Special Visual Assessment Clinic: An Audit of Northern Trust Area Services, including Regional Recommendations

August 2016

www.rqia.org.uk/GAIN

Assurance, Challenge and Improvement in Health and Social Care
## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>List of Tables</td>
<td>3</td>
</tr>
<tr>
<td>List of Figures</td>
<td>3-4</td>
</tr>
</tbody>
</table>

## Executive summary

5-6

## Clinical audit report

Project Team 7
Background/rationale 8-11
Aim 11
Objectives 11
Standards/Guidelines/Evidence Base 11-13
Sample 13
Data Source 13
Audit Type 13
Methodology 14-16
Findings and Observations 17-48
Presentation 48
Recommendations 49
References 50-52

## Appendices

<table>
<thead>
<tr>
<th>Appendix</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appendix 1</td>
<td>Special Visual Assessment Clinic Referral Form</td>
<td>54</td>
</tr>
<tr>
<td>Appendix 2</td>
<td>Special Visual Assessment Clinic Consent Form</td>
<td>55</td>
</tr>
<tr>
<td>Appendix 3</td>
<td>Eye examination Preparation Booklet</td>
<td>56</td>
</tr>
<tr>
<td>Appendix 4</td>
<td>Letter to Carer/Parent to notify them of Special Visual Assessment</td>
<td>57</td>
</tr>
<tr>
<td></td>
<td>Clinic starting</td>
<td></td>
</tr>
<tr>
<td>Appendix 5</td>
<td>Eye examination first visit proforma</td>
<td>58</td>
</tr>
<tr>
<td>Appendix 6</td>
<td>Eye examination review proforma</td>
<td>59</td>
</tr>
<tr>
<td>Appendix 7</td>
<td>Follow up letter to Carer/Parent following eye examination</td>
<td>60</td>
</tr>
<tr>
<td>Appendix 8</td>
<td>Special Visual Assessment Clinic Day Centre Staff Survey</td>
<td>61</td>
</tr>
<tr>
<td>Appendix 9</td>
<td>Focus group information sheet for patients/clients</td>
<td>62</td>
</tr>
<tr>
<td>Appendix 10</td>
<td>Focus group consent form</td>
<td>63</td>
</tr>
<tr>
<td>Appendix 11</td>
<td>Focus group questions and answers</td>
<td>64-68</td>
</tr>
<tr>
<td>Appendix 12</td>
<td>Causes of Learning Disability in the “Other” Category</td>
<td>69-70</td>
</tr>
</tbody>
</table>
List of Tables

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Table 1</td>
<td>Project Team members</td>
<td>7</td>
</tr>
<tr>
<td>Table 2</td>
<td>Learning Disability severity against IQ classifications</td>
<td>8</td>
</tr>
<tr>
<td>Table 3</td>
<td>Standards measured by the audit</td>
<td>12-13</td>
</tr>
<tr>
<td>Table 4</td>
<td>Client Needs Profile</td>
<td>18</td>
</tr>
<tr>
<td>Table 5</td>
<td>Classification of Distance Visual Acuity</td>
<td>31</td>
</tr>
<tr>
<td>Table 6</td>
<td>Categories of severity of Visual Impairment</td>
<td>32</td>
</tr>
<tr>
<td>Table 7</td>
<td>Prevalence of Common ocular Abnormalities within the SVAC Population</td>
<td>41</td>
</tr>
<tr>
<td>Table 8</td>
<td>Causes of Learning Disability in the “Other” Category for Figure 2</td>
<td>70-71</td>
</tr>
</tbody>
</table>

List of Figures

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Figure 1</td>
<td>Reasons for Special Visual Assessment Clinic non-attendance</td>
<td>17</td>
</tr>
<tr>
<td>Figure 2</td>
<td>Cause of Learning Disability</td>
<td>18</td>
</tr>
<tr>
<td>Figure 3</td>
<td>Client Needs Group</td>
<td>19</td>
</tr>
<tr>
<td>Figure 4</td>
<td>Method of Client Communication</td>
<td>20</td>
</tr>
<tr>
<td>Figure 5</td>
<td>Number of Appointments to Complete Eye Examination per Needs Group</td>
<td>21</td>
</tr>
<tr>
<td>Figure 6</td>
<td>Number of Appointments to Complete Eye Examination per total</td>
<td>21</td>
</tr>
<tr>
<td>Figure 7</td>
<td>Reason for Attendance at Hospital Eye Service</td>
<td>22</td>
</tr>
<tr>
<td>Figure 8</td>
<td>Attendance at Hospital Eye Service in Childhood</td>
<td>23</td>
</tr>
<tr>
<td>Figure 9</td>
<td>Sample Distance Visual Acuity Tests</td>
<td>24</td>
</tr>
<tr>
<td>Figure 10</td>
<td>Frequency of Visual Acuity Tests Utilised</td>
<td>25</td>
</tr>
<tr>
<td>Figure 11</td>
<td>Sample Near Visual Acuity Tests</td>
<td>25</td>
</tr>
<tr>
<td>Figure 12</td>
<td>Co-operation for Visual Acuity Test within Client Needs Group</td>
<td>26</td>
</tr>
<tr>
<td>Figure 13</td>
<td>Co-operation for Retinoscope Test within Client Needs Groups</td>
<td>28</td>
</tr>
<tr>
<td>Figure 14</td>
<td>Picture of Direct Ophthalmoscopy</td>
<td>29</td>
</tr>
<tr>
<td>Figure 15</td>
<td>Co-operation for Ophthalmoscopy within Client Needs Groups</td>
<td>30</td>
</tr>
<tr>
<td>Figure 16</td>
<td>SVAC Population Binocular Initial Distance Visual Acuity and Final Distance Visual Acuity</td>
<td>31</td>
</tr>
<tr>
<td>Figure 17</td>
<td>SVAC Population Binocular Initial Near Visual Acuity and Final Near Visual Acuity</td>
<td>34</td>
</tr>
<tr>
<td>Figure 18</td>
<td>Refractive Error for each eye using Best Vision Sphere</td>
<td>35</td>
</tr>
<tr>
<td>Figure 19</td>
<td>Astigmatic Error of each Eye</td>
<td>36</td>
</tr>
</tbody>
</table>
Figure 20  Near Visual Acuity of Presbyopic Patients before and after SVAC Clinic  37
Figure 21  Type of Spectacle correction recommended for those who required glasses  39
Figure 22  Binocular Assessment  40
Figure 23  Reason for Referral to Ophthalmologist  41
Executive Summary

Learning disability has been defined as a significantly reduced ability to understand new or complex information or to learn new skills (impaired intelligence), with:
- a reduced ability to cope independently (impaired social functioning)
- which started before adulthood, with a lasting effect on development.

