Evaluating the Effectiveness of the National Special Needs Information System in Scotland

Appendices

Project Number P01/4

November 2004

Researcher: Anne Wood
Report re-drafted by Emma Stevens (ISD Scotland)

Lead Grant-holder: Dr Zoë Dunhill
Evaluating the Effectiveness of the National Special Needs Information System in Scotland

APPENDICES

Appendix 1: Description of SNS

Appendix 2: Copy of SNS Assessment Form

Appendix 3: Summary of data held in SNS in November 2004

Appendix 4: Criteria for Evaluating the Effectiveness of SNS

Appendix 5: Read Codes for Indicator Conditions

Appendix 6: Content of Qualitative Questionnaires Used

Appendix 7: Schedule for Site Visits to NHS Boards

Appendix 8: Summary of Findings from Site Visits to each NHS Board

Appendix 9: Schedule for Focus Group Discussions with Parents

Appendix 10: Key Themes Apparent During Focus Group Discussions
Appendix 1
Description of the National Special Needs System

The main elements of SNS are as follows:
- The notification / referral process
- Registration/action by responsible clinician
- Assessment
- Further assessments / de-registration
- Summary outputs

1. Notification / Referral Process
‘Special Needs’ is a term used to describe any learning disability, language or communication impairment, emotional problems, behaviour disorders and physical problems. The system is designed to capture data about children and young people from the age of 0-19 years.

If a healthcare professional suspects that a child should be registered on the SNS then a notification form should be completed. This form is then sent to the Child Health Department and the child’s notification details are provisionally registered on the system. The system then produces a list of those who have had a notification form completed and arrangements can be made for the clinician responsible to schedule an initial assessment date.

The following are a number of examples of the details included in the notification form:

The Child’s Details:
- CHI
- Name
- Address

The Notifier’s Details:
- Name
- Address
- Job title
- Telephone number

Reasons for Referral:
- Medical
- Educational
- Social / Family

Other Details Recorded
For example:
- Record of Need completed?
- Child on Protection Register?
2. Registration / Action by Responsible Clinician
The next step of the process is for the responsible clinician to view the child’s notification form.

The responsible clinician must then decide what course of action to take:

- To assess the child straight away;
- To delay the assessment until another time in the future; or
- Not to assess the child at all if he/she feels it is unnecessary.

3. Assessment

‘The purpose of the assessment is to confirm the diagnosis, seek an underlying cause, assess strengths and weaknesses in the child and associated developmental and mental health impairments, assess family needs, and identify the resources to meet the need.’ (Baird et al, 2003).

Once a child has had an initial assessment they are only registered onto the system if the responsible clinician feels it is appropriate to do so and if parental or carer consent has been obtained.

4. Further Assessments

After the initial assessment, if the responsible clinician decides that a further assessment is required then this is recorded onto the system and a suitable assessment date can be arranged.

5. Summary output forms

Summary output forms can be produced by the SNS. This is vital for all other health professionals who are involved with the child because it keeps them informed about each child’s progress and contact with other health professionals and it also assists in the management of their overall caseload. Additionally, referral letters can be produced by the system to be sent to therapists such as educational / clinical psychologists.
The cycle of events for registering children on SNS

HP carries out examination and identifies child with SN. Then completes a Notification Form and sends to SNCHD.

Electronic Download from CHSP of children flagged as having SN

Register child on system. Produce Notification Lists and send to RC who decides on assess/de-reg. procedures.

If child is to be assessed, RC specifies proposed date of assessment (or period of time from present) within max time limit set by HB.

Completed Notification List returned to SNCHD for recording assess/de-reg. details. Assessment Forms are then produced and sent to RC.

If no assessment, de-reg letters produced and sent to referrer.

RC completes List accordingly after deciding on what action to follow.

If child is not to be assessed, RC specifies why.

If child is to be referred to a specialist, RC specifies request accordingly.

If child is to be referred, cycle restarts at notification process.

After assessment, RC completes the Assessment Form & decides if further assessment is required. Results are recorded on the system by the SNCHD.

If no further assessment, de-reg forms printed & sent to all involved professionals.

If further assessments, cycle returns to SNCHD where details are recorded.

Assessment Summary sent to involved HPs

If requested by clinician, referral letter sent to therapist

Batch Print

Individual Print

Appointment Letters can be produced and sent to the parents.

KEY:

Blue arrow = Normal cycle of events; Black arrow = Child not entered into SNS / de-registered; White arrow = Child is referred to a specialist

HP = Health Professional; RC = Responsible Clinician; SN = Special Need/s; SNCHD = Special Needs Child Health Dept; CHSP = Child Health Surveillance Programme; HB = Health Board.

Evaluating the Effectiveness of the National Special Needs Information System in Scotland
Evaluating the Effectiveness of the National Special Needs Information System in Scotland
Appendix 2

Example Copy of the SNS Assessment Form
Appendix 3
Summary of Data Held in SNS in November 2004

Children active in SNS

Number of children active in SNS\(^2\) by Health Board

<table>
<thead>
<tr>
<th>Health Board</th>
<th>Extract(^1)</th>
<th>Number of children active in SNS(^2)</th>
<th>% change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ayrshire &amp; Arran</td>
<td>1</td>
<td>2037</td>
<td>-3.0</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>1976</td>
<td></td>
</tr>
<tr>
<td>Borders</td>
<td>1</td>
<td>163</td>
<td>-1.2</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>161</td>
<td></td>
</tr>
<tr>
<td>Argyll &amp; Clyde</td>
<td>1</td>
<td>2669</td>
<td>+15.2</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>3076</td>
<td></td>
</tr>
<tr>
<td>Lanarkshire</td>
<td>1</td>
<td>696</td>
<td>+99.6</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>1389</td>
<td></td>
</tr>
<tr>
<td>Grampian</td>
<td>1</td>
<td>3649</td>
<td>+13.0</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>4123</td>
<td></td>
</tr>
<tr>
<td>Lothian</td>
<td>1</td>
<td>3249</td>
<td>+13.0</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>4133</td>
<td></td>
</tr>
<tr>
<td>Tayside</td>
<td>1</td>
<td>697</td>
<td>+45.5</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>1014</td>
<td></td>
</tr>
<tr>
<td>Shetland</td>
<td>1</td>
<td>77</td>
<td>-9.1</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>70</td>
<td></td>
</tr>
<tr>
<td>Duplicates(^3)</td>
<td>1</td>
<td>45</td>
<td>+62.2</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>73</td>
<td></td>
</tr>
<tr>
<td>All SNS Boards</td>
<td>1</td>
<td>13279</td>
<td>+13.1</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>15015</td>
<td></td>
</tr>
</tbody>
</table>

Source: CHSP-SNS, ISD Scotland
Extract 1: 04/03; Extract 2: 03/11/04

1. Extract 1 is data from the ISD SNS BO (April 2003) - used by Anne Wood for her report;
2. Extract 2 is from the latest version of SNS BO (Nov 2004).
3. Duplicates includes active chi numbers found in more than one Board AND chi numbers recorded as active twice in Argyll & Clyde.

