The Lifestyle Assessment Questionnaire
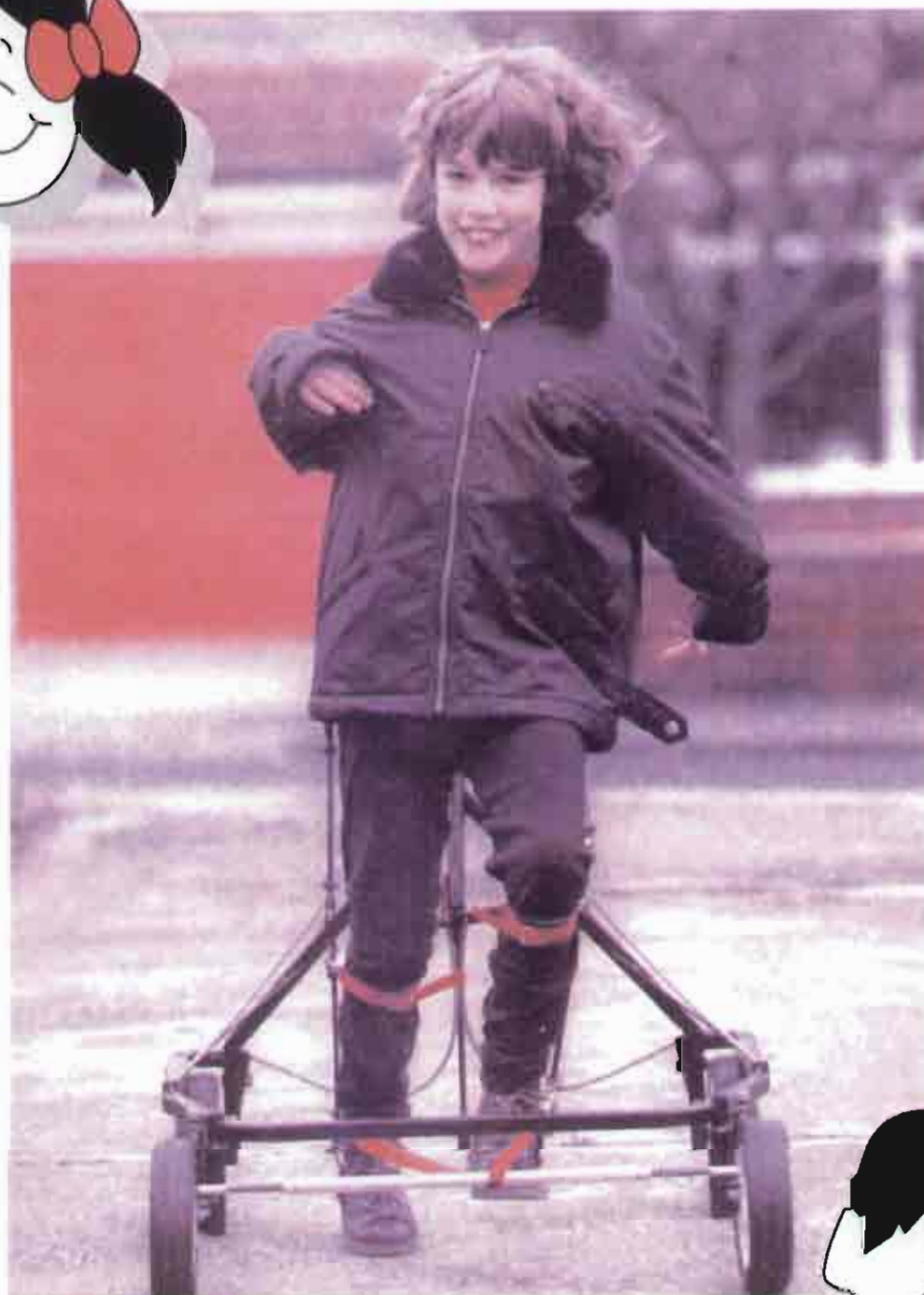
LAQ-CCP

Philip Mackie, FRIPHH, Hon MFPHM
Christine Jessen, MRCP, MRCPCH
Stephen Jarvis, MD, FFPHM
Updated May 2003

response options were presented. For a small number of questions, dichotomous response sets or free space for open answers were offered.

The resulting questionnaire was named the Lifestyle Assessment Questionnaire LAQ. The letters CP refer to the fact that it was developed for children with cerebral palsy.

C. Creation of dimensions

In aiming to create a profile of each child from the items contained within the LAQ – CP, it was necessary to derive a series of dimensions in order to provide a unifying structure. A number of techniques are available, based upon multi-variant statistical analyses designed to identify the underlying relationship between variables. In this respect, four possible types of analyses could have been used. These are regression analysis, factor analysis, cluster analysis and multi-dimensional scaling analysis (Norusis 1985; Schiffman *et al.* 1981).

Multi-dimensional scaling was preferred to the other multi-variant techniques as it allows a small number of dimensions to be identified from spatial relationships derived directly from the data. In all, three different multi-dimensional scaling models were applied to the data on 142 children with cerebral palsy in the 1964-75 birth cohort mentioned earlier. These three models (Alscal, Minissa (N) and MDPref) were applied to the 46 items comprising the new LAQ-CP, following conversion into a form which reflected their similarity. The best fit solution was found to be provided by the Minissa (N) procedure, contained within the MDS(X) statistical library.

The resulting dimensional structure identified six groups of items, which were named by ourselves to reflect elements of the ICIDH classification system, as summarised in Table 2. (It should be noted that multi-dimensional scaling techniques merely provide a spatial representation of the groups of items and do not apply dimensional names to the structures represented.)

It is noticeable that the dimension of 'orientation' is not represented, whilst 'clinical burden' (reflecting the increased burden to the family of the need for numerous contacts with professionals/services) emerges as a major dimension within the structure. The ICIDH dimensions of 'occupation' and 'economic self-sufficiency' are represented by dimensions named 'schooling' and 'economic burden'. These variations in dimensions are a consequence of representing the experiences of children and their families. The impact of the child's problems on the family emerges as an important issue. This is analogous with the concept of 'third-party handicap' as described by Wood and Badley (1980).

TABLE 2

Assessment items and their dimensional structure

DESCRIPTIONS OF THE 46 ITEMS	DIMENSIONS
Assistance needed in fulfilling the following everyday activities: Washing hands Eating a bowl of cereal Putting on a vest/T shirt Doing up buttons Getting out of bed Getting out of the bath Going to the toilet Climbing stairs Getting in/out a of car Other dependency/restraint needed Frequencies of sleep disturbances over the last week Weight related burden of lifting and carrying the child	PHYSICAL INDEPENDENCE
Frequency of doctors' appointments in the last year Number of weeks spent in plaster in the last year Number of operations in the last year Length of hospital stay(s) in weeks in the last year Length of time in weeks wearing body/leg support in the last year Number of items of special equipment in the home Frequency of therapists' appointments in the last year Number/frequency of fits/blackouts in the last year Number of medicines taken yesterday Referral for behavioural problems over the last year Number of special services needed (e.g. physiotherapy)	CLINICAL BURDEN
Furthest distance/range in yards the child covered unaided in the last week Ability to leave family home unaided Number of outings unaccompanied in last week Number of outings requiring transport in last week Purposeful movement & co-ordination Proportion of rooms in the home accessed by child in the last week Proportion of rooms in the home accessed unassisted	MOBILITY
Type of school attended Time taken to get to school from home	SCHOOLING
Cost of special equipment in the last year Other financial costs to the family in the last year Changes in parental employment Use of a special diet Number of adaptations made to the family home in the last year Number of adaptations to the family home still required	ECONOMIC BURDEN
Availability of local help Effects on parental social life Difficulty in organising family holidays Social stress on siblings Social stigma Isolation from natural parents Social stress on parents Number of friends the child has seen outside of school in the last week	SOCIAL INTEGRATION

D. Scoring systems and the creation of a descriptive profile.

The identification of items to be included in the LAQ-CP and the derivation of dimensions to which those items contribute allow for a series of scoring systems to be developed for use with the questionnaire.