An estimated two percent of Northern Ireland’s population (33,000) are thought to have a learning disability.

Prevalence rates for visual impairment amongst those with learning disability vary with figures of up to 66% having been quoted in the literature. Many causes of vision impairment including uncorrected refractive error and cataract can be treated whereas vision disability resulting from other causes (i.e. optic atrophy) can be managed.

Government policy is to enable those with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary. The Special Visual Assessment Clinic (SVAC) established by a multi-professional team of individuals with expertise in this area has evolved over a 10 year period in Northern Ireland and this project represents a comprehensive audit of the most recently established component (The service in the Northern Trust Area).

The principal aim of this audit was to evaluate the need for and effectiveness of the Special Visual Assessment Clinic (SVAC) in the Northern Trust area and to make recommendations for Service development that are applicable and relevant to Services delivered by similar multidisciplinary teams across Northern Ireland.

Of the total of 941 individuals from 11 adult centres in the Northern Trust area who would have been eligible to avail of the SVAC service 617 (66%) indicated a desire to avail of services. Of the 34% (324) who opted not to avail of the service 40% (130) were under current optometric care in the community.

Of those seen within the SVAC 40% (248/617) had never had a formal eye examination. Of the 369 individuals who had previously had an eye examination only 36% (132/369) had one within the last two years, the interval generally recommended for repeat assessment in adult populations who may have sight threatening eye disease or under/uncorrected refractive error. Those with the most severe form of Learning Disability were found to be least likely to have had a previous eye examination.

It was noted that 63% of the sub population most likely to have a form of visual disability had thus never had an eye examination. Almost half of those identified as
in need of a refractive correction or other form of ophthalmic treatment had not
identified any symptoms that would have indicated a need for an eye examination.
Cooperation with testing procedures varied according to the particular ophthalmic
test being carried out ranging from 78% cooperation to 98%. Co-operation with tests
involving subjective responses (Visual Acuity Testing) and potentially invasive
examinations (Ophthalmoscopy) was greatest in those with less severe learning
disability. Following refraction and the provision of an appropriate spectacle
correction the percentage of those achieving a distance visual acuity of 6/12
(LogMAR 0.30) or better increased from 59% to 64%, whereas the percentage of
those classified as vision impaired (VA<6/18 LogMAR 0.50) dropped from 18% to
11%. Similarly the percentage of those achieving an optimal reading/near acuity of
N8 or better rose from 64% to 74% after the prescription of appropriate spectacles.
The overall distribution of refractive errors in those with learning disability was much
broader than the distribution of refractive errors in an otherwise normal population.
The outcome of refraction was that 45% (280/617) individuals were supplied with
310 pairs of spectacles, 77% of which corrected a distance refractive error whereas
33% were for near tasks. Only five patients were provided with a bifocal correction.
Regarding significant ophthalmic pathology 10% of patients (61/617) were noted to
have cataract, 4% nystagmus and 2% keratoconus. Only 31 patients required
referral for an ophthalmic medical opinion.

Recommendations resulting from the audit and supported by qualitative data
collected from user and support staff focus groups and questionnaires indicate that
the SVAC service is deemed to be of great value. It is recognised that providing
support for patients availing of the services improves cooperation whereas training
on vision related topics helps inform staff of the benefits of the service. It is
recommended that more able residents should be encouraged to avail of community
based vision/optometry services whereas the SVAC service has a unique role for
those with more severe disability.

These results were presented to the Northern Trust, which resulted in secured
permanent funding being made available for this service. Presentation of preliminary
findings to the Western Trust has taken place and it is anticipated that a similar
service will be established in the West. The need for services for children with
learning disability is also under consideration, with the Belfast Trust undertaking an
audit to evaluate joint orthoptic/optometric assessments in Special Schools.

Final results will be presented to both optometric and learning disability professionals
in 2016/2017. It is envisaged that results will be published in a peer review journal to
ensure distribution to a wider audience. Discussions will continue with the Health and
Social Care Board (HSCB) regarding the importance of commissioning appropriate
eye care services for both adults and children with learning disabilities.
Clinical Audit Report

Project Team
All professionals involved in this project were selected for reasons that included their knowledge of
- Learning Disability
- Visual problems common amongst those with learning disability
- Assessment techniques employed
- Experience in research and clinical audit
This provided a representation from all Trusts. The report is an audit of services delivered in the Northern Trust which includes regional implications and recommendations.

Table 1: Project Team members

<table>
<thead>
<tr>
<th>Name</th>
<th>Job Title/Specialty</th>
<th>Trust</th>
<th>Role within Project (data collection, Supervisor etc.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paula McElduff</td>
<td>Specialist Optometrist</td>
<td>Belfast</td>
<td>Project Lead, data collection and analysis</td>
</tr>
<tr>
<td>Jenny Lindsay</td>
<td>Deputy Head of Optometry</td>
<td>Belfast</td>
<td>Project Lead, Supervisor</td>
</tr>
<tr>
<td>Anne McGlade</td>
<td>Equality Schemes Manager</td>
<td>BSO</td>
<td>Advisor with interest in focus groups</td>
</tr>
<tr>
<td>David Bickerstaff</td>
<td>Principal Social Worker,</td>
<td>HSCB</td>
<td>Advisor with expertise in database and questionnaire design</td>
</tr>
<tr>
<td>Donna Morgan</td>
<td>Locality Manager, Learning Disability Services</td>
<td>Northern</td>
<td>Advisor</td>
</tr>
<tr>
<td>Shirley Clarke</td>
<td>Clerical Support Worker</td>
<td>Northern</td>
<td>Administration support</td>
</tr>
<tr>
<td>Nickie Boyes</td>
<td>Senior Rehabilitation Worker</td>
<td>South Eastern</td>
<td>Client Focus Group Facilitator</td>
</tr>
<tr>
<td>Jane Robinson</td>
<td>Specialist Optometrist</td>
<td>Western</td>
<td>SVAC Service Provider</td>
</tr>
<tr>
<td>Sarah Shanks</td>
<td>Optometrist</td>
<td>Belfast</td>
<td>Optometric data input</td>
</tr>
<tr>
<td>Jonathan Jackson</td>
<td>Associate Professor. Head of Optometry</td>
<td>Belfast</td>
<td>Academic Advisor</td>
</tr>
<tr>
<td>Dalirene Masson/</td>
<td>Regional Clinical Audit Facilitator</td>
<td>GAIN</td>
<td>Clinical Audit Advisor</td>
</tr>
<tr>
<td>Robert Mercer</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


Background/Rationale

The Department of Health (Valuing People, 2001) defined learning disability as, “a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with; a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development.”