Note: Changes in User Boards between April 2003 and November 2004
In Borders NHS Board, a lack of clerical and administrative support resulted in the suspension of SNS use during part of this period. This has now been resolved and numbers are expected to grow again.
In Shetland, there has been no lead Paediatrician during this period. This has resulted in no children being newly registered into the system.
The number of children registered on Lanarkshire SNS has almost doubled, because in April 2003 the system was only just implemented in a number of areas within Lanarkshire. Additionally, Fife NHS Board are now implementing SNS (autumn 2004).
### Evaluating the Effectiveness of the National Special Needs Information System in Scotland

**Children with indicator conditions**

<table>
<thead>
<tr>
<th>Indicator condition</th>
<th>Extract¹</th>
<th>Number of children²</th>
<th>Proportion of children with each condition (%)</th>
<th>% change in number of children with conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism</td>
<td>1</td>
<td>1103</td>
<td>42</td>
<td>+53.9</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>1697</td>
<td>53</td>
<td></td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>1</td>
<td>815</td>
<td>31</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>576</td>
<td>18</td>
<td>-29.3</td>
</tr>
<tr>
<td>Downs Syndrome</td>
<td>1</td>
<td>353</td>
<td>14</td>
<td>+38.0</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>487</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>Neural Tube Defects</td>
<td>1</td>
<td>30</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>46</td>
<td>1</td>
<td>+53.3</td>
</tr>
<tr>
<td>Sensorineural Hearing Loss</td>
<td>1</td>
<td>300</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>372</td>
<td>12</td>
<td>+24.0</td>
</tr>
<tr>
<td>All indicator conditions</td>
<td>1</td>
<td>2601</td>
<td>100</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>3178</td>
<td>100</td>
<td>+22.2</td>
</tr>
</tbody>
</table>

Source: CHSP-SNS, ISD Scotland

Extract 1: 04/03; Extract 2: 04/11/04

1. Extract 1 is data from the ISD SNS BO (April 2003) - used by Anne Wood for her report; Extract 2 is from the latest version of SNS BO (Nov 2004).
2. This includes children with all 'active' status codes (status=1,2,3).

**Note:** Recordings of children with diagnoses of all indicator conditions except Cerebral Palsy have increased. Also, of those children with indicator conditions, the proportion diagnosed with Autistic Spectrum Disorders has significantly increased.

---

**Proportions of children with indicator conditions in Apr03 (extract1) and Nov04 (extract2)**

![Bar chart showing proportions of children with indicator conditions](chart.png)

Evaluating the Effectiveness of the National Special Needs Information System in Scotland
Children active in SNS, by NHS Board and age group

1. Extract 1 is data from the ISD SNS BO (April 2003) - used by Anne Wood for her report; Extract 2 is from the latest version of SNS BO (Nov 2004).
2. This includes children with all 'active' status codes (status=1,2,3).
3. Duplicates includes active chi numbers found in more than one Board AND chi numbers recorded as active twice in Argyll & Clyde.

Note: The proportions of registration of the youngest children (aged 0-4 years) have increased. This is an important progression and indicates that children are being identified and followed up from a younger age.

Source: CHSP-SNS, ISD Scotland
Extract 1: 04/03; Extract 2: 03/11/04

Evaluating the Effectiveness of the National Special Needs Information System in Scotland
Evaluating the Effectiveness of the National Special Needs Information System in Scotland

Percentage of children active in SNS with disability recordings

Source: CHSP-SNS, ISD Scotland
Extract 1: 04/03; Extract 2: 04/11/04

1. Extract 1 is data from the ISD SNS BO (April 2003) - used by Anne Wood for her report;
Extract 2 is from the latest version of SNS BO (Nov 2004).
2. This includes children with all ‘active’ status codes (status=1,2,3).

Note: The type of disability recordings have not changed much during this period. However, a higher percentage of children active in SNS have disability recordings entered in November 2004 than in April 2003.
Percentage of school-age children active in SNS with Record of Needs details entered, by indicator conditions.

Note: In November 2004, a higher percentage of school-age children with each indicator condition have details of whether or not they have a Record of Needs entered into SNS than in April 2003.
Appendix 4
Criteria for Evaluating the Effectiveness of the National Special Needs System

1. Consistency & Quality
- How many children are registered on SNS?
- What is the percentage of those registered on SNS within the community child health population?
- How many children are on SNS with indicator conditions recorded?
- What proportion of children have indicator conditions?
- What percentage of children are registered by age group?
- Are there differences in locomotor ability for children with diplegia / quadriplegia?
- What is the consistency of data recorded for muscular dystrophies?
- What are the manual disabilities of children?
- What is the level of language & communication skills recorded for children with autistic spectrum disorders (ASD)?

2. Completeness
- Are the ‘Family’ details complete?
- Are the ‘Child’s’ details complete?
- Are the ‘Disability’ details complete?
- Are Motor Deficit of Central Origin Details complete for children with cerebral palsy?

3. Ascertainment
- What are the ascertainment rates for children with autistic spectrum disorders (ASD)?
- What are the ascertainment rates for children with Downs Syndrome?
- What are the ascertainment rates for children with cerebral palsy?
- What are the ascertainment rates for children with neural tube defects?
- What are the ascertainment rates for children with sensorineural hearing loss?

4. Comparing with Other Sources of Information
- Visual Impairment Scotland register.
- The Family Fund Trust

5. Supporting Clinical Practice
The following are examples of the important elements identified that support the clinical practice:
- Site visits
- Coding differences
- Time to complete SNS forms
- Workload
- Participation
- Information suitable for commissioners
- Diagnosis
- Shared clinical notes
- Management of the process
- Use of the database
- Alterations to current recording systems
6. The Voice of Parents and Carers
The following are topics discussed with parents of special needs children:-

- Recognition of parental efforts
- Interactions with professionals
- Diagnosis
- Equity
- Initial information
- Repetition and preparation
- Transmission of information
- Sharing information
- Co-ordination of care
### Appendix 5