Two types of score are required from the questionnaire: firstly, a descriptive profile of the disadvantages experienced by the child; and secondly, an overall assessment of the total impact of disability. This section deals with the first type of score.

For each of the items from the LAQ-CP, a simple system was developed by assigning scores (from 0–4) for each point on the response set. From these scores, an overall score for each of the six dimensions may be derived by simply summating the scores associated with the individual questionnaire items relating to that dimension.

Such simple summation however creates raw scores, which are not comparable between dimensions. It is therefore necessary to scale these raw scores such that they represent points on a quasi-continuous scale from 0–100.

These scale scores for each of the six dimensions form the basis of both the descriptive profile and the overall severity scoring. In the case of the descriptive profile, the scaled score for each dimension can be converted into a standard score on an 11 point scale ranging from 0–100. These standard scores can then be used to describe the children using a descriptive profile of the type shown in Fig. 1.

Figure 1: Sample of a descriptive profile for a child with cerebral palsy

Dimension					Dimensional Score						
Physical Independence	0	10	20	30	40	50	60	70	(80)	90	100
Mobility	0	10	20	30	40	50	60	(70)	80	90	100
Clinical Burden	0	10	20	30	(40)	50	60	70	80	90	100
Schooling	0	10	20	30	40	50	(60)	70	80	90	100
Economic Burden	0	10	20	(30)	40	50	60	70	80	90	100
Social Integration	0	10	20	30	40	50	60	(70)	80	90	100

It should be noted that this descriptive profile treats each dimension as being equally scaled. As a consequence, care should be exercised in not over-interpreting descriptive profiles.

E. Creation of a total impact score: the Lifestyle Assessment Score (LAS)

The descriptive profile assumes that all dimensions impact equally on the life of a child. This, however, may not be a true representation. It is therefore critical to capture the relative importance – or weighting – of individual dimensions in their contribution to the child's total experience.

In achieving a total impact score for children with cerebral palsy (the LAS), it was decided that a linear additive model would be used to integrate each dimensional score.

The model takes the form of:

$$J = \beta_1 n_1 + \beta_2 n_2 + \ldots \beta_j n_j + C$$

where $J = LAS$

β = weighting applied to each dimensional score

n = dimensional score

C = the constant term of the model.

A similar approach was adopted by the OPCS in assessing the severity of disability as part of their national disability survey undertaken in the mid–1980's, where weightings were derived from panels of expert, clinical judges, who used written vignettes to assign a relative disability on standard scales for specific functional abilities (OPCS 1989).

To assess the impact on the family in areas such as social integration and economic burden, it was important to include parents as judges. This required that a new technique be developed, which allowed clinical and parental judges to assess severity on the basis of the same information.

To do this, we created a series of standard video vignettes, which represented items from each of the six dimensions contained within the LAQ-CP. To identify a representative sample of children suitable for participation in the videos, the data from the 1964–75 cohort, contained within the register of the NECCPS, was again used to calculate dimensional scores based on the 46 items contributing to the LAQ-CP.

Common 'patterns' of impact of disability, coded as mild, moderate and severe, were then identified for each dimension. From these common patterns, twelve were further identified which gave a moderate and severe classification for each of the six dimensions

contained within the LAQ-CP, and then used as selection criteria. Twelve children who closely matched these patterns were invited to participate in the videos.

A further 13 children were also invited because they were found to display a common or interesting pattern of disability. Of the 25 children invited to participate in the video-ing element of this research, 19 children aged 4–8 years, actually took part. These 19 children were video-ed in a number of standard environments, with a clip representing each of the six dimensions of impact of disability. This visual representation was augmented by appropriate commentary, which not only described each dimension, but also identified those contributing items which could not be represented visually.

Each dimension was allocated roughly the same time span, and a list of the clips of video representing the dimensions is shown in Table 3.

TABLE 3

Video clip representation of dimensions.

DIMENSION	CLIP
Physical Independence	Dressing, washing and climbing stairs.
Mobility	Showing a child going through a door and picking up an object from the floor in the room beyond, returning carrying the object and closing the door behind them.
Clinical Burden	A graphic representation of a year planner, showing the typical involvement, pain and suffering and inconvenience experienced by the child and family over a year.
Economic Burden	Showing a child using any special equipment that was necessary for them, or in the absence of any specialised equipment, showing the child at play.
Schooling	A graphic representation of a map of the Northern Region showing the relative location of home and school and the time taken to travel between the two.
Social Integration	Showing the child at play.

The video material was used to elicit judgements from three panels of judges.

These were:

1. four paediatricians with expertise in the management of children with cerebral palsy;

2. 27 parents/carers of children with cerebral palsy; and

3. 43 parents/carers of children without disability.

For each video, the judges were required to rate the degree of impact on the child's life for each of the six dimensions, and to make a final judgement of the overall experience for that child. Guidance notes were provided, asking the judges to make ratings along a visual analogue scale (10 cm long) anchored with "no disadvantage" and "most severe disadvantage imaginable".

As a check of internal validity, the judges were also asked to make comparisons between five pairs of videos: a video clip representing a dimension of a given severity was followed by a second clip. Judges were required to choose which of the two clips represented the more severe impact of disability.

To derive an appropriate structure for weighting, a judgement value for each of the six dimensions and for the overall severity rating was derived for each judge with regard to each of the 19 children. A random sample of these were compared within subjects against their choices when undertaking paired comparisons. Results suggested that judges were internally valid in their judgements.

To derive the weightings themselves from these judgement values, it was decided to adopt regression techniques (Norusis 1985), as this method creates weights which are highly suitable for inclusion within linear additive models of the type used to calculate an overall severity score. For each panel of judges separately, the overall severity judgements were used as criterion variables within a simple linear multiple regression model, with each of the six individual judgements forming predictor variables within the model. Table 4 contains the weights derived from these regression models.

Reference to Table 4 identifies that for all three groups of judges, high values of r^2(adj) were observed. This value represents the model fit and in all cases suggests that a good fit was achieved between the six individual scores and the overall severity score.

As might be expected, there is a high weighting given to both the physical independence and mobility dimensions for all three groups of judges. Unexpected, however, was the high weight given for social integration by all three groups. Also of note is the negative weight given by clinicians to schooling. Within this context, a negative weight means that the judges felt that the area was contributing to the *reduction* of overall impact of disability. Therefore, clinicians saw special schooling as reducing disability, possibly as a result of an inability to separate out the notion of disadvantage associated with the stigma of attending a special school from the benefit of being in appropriate schooling.

Table 4
Weighting for dimensions of impact of disability.

	r^2(adj)	Physical Independence	Mobility	Clinical Burden	Schooling	Economic Burden	Social Integration
Consultants	83.6%	0.430	0.219	0.128	-0.014	0.270	0.268
Parents of children in main stream schools	77.1%	0.344	0.270	0.022	0.028	0.110	0.225
Parents of children with cerebral palsy	79.5%	0.359	0.280	0.040	0.008	0.034	0.230
All	78.2%	0.357	0.270	0.033	0.016	0.082	0.224

As comparisons between the groups of panel judges suggested that, generally speaking, their weighting structures were similar, it was decided to collapse all groups together to form a single weighting model based upon a re-calculated regression model. The weightings derived from this regression analysis are contained within Table 4.

The weights derived from the overall regression model were used to form a procedure for calculating an overall severity score by multiplying the weights associated with each of the dimensions by the dimensional score derived from the LAQ-CP within the linear additive model described earlier.

This linear additive model then takes the form of:

LAS	=	0.357 x dimensional score for physical independence
	+	0.270 x dimensional score for mobility
	+	0.033 x dimensional score for clinical burden
	+	0.016 x dimensional score for schooling
	+	0.082 x dimensional score for economic burden
	+	0.224 x dimensional score for social integration
	+	4.05 (constant).

This calculation yields an overall severity score for each child on a scale from 0–100.