Although the United Kingdom uses the term ‘learning disability’, an increasing number of international organisations and countries (e.g. USA, Canada, and Australia) are using the term ‘intellectual disability’ and it is interchangeable with the UK term learning disability.

In 2003 it was estimated that 2% of the population (equating to about 33,000 people) in Northern Ireland had a learning disability (http://www.dhsspsni.gov.uk/prevalence study-03.pdf).

The degree or severity of learning disability is classified according to IQ as shown in the table below which is taken from the World Health Organisation (WHO) International Classification of Diseases (ICD).

**Table 2: Learning Disability severity against IQ classifications**

<table>
<thead>
<tr>
<th>Level</th>
<th>IQ</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>50-69</td>
</tr>
<tr>
<td>Moderate</td>
<td>35-49</td>
</tr>
<tr>
<td>Severe</td>
<td>20-34</td>
</tr>
<tr>
<td>Profound</td>
<td>&lt;20</td>
</tr>
</tbody>
</table>

Chapter 4 of the Government’s 2001 White paper “Valuing People: A New Strategy for Learning Disability for the 21st Century” focuses on health and recognises that those with learning disability have substantial health needs that are not being met. The Government’s objective is to “enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary.”

In July 2008, Sir Jonathan Michael published a report on the “Health Care for All” enquiry, which concluded that “insufficient attention is given to making reasonable adjustments to support the delivery of equal treatment, as required by the Disability Discrimination Act. Adjustments are not always being made to allow for communication problems, difficulty in understanding (cognitive impairment), or the anxieties and preferences of individuals concerning their treatment”.

In August 2009, the Special Visual Assessment Clinic (SVAC) was established in the Northern Trust area to address the concerns relating to eye care and overcome the
barriers encountered by adults with learning disability when trying to access appropriate services.

It is well documented that visual impairment is more common among adults with learning disability\(^1\) than in the general population, especially in those with severe and profound learning disability\(^2\). The presence of a visual impairment can significantly impair the independence and quality of life of adults with learning disability and indeed has been proven to compound the learning disability\(^3\).

Prevalence rates for visual impairment amongst those with learning disability vary as seen in a literature review published by Warburg in 2001. They depend on the definition of visual impairment used and the learning disabled population surveyed.

Van Splunder (2006) found a prevalence of visual impairment ranging from 2% in young adults with mild learning disability and no Down’s Syndrome to 67% in older adults with profound learning disability and Down’s Syndrome. He took a random sample from a base population of adult users of learning disability services and from this calculated a weighted prevalence rate of visual impairment and blindness in the total Dutch population of adult users of learning disability services as 14%.

This compares with about 3% of the UK population as a whole that have some degree of visual impairment. About two thirds of these are thought to have sufficiently severe problems to qualify for blind (severely sight impaired) or partial sight (sight impaired) registration\(^4\).

This increased prevalence rate of visual impairment among adults with learning disability is not solely due to congenital problems (such as optic atrophy and nystagmus) but also uncorrected refractive errors (e.g. short sightedness) and the delayed diagnosis of treatable ocular pathology such as cataracts and glaucoma\(^5\).

Down’s Syndrome\(^6\), severe or profound learning disability\(^7\) and an age of greater than 50 years\(^8\) further increase the risk of specific ocular disorders.

Woodhouse (1998 & 2000) found an incidence significantly greater than the general population for refractive errors (myopia, hypermetropia and astigmatism), strabismus (squint) and below normal visual acuity.

---

\(^2\) Van den Broek 2006, Van Splunder 2006
\(^3\) Barr 1991, Evenhuis 2009
\(^4\) Denniston & Murray 2008
\(^6\) Maata 2006
\(^7\) Van Splunder 2006, Emerson & Robertson 2011
\(^8\) Evenhuis 1995
In 2011, See Ability and Royal National Institute of Blind People (RNIB) published research undertaken on their behalf by Emerson and Robertson of the Centre for Disability Research (CeDR). They found that adults with learning disability are ten times more likely to be blind or partially sighted than the general population and that six out of ten people with learning disability need glasses.

The above data confirms the importance of adults with learning disability attending for regular eye examinations. However, research and anecdotal evidence has shown that this is not the case. Mencap’s study by Band (1998) found that of 2,700 adults with learning disability, only 53% had attended for an eye examination in the last two years. Lindsay (2006) reported that in a sample of 95 adults with learning disability, 43% had never had a previous eye examination.

There are many possible reasons for this lack of eye examinations. Emerson and Robertson (2011) reported that people with learning disability may not know they have a sight problem and that many people think that the person with the learning disability can see perfectly well. Levy (2004) found that carers perceived adults with learning disability as being too disabled to receive eye care. There is a lack of adequate accessible eye care for adults with learning disability and lack of awareness about visual problems in this population subgroup among carers and clinicians.

The SVAC was set up to improve access to eye care services for adults with learning disability. It is an optometry led outreach service that aims to provide high quality optometric services to adults with learning disability, in addition to promoting the importance of regular eye examinations and improving the uptake of visual assessments among this subgroup of the population.

In August 2009, the service was set up to provide eye clinics in day centres throughout the Northern Trust. It was funded as a pilot scheme for two years and was based on a similar service to that operating in the South Eastern Trust since 2000 and in the Belfast Trust since 2003.