#### Read Codes for Indicator Conditions

<table>
<thead>
<tr>
<th>Condition Description</th>
<th>Code Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infantile autism</td>
<td>E140 aut</td>
</tr>
<tr>
<td>Active infantile autism</td>
<td>E1400 aut</td>
</tr>
<tr>
<td>Residual infantile autism</td>
<td>E1401 aut</td>
</tr>
<tr>
<td>Infantile autism NOS</td>
<td>E1402 aut</td>
</tr>
<tr>
<td>[X] Atypical autism</td>
<td>Eu841 aut</td>
</tr>
<tr>
<td>Rett's Syndrome</td>
<td>Eu842 aut</td>
</tr>
<tr>
<td>[X] Childhood autism</td>
<td>Eu840 aut</td>
</tr>
<tr>
<td>Asperger's Syndrome</td>
<td>Eu845 aut</td>
</tr>
<tr>
<td>Downs syndrome trisomy 21</td>
<td>PJ0.. downs</td>
</tr>
<tr>
<td>Downs syndrome NOS</td>
<td>PJ0z downs</td>
</tr>
<tr>
<td>Trisomy 21 - meiotic nondisjunction</td>
<td>PJ00.. downs</td>
</tr>
<tr>
<td>Trisomy 21 - mitotic non-disjunction mosaicism</td>
<td>PJ01 downs</td>
</tr>
<tr>
<td>Trisomy 21 - translocation</td>
<td>PJ02 downs</td>
</tr>
<tr>
<td>Partial trisomy in down's syndrome</td>
<td>X76EI downs</td>
</tr>
<tr>
<td>Sensorineural hearing loss</td>
<td>F59.1 snhl</td>
</tr>
<tr>
<td>Neural hearing loss</td>
<td>F5912 snhl</td>
</tr>
<tr>
<td>Congenital sensorineural deafness</td>
<td>F5914 snhl</td>
</tr>
<tr>
<td>Sensorineural hearing loss, bilateral</td>
<td>F5916 snhl</td>
</tr>
<tr>
<td>Combined perceptive hearing loss</td>
<td>F591y snhl</td>
</tr>
<tr>
<td>Sensorineural hearing loss, unilateral unrestricted hear / contralateral side</td>
<td>F5917 snhl</td>
</tr>
<tr>
<td>Mixed conductive and sensorineural deafness</td>
<td>F592. snhl</td>
</tr>
<tr>
<td>Sensory hearing loss</td>
<td>F5911 snhl</td>
</tr>
<tr>
<td>Perceptive hearing loss</td>
<td>F591z snhl</td>
</tr>
<tr>
<td>Anencephalus</td>
<td>P00.. ntubes</td>
</tr>
<tr>
<td>Spina bifida</td>
<td>P1.. ntubes</td>
</tr>
<tr>
<td>Spina bifida occulta</td>
<td>PG17. ntubes</td>
</tr>
<tr>
<td>Spina bifida with hydrocephalus</td>
<td>P10.. ntubes</td>
</tr>
<tr>
<td>Unspecified spina bifida with hydrocephalus</td>
<td>P100. ntubes</td>
</tr>
<tr>
<td>Spina bifida with hydrocephalus</td>
<td>P1000 ntubes</td>
</tr>
<tr>
<td>Cervical spina bifida with hydrocephalus</td>
<td>P1001 ntubes</td>
</tr>
<tr>
<td>Thoracic spina bifida with hydrocephalus</td>
<td>P1002 ntubes</td>
</tr>
<tr>
<td>Lumbar spina bifida with hydrocephalus</td>
<td>P1003 ntubes</td>
</tr>
<tr>
<td>Spina bifida with hydrocephalus NOS</td>
<td>P100z ntubes</td>
</tr>
<tr>
<td>Spina bifida with hydrocephalus open</td>
<td>P1002 ntubes</td>
</tr>
<tr>
<td>Unspecified spina bifida with hydrocephalus - open</td>
<td>P1020 ntubes</td>
</tr>
<tr>
<td>Cervical spina bifida with hydrocephalus - open</td>
<td>P1021 ntubes</td>
</tr>
<tr>
<td>Thoracic spina bifida with hydrocephalus - open</td>
<td>P1022 ntubes</td>
</tr>
<tr>
<td>Lumbar spina bifida with hydrocephalus - open</td>
<td>P1023 ntubes</td>
</tr>
<tr>
<td>Sacral spina bifida with hydrocephalus - open</td>
<td>P1024 ntubes</td>
</tr>
<tr>
<td>Spina bifida with hydrocephalus - open NOS</td>
<td>P1022z ntubes</td>
</tr>
<tr>
<td>Spina bifida with hydrocephalus - closed</td>
<td>P103.. ntubes</td>
</tr>
<tr>
<td>Unspecified spina bifida with hydrocephalus - closed</td>
<td>P1030 ntubes</td>
</tr>
<tr>
<td>Cervical spina bifida with hydrocephalus - closed</td>
<td>P1031 ntubes</td>
</tr>
<tr>
<td>Thoracic spina bifida with hydrocephalus - closed</td>
<td>P1032 ntubes</td>
</tr>
<tr>
<td>Lumbar spina bifida with hydrocephalus - closed</td>
<td>P1033 ntubes</td>
</tr>
<tr>
<td>Sacral spina bifida with hydrocephalus - closed</td>
<td>P1034 ntubes</td>
</tr>
<tr>
<td>Spina bifida with hydrocephalus - closed NOS</td>
<td>P1032z ntubes</td>
</tr>
<tr>
<td>Spina bifida with hydrocephalus of late onset</td>
<td>P104. ntubes</td>
</tr>
<tr>
<td>Spina bifida with stenosis of aqueduct of sylvius</td>
<td>P105. ntubes</td>
</tr>
<tr>
<td>Other specified spina bifida with hydrocephalus</td>
<td>P10y. ntubes</td>
</tr>
<tr>
<td>Dandy-Walker syndrome with spina bifida</td>
<td>P10y0 ntubes</td>
</tr>
<tr>
<td>Condition</td>
<td>Code</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>----------</td>
</tr>
<tr>
<td>Other spina bifida with hydrocephalus NOS</td>
<td>P10yz</td>
</tr>
<tr>
<td>Spina bifida with hydrocephalus NOS</td>
<td>P10z</td>
</tr>
<tr>
<td>Spina bifida without mention of hydrocephalus</td>
<td>P11..</td>
</tr>
<tr>
<td>Spina bifida without mention of hydrocephalus, unspecified</td>
<td>P110.</td>
</tr>
<tr>
<td>Cervical spina bifida without mention of hydrocephalus</td>
<td>P1101</td>
</tr>
<tr>
<td>Thoracic spina bifida without mention of hydrocephalus</td>
<td>P1102</td>
</tr>
<tr>
<td>Lumbar spina bifida without mention of hydrocephalus</td>
<td>P1103</td>
</tr>
<tr>
<td>Unspecified spina bifida without hydrocephalus NOS</td>
<td>P110z</td>
</tr>
<tr>
<td>Spinal hydromeningocele, unspecified</td>
<td>P1110</td>
</tr>
<tr>
<td>Spinal hydromeningocele NOS</td>
<td>P111z</td>
</tr>
<tr>
<td>Spinal hydro meningocoele</td>
<td>P111.</td>
</tr>
<tr>
<td>Hydromyelocele</td>
<td>P112z</td>
</tr>
<tr>
<td>Hydromyelocele of unspecified site</td>
<td>P1120</td>
</tr>
<tr>
<td>Hydromyelocele</td>
<td>P112.</td>
</tr>
<tr>
<td>Lumbar spinal meningocoele</td>
<td>P113.</td>
</tr>
<tr>
<td>Thoracic spinal meningocoele</td>
<td>P1132</td>
</tr>
<tr>
<td>Cervical spinal meningocoele</td>
<td>P1131</td>
</tr>
<tr>
<td>Spinal meningocoele of unspecified site</td>
<td>P1130</td>
</tr>
<tr>
<td>Spinal meningocoele</td>
<td>P113.</td>
</tr>
<tr>
<td>Meningomyelocele</td>
<td>P114.</td>
</tr>
<tr>
<td>Myelococle</td>
<td>P115.</td>
</tr>
<tr>
<td>Myelocystocoele NOS</td>
<td>P116z</td>
</tr>
<tr>
<td>Lumbar myelocystocoele</td>
<td>P1163</td>
</tr>
<tr>
<td>Thoracic myelocystocoele</td>
<td>P1162</td>
</tr>
<tr>
<td>Cervical myelocystocoele</td>
<td>P1161</td>
</tr>
<tr>
<td>Myelocystocoele of unspecified site</td>
<td>P1160</td>
</tr>
<tr>
<td>Myelocystocoele</td>
<td>P116.</td>
</tr>
<tr>
<td>Spina bifida without hydrocephalus - open</td>
<td>P117.</td>
</tr>
<tr>
<td>Sacral spina bifida without hydrocephalus - open</td>
<td>P1174</td>
</tr>
<tr>
<td>Spina bifida without hydrocephalus - open NOS</td>
<td>P117z</td>
</tr>
<tr>
<td>Spina bifida without hydrocephalus - closed</td>
<td>P118.</td>
</tr>
<tr>
<td>Unspecified spina bifida without hydrocephalus - closed</td>
<td>P1180</td>
</tr>
<tr>
<td>Cervical spina bifida without hydrocephalus - closed</td>
<td>P1181</td>
</tr>
<tr>
<td>Thoracic spina bifida without hydrocephalus - closed</td>
<td>P1182</td>
</tr>
<tr>
<td>Lumbar spina bifida without hydrocephalus - closed</td>
<td>P1183</td>
</tr>
<tr>
<td>Sacral spina bifida without hydrocephalus - closed</td>
<td>P1184</td>
</tr>
<tr>
<td>Spina bifida without hydrocephalus - closed NOS</td>
<td>P118z</td>
</tr>
<tr>
<td>Other specified spina bifida without hydrocephalus</td>
<td>P11y.</td>
</tr>
<tr>
<td>Spina bifida without mention of hydrocephalus NOS</td>
<td>P11z.</td>
</tr>
<tr>
<td>Spina bifida NOS</td>
<td>P1z.</td>
</tr>
<tr>
<td>Spina bifida occulta</td>
<td>PG17.</td>
</tr>
<tr>
<td>Closed spina bifida with Arnold-Chiari malformation</td>
<td>P101.</td>
</tr>
<tr>
<td>Cerebral palsy, non congenital or infantile, acute</td>
<td>G669</td>
</tr>
<tr>
<td>Other congenital cerebral palsy</td>
<td>F23y.</td>
</tr>
<tr>
<td>Congenital cerebral palsy NOS</td>
<td>F23z.</td>
</tr>
<tr>
<td>Other congenital cerebral palsy</td>
<td>Fy23.</td>
</tr>
<tr>
<td>Dyskinetic cerebral palsy</td>
<td>F23y3</td>
</tr>
<tr>
<td>Ataxic infantile cerebral palsy</td>
<td>F23y0</td>
</tr>
<tr>
<td>Athetoid cerebral palsy</td>
<td>F1370</td>
</tr>
<tr>
<td>Flaccid infantile cerebral palsy</td>
<td>F23y1</td>
</tr>
<tr>
<td>Spastic cerebralalsy</td>
<td>F23y2</td>
</tr>
<tr>
<td>Congenital Cerebral palsy</td>
<td>F23..</td>
</tr>
<tr>
<td>Other infantile cerebral palsy</td>
<td>F23yz.</td>
</tr>
<tr>
<td>Cerebral palsy with spastic diplegia</td>
<td>F2301</td>
</tr>
<tr>
<td>Congenital cerebral palsy NOS</td>
<td>F23z.</td>
</tr>
<tr>
<td>Vogt's disease</td>
<td>F4423</td>
</tr>
</tbody>
</table>
Questionnaires for Clinicians and Administrative Personnel

