

## Personal practice

# Follow up studies during the first five years of life: a pervasive assessment of neurological function

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... indeed, it is not easy to be accurate in an account of anything, however simple. Zoologists often disagree in their descriptions of the curve of a shell, or the plumage of a bird, though they may lay their specimen on the table, and examine it at their leisure; how much greater becomes the likelihood of an error in the description of things which must be in many parts observed from a distance, or under unfavourable circumstances of light and shade; and of which many of the distinctive features have been worn away by time. I believe few people have an idea of the cost of truth in these things; of the expenditure of time necessary to make sure of the simplest facts, and of the strange way in which separate observations will sometimes falsify each other, incapable of reconciliation, owing to some imperceptible inadvertency.<sup>1</sup>

These words were written by Ruskin in 1851, but they express precisely the problem that research workers face today when defining measures of outcome for use in follow up studies. Ruskin's comments have particular relevance to the collection and recording of data concerning the constellation of disorders generally referred to as 'cerebral palsy'.<sup>1</sup>

In the past, cerebral palsy was the commonest neurodevelopmental impairment reported in follow up studies of low birthweight or very preterm infants.<sup>2,3</sup> In particular, spastic diplegia was generally regarded as a typical condition among infants whose neonatal courses were complicated by apnoea and bradycardia. These impairments were believed to be so typical in infants who survived before the introduction of modern neonatal intensive care that it was proposed that their prevalence could be used as a measure of the quality of survival for audit, and comparative and epidemiological studies.<sup>4</sup> As interest widened and large epidemiological studies

were planned, the need for a universally agreed, simple definition of cerebral palsy was recognised; agreement proved difficult. Various suggestions were made ranging from a simple description based on Little's original proposal,<sup>5,6</sup> to a complex standardised physiopathological classification of syndromes of cerebral palsy that was put forward by paediatric neurologists.<sup>7</sup> Interobserver agreement was studied and found to be poor according to either type of definition.<sup>8</sup> Longitudinal studies also indicated that the diagnosis of cerebral palsy was not consistent over time in individual children, at least not until they were older, and aged 5 years or more.<sup>9</sup> As a result of these observations warnings were expressed that perhaps cerebral palsy was unsuitable to use as an outcome measure, particularly among young children.<sup>9,10</sup>

While perceptions of the nature of cerebral palsy and its use as a measure of outcome were changing, so also were the circumstances in which the condition occurred. For example, as methods of neonatal care were progressively refined, so the pattern of insults to the newborn brain changed in character and extent. Many potentially damaging events were avoided, or at least ameliorated, although homeostasis was not guaranteed. Indeed, infants began to survive after insults that had previously been thought to be fatal. As a consequence there was a change, both in the type of infants surviving and the brain lesions that they suffered.<sup>11</sup> For example, in a recent study even using the most liberal definition, cerebral palsy seemed to affect a minority of the neurologically impaired and disabled children.<sup>12</sup> Thus to describe the outcome of a group of infants solely according to the prevalence of cerebral palsy is both inadequate and misleading.

## Proposals

We believe the problem could be overcome by

describing the neurological condition of each infant objectively according to clearly defined standards. This approach would eliminate the need to interpret findings to fit them into specific diagnostic categories, and it is likely that it would also overcome the problem of the apparent variation of diagnosis with age in individual children. There is already evidence indicating that it is the manifestations of brain damage that vary according to age, and not the underlying lesions.<sup>13-17</sup> For example, infants with neurological impairments in the first year of life have been reported to have significantly poorer scores in tests of cognitive function than their unaffected peers,<sup>17 18</sup> and they are believed by some to be particularly liable to present with learning difficulties as they grow older.<sup>13 15 16 18 19</sup> Thus these children represent an aspect of perinatal brain damage that is important as an index of outcome, but which may not be recognised as such because the early neurological signs seem transient and the learning difficulties are not identified until the children are much older and the early signs have been forgotten. In fact the transience of the early neurological signs is probably apparent rather than real. It is more likely that the signs are present but are often not detected because of the power of the toddler to defy neurological assessment between the ages of about 2 and 4 years.