Experienced hospital optometrists skilled in the visual assessment of adults with learning disability use a domiciliary visual testing kit that is specifically equipped for this population group. The majority of eye examinations are carried out at the client’s day centre (a familiar environment) and patients are accompanied by either a day care worker or carer to ease anxiety.

Prior to the eye examination, carers are asked to complete a questionnaire which provides details on past ocular history, visual needs and concerns, general medical problems and on communication, hearing, mobility and challenging behaviour.

---

9 Woodhouse 2000, Kerr 2003
10 Woodhouse 2000
(Appendix 1). Written consent from the client is obtained where possible; otherwise their carer provides written consent (Appendix 2).

An eye examination preparation booklet, written with input from Speech and Language Therapists is made available to each day centre to help prepare the clients for the eye examination, with the aim of increasing co-operation rates. This booklet uses symbols, photographs and easy words to explain the eye examination process (Appendix 3).

Visual Awareness Training is offered to staff in the day centres. This is provided by the optometrists but uptake for this is variable, with not all centres taking the opportunity to avail of it. The training highlights the likelihood of adults with learning disabilities having visual problems and demonstrates the techniques employed during the eye examinations.

Aim
The purpose of this audit was to evaluate the effectiveness of the SVAC in the Northern Trust area and to make recommendations for Service development that are applicable and relevant to Services delivered by similar multidisciplinary teams across Northern Ireland.

Objectives
- To assess the number of adults with learning disability not currently accessing eye care services
- To measure the uptake of the SVAC service
- To identify the reasons for non-utilisation of the service
- To evaluate assessment techniques utilised and measure co-operation rates
- To assess the incidence of spectacles required
- To measure the prevalence rates of visual problems
- To document the incidence of onward referral to other professionals
- To ascertain the views of service users and carers through focus groups
- To gain feedback from day centre staff of their views of the service through questionnaires

Standards/Guidelines/Evidence Base
Standards and targets for eye care services for adults with learning disability do not currently exist. Only guidelines for best practice and improving standards of care are available (www.lookupinfo.org). The published evidence base highlights an unmet need in that adults with learning disabilities have an increased risk of ocular problems but yet many are not accessing eye care services.
<table>
<thead>
<tr>
<th>Criteria</th>
<th>Target (%)</th>
<th>Exceptions</th>
<th>Source &amp; Strength* of Evidence</th>
<th>Instructions for where to find data</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Ensure that day centre attendees are accessing eye care services</td>
<td>100</td>
<td>Some day centre clients will be seen by community (GOS) optometry and not within the SVAC</td>
<td>Published papers</td>
<td>References available on request (See Appendix)</td>
</tr>
<tr>
<td>2. Measure the high prevalence rate of visual problems amongst adults with learning disabilities</td>
<td>N/A</td>
<td>Measurement rates vary from paper to paper</td>
<td>Published papers</td>
<td>References available on request (See Appendix)</td>
</tr>
<tr>
<td>3. Ensure that, where appropriate, spectacles are prescribed</td>
<td>100</td>
<td>Clinical decision making based on perceived likelihood of tolerating spectacles and benefit to be gained by patient</td>
<td>Published papers</td>
<td>References available on request (See Appendix)</td>
</tr>
<tr>
<td>4. Ensure that onward referral is initiated for treatable ocular pathology</td>
<td>100</td>
<td>Only ocular pathology with treatment options will be referred</td>
<td>Published papers</td>
<td>References available on request (See Appendix)</td>
</tr>
<tr>
<td>5. Measure co-operation rates (through the utilisation of appropriate assessment techniques) for: a) Vision Check b) Spectacle Check c) Eye Health Check</td>
<td>86%*</td>
<td>Co-operation rates will reduce for those with severe and profound learning disabilities</td>
<td>Published papers</td>
<td>Lindsay et al, 2006</td>
</tr>
</tbody>
</table>
### Sample
All clients attending learning disability day centres in the Northern Trust were offered an eye examination. All those who availed of the service (617 clients) formed part of this audit. Eye examinations were carried out between August 2009 and November 2011.

### Data Source
Optometric clinical record sheets were used to record demographic data and outcomes of the eye examinations. Written questionnaires were devised to ascertain the views of day centre staff. Finally a focus group was set up to collect the views of service users.

### Audit Type
Retrospective.

---

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Target (%)</th>
<th>Exceptions</th>
<th>Source &amp; Strength* of Evidence</th>
<th>Instructions for where to find data</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.0 Ascertain if the Special Visual Assessment Clinic has improved quality of life for those who accessed the service</td>
<td>N/A</td>
<td>Will only apply to those identified as having ocular problems (qualitative rather than quantitative data)</td>
<td>Published papers</td>
<td>References available on request (See Appendix)</td>
</tr>
</tbody>
</table>

*This figure was obtained from patient participation observed by Lindsay et al 2006.*
Methodology
The vast majority of Adult SVACs in Northern Ireland have been established over a 10 year period by a small multiprofessional team of clinicians and advisers based in Belfast. The Service in the Northern Trust is one of the most recent to have been established and represents an evolution of current services.

Given the funding available to the team it was decided to comprehensively audit the most recently established service and to compare and contrast the data acquired with that from pre-existing audits of other local services and published material relating to services outside Northern Ireland. Recommendations drawn from the audit would subsequently be applied regionally by members of the team drawn from across Northern Ireland. The Northern Trust was in addition a geographical region within which the Team were confident that they could recruit multi-professional support to undertake the Audit and where there was access to sufficient patients to have a representative sample.

There are 11 Adult Centres throughout the Northern Trust and all 941 adults with learning disabilities attending these centres were offered an appointment within the SVAC. Day centre staff notified all parents/carers and clients about the service via a letter (Appendix 4). All were asked to complete the SVAC consent form (Appendix 2) and those who did not wish to attend were asked to provide a reason why. Those that consented to the eye examination were asked to complete a referral form (Appendix 1). During the eye examination all data was recorded on a first visit and review proforma (Appendix 5 and 6).

Following the assessment, verbal advice on the level of vision and the need for a spectacle prescription was given to each patient. This information was further re-enforced with a feedback letter (Appendix 7). This letter was written using clinical terms that were explained in “plain English”. It was sent to the patient or their parent/carer, with copies to the adult centre and the patient’s GP, so that all were aware of the outcome of the eye examination and thus able to assist with the implementation of recommendations.