Questions for users of the Special Needs System

A flow chart of the Special Needs System was provided, with numbered questions posed alongside. Subsequent pages provided blank text boxes for respondents to write in their responses to each question.

1. Is there anyone in particular that has ownership of data gathering for the system? If so, please state their current position (e.g. paediatrician / head of administration). Furthermore, do they actively participate in gathering / keying in information?

2. What are the main reasons you use your database? Please select one (or more) and write in the answer box:
   (A) Data on diagnosis
   (B) Audit
   (C) Planning
   (D) Improving Care of Individuals
   (E) Monitoring of Service Need
   (F) Info for families
   (G) Ensure children get services required
   (H) Other

3. How many special needs children are on your system?

4. Who is it that carries out the referrals in your Health Board?

5. Can all health professionals refer children to the system and, if so, do they all refer?

6. Are people put off from registering children onto SNS if they do not have a diagnosis for the child?

7. What about children who go to development centres? Are they registered on your special needs system?

8. Is written parental / carer consent provided?

9. Who usually undertakes the assessments?

10. How many Consultants, Health Visitors, Physios and Occupational Therapists are in your Health Board area / Trust?

11. Are any information leaflets available for parents?

12. Are any validity checks done on the system? If so, please give details.

13. Is there any admin support at a senior level? If so, what is set up?

14. Who keys in the information?

15. How often are children de-registered?

16. How much does this affect the validity of the system?

17. What happens to the data of those who are school leaving age?

18. What happens at the age of 19 years?

19. Is there any way of recording a family recent concern (For example: about the recent deterioration of their child.) or their concerns about the services their child or children receive? If so, please explain the procedures involved.

20. How often are shared clinical notes used?

21. What are the other agencies your special needs services are co-ordinated with?

22. Who receives the summary information?
23. What are the other means of communication between health professionals, such as education and social work?
24. Is the data that is gathered used in planning? If so, please provide concrete examples.
25. What forms are shredded?
26. What paper copies of SNS forms are kept?
27. Do any telephone reviews with parents take place between assessments? If so, please give details.

Questions for users of local database special needs systems

Again, a flowchart of the national Special Needs System was provided, with numbered questions posed alongside. As with the questionnaire for users of SNS, subsequent pages provided blank text boxes for respondents to write in their responses to each question.

1. What are the main reasons you use your database? Please select one (or more) and write in the box provided in the answer sheet:
   (A) Data on diagnosis
   (B) Audit
   (C) Planning
   (D) Improving care of individuals
   (E) Monitoring of service need
   (F) Info for families
   (G) Ensure children get services required
   (H) Other

2. Is there a method for registration used, such as an Access database, an Excel spreadsheet, a log book or any other means of identifying / tracking children recognised as having a special need? If yes, please specify. If no, what methods are used for tracking children with special needs?

3. Is there anyone in particular that has ownership of data gathering for the system? If so, please state their current position (e.g. paediatrician / head of administration).