CHAPTER 3

RESULTS

An instrument which aims to distinguish between individuals at a given point in time is a discriminative/descriptive tool. As such it needs to demonstrate the properties of reliability, validity and interpretability (Guyatt *et al.* 1992). In this section, the analyses undertaken to test these properties of the LAQ-CP are described.

A. Reliability

The LAQ-CP must generally demonstrate on repeated administration:

1. the same results within individuals, and

2. large and stable differences between individuals.

To test the reliability of the LAQ-CP, the parents of 33 children with cerebral palsy from the 1967-75 birth cohort contained within the register of the NECCPS completed a second LAQ-CP after an interval of four years. Mean LAS for the first use was 41.9 ($\pm$ 24.5) and for the second was 36.5 ($\pm$ 27.9). These are plotted in Fig. 2. The two data sets are found to be significantly correlated ($r = 0.97$, $p<0.0001$).

Figure 2: Scatterplot of first and second Lifestyle Assessment Scores for 33 children with cerebral palsy
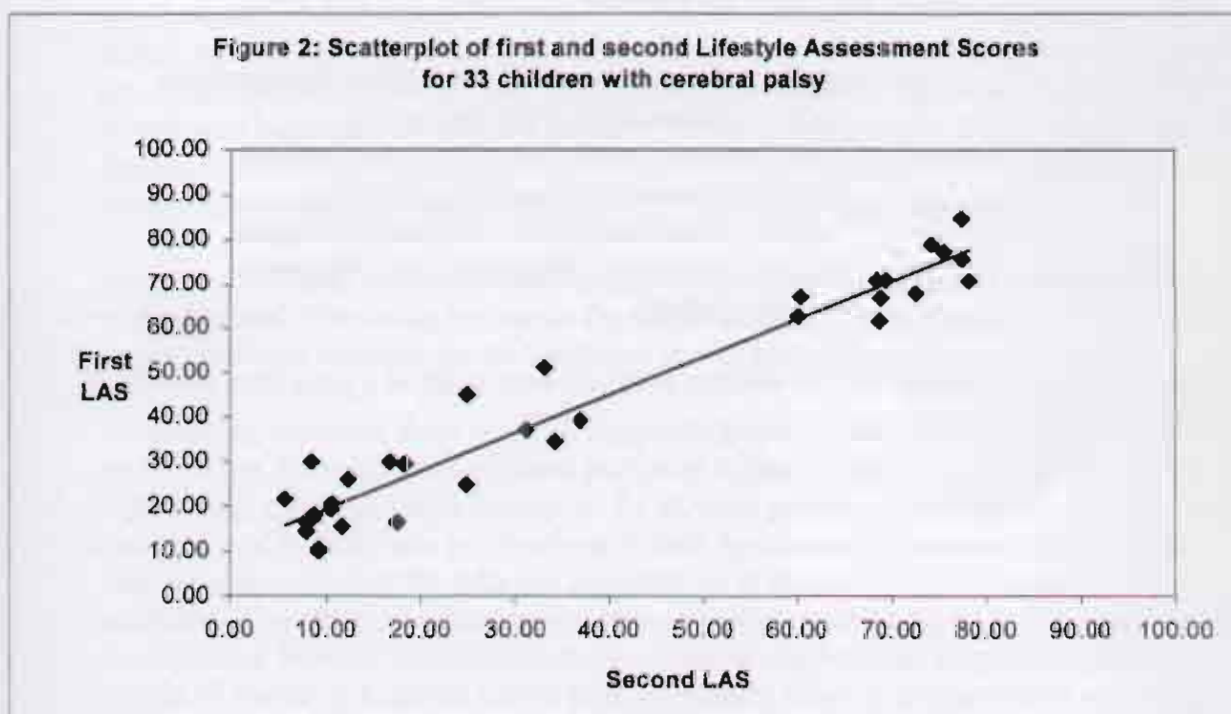
Inspection of Fig. 2 highlights that there is a tendency for the second LAS to be lower than the first.

To test whether the difference between two individuals' score remained large and stable within the re-test, a Friedman's two way, non-parametric analysis of variance (Siegel & Castellan 1988) was undertaken. This showed there was no significant variation between the two data sets ($x^2 = 0.29$, ns) and is indicative of large and stable variations between individuals' first and second LAS.

B. Validity

Validity has to do with whether the instrument is measuring what it is intended to measure. One way of testing this is to look at the extent to which a measure correlates with a 'gold standard'. In the absence of such a 'gold standard' for children with cerebral palsy, we were forced to use a construction to validate the instrument (Guyatt *et al.* 1993).

The construction was derived from the theoretical work of Wood (1980) when he specifies an interactive relationship between disability and the socio-cultural environment. We therefore hypothesise that children with increasing disability, measured as functional limitations, will gain a higher LAS.

The Central Motor Deficit Form (CMDF) is a standard method of recording the clinical findings in children with cerebral palsy (Evans *et al.* 1989). Contained within the CMDF are codes for recording the severity of disability as perceived by the clinician. Additional problems, such as learning difficulty, epilepsy and sensory impairments are also highlighted.

For the 1980–85 birth cohort contained within the register of the NECCPS, the LAQ was completed by the parents/carers, whilst the CMDF was simultaneously administered by a paediatrician. For 44 of the 129 children in this birth cohort, complete LAQ and CMDF data is available for analysis.

The CMDF for each child was scored in such a way as to highlight increasing functional limitation in relation to: head, neck and trunk control; upper and lower limb function; impairment of hearing and/or vision; and communication difficulties.

For example, question 5 in the CMDF asks about head and neck control, classifying as follows:

> *normal head control*
> *abnormal head control*
> *poor head control, but can hold head up for short periods of time*
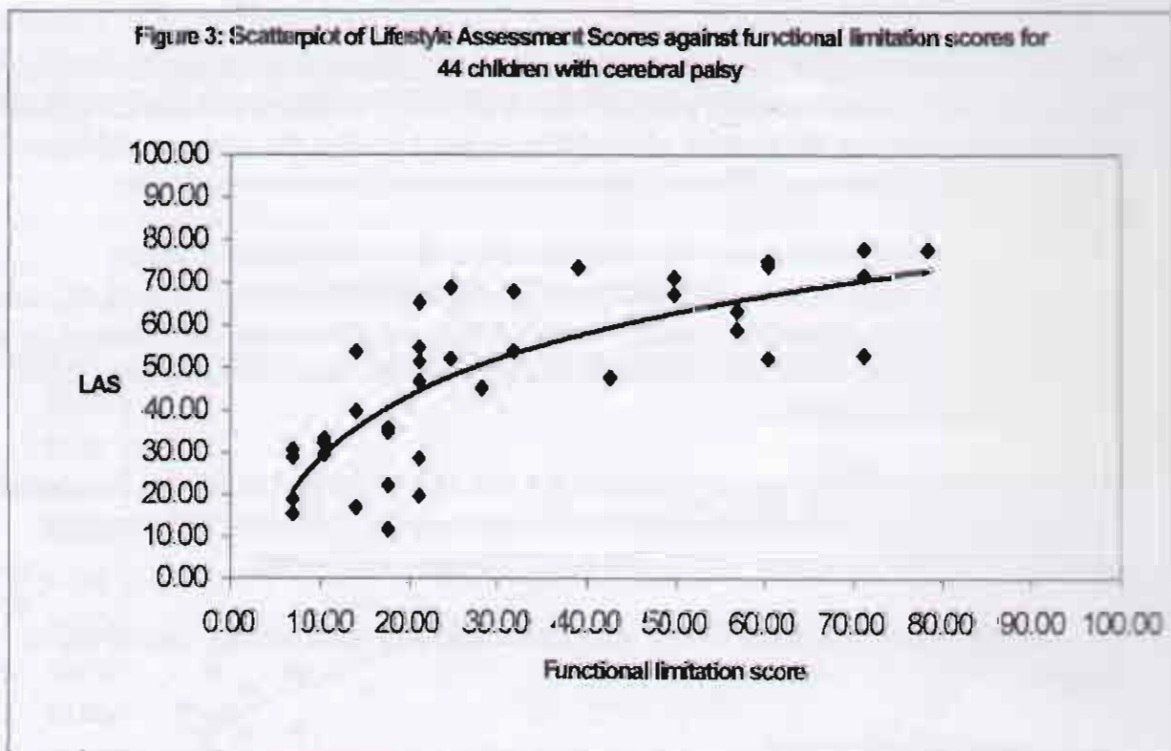> *no obvious head control.*

Abnormal head control was given 1, *poor head control* was given 2 and *no head control* was given 3 functional limitation points.