Optometric/Clinical Audit
A SPSS database was designed to record data retrospectively from the optometric clinical records. Each patient was given a number to maintain their anonymity. The data was inputted by optometric members of the team. Results collated included information on patient demographics (e.g. gender and age), additional disabilities (e.g. communication difficulties, hearing impairment, mobility problems and challenging behaviour), past ocular history, visual function measurements (e.g. visual acuity and refraction) and outcomes of the assessment (e.g. co-operation rates, glasses issued and onward referral).
This database was based on a review of patient data from low vision, domiciliary and SVAC audits carried out within Northern Ireland and following the review minor modifications were made. The data of all patients that attended the clinic from August 2009 to November 2011 was inputted into the database. To ensure input accuracy and data validation, 10% of patients’ data was rechecked by a second optometrist. Results were then analysed using SPSS and represented in tabular and graphical format using Microsoft Excel. Responsibility for this section of the report was undertaken by the Project Leads and supported by other project team members.

In order to simplify the message, data presented in this report will primarily be reported in percentage format. As in many cases, the percentages expressed will relate to sub groups within the overall sample, where appropriate, actual numbers will be included in brackets following the percentage figure. Thus when a percentage figure is followed by \((X/Y)\), where \(X\) and \(Y\) are numbers, this indicates the number of individuals identified with a particular finding “\(X\)” followed by the number within the overall sample for whom data could be collected “\(Y\)”. In some cases “\(Y\)” will be the number of clients/patients in receipt of day care services in the Trust (941). In most, but not all cases “\(Y\)” will be the number of individuals seen within the SVAC service (617). In smaller sub groups “\(Y\)” may be the number of clients/patients provided with a spectacle prescription whereas “\(X\)” will be the number of those with a particular type of prescription (i.e. bifocals).

**Day Centre Staff Questionnaires**

To support the audit exercise a service evaluation survey was conducted amongst day centre staff with the intention of eliciting their views and perceptions of the SVAC. The survey was designed so that it was easy to complete, incorporated a number of closed and scaled questions, and also provided the opportunity for additional comments. The questionnaire is attached as Appendix 8.

A number of diverse areas were covered including:

- staff details
- Day Centre staffs’ knowledge and awareness of visual problems amongst members, pre and post the development of SVAC
- views on the contribution of training
- notable changes in the behaviour of members in terms of their willingness to wear glasses.

Day Centre staff were also challenged to think creatively and consider if the money required to resource the SVAC would be better spent on other services. Another key area covered in the questionnaire was to establish Day Care Workers’ views on the best location where members could avail of a visual assessment when needed.

The questionnaire was piloted with staff working in adult learning disability centres in two other Trust areas and wording modified accordingly. Support for the
administration of the questionnaire was obtained from the Trust’s Day Centre Managers and their Administrative Officers who coordinated the dissemination and the collation of completed returns. The exercise, which was commenced in August 2011, required a number of follow up requests to Day Centres in order to obtain completed questionnaires. This exercise took several months and the analysis was undertaken in May 2012 by two members of the project team.

Data was populated onto a system file written in SPSS (Statistical Package for Social Scientists). This allowed both descriptive and inferential analyses to be performed.

**Focus Groups**

The views of service users supported the audit through a focus group which was conducted by an impartial professional who was not a member of the project team. Thus client’s opinions were not influenced by those delivering the service.

Difficulties were encountered in trying to facilitate the focus group. Initially a private company with expertise in this area had been considered but funding issues ruled it out. The University of Ulster offered their skills but difficulties arose regarding the organisation of these groups and unfortunately the opportunity was missed. We then availed of the services of a Senior Rehabilitation Worker in the South Eastern Trust Area, who has been involved in a similar service in her own Trust for many years.

Information and consent forms were devised and distributed (Appendix 9 and 10) prior to the focus group, held in April 2013.

Questions for the focus group were finalised by the Project Team, utilising the experience of the Equality Services Manager who carried out a similar piece of work as part of a Masters Project evaluating the impact of eye examinations among those with learning disability (Appendix 11).
Findings and Observations

Optometric/Clinical Audit
Clinics commenced in August 2009 and rotated around all 11 centres concluding in November 2011. During this time 66% (617/941) of all clients within adult centres in the Northern Trust attended the Special Visual Assessment Clinic (SVAC). Ages of those assessed ranged from 19 to 72 years with a mean age of 38 years (standard deviation +/- 13 years). A total of 58% (355/617) were male.

Figure 1 highlights the reasons for non-attendance. Of note is the fact that 34% (324/941) of the total potential client cohort did not attend SVAC, the principal reason being that 15% (138/941) were under the care of a community optometrist and are happy with the care that they receive.
**Figure 2** - The main causes of learning disability, including Down’s syndrome, Cerebral Palsy and Autism

The main causes of learning disability, including Down’s syndrome, Cerebral Palsy and Autism are detailed in Appendix 12. Noticeably the cause of learning disability was unknown for nearly half of the 617 patients that attended the SVAC. This is not an unusual finding as often in cases of learning disability, no specific cause has been identified. In some cases environmental and genetic factors may be contributory factors. For example exposure to alcohol and other toxins prior to birth, or hypoxia at the time of birth, are factors for which historical data may not be available.

**Client Needs Profile**

Within the Northern Trust all clients are classified according to their needs. This assists with determining staffing levels in each centre and highlights the support required by each client. The table below documents the client needs profile.

**Table 4 - Client Needs Profile**

<table>
<thead>
<tr>
<th>Classification</th>
<th>Meaning</th>
<th>Percentage of SVAC population</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Complex Needs (high dependency needs)</td>
<td>17</td>
</tr>
<tr>
<td>B</td>
<td>Challenging Behaviour (known to the CB team)</td>
<td>5</td>
</tr>
<tr>
<td>C</td>
<td>Assessed as requiring 1:1 support or higher (assessed by named worker)</td>
<td>3</td>
</tr>
<tr>
<td>D</td>
<td>General Needs</td>
<td>11</td>
</tr>
<tr>
<td>E</td>
<td>Suitable for Day Opportunities Programme</td>
<td>25</td>
</tr>
<tr>
<td>F</td>
<td>Suitable for Satellite Site Transfer (Changing Needs Group)</td>
<td>35</td>
</tr>
</tbody>
</table>
Thirty (5%) clients attending the day centres had not had a client needs profile assigned to them at the time of completion of SVAC clinics in the Northern Trust (30/617).