4. How many children are on your system?

5. What means do you have for recording the severity of a child’s status?

6. Are any validity checks done on the system? If yes, please state.

7. How do the administration staff keep track of the children that are recorded as having a disability?

8. Do you feel that your infrastructure for your way of working is adequate? If not, then what would you change?

9. Does this trust / board use information leaflets to give to parents, if they suspect their child may have a disability?

10. Do parents give their consent to put their children onto the register? Is this written or oral consent?

11. Does your system involve the use of read codes, or any other form of coding used? If so, please specify.

12. (Relating back to Question 1) If your data is used for planning of services, please provide examples such as respite care.

13. What procedures do you have for de-registering a child?

14. If a family has recent concerns about the deterioration of their child, is there any way of recording these concerns? If yes, please describe the procedure.

15. What happens to the data of those who are at school leaving age?

16. Does your system produce any outputs, such as summary notes or information on the health professionals involved?

Evaluating the Effectiveness of the National Special Needs Information System in Scotland
17. Who receives feedback from the system?
18. What are the other means of communication between health professionals / education etc? Please provide examples.
19. Do you have any means of sending summaries or assessment to all the health professionals involved? If so, please state.
20. Has the data been used in planning of services such as education and social work? If so, please state which.

Additional Comments:
If the process of your information system is very different from SNS, perhaps you would like to draw a diagram or flow chart. This will aid in our understanding of your system.

**Questionnaires for Allied Healthcare Professionals**

*Questions for Health Visitors / Physiotherapists / Occupational Therapists / Speech & Language Therapists*

The questions were posed alongside a blank box for respondents to write in their responses to each.

1. How would you describe the communication between yourself and other professionals involved with children who have special needs?
2. (a) Do you receive any summary information about special needs children from your system on a regular basis? If so, what outputs do you receive?
   (b) (If answered yes to Question 2a) Do you feel the information you receive is enough to contribute to the effective management of a child?
3. Do you have any concerns about the way special needs information system works in your Health Board / Trust?
4. (If you feel you know enough about the system to comment) Is there anything about your system that you would alter? If so, what would you change and why?
5. Is there anything else that you would like to see from the special needs system in your area?
6. Are there any meetings that take place between the clinicians and other professionals involved with children who have special needs? If so, how regularly do they take place and what issues do they usually cover?
7. If you would like to add any extra comments or concerns about the way in which special needs information is recorded in your area, please use the space below.
Appendix 7  
Schedule for Site Visits to NHS Boards

Each of the NHS Boards visited have very different procedures in place to record data on children with special needs. Even those Boards that use SNS have not necessarily implemented the system in the same way. For this reason, a fixed list of questions to be asked of all personnel at each Board was not appropriate. A semi-structured format was therefore adopted. This ensured that necessary topics were covered, whilst allowing the flexibility to focus on issues most relevant to the interviewee. The topics were discussed in the order in which they naturally came into the discussion, which was not necessarily the order outlined in the format below.

The semi-structured format for the site visits was as follows:

<table>
<thead>
<tr>
<th>Type of system used in the NHS Board</th>
</tr>
</thead>
<tbody>
<tr>
<td>- What type of system is currently used in the Board?</td>
</tr>
<tr>
<td>- Is this used throughout the Board, in all areas?</td>
</tr>
<tr>
<td>- What is the format of this system (paper / electronic, software/s, networking of system)?</td>
</tr>
<tr>
<td>- Has any other system been used previously in this Board?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Implementation of the system</th>
</tr>
</thead>
<tbody>
<tr>
<td>- How was the system implemented?</td>
</tr>
<tr>
<td>- Has training been provided?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Type of information recorded</th>
</tr>
</thead>
<tbody>
<tr>
<td>- What type of data is recorded? Is a list of fields / core data available?</td>
</tr>
<tr>
<td>- Are conditions coded? If so, what coding system is used?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Users of the system</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Who uses the system in place?</td>
</tr>
<tr>
<td>- Do users have different kinds of access?</td>
</tr>
<tr>
<td>- Are all users using the system effectively? How / why?</td>
</tr>
<tr>
<td>- Are there currently any issues with the use of the system?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Main purpose of the system</th>
</tr>
</thead>
<tbody>
<tr>
<td>- What is the system (and its outputs) mainly used for?</td>
</tr>
<tr>
<td>- Does it fulfil this purpose / these purposes? How / why?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Feelings about the system</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Would you describe your attitude towards this system as generally positive or negative?</td>
</tr>
<tr>
<td>- What about other users or groups of users – how do you think they feel about the system?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Future plans</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Are there plans to make changes to the system in use or to adopt a different system?</td>
</tr>
<tr>
<td>- Specifically - If SNS is already used, will this continue?</td>
</tr>
<tr>
<td>If SNS is not currently used, is it likely to be adopted?</td>
</tr>
</tbody>
</table>
Appendix 8
Summary of Findings from Site Visits to each NHS Board

The following information summarises the findings of discussions during site visits to NHS Boards. For reasons of confidentiality each visit has been anonymised to a simplified format of Boards ‘A – M.’

These findings highlight the strengths and weaknesses of the special needs data recording systems used in the different Boards and enable common themes to be identified. It should also be noted that in Boards where it was apparent that little or no recording of data takes place, personnel were sometimes reluctant to discuss issues openly.

The schedule for these visits is outlined in Appendix 7.

NHS Board A - Non user of SNS with no current register in place
NHS Board A currently do not use national Special Needs System (SNS) and have no locally devised register in place. The tracking of children with special needs is done by individual doctors and their secretarial staff, using individually held Microsoft Excel spreadsheets.

At present, only minimal data is collected. There are no means of coding, enumerating, or planning of children’s services. Furthermore, the level of Information Technology (IT) literacy within the community paediatric division, and the amount of time and commitment paediatricians can offer to the development of IT skills, varies considerably.

In terms of future requirements, identifying the limitations of the current data collection system is a positive step as it highlights the necessary changes to be made if NHS Board A are to enhance their special needs data collection. Given that they do not have an electronic system dedicated to the recording of information about children with special needs, some credit should be given for the fact that any details at all are recorded electronically.

However, the information currently gathered in this board enables very limited tracking of children with special needs.

NHS Board B - User of SNS, but with low recording activity
NHS Board B uses SNS, but the number of children registered on the system is relatively low compared to the size of their total child population. For some users in this Board, implementation is still in progress and the process of registration is also slow in a number of areas. Nevertheless, numerous constraints were identified during the site visits, which could provide explanations for slow registrations. For example, there have been local network problems in one area and a shortage of clinical staff in another. Furthermore, the clinical and
administrative teams felt that recording children on the system was proving to be more work than first anticipated.

This Board is reasonably able to support SNS from a clerical/administrative perspective but there are acute medical staffing problems in some areas, resulting in difficulties seeing children. Nevertheless, despite their local limitations NHS Board B are persevering in registering children on SNS, and are adjusting well to the use of the system. They are optimistic that their coverage of children with special needs in SNS will improve with time.