Additional problems associated with muscle tone, inco-ordination, involuntary movements, epilepsy and learning difficulties were also taken as contributing to overall functional limitation.

Thus, CMDF question 2 asks whether tone is *within normal range, increased, decreased* or *varying* between the two. An additional functional limitation point was assigned if the answer to any of the options other than *within normal range* was "yes".

A simple scoring scheme, reflecting increasing functional limitation, was identified. A maximum score of 29 functional limitation points was possible. Each child's individual score was expressed as a percentage of this possible maximum. Further details about this particular approach to scoring the CMDF can be obtained from the authors upon request.

Fig. 3 plots each child's LAS against the functional limitation score. There is a significant correlation between these two scores ($r = 0.76$, $p<0.0001$). However, trend fitting shows that the relationship between functional limitation and LAS is better described by a log-linear trend ($y = 21.6Ln(x) - 21.6$, $r^2 = 0.63$) than a linear one ($y = 0.69 + 25.7$, $r^2 = 0.58$).

Figure 3: Scatterplot of Lifestyle Assessment Scores against functional limitation scores for 44 children with cerebral palsy

LIFESTYLE ASSESSMENT QUESTIONNAIRE (LAQ-CP):
AN INSTRUMENT TO MEASURE
THE IMPACT OF DISABILITY ON THE LIVES OF
CHILDREN WITH CEREBRAL PALSY
AND THEIR FAMILIES

Philip Mackie, FRIPH, FFPH
Senior Specialist in Public Health
Lothian NHS Board, Edinburgh

Christine Jessen, MRCP, FRCPCH
Consultant in Community Paediatrics
Northumberland Care Trust

Stephen Jarvis, MD, FFPHM
Professor of Community Child Health
University of Newcastle upon Tyne

North of England Collaborative Cerebral Palsy Survey
November, 1998 - updated May, 2003

The front cover shows Kay in her David Hart walker. The authors are grateful to
Kay's parents for permission to print her picture.

C. Interpretability

Interpretability is the third property required of an accurate descriptive tool. A particular score should signify whether children are functioning near-normally, or whether experienced disabilities have a moderate or severe impact on their lives. In the absence of formal approaches to interpretability, simple descriptions of children at differing levels of experienced disadvantage need to be congruent with clinical impression.

The LAS is expressed out of 100 and is described, for ease, as a percentage score. A maximally disadvantaged child scores 100%. General descriptions of children can be mapped onto overall scores.
Thus:

1. a child with LAS of 30% would be completing most, but not all, self-help activities alone, posing little or no economic burden on the family and attending mainstream school with minimal extra assistance;

2. a child with a 50% score would be assisted in many self-help activities, would limit the economic status of the family and would be receiving educational support;

3. a child with a 70% score would be undertaking only very few self-help activities, would be experiencing marked economic effects through the family and would be in a specialised educational setting. The impact of this child's disability on their own life and that of their family is severe.

CHAPTER 4

DISCUSSION

The LAQ–CP reliably measures, at a given point in time, the impact of disabilities on the lives of children with cerebral palsy and their families, as perceived by the child's parent or carer.

Whilst it may be argued that the ICIDH can be seen in this light, it should be remembered that the ICIDH was written specifically for adults and only offers a *classification* scheme for disabilities and handicap, without specifying the mechanisms by which classifications should be made. The ICIDH also neglects the parent/carer perspective.

We have demonstrated a high level of concordance between LAS and a functional limitation score from a simultaneously administered CMDF. This suggests that parental perceptions of the impact of children's disability on their life and family is broadly consistent with medically–derived assessments of central motor function. On the basis of the sample of 44 children studied, LAS increased with increasing functional limitation. However, the relationship was not shown to be linear, with the degree of impact experienced increasing more sharply at lower levels of functional limitation. This is consistent with the theoretical stance taken by the ICIDH, when it argues that disability and its impact (handicap) are closely related, but not interchangeable.

In developing the LAQ-CP, it was argued that it should have three main characteristics: to provide a descriptive profile of the child, to assess impact of disabilities on a child's life, and to provide a single score. Each of these is incorporated into the LAQ-CP.

A. Limitations of the LAQ–CP

It must be stressed that the LAQ–CP is only validated as a descriptive/discriminative tool. It is able to discern variations between individual children at a given point in time.

Stability (or reliability) over a period of time is an important characteristic of the LAQ-CP, and such stability has been demonstrated (see **Chapter 3, A.**). It is however, interesting to note that some reduction in disadvantage appeared to have occurred during the test-retest interval of four years. In the absence of formal, longitudinal studies of children with cerebral palsy, one can only speculate that this could be a consequence of either developmental progression or changes in the children's environment. No studies have at present been done to assess whether the LAQ–CP is capable of detecting changes in a child's total impact score in response to therapeutic and/or service interventions. Although the LAQ-CP is useful in assessing the current status of a child with cerebral palsy, and as such can be used to provide a reliable "snap shot", it has not yet been demonstrated that the LAQ-CP is able to pick up changes over time in response

to a therapeutic programme, if such change actually occurs (i.e. whether it fulfils the necessary properties of an *evaluative* tool).

Similarly, no studies have as yet been undertaken to assess whether a particular total impact score in a child will predict that child's clinical course. Further longitudinal studies, accurately documenting the natural history of cerebral palsy, are necessary to determine whether the LAQ-CP has the necessary properties of a *predictive* tool (Guyatt *et al.* 1992 and 1993).

B. Uses of the LAQ–CP

The LAQ–CP is an ideal tool for use with cerebral palsy registers, and is now used routinely to collect data on children with cerebral palsy born in the North of England (North of England Collaborative Cerebral Palsy Survey 1997 and 1998; Colver *et al.* in prep).

Although some older children have been assessed using this questionnaire, most of the validation has been done with children aged 3-10 years. The LAQ-CP should not be used outside this age range.

In excess of 500 children born from 1964 to date have been assessed using the LAQ-CP. Experience indicates that the LAQ-CP takes about 20 minutes to complete and is considered user-friendly by parents/carers and professionals alike. Including an impact of disability score in data held on cerebral palsy registers has three principle benefits for clinicians and health service planners:

1. it allows greater precision in assessing population health care needs;

2. it provides a severity threshold which can be used within a robust case definition, removing inconsistencies in diagnosis associated with presentation of children with mild forms of cerebral palsy; and

3. it improves epidemiological information by allowing a breakdown of data to look for major changes in prevalence in children with different cerebral palsy syndromes.

The LAQ-CP helps to qualify enduring health problems in childhood cerebral palsy in a way which reflects the experience of children and their families. Without such measures, clinicians and health service planners will continue to describe the health of children without the required precision.