## Methods

The scheme we propose is designed to record the consequences of brain damage in a purely objective manner. Objective neurological information is obtained from a structured neurological examination using standardised procedures to elicit the signs and to judge the findings. Throughout the first year of life the scheme and standards for neurological examination already described by one of us may be used.<sup>20</sup> The scheme includes detailed instructions for eliciting the signs. The same principle and methods may be applied from the second year of life using age-appropriate standards to judge the findings. Experience has shown that by the end of the first year of life all major impairments can be detected, and any persisting minor impairments must be regarded as significant. Thus categorisation of neurodevelopmental condition at this age may have both meaning and predictive value.<sup>17</sup> We therefore give here standards starting from the age of 9 months (table 1) although standards for use throughout the first year are available elsewhere.<sup>20</sup> A record form for the neurological data that are obtained at each examination is provided (table 2). We recommend that each child should have an individual record form. Findings should be recorded on this form

either according to the presence or absence of a sign or as absolute measurements of angles in degrees. The findings may then be judged according to the standards appropriate for age given in table 1 and added to the results of assessments of hearing, vision, and behaviour, measurements of head growth, and of psychometric testing, to give a comprehensive assessment of a child at a particular age. The choice of methods for tests of hearing and vision, and of psychometric assessments, depends on the age of the child and the availability of the tests.

Findings judged to be normal because—for example, the size of an angle or a test score falls within the range appropriate for age—may be coded 0. Findings judged to be mildly deviant on the basis of angle measurements or test scores may be coded 1, and severely deviant findings may be coded 2. This coded information may be recorded on the chart given in table 3 to provide a summary of all the findings in an individual child at a particular age. When making this summary a single mildly deviant item (coded 1) may be ignored. Two or more mildly deviant items (giving a total of 2 or more) indicate abnormality, and severely deviant items (coded 2) always indicate abnormality, even if there is only one item in this category. Finally, on the basis of this coded information, neurodevelopmental condition can be described as 'unimpaired', 'impaired, but without disability' (mildly deviant), or 'impaired with disability' (severely deviant).

Because the type of records that we propose may form the basis of a minimum set of data for an individual child that may be used to monitor progress or to provide information for research, provision has been made on the summary form (table 3) for recording some additional facts, under the heading 'other information'. These include conditions which, although not necessarily developmental in origin, may influence a child's progress; they can also be used to provide a wider definition of abnormality if required. Examples include refractive errors, chronic lung or gastrointestinal disease, and growth.

## THEORETICAL BASIS OF THE SCHEME FOR NEUROLOGICAL EXAMINATION

In an earlier report Amiel-Tison described a waxing and waning pattern of neuromotor development from 28 weeks' gestation to the end of the first year of life.<sup>21</sup> This description was based on the clinical evaluation both of posture and passive tone at rest, and of motor activity and postural reactions; it conformed with proposals originally made by both Thomas and Saint-Anne Dargassies,<sup>22</sup> and by Peiper.<sup>23</sup> For example, from 28 to 40 weeks' gestation the acquisition of muscle tone and motor