**NHS Board C - Users of SNS, with high level of ascertainment**

NHS Board C uses SNS and appears to have an accurate and up-to-date dataset. However, despite the high level of data input by the administrative team, it is apparent that hospital paediatricians do not contribute fully to the system. This issue has been highlighted for change in the future. Additionally, it was mentioned that regional IT issues impede upon the operational process of the system in this Board.

The level of communication, along with dedication and enthusiasm towards SNS has resulted in a high level of case ascertainment in Board C. Despite this, the responsible clinician made a number of suggestions, which may be of benefit for those who are planning to put SNS into operation in the future. It is felt that some of the problems NHS Board C encountered could have been avoided had a more detailed implementation strategy for SNS been available.

**NHS Board D - User of SNS**

NHS Board D currently uses SNS. At present, the level of ascertainment is relatively low in this board. This is due to the fact that two areas within the Board have only recently implemented the system. Also, there are still a number of practical issues concerning the registration of a child. However, there are currently ten employees in the administration team in board D, all of whom contribute to the input of data. Thus, dedicated staff time and managerial support is apparent.

The maintenance of SNS does prove quite timely, due to the difficulties already noted. There are also a number of specialist registrars and temporary doctors in training who do not participate in maintaining the system. Hence, maintaining consistency of assessments and referrals has been problematic. Despite this, there remains much enthusiasm and commitment toward the use of SNS in NHS Board D.

**NHS Board E – User of SNS, with good ascertainment**

NHS Board E also uses SNS. The system in this Board is used for data on diagnosis, as a planning tool, and also to provide information for parents. Furthermore, relevant data is
forwarded to both education and social work departments on a ‘need to know’ basis. Hence, NHS Board E demonstrates the flexible nature of the SNS system.

However, the outputs from SNS were an issue for some users. It was mentioned that the output system is not very flexible. For example Health Visitors would not receive any feedback on a child if they were referred to a specialist outside the NHS Trust. This highlights the rigidity of information sharing across NHS areas.

Despite this, the system generally seems to be working successfully with minimal complications in NHS Board E.

NHS Board F – Non-user of SNS, with a limited recording system

NHS Board F previously adopted SNS but discontinued use because users were not entirely content with the system. Board F now has Microsoft Access databases holding approximately 6,000 records, plus two databases with approximately 3,000 records on school-age children. The systems are not networked across the Board and have no Read / ICD coding system.

The local databases of NHS Board F contain the following details: child’s name, address, date of birth, initial assessment and appointment date & time. It can also produce referral letters and assessment letters to those healthcare professionals involved with the child.

Parental consent to hold a child’s details on these databases is not obtained as the data is not currently used for research or planning purposes. This is a recognised weakness in the current information system. In order to maximise the potential of child health information, data should be used to plan the service requirements for children with special needs.

Hence, to undertake individual audits or research, NHS Board F acknowledge that they have a number of changes to make to their current system. The intention in the future is to create one unified system, whether this involves altering their current systems or implementing SNS is still a decision that NHS Board F is considering.

NHS Board G - Uses SNS and appears to be content with the capabilities of the system

NHS Board G uses SNS and appears to do so successfully, with minimal problems. They also have reasonably high level of case ascertainment. Many paediatricians in board G are enthusiastic about the use of the system and have put a great deal of effort into ensuring that it runs smoothly. However, as is the case for most boards, some are more enthusiastic than others.

It is worth mentioning that there are a number of children attending development centres with severe and complex problems who are not registered on the system. Thus, there are questions over whether or not psychologists and psychiatrists should actively participate in using SNS.
Although the system is generally working well in NHS Board G there were a number of specific problematic issues which were highlighted during the site visits. For example, it was mentioned that there is questioning around whether ‘looked after’ children should be included on the system.

Generally though, this is one of the NHS Boards that has minimal operational difficulties. The overall feedback about their use of SNS was very positive.

**NHS Board H - Non-user of SNS, with no register in place**

NHS Board H does not use SNS or any method of recording children with special needs other than a personalised system for paediatricians. Children are followed up at school and in clinics by relevant clinicians and school medical staff. However, this Board is hoping to develop a joint database with the social work department and are co-operating with the Same as You (SAY) database for individuals with learning difficulties. NHS Board F has also recently looked into the implementation of SNS and is considering taking on the system in the future.

Despite this Board not having any formalised means of recording data for special needs children, they have found ways around their current difficulties and there is a great deal of research going on within the Board towards improvement. For example, work has been completed regarding parents of children with ASD. This research focused on how parents see the health services and their involvement of decisions made for their child. The results of this report have assisted in the construction of a Care Pathway design for children.

From a planning perspective there is little robust information that can be used to identify the number of single agency or multi-agency referrals within this Board. It is not possible to use referral data to inform planning on a routine basis although ad hoc work has been undertaken to plot pathways of referrals. Only national data has been used to inform planning on service use. This is an issue that needs to be addressed.

Professionals in this NHS Board do however seem to be aware that there is low data recording for special needs children and there are a number of discussions taking place with regards to future developments.

**NHS Board I - Has a local special needs register, which also holds information on ‘looked after’ children.**

NHS Board I holds a local register of children with special needs or with any medical condition likely to affect a child’s development or require special provision in school / nursery. This database is used mainly for scheduling reviews and for statistical purposes.
This register does not use Read or ICD codes, but does however have a more simplified system, which has 50 general codes. These include ‘looked after’ children, specialist child protection support and extreme prematurity. NHS Board I also use the information derived from the register for planning purposes. For example, the prevalence of children with autistic spectrum disorders is provided to the Local Authority for the planning of support services for parents. This localised register is not as advanced as SNS, but credit should be given to this NHS Board for their efforts in maintaining their current system.

**Special Needs Register Code Numbers (NHS Board I)**

1. Hearing Impairment Profound loss of >70db in better ear. Moderate loss of 40-60db in better ear or significant unilateral loss
2. Visual Impairment perhaps requiring aids. Albinism
3. Autism including Asperger’s syndrome. Pervasive development disorder
4. Coeliac disease
5. Neurofibromatosis
6. Foetal Alcohol Syndrome
7. Turner’s Syndrome
8. Prader Willis Syndrome
9. Williams Syndrome
10. Mild learning difficulties (including specific learning difficulties.)
12. Severe learning difficulties in special school.
14. Psychosis
15. Behavioural / emotional problems (unspecified).
16. Cerebral palsy of any aetiology e.g. trauma, CVA, infection, genetic etc.
17. ADHD
18. Epilepsy, any type.
20. Speech and language problems (not secondary to global delay).
21. Syndromes (other).
22. Chromosomal abnormalities (other).
23. Skull deformities (inc. craniosynostosis).
24. Dyspraxia / developmental co-ordination disorder.
25. Tuberculous sclerosis.
26. Tumours.
27. Absence of any limb.
29. Defect of spine (not spina bifida).
30. Paralysis of limb or trunk.
31. Orthopaedic problems. Achondroplasia / Rheumatoid / Brittle bones
32. Cystic Fibrosis.
34. Heart disease: congenital or acquired.
35. Diabetes mellitus.
36. Other metabolic disease. Addisons / Hypothyroidism / Pituitary insufficiency.
37. Cleft lip / palate.
45. Asthma.
46. Skin conditions.
47. Allergic conditions. Epipen use.
48. Other.
49. Downs Syndrome.
51. Renal disease / malformation (inc. Diabetes insipidus)
98. LAC (Looked After Children).
99. Extreme Prematurity / Very low birthweight. <32 weeks gestation or <1500gms.