Those clients in the first three groups i.e. A, B and C were deemed by staff to have more complex needs or challenging behaviour and required additional support. For the purposes of this audit we have referred to these clients as having “increased needs”. The remaining clients were generally more able, with a mild or moderate learning disability and we will refer to them as having “less needs”.

Challenging Behaviour
On the SVAC referral form, 21% (129/617) of the total SVAC population were reported by parents and carers at home to have challenging behaviour. Of those considered to have “increased needs”, 41% (63/155) were recorded as having challenging behaviour, compared to 15% (63/432) of those considered to have “less needs”.

Method of Client Communication
Figure 4 shows that the majority of clients, 63% (391/617), had good verbal communication. A significant proportion, 23% (140/617) relied on other methods of communication such as Makaton\textsuperscript{11}, gestures or body language.

\begin{figure}[h]
\centering
\includegraphics[width=0.5\textwidth]{Figure3.png}
\caption{Client Needs Group (n=617)}
\end{figure}

\begin{figure}[h]
\centering
\includegraphics[width=0.5\textwidth]{Figure4.png}
\caption{Method of Client Communication}
\end{figure}

\textsuperscript{11} Makaton is a language programme using signs and symbols to help people to communicate. It is designed to support spoken language and the signs and symbols are used with speech, in spoken word order.
Three hundred and thirty three, 77% (333/432), of those in the “less needs” group had good verbal communication, compared to only thirty six, 23% (36/155) of those in the “increased needs” group.

**Optometric Assessment**
Each patient was given an appointment slot of 45 minutes for the eye examination. However, time and the number of appointments needed to complete the assessment varied depending on a number of factors including co-operation rates, attention span, challenging behaviour and anxiety issues. Review appointments were also necessary for those who required a visual acuity check with glasses prescribed as a result of cycloplegic refraction, as detailed in the clinical results section.

**Number of Appointments Required to Complete the Eye Examination**
Most of the eye examinations, 63% (371/587), were completed in one visit., The figure increasing to 94% (547/587) for those whose examination was completed over two visits There appears to be no relationship between client need (severity of learning disability) and the number of visits it took to complete the eye examination (Figure 5 and 6).
Client Past Ocular History
Of those attending for an eye examination, 40% (248/617) had never previously been seen by an optometrist. Of those who had previously been seen by an optometrist only 36% (132/369) had been seen within the last two years. Therefore only 21% (132/617) of clients were under regular optometric review.

Clients with “increased needs” are considered more likely to have visual problems and yet, 63% (98/155) had never been seen by an optometrist. This contrasts with “less needs” clients where only 32% (139/432) had never been seen by an optometrist.
**Attendance at Hospital Eye Service**

One in four patients, 27% (166/617), was noted to have previously attended the hospital eye service. Half of the sample (83/166) attended in childhood and were discharged from the service as children. Figure 7 and Figure 8 show the reasons for attendance at the hospital eye service.

Childhood visual assessments of those with learning disability are generally undertaken for diagnostic purposes and thereafter for the management of refractive error or to monitor progression. Limited attention is paid to the management of visual impairment.

---

**Figure 7: Reason for Attendance at Hospital Eye Service (n=166)**

- **83 (50%)**  [Childhood]
- **13 (8%)**  [Cataract]
- **41 (25%)**  [Corneal Problems]
- **3 (2%)**  [Glaucoma]
- **15 (9%)**  [Other]
- **2 (1%)**  [Unknown]
- **3 (2%)**  [No answer]

**Figure 8: Attendance at Hospital Eye Service in Childhood (n=83)**

- **45 (54%)**  [Childhood squint]
- **26 (31%)**  [Childhood - lazy eye]
- **8 (10%)**  [Childhood – glasses]
- **4 (5%)**  [Childhood – other/unknown reason]
**Visual Concerns**
Parents and carer were asked to comment on the SVAC referral form if they had any visual concerns.

Only 14% (89/617) of parents or carers reported that they had any visual concerns regarding the client or patient they cared for. However, 46% (240/528) of those for whom no concerns were reported, were issued with a new prescription for glasses, 3 were referred to a rehabilitation worker regarding sight loss, 6 were referred to a GP (1 blood pressure check, 5 other) and 26 were referred to an ophthalmologist (3 cataracts, 10 suspect glaucoma, 3 keratoconus and 10 other). Despite the absence of visual concerns as expressed by carers, a substantial number benefited from the service with the provision of aids and appliances or with advice that would either specifically improve vision or improve or preserve ocular health. This demonstrates that carers cannot be relied upon to identify visual problems.

**Assessment Techniques and Co-operation Rates**

**Visual Acuity (VA)**
Standard clinical practice, when assessing VA, is to start with a conventional letter chart, asking patients to identify and name letters individually. In cases where patients find this task difficult or simply cannot undertake it, one then moves to the next best test.

**Visual Acuity Tests**
- **Keeler Log MAR Test**: Crowded letter naming or matching test. Generally used at a working distance of 3 metres.
- **Crowded Kay Pictures**: Crowded picture naming or matching test. Generally used at a working distance of 3 metres.
- **Sheridan Gardiner**: Single letter naming or matching test. Generally used at a working distance of 3 metres.
- **Kay Pictures Singles**: Single picture naming or matching test. Generally used at a working distance of 3 metres.
- **Cardiff Acuity Cards**: Preferential looking test. Generally used at a working distance of 1 metre. The patient looks towards a picture and the optometrist watches the patient’s eye movements to determine if they can see it.

---

12 Visual Acuity refers to sharpness or clearness of vision; the visual ability to resolve fine detail i.e. distinguish details and shapes of objects.
The same test was used to measure the visual acuity in each eye were possible. In exceptional circumstances when symbols could not be named or identified, counting fingers at a specified distance was used to quantify vision. In those cases, were patients could not identify target detail at all, hand movements were recorded as a form of motion vision and only in cases were motion vision could not be determined was vision recorded as perception of light or no perception of light.