Table 1 Standards for coding neurological data

	9-17 months	18-60 months		9-17 months	18-60 months
<b>1 (a) Neuromotor: hypertonia</b>			<b>1 (a) Reflexes (cont.)</b>		
<i>Arms:</i>			<i>Postural—lateral propping/parachute</i>		
<i>Scarf</i>			Nil at 10 months	1	—
Anterior axillary line to midline	1	1	Nil at 12 months	2	—
Less than anterior axillary line	2	2	Hesitant	—	1
Candlestick posture*:			Absent	—	2
present/fixed	2	2	<i>Hands—fisting/cortical thumbs, tendency fixed</i>	1	1
Hand flapping:				2	2
tightening	1	1			
nearly absent	2	2	<b>1 (a) Asymmetry</b>		
<i>Legs:</i>			Asymmetrical findings (difference of ≥1 grades or ≥10° passive tone or both)	1	1
Adductor angle 110°-40°	1	1			
<40°	2	2	<b>1 (a) Cranial nerves</b>		
Heel-car angle 110°-100°	1	—	Abnormal	1	1
100°-90°	—	1			
<100°	2	—	<b>1 (b) Neuromotor—consequences at examination—record abnormality as 'yes'</b>		
<90°	—	2	<i>Head control:</i> imperfect or absent		
Popliteal angle 110°-100°	1	1	<i>Sitting:</i> unstable—falls forward or back — or absent		
<100°	2	2	<i>Standing:</i> unsteady or absent		
Ankle angle 80°-90°	1	1	<i>Walking:</i> few steps or absent after 18 months		
>90°	2	2	<i>Gait:</i> 'inelegant' or abnormal		
Ankle stretch response—			<i>Use of right upper limb impaired</i>		
phasic	1	1	<i>Use of left upper limb impaired</i>		
tonic	2	2	<i>Use of right lower limb impaired</i>		
clonus	2	2	<i>Use of left lower limb impaired</i>		
<i>Axis:</i>			<b>2 Neurosensory</b>		
Imbalance of tone			<i>Hearing:</i>		
Excessive extension v flexion	1	1	Sensory loss, high tone, present	1	1
Permanent opisthotonus	2	2	Sensory loss speech frequencies, present	2	2
Falls back from sitting—present	2	2	<i>Eyes/vision:</i>		
'Scissoring', held up—present	2	2	'Fix-track' behaviour: Poor, brief, one plane only, or absent	2	2
<b>1 (a) Neuromotor: hypotonia</b>			Nystagmus or roving eye movements: present	2	2
<i>Arms:</i>			<b>3 Neurobehavioural</b>		
<i>Scarf:</i>			<i>Seizures:</i> with or without treatment, present	2	2
Minimal resistance	—	1	<i>Hyperexcitability:</i> one or all present	1	1
Flaccid (no resistance)	2	2	<i>Lethargy:</i> one or all present	1	1
Hand-flapping—flaccid (no resistance)	2	2	<i>Involuntary movements:</i> present	2	2
<i>Legs:</i>			<i>Sucking or swallowing:</i> absent	2	2
Adductor angle:	Impossible to define	Impossible to define	<i>Drooling:</i> present	1	1
Heel-car angle:	Impossible to define	—	<b>4 Head growth</b>		
>150°	—	1	<i>Head circumference:</i>		
Popliteal angle:	Impossible to define	—	Two standard deviations above or below the mean	2	2
>160°	—	1	<i>Growth velocity:</i> <10 or >90 centile	2	2
Ankle angle:	Impossible to define	Impossible to define	<i>Ventriculoperitoneal shunt:</i> present	1	1
<i>Axis:</i>			<b>5 Psychometric tests—define abnormality according to test instructions—for example:</b>		
Global hypotonia (excessive flexion and extension):			<i>McCarthy scale of children's abilities:</i>		
'Rag doll'†	2	2	General Cognitive Index—70-79: Impaired		
Falls forward, sitting—present	2	2	General Cognitive Index—<70: Impaired with disability		
Supporting/standing response—feeble/nil	2	2			
<b>1 (a) Reflexes</b>					
<i>Limbs:</i>					
Tendon—very brisk	1	1			
clonus	2	2			
<i>Primitive—</i> asymmetrical tonic neck reflex present	2	2			

\*Upper arm in line with shoulder with maximum supination and flexion to 90° at elbow; †very floppy with unlimited extensibility.