**NHS Board J - Implemented SNS but have suspended use.**

NHS Board J previously implemented and used SNS, but has now suspended its use due to staffing shortages. They do however hope to start using it again in the near future. The child health commissioner for Board J is very aware of the system’s potential in this respect and the hope is the system will be up and running again soon.

**NHS Board K - This NHS Board uses SNS**

This Board uses SNS. Unfortunately however, this board had no lead paediatrician during the period of this evaluation and it was therefore very difficult to elicit any qualitative information from their personnel. Analysis of data from their SNS has nevertheless been included in this report.

**NHS Board L - This NHS Board uses SNS**

This NHS Board implemented SNS fairly recently. They have good ascertainment, although it is apparent that many of the data fields on the forms are not yet being completed. This Board has three phases for implementing and utilising SNS. They are the following:-

**Phase 1:** Internal issues around SNS.
**Phase 2:** HV, notification forms. Introducing child development units and multi-disciplinary teams to SNS.
**Phase 3:** A fully integrated system with involvement of acute consultants where possible.

At the moment this Board is still in phase 1 of their plans. Designated time is needed if developments are to take place. However, at the end of the first year of using SNS, a local evaluation of the system was undertaken. The overall yearly evaluation revealed a good positive response to SNS. The following are some comments received:

- 100% of responses stated that implementing SNS has increased staff workload.
- 90% of the responses stated that the completion of the form was not realistic to the time constraints at clinic / in the home.
- 90% of the responses stated that they did not find the disability coding section a useful component of the assessment process.
60% of the responses stated that they did not think the system for recall is working efficiently for the area to plan their work schedule.

90% were aware that it is possible to refer to another agency / professional via SNS, but only 50% of the staff were utilising this option.

70% of the medical staff were satisfied with the reports generated following assessment.

50% stated that SNS has made a difference to the co-ordination of care for children and families. Those who had stated that it has made a difference mentioned better communication & less duplication. Also, that parents have full information on who is involved with their child.

Finally, 75% stated that if they were more informed about the caseload of special needs children, they would be able to improve their existing work planning process.

During the site visits to this Board the views expressed did appear to reflect that of the local evaluation. However there were also a number of additional concerns expressed. One for example was concerns about issues related to referral. It was mentioned that a diagnosis for autistic spectrum disorders (ASD) could often be quite slow. In order to diagnose a child with ASD the psychology department also have to undertake an assessment. The waiting list for the clinical psychology department is lengthy. Hence, this affects how quickly children are diagnosed. Additionally, the referral of children with ADHD is also low in NHS Board L. The reason for this is that there are mixed feelings amongst clinicians about whether or not children with ADHD should be recorded on the system.

Operationally, things are moving in this NHS Board. They have faced a number of local issues since implementing the system, but nevertheless they are slowly progressing.

**Board M - This NHS Board does not use SNS**

NHS Board M has not yet adopted SNS. They currently have staffing shortages. Furthermore, a number of the community paediatricians also work part time, hence it is proving a challenge to find an enthusiastic member of staff who would be willing to encourage and promote use of SNS.

Although NHS Board M currently has no single information system for recording children with special needs, they do have an information system held by the community nursing team, and also with the children’s development centres. This holds data on children with complex needs. However, it has no formalised means of coding. One of the difficulties in this area appears to be the low enthusiasm towards using a computerised system.

Overall, representatives of Board M seem keen to consider the adoption of SNS in the future.
Appendix 9
Schedule for Focus Group Discussions with Parents of Special Needs Children

Below is the topic guide and example questions used to guide the focus group discussions with parents. The focus groups were run by a trained facilitator and also observed by the main researcher for this project. This semi-structured format ensured that necessary topics were covered, whilst enabling particular focus to be given to areas most relevant to the participants. The topics were covered as they most naturally came into the discussion with each group, which may not have been in the order below. The facilitator also ensured that all participants had their say, so that the discussion was not dominated by minority opinions.

**Introduction**
Each parent was invited to introduce themselves and briefly to describe their child or children (age and type of special need or needs).

**Information given to parents**
- When your child was first diagnosed, what information were you as parents given?
- Where did this information come from (e.g. health professionals / other organisations)?
- Since diagnosis, what other information have you got? Where from?
- Has the information you’ve got been enough for you to make sense of your child’s needs?

**Transmission of information / information sharing**
- Are you aware of the information held by health professionals about your child?
- What kind of records do you think should be kept about your child?
- Who do you think has access to records about your child?
- Do you think this information is shared between health professionals and other agencies involved in your child’s care (such as education, social services)? Should it be?
- What else do you think happens to this information about your child? How do you feel about this?

**Co-ordination of care**
- Do you know of any system that helps health professionals track your child’s progress?
- Who is the co-ordinator of your child’s care?
- Who do you think should be responsible for the co-ordination of your child’s care?
- How do you feel about co-ordinating your child’s care yourself?
- Do you think there should be changes to the co-ordination of care? If so, in what way?

**Interaction with health professionals**
- How would you describe your contact with health professionals regarding your child?
- Do you get to see the same health professionals at each appointment?
- Is there a point of contact for you if you have any concerns or worries?

**Service provision**
- How do you feel about the services that have been available to support you and your child?
- How do you get access to these services?
- Do you think it matters where you live?
Appendix 10

Key Themes Apparent During Focus Group Discussions

1. Family Issues
Parents often reported that within their multitude of roles, the main role as a parent was often forgotten. Due to the stressful and demanding tasks that they are expected to undertake in caring for their child, they often felt their other children in the family were missing out on the ‘normal’ family activities and interactions. There appeared to be a considerable amount of associated anxiety with regard to this.

Often reported by parents was the fact that health professionals habitually viewed their child as merely a catalogue of common symptoms, for example, ‘a Down’s Syndrome child.’ The child as an individual was therefore seemingly lost or forgotten. This caused some frustration amongst parents.

‘Treat them like a person.’
Focus Group 2, participant 5.

‘They don’t look at the whole child, everyone is just doing bits.’
Focus Group 2, participant 7.

Overall, parents want professionals to appreciate that their child or children do not live in a vacuum, but are part of a wider organism and network of relationships, which is the family. According to parents it seems that the other parental, spousal and wider family demands are often forgotten by professionals - ‘tunnel vision’ is adopted, seeing only the child’s medical needs.