CHAPTER 5

Update 2003

The LAQ-CP instrument has now been reported in two academic papers:

- Mackie PC, Jessen EC, Jarvis SN. The lifestyle assessment questionnaire: an instrument to measure the impact of disability on the lives of children with cerebral palsy and their families. *Child: Care, Health and Development.* 1998:**24**: 473-486
- Mackie PC, Jessen EC, Jarvis SN. Creating a measure of impact of childhood disability: statistical methodology. *Public Health* 2002:**116**:95-101

The authors of the instrument have used the measure in a number of epidemiological analyses:

- Colver AF, Gibson M, Hey EN, Jarvis SN, Mackie PC, Richmond S. Increasing rates of cerebral palsy across the severity spectrum in northeast England 1964-93. *Archives of Disease in Childhood, Fetal and Neonatal Edition* 2000:**83**:F7-F12
- Hutton JL, Colver AF, Mackie PC. Effect of severity of disability on survival in northeast England cerebral palsy cohort. *Archives of Disease in Childhood* 2000:**83**:468-473
- Drummond P M, Colver A F. Analysis by gestational age of cerebral palsy in singleton births in northeast England 1970-1994. *Paediatric and perinatal epidemiology.* 2002:**16**:172-180

Great interest has been shown in the instrument. It is being used in the following active studies:

- A multi centre trial of intrathecal baclofen - UK
- A trial of intervention following gait analysis - Northern Ireland
- A study relating Activity Limitations to Participation – Oxford

Whilst the LAQ-CP was developed for use in children with cerebral palsy, there is little which constrains its use to that condition. With minor modifications, this instrument could be applicable to children who are disadvantaged as a result of other types of physical disability such as spina bifida or muscular dystrophy. We are engaged at the moment in discussions about its use in a study of children with Duchenne muscular dystrophy.

The LAQ-CP has recently been modified to allow its use as a generic measure of impact of disability, allowing total impact score to be calculated for children with all types of disability. This new measure, the Lifestyle Assessment Questionnaire for Generic use (LAQ-G) has successfully undergone pilot studies and field-testing in the district of Northumberland. This has been reported in:

- Jessen EC, Colver AF, Mackie PC, Jarvis SN. Development and validation of a tool to measure the impact of childhood disabilities on the lives of children and their families *Child: care, health and development.* 2003:**29**:21-34

REFERENCES

Bax, M. (1964) Terminology and Classification of Cerebral Palsy. *Developmental Medicine and Child Neurology*, **6**, 295-307.

Butler, N., Gill, D. & Pomeroy, D. (1976) Housing problems of handicapped people in Bristol. *University of Bristol Child Health Research Unit.*

Colver, A.F., Gibson, M., Hey, E.N., Mackie, P.C., Jarvis, S.N. & Richmond, S. On behalf of the NECCPS. (1999) Cerebral Palsy in the North of England 1964-1993: Importance of Measuring Severity. *In prep.*

Evans, P., Johnson, A. & Mutch, L. (1989) A standard form for recording clinical findings in children with a motor deficit of central origin. *Developmental Medicine and Child Neurology*. **31**, 117-129.

Evans, P.M., Evans, S.J.W. & Alberman, E. (1990) Cerebral Palsy: why we must plan for survival. *Archives of Disease in Childhood*, **65**, 1329-1333.

Guyatt, G.H., Kirchner, B. & Jaeschke, R. (1992) Measuring health status: What are the necessary measurement properties? *Journal of Clinical Epidemiology*, **45**, 1341-1345.

Guyatt, G.H., Feeny, D.H. & Patrick, D.L. (1993) Measuring Health-related Quality of Life. *Annals of Internal Medicine*, **118**, 622-629.

Hewett, S., Newson, J. & Newson, E. (1970) The family and the handicapped child. *Allen and Unwin, London.*

Hirst, M. & Cooke, K. (1988) Grading severity of childhood disablement: Comparing survey measures with a Paediatrician's assessment. *Child: care, health and development*, **14**, 111-126.

Hutchinson, T. (1995) The classification of disability. *Archives of Disease in Childhood*, **73**, 91-99.

Jarvis, S.N. (1979) The Handicaps and Ergonomics of Children who use Wheelchairs. M. D. Thesis. *University of London.*

Jarvis, S.N. & Hey, E.N. (1984) Measuring disability and handicap due to cerebral palsy. In: Stanley, F. & Alberman, E. The epidemiology of the cerebral palsies. *Clinics in Developmental Medicine, Spastics International Medical Publications*, **87**, 35-45.

Jarvis, S.N., Holloway, J.S. & Hey, E.N. (1985) Increase in cerebral palsy in normal birthweight babies. *Archives of Disease in Childhood*, **60**, 1113-1121.

Nicholson, A. & Alberman, E. (1992) Cerebral palsy – an increasing contributor to severe mental retardation? *Archives of Disease in Childhood*, **67**, 1050-1055.

North of England Collaborative Cerebral Palsy Survey (1997 and 1998) Annual Reports. *University of Newcastle upon Tyne Department of Epidemiology and Public Health.*

Norusis, M.J. (1985) SPSSX: Advanced statistics guide. *London McGraw.*

OPCS Survey of disability in Great Britain Report 3. (1989) The prevalence of disability in children. *HMSO, London.*

Pharoah, P.O.D., Platt, M.J. & Cooke, T. (1996) The changing epidemiology of cerebral palsy. *Archives of Disease in Childhood,* **75,** 169-173.

Pharoah, P.O.D., Cooke, T., Johnson, M.A. & Mutch, L. (1998) Epidemiology of cerebral palsy in England and Scotland 1984-9. *Archives of Disease in Childhood,* **79,** F21-F25.

Rutter, M., Tizard, J. & Whitemore, K. (1970) Education, health and behaviour. *Longman Group.*

Schiffman, S.S., Reynolds, M.L. & Young, F.W. (1981) Introduction of multi-dimensional scaling – theories, methods and applications. *Academic Press, London.*

Siegel, S. & Castellen, N.L. (1988) Non-parametric Statistics for the Behavioural Sciences. *The Grove Hill, London.*

Wood, P.N.H. (1980) World Health Organisation International Classification of Impairments, Disabilities, and Handicaps. *Office of Publications, WHO, Geneva.*

Wood, P.N.H. & Badley, E.M. (1980) People with disabilities – towards acquiring information which reflects more sensitively their problems and needs. *World Rehabilitation Fund International Exchange on Information.*

APPENDIX 1

NORTH OF ENGLAND COLLABORATIVE CEREBRAL PALSY SURVEY

The Regional Maternity Surveys' Office
25 Claremont Place
Newcastle upon Tyne
NE2 4AA
Telephone: 0191 2331658

Cerebral palsy is one of the commonest causes of physical disability, and increasingly contributes to severe disability amongst children and significant disadvantage in families.

Accurate data on children with cerebral palsy are therefore desirable, and surveys of children with cerebral palsy are important monitors of "peri-natal" developments and standards of care. They can also be used to predict service need.

The decision to establish a prospective survey in the former Northern Region was strongly influenced by two factors:

1. A retrospective survey of cerebral palsy has been carried out on successive 5 year cohorts of children born since 1960 in Newcastle, Northumberland and North Tyneside. Considerable experience has been gained from this study, which formed the basis for developing the measure of impact of disability.

2. The former Northern Region has considerable experience of prospective surveys in the Peri-natal Mortality Survey since 1981 and the Northern Congenital Abnormality Survey since 1984. Since 1996, all three surveys have been administered from the same office and within the University Department of Epidemiology and Public Health.

The cerebral palsy survey covers all births in 16 Northern Districts of the Northern and Yorkshire Region from 1991.
Each District has its own District Convenor, who notifies cases to the survey at the time of diagnosis. Further details are sought when the child reaches age three years, so that the diagnosis can be confirmed and a measure of impact of disability assigned.

Overall strategic direction of the survey is based upon the advice of an Executive Committee, which meets every three months. Overall decision making resides with the District Convenors, who meet twice a year. One of these meetings coincides with an annual study day, at which an Annual Report is produced. Copies of Annual Reports can be obtained from The Regional Maternity Surveys' Office.

The survey is called the North of England Collaborative Cerebral Palsy Survey (NECCPS), and its aims are:

1. to describe the changing epidemiology of cerebral palsy;

2. to describe the adverse impact of cerebral palsy on children and families;

3. to evaluate interventions to reduce such adverse impact; and

4. to provide data for research.

The NECCPS is planning to participate in a collaborative network involving four other cerebral palsy registers within the UK, and is also linked to similar surveys across the European Community. Common data sets, methods for determining accuracy and research questions are being developed as a result.