Table 2 Individual record form for neurological data

Section	1	2	3	4	5	
1 Passive tone	Upper limb:	Scarf sign	Value			
		Candlestick*	No/yes			
	Lower limb:	Hand flapping	OK/not			
		Adductor angle	Value			
		Heel-car angle	Value			
		Popliteal angle	Value			
		Ankle angle	Value			
	Axis:	Ankle stretch response	Type			
		Ventral flexion	OK/not			
		Dorsal extension	No/yes			
Opisthotonic posture		No/yes				
1 Active tone	Head control:		Yes/no			
	Sitting:		Yes/no			
		Falls backwards	No/yes			
	Standing:	Falls forward	No/yes			
		'Scissoring'	Yes/no			
	Walking:		No/yes			
	Gait:		Yes/no			
	Use of lower limbs:		OK/not			
	1 Reflexes	Primitive:	Use of lower limbs:	Yes/no		
			Moro response	No/yes		
Tendon:		Asymmetrical tonic neck reflex	No/yes			
		Biceps	OK/not			
		Knee	OK/not			
Clonus:		Ankle	OK/not			
			No/yes			
Protective:		Propping	Yes/no			
		Parachute	Yes/no			
Hands (right/left):		Fisting	No/yes			
	Cortical thumbs	No/yes				
Use of upper limbs and hands:		OK/not				
1 Asymmetry	Arms/legs/axis:		No/yes			
1 Cranial nerves			OK/not			
2 Ears	Pure tone audiogram (SOM/HTHL/SNHL)†:		OK/not			
2 Eyes	'Fix'/'track' behaviour:		OK/not			
	Nystagmus/roving movements:		No/yes			
	Visual field:		OK/not			
	Visual acuity (right/left):		Value			
	Squint:		No/yes			
	Sunset:		No/yes			
3 Seizures (treated or not)			No/yes			
3 Hyperexcitability	Tremor/clonic movements:		No/yes			
	Sleep disorders:		No/yes			
	Excessive crying:		No/yes			
	3 Lethargy	Reduced activity:		No/yes		
	Drowsy:		No/yes			
	Infrequent crying:		No/yes			
3 Involuntary movements	Upper limbs:		No/yes			
	Lower limbs:		No/yes			
3 Sucking/swallowing			OK/not			
3 Drooling			No/yes			
4 Head growth	Head circumference (cm):		Value			
	Velocity (centile):		Value			
4 Ventriculoperitoneal shunt			No/yes			

\*Upper arm in line with shoulder with maximum supination and flexion to 90° at elbow; †secretory otitis media, high tone hearing loss, sensory neural hearing loss. Full details of procedures to elicit neurological signs have been previously published.<sup>20</sup>

Table 3 Record form to summarise neurodevelopmental state at any age within the first five years of life

Name ..... Date of birth ..... Date of test ..... Gestational age ..... Corrected age .....