If a patient could not participate in any of the visual acuity tests, an informal/functional visual assessment was performed. Hundreds and thousands (small cake decorations) were held in the palm of the hand at a distance of approximately 50cm and the patient was observed to see if the presence of the decorations attracted their attention, if they reached for it or if they attempted to pick them up. If the hundreds and thousands did not gain their attention a small coloured object was utilised and the patients reaction observed.
Figure 10 shows the results on the frequency of each visual acuity test used in the right eye only, as the results for each eye were similar.

**Figure 10: Frequency of Visual Acuity Tests Utilised (n=617)**

<table>
<thead>
<tr>
<th>Visual Acuity Test</th>
<th>Percentage of SVAC Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keeler Logmar naming</td>
<td>229</td>
</tr>
<tr>
<td>Keeler Logmar matching</td>
<td>74</td>
</tr>
<tr>
<td>Kay pictures crowded - naming</td>
<td>108</td>
</tr>
<tr>
<td>Kay pictures singles</td>
<td>51</td>
</tr>
<tr>
<td>Sheridan Gardiner</td>
<td>94</td>
</tr>
<tr>
<td>Cardiff acuity cards</td>
<td>4</td>
</tr>
<tr>
<td>Counting fingers</td>
<td>8</td>
</tr>
<tr>
<td>Hand movements</td>
<td>1</td>
</tr>
<tr>
<td>Perception of light</td>
<td>5</td>
</tr>
<tr>
<td>No perception of light</td>
<td>7</td>
</tr>
<tr>
<td>Informal assessment</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td>617</td>
</tr>
</tbody>
</table>

**Figure 11: Sample Near Visual Acuity Tests**

Near visual acuities were measured at the patient’s habitual working distance using the Sheridan Gardiner Near Test or the Kay pictures Near Test.
Co-operation for Visual Acuity Testing

The vast majority, 93% (575/616), of all patients were able to co-operate with VA testing. Those with some vision who could not complete a conventional VA test, 7% (41/616), had vision quantified using a functional visual test. Informal tests such as motion detection, hundreds and thousands and visual observation were used to identify any signs of visual loss in those who found testing particularly difficult.

Figure 12 demonstrates the variation in co-operation rates for VA testing depending on client need.

Of the 40 adults who could not co-operate with formal VA testing, 85% (34 adults) were considered “increased needs” (based on the client needs profile).
Co-operation for Retinoscopy
Refractive errors occur when the shape of the eye prevents light from focusing directly on the retina. The length of the eyeball (longer or shorter), changes in the shape of the cornea, or aging of the lens can all cause refractive errors. Uncorrected refractive errors are a frequent cause of reduced visual acuity.

Refractive error was determined using the objective method of retinoscopy. (The examiner uses a retinoscope to shine light into the patient’s eye and observes the reflection (retinal reflex) in the patient’s pupil. While moving the streak or spot light target across the pupil the examiner observes the movement of the reflex and then places trial lenses in front of the eye to "neutralize" the reflex.) Subjective refinement was carried out where possible (i.e. when responses were deemed reliable). Cyclopentolate drops (1%) were instilled if there was difficulty controlling accommodation (the focusing ability of the eye) or if retinoscopy was difficult due to media opacities, such as cataract.

The majority of patients, 82.6% (509/616), were able to fully co-operate during retinoscopy. Only 1.9% (12/616) of adults could not co-operate at all. The remainder, 9.6% (59/616) demonstrated either partial co-operation, or had a difficult or unusable retinoscopy reflex due to the presence of ocular pathology (5.8%, 36/616).
Figure 13: Co-operation for Retinoscope Test within Client Needs Groups (n=617)

As with Visual acuity testing Figure 13 shows that co-operation rates were lower for those deemed “increased needs” compared to those with “less needs”.

<table>
<thead>
<tr>
<th>Client Needs Group</th>
<th>Percentage</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>No answer</td>
<td>0.00%</td>
<td>0</td>
</tr>
<tr>
<td>No reflex due to pathology</td>
<td>4.50%</td>
<td>29</td>
</tr>
<tr>
<td>difficult reflex</td>
<td>5.80%</td>
<td>37</td>
</tr>
<tr>
<td>No co-operation</td>
<td>5.80%</td>
<td>46</td>
</tr>
<tr>
<td>Partial co-operation</td>
<td>25.20%</td>
<td>106</td>
</tr>
<tr>
<td>Full co-operation</td>
<td>58.70%</td>
<td>525</td>
</tr>
<tr>
<td>Less Need</td>
<td>91.00%</td>
<td>393</td>
</tr>
<tr>
<td>Not Available</td>
<td>83.30%</td>
<td>25</td>
</tr>
</tbody>
</table>
Ocular Health Check
A direct ophthalmoscope was used to detect ocular disease and pathology (Figure 14). Tropicamide (0.5%) was instilled when pupil dilation was required to aid examination of the retina. The exception to this, was in cases were Cyclopentolate (1%) was used to achieve paralysis of accommodation to facilitate retinoscopy, as pupil dilation occurs as a consequence.

Figure 14: Picture of Direct Ophthalmoscopy

http://cardiffoptometrypeertutoring.weebly.com/ophthalmoscopy.html

Ophthalmoscopy in this population group proved the most difficult procedure/test as it involved using a bright light at a restricted working distance. Ophthalmoscopy is a relatively obtrusive test during which the practitioner’s eye is required to be very close to the patient’s eye, as illustrated in Figure 14. As a result, only 61.3% (378/617) of adults fully co-operated. A further 26.9% (166/617) partially co-operated. Only 3.1% (19/617) were unable to co-operate. Pathology restricted ophthalmoscopy (limited or no view) in 8.3% (51/617) of patients, whereas two patients did not have ophthalmoscopy carried out as it was not appropriate e.g. phthisical eye. A single patient declined the eye exam half way through and therefore ophthalmoscopy was not performed.

13 Phthisical Eye – A condition where, as a result of disease or trauma, the globe of the eye has become shrunken and scarred.
Figure 15 demonstrates that once again co-operation rates for ophthalmoscopy were lower for those with “increased needs”.

![Co-operation for Ophthalmoscopy within Client Needs Groups (n=617)](chart.png)
Outcomes of Visual Acuity Assessment

Distance Visual Acuity measurements were banded using a classification (Figure 16) similar to that used by Woodhouse (2000) “The prevalence of ocular defects and the provision of eye care in adults with learning disabilities living in the community”.