2. Recognition of Parental Efforts
Parents clearly feel that they provide the main role in terms of co-ordination of care, provision of care, advocacy and pseudo-clinical intervention and treatment. They feel that this highly stressful and demanding job comes with very little recognition on the part of the health care professionals. This is an issue that needs to be addressed. Parents described a constant cycle of stress and worry of organising services and looking after their children and their frustrations are heightened when they feel that their continuous efforts are not being recognised.
3. Interactions with Professionals
Repeatedly during the discussions, parents used the term ‘fight’ to describe their interactions with health care professionals. They described an ongoing battle for resources, services, diagnoses and treatment interventions. Many of the parents felt that as a consequence they were perceived as reluctant battle-hardened veterans of ‘the system’. According to what parents said, there was a genuine sense of a ‘them’ and ‘us’ situation between themselves and the health care professionals.

4. Diagnosis
Changes in terminology describing their child’s medical conditions also seemed to have caused problems for parents. It seemed that often a child’s diagnosis would change over time, as new terms came into vogue or other symptoms that the child exhibited became more prominent. For the parent, however, this seemed to be confusing and amongst some may have been perceived as a reason to distrust the health care professionals.

Some parents felt that they were very reluctant to have any kind of label attached to their child. In contrast, others recognised that without a label, accessing health services can be increasingly difficult. These parents felt that having a diagnosis ‘label’ allowed them to get in touch with support services, self-help groups, specialist websites and gave them a ‘name’ to explain to others if they were asked about the child’s needs.

‘I personally like labels, both professionally and maternally because I think it lets you look in the right places such as on the internet for information on your child’s condition. It also lets you get in touch with other parents and join the right support groups...but it is getting the professionals to look beyond the label. You have to look at the child.’
Focus Group 2, participant 7

‘I’ve never been a big fan of labelling kids with any particular...you know, description of sort. But what we found was that when we moved two years ago, we have really struggled to get support. So now we are pushing for a diagnosis because we feel that without it we are just not getting the support at all.
-focus Group 4, participant 17.

Finally, parents consistently talked about health professionals assuming that they could ‘cope’ with information about their child’s diagnosis without need for any further support. It seems therefore that more information at diagnosis would have helped parents.

5. Equity
There was an awareness of the lack of equity in services expressed during the discussion. Parents expressed great concern for other mums, dads or carers who are non-literate or were
not very assertive when trying to access services. Many parents stated that you don’t get the services unless you ‘shout loud enough.’

6. Services and Geographical Location
Geographically there appeared to be differences in the access to healthcare services and service provision. Some parents talked about being offered services they didn’t need, whilst others said they were turned down for services for which they were desperate. Parents stated that this had a direct, measurable effect on their child’s health, well-being and ongoing development.

7. Initial Information
It became apparent that these parents initially received very little information with regards to either clinical or service information. Whether SNS was established in the NHS Board or not did not seem to affect the amount of information that was provided to parents. It appears that there is no one person who takes responsibility for guiding parents through the traumatic episode of diagnosis or assisting him / her to navigate through the services system. There was a general consensus that this would be of particular benefit.

‘You need an information pack, and you need a person, a professional that can come to you and explain things.’
Focus Group 4, participant 20.

Many parents also reported that initially they had been ‘promised’ leaflets or written documentation, but that these often failed to appear.

‘I got very little information. Nobody sat down and told me what cerebral palsy is! It was through my own research. Thankfully, I am a very pro-active parent.’
Focus Group 2, participant 5.

However, some parents were more fortunate than others:

‘We had very little information at the start. We got in touch with the Down’s Syndrome Association, but no one told us how. However, then we were very fortunate that the paediatrician who was new had a particular interest in Down’s Syndrome and we got information that way.’
Focus Group 3, participant 7

8. Repetition and Preparation
Much of the dissatisfaction felt by parents appeared to be associated with having to repeat their child’s basic case history again and again, often going back to the birth trauma or event.

Evaluating the Effectiveness of the National Special Needs Information System in Scotland
‘A lot of mums say they keep on having to tell the same story over and over again...now I don’t answer questions I don’t want to - I just say, look at his notes.’
Focus group 5, participant 17.

For most parents the repetition of information seems unnecessary, especially when they were attending a professional for a basic medical issue or examination. It also became apparent that parents perceived this continual repetition as evidence for the lack of clinical preparation on the part of the health care professional.

9. **Sharing Information**

There were positive feelings expressed about the sharing of information with other professionals involved in their child’s care, both within healthcare and across other services.

> ‘Sharing of information is a good concept but it depends on whether they look at the information.’
> Focus Group 2, participant 5.

The main concern was that before any information is stored, parents should have access to it, in order to check the quality and accuracy of the content. Incorrect data disgruntles parents, and the duplication of incorrect data multiplies their dissatisfaction. It was also noted that parents felt they should have a say about what information should be shared.

> ‘I think we should be asked if we want to share the information. I don’t think it should be presumed that it should be shared. We actually know our children better than anyone else but people seem to presume that they know better than we do.’
> Focus Group 4, participant 17.

At present, parents seem to have little knowledge of who has access to their child’s information and where the information is getting transferred from/to. There appeared to be a suspicion that the medical records were in fact just a ‘place’ to hold all the information together, as opposed to useful information, which can enhance information sharing across service provisions.

10. **Information recommendations**

There was a desire to have a ‘known’ point of contact - someone who could guide and advise parents at any time. It was reported that many of the services had been stumbled upon through ‘luck’ or through discussion with other parents. Often parents reported that they were just sent home and told to get in touch if they had any difficulties. There did not appear to be
any follow-up or tracking of the child from hospital to community, this appeared to be a big hole in transitional service provision.

11. Co-ordination of Care

There was no evidence of co-ordination of care by health professionals involved with the child. Essentially, parents perceive themselves as the co-ordinators of their child’s care. This, of course, is incredibly stressful, time-consuming and something that parents had to learn to do over time. Nevertheless, parents appeared to do a very good job of this, with little or no training and again there appeared to be a network of support mainly coming from other parents.

‘I think any co-ordination of care if you are a parent with a child with special needs, you co-ordinate it yourself.’

Focus Group 5, participant 18.

Although acknowledged as stressful and difficult, there was some debate as to whether parents would like to hand over this responsibility to professionals. One of the main problems foreseen was the rapid changeover in staff. Many parents reported that often they developed a relationship with a professional, only for that professional to then move on to another service. This could be very disheartening for a parent and necessitated the development of a new relationship, with all the repetition that this involved.

Conclusions

There are no notable differences between parents’ perceptions of the services those living in SNS users boards receive in comparison to non-user boards. Without exception, every parent participating in the focus groups demonstrated many frustrations with current healthcare service provision and access to services.

The implementation of SNS or a similar information system in those non-user areas could however assist in reducing some parental difficulties (such as reducing the repetition of information, communication and co-ordination of care).

Nevertheless, there are also issues that an information system cannot change, such as a main point of contact and information at diagnosis. Parents consistently called for:

- A main point of contact
- Information distribution at diagnosis
- Co-ordination of care by health professionals