<p>1 Neuromotor (tone and reflexes)</p> <p>(a) Findings:</p> <p>Axis: Global hypotonia Imbalance (extensor&gt;flexor)</p> <table border="1" style="width:100%; text-align: center;"> <tr> <td></td> <td>Right Arm</td> <td>Right Leg</td> </tr> <tr> <td></td> <td></td> <td></td> </tr> <tr> <td></td> <td></td> <td></td> </tr> </table> <p>Limbs: Hypertonia</p> <table border="1" style="width:100%; text-align: center;"> <tr> <td></td> <td>Left Arm</td> <td>Left Leg</td> </tr> <tr> <td></td> <td></td> <td></td> </tr> <tr> <td></td> <td></td> <td></td> </tr> </table> <p>Hypotonia</p> <p>Asymmetry</p> <p>Exaggerated tendon reflex</p> <p>Abnormal hands</p> <p>Abnormal postural reflex</p>		Right Arm	Right Leg								Left Arm	Left Leg							<p>(b) Consequences at examination:</p> <table border="1" style="width:100%; text-align: center;"> <tr> <td></td> <td>Yes</td> <td>No</td> </tr> <tr> <td>Head control</td> <td></td> <td></td> </tr> <tr> <td>Sitting</td> <td></td> <td></td> </tr> <tr> <td>Standing</td> <td></td> <td></td> </tr> <tr> <td>Walking</td> <td></td> <td></td> </tr> <tr> <td>Normal gait</td> <td></td> <td></td> </tr> <tr> <td>Use of right upper limb/hand</td> <td></td> <td></td> </tr> <tr> <td>Use of left upper limb/hand</td> <td></td> <td></td> </tr> <tr> <td>Use of right lower limb</td> <td></td> <td></td> </tr> <tr> <td>Use of left lower limb</td> <td></td> <td></td> </tr> </table>		Yes	No	Head control			Sitting			Standing			Walking			Normal gait			Use of right upper limb/hand			Use of left upper limb/hand			Use of right lower limb			Use of left lower limb			<p>2 Neurosensory</p> <p>Hearing loss</p> <p>Nystagmus</p> <p>Cortical blindness</p> <p>3 Neurobehavioural</p> <p>Seizures (treated or not)</p> <p>Irritability</p> <p>Depression</p> <p>No sucking</p> <p>Drooling</p> <p>Abnormal cranial nerves</p> <p>4 Head growth</p> <p>Occipitofrontal circumference:</p> <table border="1" style="width:100%; text-align: center;"> <tr> <td>&lt;two SD</td> <td></td> </tr> <tr> <td>&gt;two SD</td> <td></td> </tr> <tr> <td>Ventriculo-peritoneal shunt</td> <td></td> </tr> </table> <p>Velocity</p> <p>Cm/year</p> <p>Centile</p>	<two SD		>two SD		Ventriculo-peritoneal shunt		<p>5 Psychometric tests</p> <p>Subscales</p> <table border="1" style="width:100%; text-align: center;"> <tr> <td>1</td> <td></td> </tr> <tr> <td>2</td> <td></td> </tr> <tr> <td>3</td> <td></td> </tr> <tr> <td>4</td> <td></td> </tr> <tr> <td>5</td> <td></td> </tr> <tr> <td>Overall</td> <td></td> </tr> <tr> <td>Achievement score</td> <td></td> </tr> </table> <p>Value Standard score</p>	1		2		3		4		5		Overall		Achievement score		<p>Other information</p> <p>1 Severe refractive error or retinopathy, or both</p> <p>2 Squint</p> <p>3 Conductive hearing loss</p> <p>4 Chronic lung disease</p> <p>5 *Chronic gastrointestinal disease</p> <p>6 Growth problem</p> <p>7 Congenital malformation</p> <p>8 Socioeconomic deprivation</p> <p>9 Other</p>
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<p>6 Conclusions</p> <p>1 Neuromotor</p> <p>(a) impairment</p> <p>(b) function affected</p> <p>2 Neurosensory</p> <p>3 Neurobehavioural</p> <p>4 Head growth</p> <p>5 Psychometric tests</p>	<p>1</p> <p>2</p> <p>3</p> <p>4</p> <p>5</p>	<p>1</p> <p>2</p> <p>3</p> <p>4</p> <p>5</p> <p>6</p> <p>7</p> <p>8</p> <p>9</p>	<p>1</p> <p>2</p> <p>3</p> <p>4</p> <p>5</p> <p>6</p> <p>7</p> <p>8</p> <p>9</p>																																																																					

Normal     Impaired     Impaired with disability

**Normal:** a total of 1 or less in sections 1-4 and scores in section 5 within the normal range for the test used. **Impaired without disability:** a total of 2 or more in section 1 (a) and no functional consequences recorded in 1 (b); and/or a total of 1 in sections 2, 3, and 4, and/or scores in section 5 within the 'doubtful' range. **Impaired with disability:** a total of 2 or more in section 1 (a) with functional consequences recorded in 1 (b); and/or 2 or more in sections 2, 3, and 4, and/or scores in the abnormal range for the test used in section 5, or a combination of these. **Other information** is not scored or used in the conclusions.   
 \* = usually after necrotising enterocolitis.

function spreads from the lower extremities in the direction of the head. After full term the process is reversed so that relaxation and the development of motor control proceed downwards for the next 12 to 18 months. Thus the upper limbs and extremities begin to relax and acquire skills before the lower limbs, and in the axis head control is acquired first, followed by the ability to sit, to stand, and finally—to walk. The timing of this sequence is subject to wide individual variations in addition to familial and ethnic influences, but the order is constant in all normal individuals. Thus from a knowledge of the successive stages of maturation throughout the sequence it is possible to detect abnormal clusters of responses that may be used to identify deviant development. Using these observations a scheme for the evaluation of neurological development during the first year of life was designed.<sup>20</sup> In practice this scheme may be applied up to the age of 18 months. We believe that this is justified because, owing to wide individual variations, the sequence culminating in independent walking is often not completed by the end of the first year of life in infants who later prove to be normal. Independent walking, however, should be achieved by 18 months; failure to do so usually indicates abnormality.<sup>24</sup>

The orderly progression of neuromotor development continues after the first year though the changes are more subtle and result largely from improvements in motor organisation. The advances in motor control that result may be identified and assessed,<sup>25</sup> and passive tone at rest may still be measured. Thus the same type of assessment based on observation and manipulation of the child that is used to evaluate progress in the first year of life may be applied as the child grows older.