EXECUTIVE COMMITTEE

CHAIRMAN TO THE SURVEY	Dr Allan Colver
CLINICAL DIRECTOR, SURVEYS' OFFICE	Dr Martin Ward Platt
ADMINSTRATIVE ASSISTANT	Mary Bythell
ACADEMIC ADVISOR	Professor Steve Jarvis
DISTRICT REPRESENTATIVE	Dr Surendra Pandey
HOSPITAL REPRESENTATIVE	Dr Peter Morrell
DEVELOPMENTAL PAEDIATRICIAN	Dr Mary Gibson

DISTRICT CONVENORS

DARLINGTON	Dr Ruth Carpenter
DURHAM	Dr Nnenna Cookey
EAST CUMBRIA	Dr Arthur Paynter
GATESHEAD	Dr Rosemary Menzies
HARTLEPOOL	Dr Kailish Agrawal
NEWCASTLE	Dr Mary Gibson
NORTH TEES	Dr Jemma Dobson
NORTH TYNESIDE	Dr Allan Colver
NORTHUMBERLAND	Dr Christine Jessen
NORTH WEST DURHAM	Dr Surendra Pandey
SOUTH TEES	Dr Eileen Lee
SOUTH TYNESIDE	Dr Nigel Brewster
SOUTH WEST DURHAM	Dr Angela Johnston
SUNDERLAND	Dr Karen Whiting
WEST CUMBRIA	Dr Sheila Precious

LAQ-CP WITH SCORING KEY

The scoring key has been included in the questionnaire here, although usually it is held separately. We have also omitted the introductory front sheet.

Parents generally complete the questionnaire very thoroughly. However, occasionally a question is left blank, and a score of 0 is then assigned. If more than 5 questions have been left blank, the LAQ-CP becomes invalid.

1. How many times has your child been seen over the last year by a doctor other than the school doctor or your family doctor?   (Please circle one of the following)

	0	1	2-5	6-12	13+
Score	0	1	2	3	4

2. Has your child had to stay in hospital for any length of time over the last year? Please indicate in weeks the total amount of time spent in hospital. (Please circle one of the following)

	0	<1	1-3	4-26	27+
Score	0	1	2	3	4

3. How many operations have been carried out on your child over the last year? (Please circle one of the following)

	0	1	2	3	4+
Score	0	1	2	3	4

4. Has your child had a leg, arm or other part of his/her body in plaster over the last year? Please indicate in weeks the total time your child has spent in plaster.   (Please circle one of the following)

	0	≤6	7-11	12-17	18+
Score	0	1	2	3	4

5. Has your child had to wear some form of body or leg support over the last year? Please indicate in weeks the total time the support was worn.   (Please circle one of the following)

	0	1-16	17-32	33-51	52
Score	0	1	2	3	4

6. How many tablets, pills or doses of medicines did your child take yesterday? (Please circle one of the following)

	0	1-4	5-8	9-12	13+
Score	0	1	2	3	4

7. Is your child currently receiving a special diet for any reason?   (Please circle one of the following)

	YES	NO
Score	4	0

8. How many times has your child suffered from any fits or blackouts over the last year?
(Please circle one of the following)

	Score
No Fits at all	0
Occasional fit during day averaging one per month	1
Some fits most weeks day or night	2
Many fits on most days and nights	3
Constant fits in frequent succession	4

9. Has your child been seen by a specialist about difficulties with his/her behaviour over the last year?
(Please circle one of the following)

	YES	NO
Score	4	0

10. How often has your child been seen by any sort of therapist over the last year? (Please circle one of the following)

	0	1	2-12	13-52	53+
Score	0	1	2	3	4

11. Which of the following services/allowances is your child currently receiving?
(Please circle all of those currently received)

| **Visits from** | **Visits from** | **Visits from** |
| Health Visitor | Home Help | Social worker |

| **Visits from** | **Voluntary Services** |
| Community Nurse | |

Number of services provided	0	1-2	3+
Score	0	2	4

12. How many items of special equipment are there in the home which are currently, or have been, essential for your child?
(Please circle one of the following)

	0	1-3	4-7	8-10	11+
Score	0	1	2	3	4

13. What has been the financial cost to the family for your child **over the last year** in purchasing and maintaining such special equipment? (Please circle one of the following)

	£0	£1-100	£101-200	£201-300	£301+
Score	0	1	2	3	4

14. What has been the extra financial cost to the family **over the last year** other than in purchasing special equipment, which was not covered fully by grants and allowances? (Please circle one of the following)

	£0	£1-100	£101-200	£201-300	£301+
Score	0	1	2	3	4

15. Has your child's present home been adapted in any way **over the last year** because of your child?
(Please circle one of the following)

	YES	NO
		0

If yes how many adaptations have been made? (Please circle one of the following)

	1-3	4-7	8-10	11+
Score	1	2	3	4

16. Please indicate how many (further) adaptations are planed or are considered necessary?
(Please circle one of the following)

	0	1-3	4-7	8-10	11+
Score	0	1	2	3	4

17. For each of the following activities, please tick **one** of the spaces to indicate how much help you would normally give to your child to complete that activity.

	No Help given	Some help/ supervision given	Has to be done for him/her
Washing hands	....	....	....
Eating a bowl of cereal	....	....	....
Putting on a vest/T-shirt	....	....	....
Doing up buttons or buckles	....	....	....
Getting out of bed	....	....	....
Getting out of the bath	....	....	....
Going to the toilet	....	....	....
Climbing stairs	....	....	....
Getting in and out of a car	....	....	....
Opening doors	....	....	....
Picking up an object from the floor	....	....	....
Carrying a drink the length of a room	....	....	....

Score

		No Help	*Some Help*	*Has to be done for them*
(i)	*Washing hands*	*0*	*2*	*4*
(ii)	*Eating cereal*	*0*	*2*	*4*
(iii)	*T-shirt*	*0*	*2*	*4*
(iv)	*Buttons/Buckles*	*0*	*2*	*4*
(v)	*Getting out of bed*	*0*	*2*	*4*
(vi)	*Getting out of bath*	*0*	*2*	*4*
(vii)	*Toilet*	*0*	*2*	*4*
(viii)	*Climbing stairs*	*0*	*2*	*4*
(ix)	*In/out of car*	*0*	*2*	*4*

17 (i - ix) renders nine separate scores

CONTENTS

17 (x – xii) renders one score as follows:

Opening doors	0	2	4
Picking up objects	0	2	4
Carry drinks	0	2	4

Add the values for 17 (x – xii) and assign final score as follows:

Added Value	0	2	4-6	8-10	12
Score	0	1	2	3	4

18. How many times did you need to lift your child on the last occasion you spent a **full day** with him/her?

   Multiply the number of lifts from this question by the appropriate weight on the front sheet.

   If weight given in stones and pounds, convert to stones and round up or down to one decimal point. Score the product as follows:

< 0.5	=	0
0.5 - 9.4	=	1
9.5 - 22.4	=	2
22.5 - 43.9	=	3
44 +	=	4

   If weight given in kilograms and grams, convert to kilograms and round up or down to one decimal point. Score the product as follows:

<3.2	=	0
3.2 - 60.4	=	1
60.5 - 143	=	2
143.1 - 279.9	=	3
280 +	=	4

19. How often has your child required assistance during the night **over the last week**? (Please circle one of the following)

	0	1-3	4-7	8-10	11+
Score	0	1	2	3	4

20. Please list any other areas where your child requires assistance in the course of a normal day?

Score	*No areas noted*	=	0
	1 area noted	=	1
	2 areas noted	=	2
	3+ areas noted	=	3
	Constant supervision	=	4

21. (a) How many rooms (excluding halls and passages) are there in your child's usual place of residence ?
    (b) Over the past week, how many of these did your child go into?
    (c) How many of these did your child enter unassisted?
    Score: *Two scores are calculated for this question: ACCESS 1 and ACCESS 3*

   Calculate ACCESS 1 by using the values given for 21a and 21b as follows:
   Multiple 21b by 100 and divide the product by 21a.

