters) were considered paired data and were analysed using Wilcoxon signed rank, with cases and controls analysed separately. The analysis was undertaken using difference testing (rather than correlational analysis) in order to establish whether scores differed (or not) between paired samples.

All p values were two-sided. As each analysis was discrete, the p value was not adjusted from <0.05 level.

Creating health domains and testing internal consistency

In order to document a child’s experience meaningfully, a unifying structure had to be derived which allowed the identification of groupings of items into domains. A number of multi-variant techniques exist which allow an underlying relationship between variables to be identified [9]. Multi-dimensional Scaling MDS identifies spatial relationships derived directly from ordinal data, and as we had prior experience of using it in the development of the original LAQ, it was decided to use MDS again on this occasion.

MDS uses similarity ratings to construct a set of co-ordinates for each item, which can then be graphically represented in an n-dimensional space [10]. MDS chooses the most appropriate configuration by making repeated iterative comparisons between the ideal and the statistical configurations, until a “best fit” solution is found. This iterative process continues for as long as there is improvement in the overall “fit” of the model. When improvement falls below a set value – called the tolerance – the iterative process stops.

MDS allows the data to structure itself as a spatial relationship and is not limited by the number of dimensions in which it can calculate similarity co-ordinates. Varying the number of dimensions can increase the “best fit” configuration, although in practice allowing more than five dimensions will tend to make the complexity of the model unmanageable. An ideal “best fit” solution accounts for 100% of the variation between the data, and is expressed as Dispersion Accounted For (or D.A.F) which should be as close as possible to 1.

The multi-dimensional scaling model used in this research was PROXSCAL [11] and applied to case data only. The iterative process was set to continue until improvement became <0.001 (tolerance). Both two and three dimensional models were constructed.
Domains were then identified by looking at how items related spatially and grouping them according to their spatial “clustering”. Conceptual relationships between items also contributed to a lesser degree to their allocation to domains.

Internal consistency (also called internal reliability) is the extent to which there is correlation between different items in a domain. Once a domain solution had been identified, internal consistency was checked by analysing item inclusion within each domain using Cronbach’s alpha [12].

As outlined above, for each of the questionnaire items, a simple scoring system was developed by assigning a score for each point on the response set. From these item scores, a raw score for each domain was derived by summatating the scores for the items relating to that domain. As individual domains did not contain the same number of items, raw scores were not comparable between domains. In order to have comparable anchor points, it was necessary to scale the scores, such that they represented points on a quasi-continuous scale, with 0 as the lowest and 100 the highest chosen anchor point. Increasing scores reflect increasing restrictions in participation.

Validation

Face validity
Respondents were more likely to fill in a questionnaire which appeared relevant to them, and would tend to omit items that appear irrelevant. Therefore, omitted items and their frequency were noted. In addition, responders were invited to make comments about the questionnaire.

Construct validity
This is assessed when, as is the case here, there is no previously validated “gold standard” with which to compare results, and involves looking at
- association with measures of similar constructs
- extent to which results reflect previously determined “common sense” hypotheses.

For the purposes of this study, two constructs were considered:
- association with a measure of functional limitation
- predictable differences between diagnostic groupings

and the following hypotheses were tested:
- children with increasing functional limitation would have higher scores
- children with different medical diagnoses would show predictable differences in their scores.


11. DTSS, *PROXSCAL, Version 1.0.*: Leiden University.