In order to derive standards from the second year of life we considered both the original data of Saint-Anne Dargassies<sup>26</sup> (that were obtained by examination of a group of normal infants followed up to the age of 2 years) and the data from our own follow up studies of infants born at full term<sup>13 27</sup> and those born very preterm (Stewart *et al*, unpublished observations).<sup>12 17 28 29</sup> Our own findings were in agreement with the standards for neuromotor function proposed by Saint-Anne Dargassies<sup>26</sup> up to the end of the second year of life. Thereafter we observed little change with age in posture and passive tone at rest, or in motor activity and postural reactions. We therefore consider that standards for these measures remain more or less constant from the end of the second year to the age of 4 or 5 years, and in practice can be applied from the age of 18 months when the early standards cease to apply.

When examining our own data we noted that the range of normal variation was as wide in the older

children as had been observed during the first year of life in the earlier studies.<sup>20</sup> To take account of this observation the definitions of abnormality have to be fairly stringent to avoid including minor variations that may be of little consequence.

#### EXPERIENCE OF THE SCHEME IN USE

We have been using the scheme for neurological examination<sup>20</sup> and teaching it to paediatricians and physiotherapists for many years. Familiarity with examining and handling infants and young children is the only essential requirement for acquiring competence, but a basic knowledge of paediatric neurology helps with interpretation as it permits the examiner to extend the examination if there are abnormal or equivocal findings. We have found that successive generations of research fellows of variable experience have quickly become skilled with good interobserver reliability, a matter that is discussed in more detail elsewhere.<sup>20</sup>

The neurological examination takes about 10 minutes to carry out. Though it has been designed to be objective as far as possible, there are a few circumstances in which particular caution must be exercised when interpreting the findings.

*Wide individual variation* in passive tone makes the definition of mild symmetrical abnormalities difficult; as a consequence these conditions are probably underestimated. By contrast, asymmetry is usually accurately recognised though it does not necessarily indicate that one side is normal.

*Struggling* with defiant, uncooperative children may affect the precision of the examination. This tends to be a problem when examining 2–3 year olds who resent procedures designed to elicit passive tone, such as the 'scarf' sign, and occasionally their behaviour prevents completion of the examination. When struggling does occur, results will always be biased in the direction of hypertonicity.

*Postural deformities* secondary to prolonged immobilisation during intensive care may affect some measurements. For example, shortening of upper limb girdle muscles or of the extensor group of neck muscles may occur during prolonged periods of mechanical ventilation. This may mimic increased passive tone and lead to difficulties in interpretation.<sup>21</sup> Likewise, 'scissoring' within the first year may have similar postural origins. In this circumstance the sign does not necessarily support a diagnosis of spastic diplegia.<sup>30</sup> In general when such findings are isolated ones they are more likely to be postural than central.

#### Conclusions and implications

In clinical practice, follow up teams may use this

scheme to help them offer continuous care to infants and their parents from the time the infants go home. If the findings are normal it will be possible to reassure many parents at an early stage,<sup>29</sup> and infants with impairments may be recognised so that treatment can be started and help provided for the parents as soon as possible. Infants with movement disorders or cerebral palsy will be included among those with neurological impairments and treated as soon as they are recognised, though they may not be labelled precisely until years later.

In research the scheme provides objective data that can be used in longitudinal studies and analysed in detail, item by item. In epidemiological studies these data permit categorisation of neurodevelopmental condition without the need to use any physiopathological nosology. Thus it should be possible to trace the influence of perinatal events right through infancy and the preschool period to the age when the diagnosis of learning difficulties and other school problems is possible.

Difficulties are inherent in the examination of the preschool child; they cannot be ignored or bypassed. From our own experience, however, we believe that an analytical approach to the assessment of neurological function is feasible, with interobserver reliability and consistency over time in an individual child. We also believe that this approach can help to overcome many of the problems of recording and reporting in follow up studies, so aptly described by Ruskin's elegant prose.<sup>1</sup>

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