Score as follows:	100	=	0
	75 - 99	=	1
	50 - 74	=	2
	25 - 49	=	3
	0 - 24	=	4

   Calculate ACCESS 3 by using the values given for 21b and 21c as follows:
   If 21c = 0, then score 4.
   If 21c = 1 or more, then multiple 21c by 100 and divide the product by 21b.

Score as follows:	100	=	0
	66.6 - 99.9	=	1
	33.4 - 66.5	=	2
	1 - 33.3	=	3

22. Does you child normally need help in getting in and out of the house? (Please circle one of the following)

	YES	**NO**
Score	4	0

23. What is the furthest distance your child has gone outside without assistance **over the past week**?
    (Please circle one of the following)

	0	1-100 yards	101-440 yards	1/4 - 1/2 mile	1/2 + miles
Score	4	3	2	1	0

24. How often has your child been out of the house by himself/herself **over the past week**?
    (Please circle one of the following)

	0	1-7	8-13	14-20	21+
Score	4	3	2	1	0

25. Excluding trips to and from nursery/school, how many times has your child been on a longer outing **over the past week**, which required some form of transport?   (Please circle one of the following)

	0	1-3	4-7	8-10	11+
Score	4	3	2	1	0

26. What type of nursery/school, is your child currently attending?   (Please circle one of the following)

    None
    Pre-school (e.g. Nursery, Playgroup etc.)
    Special Pre-school
    Infant/Primary without Special Support Unit attached
    Infant/Primary with Special Support Unit attached
    Special School: Physical disability
    Special School: Learning difficulties
    Home teaching (Including Portage)
    Other (please specify) ....

27. How often does your child attend school?   (Please circle one of the following)
    Part-time
    Daily
    Weekly boarding
    Full boarding

Assign one score for questions 26 & 27, and take into account child's age as follows:.

	Not school age, not at school	
Part time or daily	*Not school age, Pre-school (e.g. nursery, playground)*	*0*
	School age, Infant/primary without special unit	
	School age, Infant/primary with special unit	
	Not school age, Special pre-school	*1*
	School age, Special school – physical disability	
	School age, Special school – learning difficulties	*2*
	School age, Home teaching/ not at school	*3*
Boarding		*4*

28. Approximately how long does it take for your child to travel from home to school?
    (Please circle one of the following)

	0-15mins	16-30 mins	31-45mins	46-1hr	1hr +
Score	0	1	2	3	4

29. How many friends has your child seen outside of school hours **over the past week**?
    (Please circle one of the following)

	0	1-3	4-7	8-10	11+
Score	4	3	2	1	0

30. Do you have any family or friends locally to whom you can turn for help if necessary?
    (Please circle one of the following)

	YES	NO
Score	0	4

31. Do you think that the people in your local area are generally supportive and understanding where your child is concerned?   (Please circle one of the following)

	YES	NO	SOMETIMES
Score	0	4	2

32. Do you think that your child restricts your social life in any way?   (Please circle one of the following)

	YES	NO	SOMETIMES
Score	4	0	2

33. Do you have any difficulties in organising family holidays because of your child? (Please circle one of the following)

	YES	NO
Score	4	0

34. How many other members of your child's family are living at the same residence as your child? Please state their relationship to your child.

If this question is left blank, assume the child is living with both natural parents.

Assign Score	If the child is living with both natural parents	=	0
	If the child is living with only one natural parent	=	2
	If child living with neither natural parent or in an institution	=	4

35. Please describe if any member of the family has had to change their employment situation to make caring for your child easier.

If this question is left blank, assume no changes have been made to family employment.

Assign Score	No changes to family employment	=	0
	Temporary/occasional interruption or difficulty to either parent	=	2
	Permanent change in employment situation for either parent	=	4

36. Do you think that your child has placed any extra stress on you as parents/carers?
(Please circle one of the following)

	NONE	SLIGHT	SEVERE
Score	0	2	4

37. Do you think that your child has placed any stress on any other children within the family?
(Please circle one of the following)

	NO OTHER CHILDREN	NONE	SLIGHT	SEVERE
Score	0	0	2	4

APPENDIX 3

SCORING PROCEDURE

Use the scored questionnaire with the Scoring Form to complete this procedure.

Create a **raw score** by summating the scores for the questions pertaining to each dimension as follows:

Physical independence	Questions	17(i),17(ii),17(iii),17(iv), 17(v),17(vi),17(vii), 17(viii),17(ix),18,19,20
Clinical burden	Questions	1,2,3,4,5,6,8,9,10,11,12
Mobility	Questions	17(x - xii), 21ACCESS 1, 21ACCESS 3,22,23,24,25
Economic burden	Questions	7,13,14,15,16,35
Social integration	Questions	29,30,31,32,33,34,36,37
Schooling	Questions	26&27,28

Convert this into a **dimensional score** out of 100, which is comparable between dimensions, by multiplying the raw score for each dimension by the appropriate dimension constant:

Physical independence	2.0834
Mobility	3.5714
Clinical burden	2.2728
Schooling	12.500
Economic burden	4.1667
Social integration	3.1250

Create the overall Lifestyle Assessment Score (LAS) by using the weighted additive model:

$$J = \beta_1 n_1 + \beta_2 n_2 + \beta_3 n_3 + \beta_4 n_4 + \beta_5 n_5 + \beta_6 n_6 + C,$$

where:
$J = \text{LAS}$
$\beta = $ weighting applied to each dimensional score
$n = $ dimensional score
$C = $ constant term $= 4.05$

by using the following weightings with each dimensional score:

Physical independence	0.357
Mobility	0.270
Clinical burden	0.033
Schooling	0.016
Economic burden	0.082
Social integration	0.224

Multiply each dimensional score by its weighting, to create a **weighted score**. Summate the weighted scores and the constant term C to arrive at the LAS.

SCORING FORM

Use this form in conjunction with each completed and scored questionnaire, and refer to the Scoring Procedure as described under Appendix 3 of the LAQ-CP Manual.

CHILD'S NAME: ....

Physical Independence
Raw Score =.......... x 2.0834 = ... *(Dimensional Score)* x 0.357 = ... *(Weighted Score)*

Mobility
Raw Score = ... x 3.5714= .... *(Dimensional Score)* x 0.270 = ... *(Weighted Score)*

Clinical Burden
Raw Score = ... x 2.2728 = ... *(Dimensional Score)* x 0.033 = ... *(Weighted Score)*

Schooling
Raw Score = ... x 12.500 = ...*(Dimensional Score)* x 0.016 = ... *(Weighted Score)*

Economic Burden
Raw Score = ... x 4.1667 = ... *(Dimensional Score)* x 0.082 = ... *(Weighted Score)*

Social Integration
Raw Score = ... x 3.1250 = ... *(Dimensional Score)* x 0.224 = ... *(Weighted Score)*

Sum of Weighted Scores = ...+ 4.05

= **LAS** [ ]

Standardised descriptive profile of Dimensional Scores:

Physical	0	10	20	30	40	50	60	70	80	90	100
Mobility	0	10	20	30	40	50	60	70	80	90	100
Clinical	0	10	20	30	40	50	60	70	80	90	100
Schooling	0	10	20	30	40	50	60	70	80	90	100
Economic	0	10	20	30	40	50	60	70	80	90	100
Social Int.	0	10	20	30	40	50	60	70	80	90	100

PREFACE

Thank you for showing an interest in the Lifestyle Assessment Questionnaire (LAQ-CP), which is a parent/carer completed questionnaire measuring, at a given point in time, the impact of disability on the lives of children with cerebral palsy and their families.

It was developed specifically for use in the North of England Collaborative Cerebral Palsy Survey (NECCPS - see Appendix 1), and particularly seeks to capture the *impact* of disabilities associated with cerebral palsy. Central to this work is our belief that parents are critical informants in assessing such impact.

The LAQ-CP is a 46-item questionnaire, organised into six dimensions through the application of multi-dimensional scaling. Dimensions are named to reflect elements of the International Classification of Impairments, Disabilities, and Handicaps (Wood 1980).

The LAQ-CP is a descriptive/discriminative tool, and we have demonstrated that it possesses the necessary properties of reliability, validity and interpretability. It provides a useful "snap shot" of a child's experience from the parental/carer perspective and has enhanced the usefulness of information kept on our register for children with cerebral palsy. It allows greater precision in assessing population health care needs, provides a severity threshold for ascertainment purposes and improves epidemiological information generally.

We appreciate the interest you have shown in our questionnaire, and would welcome any feedback. If you decide to use the LAQ-CP, we would be very interested to know how it will be applied.

If you are planning a major research study, it may be worth discussing with us the use of appropriate software to assist with storing data and calculating scores. Before deciding on the LAQ-CP, please pay particular attention to the discussion on its limitations and uses in Chapter 4.

We would appreciate it if you could share any findings with us, as this will enhance our understanding of the use of the LAQ-CP in other settings.

ACKNOWLEDGEMENTS

CHAPTER 1

INTRODUCTION

A. Definitions and representation of impact of disability

Cerebral palsy is defined as a disorder of movement and posture due to a defect or lesion of the immature brain (Bax 1964).

Research has indicated that it is an increasing contributor to the total number of children with enduring health problems in the United Kingdom (Jarvis *et al.* 1985; Evans *et al.* 1990; Nicholson & Alberman 1992; Pharoah *et al.* 1996 and 1998).

Such studies of birth prevalence however do not address the quite significant variations in the degree of morbidity experienced by these children. To capture these variations, measures of health other than mortality (for example, measures of health status or of quality of life) are necessary.

Developing such measures for children is a particular challenge, because of the length of time for which chronic disabilities may persist, and because of the special interaction between the child's condition, developmental stage and experienced social and cultural milieu, which gives rise to disadvantage. The International Classification of Impairments, Disabilities, and Handicaps (ICIDH) defines such disadvantage as 'handicap' (Wood 1980).

The definitions adopted within this paper follow those laid down in the ICIDH. Within this taxonomy, 'handicap' is used to describe the interaction between people with impairments and the environment in which they find themselves. However, in common usage the term 'handicap' is associated with the individual, and does not reflect the disabling role of a society often obsessed with normality. As such, it may be seen as seeking to capture human experience largely within the context of the medical model. Moreover, use of the terms 'handicap' and 'disability' interchangeably by clinicians has prompted one author to argue that we should "consign the word handicap to historical contexts or use it strictly in the way it was defined within the ICIDH" (Hutchison 1995). As a means of clarifying the relationship between 'disability' and 'handicap', Hutchison further argued that consideration be given to use of the term 'impact of disability'. We have now adopted this synonym for 'handicap'.

In representing the impact of disability, we have used the ICIDH model of describing handicap along seven dimensions (Table 1), in which competence is assumed to be necessary for survival. While retaining the dimensional approach of the ICIDH, we have developed an instrument, which includes both medical and social experiences, and which can measure, at a given point in time, the impact of childhood cerebral palsy on the lives of individual children and their families.

<div align="center">

Table 1
List of handicap dimensions

</div>

Orientation	The individual's ability to orient themselves in relation to their surroundings.
Physical Independence	The individual's ability to sustain a customarily effective independent existence.
Mobility	The individual's ability to move about effectively in their surroundings.
Occupation	The individual's ability to occupy their time in a manner customary to age, sex and culture.
Social Integration	The individual's ability to participate in and maintain customary social relationships.
Economic Self-sufficiency	The individual's ability to sustain customary socio-economic activity and independence
Other	Other circumstances that may give rise to disadvantage.

<div align="right">

From Wood (1980)

</div>

B. Review of the literature

Older epidemiological studies on disabling childhood conditions have occasionally included scales which specifically attempt to assess the impact of disability in such areas as mobility, activities of daily living, continence and cognitive function.

Hewett et al. (1970) used an interviewer–led questionnaire to capture children's abilities, and summated the results from eleven areas of functioning to create a 'handicap score'. Rutter et al. (1970) rated children with intellectual, psychiatric and physical disabilities on a five-point severity scale, with results based on a combination of group tests and parental/teacher questionnaires.

Other and similar attempts at determining how severely disadvantaged children and families can be as the result of childhood disability include work by Butler et al. (1976) and Hirst and Cooke (1988). Only Hewett et al. (1970) dealt specifically with children with cerebral palsy.

More recently, Pharoah et al. (1996 and 1998) have categorised children with cerebral palsy according to sensory deficits and disabilities in ambulation, manual dexterity and learning. Children are rated on a four-point scale in each of these areas of functioning.

Generally, the above studies have focussed on physical independence and mobility, and have only looked at other dimensions in a superficial way. In the main, they measure aspects of disability rather than its impact, and in addition they have tended to categorise children's experiences on the basis of subjective opinions of professionals, often purely from a 'health' perspective. None of the studies allowed disadvantages within various areas of functioning to be converted into one overall score.

However, Jarvis and Hey in 1984 developed a 71-item questionnaire for the assessment of children with cerebral palsy. In developing these items, they drew on two sources of information: observational data acquired during a study on wheelchairs (Jarvis 1979), and experiences gathered during the assessment of children with disabilities as a result of thalidomide.

The 71 data items, collected through a mixture of parental self-report and clinical observation, were representative of some of the dimensions of disability and handicap identified by the ICIDH. Questionnaire results from 100 children with cerebral palsy were used to calculate a single functional severity score, based on a principal component analysis, which in turn was validated by correlation with three objective measures of the child's motor disability.

C. Aims of the study

As mentioned earlier, epidemiological studies of the prevalence of childhood cerebral palsy often do not address the quite significant variations in the degree to which the resultant disabilities impact on the lives of these children and their families.

Our aim was to create an appropriate measurement tool to capture such impact of disability, and to use this tool to enhance the usefulness of information kept on the register of the North of England Collaborative Cerebral Palsy Survey (NECCPS – see Appendix 1).

The considerations outlined under B. above identified that the measurement tool should have the following characteristics:

1. it should provide a profile of the child's experience based upon a systematic representation of a number of appropriate dimensions contained within the ICIDH;

2. it should assess the *impact* of impairments or disabilities on the life of the child;

3. it should be capable of creating a single score based upon a continuous (or quasi-continuous) scale.

CHAPTER 2

METHODS OF QUESTIONNAIRE DEVELOPMENT

A. Item selection and reduction

The tool developed by Jarvis and Hey (1984) was selected as the starting point as it used the dimensional approach of the ICIDH and was specific to children with cerebral palsy.

Item reduction was achieved by applying three exclusion criteria:

1. removal of clinical observational items, to allow the questionnaire to be completed by parents/carers;

2. removal or reconstruction of all questions which focussed on disability rather than its impact, so that questions represented what children *did* do every day, rather than what they *could* do if pressed;

3. removal of items which were duplicate or highly correlated to other items contained within the instrument.

This created a set of 46 items, which are shown in Table 2.

The tool includes a number of questions aimed at assessing children's use of therapy and services. Only provisions assumed to be universally available in the United Kingdom were included. This allows recognition of the fact that there is the potential for an actual increase in disadvantage associated with receiving a plethora of services in an uncoordinated manner from different people. It also allows the effect of useful services to be measured in terms of their impact on other aspects of a child's life.

B. Creation of response options.

The 46 items were converted into 37 questions in clear simple English, focussing on the actual functioning of the child in everyday terms, and avoiding historical data. Where appropriate, the question asked for a response within a specific, actual time period (e.g. "in the past week") rather than a general reference to a time frequency such as "often".

To facilitate uniform interpretation of responses, response sets were presented which were to be simply circled by the parent/carer completing the questionnaire. The range of responses offered was based on that given for each particular item in relation to the 142 children (born 1964 – 1975) who had been assessed using the original measure and contained within the NECCPS's register (Jarvis & Hey 1984). Generally, three or five