Table 5: Classification of Distance Visual Acuity

<table>
<thead>
<tr>
<th>Log MAR score</th>
<th>Snellen equivalent</th>
<th>Classification of visual impairment</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.0 or better</td>
<td>6/6 and better</td>
<td>Normal</td>
</tr>
<tr>
<td>0.1 to 0.3</td>
<td>6/7.5 to 6/12</td>
<td>Mild/Sub-normal</td>
</tr>
<tr>
<td>0.4 to 0.5</td>
<td>6/15 to 6/18</td>
<td>Mild</td>
</tr>
<tr>
<td>0.6 to 0.7</td>
<td>6/24 to 6/30</td>
<td>Moderate</td>
</tr>
<tr>
<td>0.8 to 0.9</td>
<td>6/36 to 6/48</td>
<td>Moderate</td>
</tr>
<tr>
<td>1.0 to 1.2</td>
<td>6/60 to 6/96</td>
<td>Profound/Severe</td>
</tr>
<tr>
<td>1.3 or less</td>
<td>6/120 (3/60) or less</td>
<td>Registerable as Blind</td>
</tr>
</tbody>
</table>

The measurements for initial (before glasses prescription updated at SVAC) and final (after glasses prescription updated at SVAC) binocular distance visual acuities are presented in Figure 16 and illustrate that binocular visual acuity improved following refraction.

*The percentage of the population who did not have a final visual acuity recorded was higher than the percentage who did not have an initial visual acuity recorded, as those that had their vision measured using Cardiff Acuity Cards initially, did not have their final vision measured as it is too difficult to assess eye movements through small aperture trial lenses.*
A visual acuity of 6/12 (LogMAR 0.30) equates to the legal standard required for driving and as such an acuity of better than 6/12 (LogMAR 0.30) can be considered to be a reasonable level of vision which should cause the individual no or only minimal practical difficulties.

Initially only 59.5% of the population (367/617) had a binocular visual acuity of 6/12 (LogMAR 0.30) or better with or without spectacle correction. On completion of the eye examinations, this improved to 64.2% (396/617) following correction of the patients’ refractive error.

The WHO categorises visual impairment detailed below in Figure 18.

**Table 6: Categories of severity of visual impairment according to the International Statistical Classification of Diseases (WHO, 2003)**

<table>
<thead>
<tr>
<th>Category of Visual Impairment</th>
<th>Visual acuity with best possible correction</th>
<th>Or central visual field*</th>
<th>Classified as</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Maximum less than 6/18</td>
<td>Minimum equal to or better than 6/60</td>
<td>Low Vision</td>
</tr>
<tr>
<td>2</td>
<td>6/60</td>
<td>3/60</td>
<td>Low Vision</td>
</tr>
<tr>
<td>3</td>
<td>3/60</td>
<td>1/60</td>
<td>Blindness</td>
</tr>
<tr>
<td></td>
<td></td>
<td>10 degrees or less but more than 5 degrees</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>1/60</td>
<td>LP</td>
<td>Blindness</td>
</tr>
<tr>
<td>5</td>
<td></td>
<td>NPL</td>
<td>Blindness</td>
</tr>
<tr>
<td>9</td>
<td>Undetermined or unspecified</td>
<td></td>
<td>unspecified</td>
</tr>
</tbody>
</table>

*Visual Field restriction criteria applicable even if visual acuity is better than for that category of visual impairment.

As can be seen from Figure 18 above, the World Health Organisation (WHO) defines visual impairment as VA worse than 6/18.

An initial binocular VA was recorded, using a LogMAR Score/Snellen equivalent, for 92% of the sample (569/617). Of those 15% (84/569) had an initial binocular distance VA of less than 6/18 (LogMAR 0.50). Following refraction the figure had reduced to 7% (32/489) of patients with a final binocular distance VA of less than 6/18 (LogMAR 0.50). The number of the sample that had a final VA recorded using a LogMAR Score/Snellen equivalent is lower than the number that had an initial binocular VA recorded using a LogMAR Score/Snellen equivalent. This is because we were unable to check final VA on those that had their VA measured with Cardiff Acuity Cards (CAC) as the technique relies on observing a patient’s eye movements and this is too difficult to do when a patient is wearing small aperture trial lenses.
Distance Visual Acuity Testing Strategies
Forty one of the 617 patients (7%) had their vision assessed using a vision function assessment test and of this group 19 (46%) were deemed to be vision impaired. An additional 7 who were severely vision impaired had vision recorded as counting fingers (CF), hand movements (HM), perception of light (PL) or no perception of light (NPL).

Adding the 19 patients suspected of having a visual impairment from a functional assessment and the 7 patients with a vision of CF, HM, PL or NPL to our original figure of those who had a binocular VA less than 6/18 (84), the initial rate of visual impairment becomes 18% (110/617). The final rate of vision impairment, determined following eye examination and the provision of any appropriate spectacles, is 11% (58/537). The final figure is calculated out of a population of 537 as 80 patients did not have their final VA measured as it is too difficult to measure VA using CAC through small aperture trial lenses as detailed previously.

Near Visual Acuity
Near visual acuity measurements were banded as:
- N5 or better (Excellent Near Vision)
- N6-N8 (Good Near Vision)
- N12-N18 (Moderately Impaired Near Vision)
- Worse than N18 (Severely Impaired Near Vision)

Of the 617 patients, 396 (64%) had an initial binocular near VA of N8 (equivalent to small newspaper print) or better with or without spectacle correction. On completion of the eye examinations this improved to 74% (457/617).

One hundred and thirty five of the 617 patients (22%) were unable to have their near vision formally measured. These were the patients who had their vision measured using the Cardiff Acuity Cards or a functional vision assessment.
The measurements for initial and final binocular near acuities are presented in Figure 17.
Refractive Error
Spherical refractive error\textsuperscript{14} was classified following the same classification system used by Dr Woodhouse in her 2000 and 2004 papers:

**Spherical Errors**
- Emmetropia (-1.00 to +0.90)
- Low Hypermetropia (+1.00 to +2.90)
- Moderate Hypermetropia (+3.00 to +5.90)
- High Hypermetropia (+6.00 and over)
- Low Myopia (-1.10 to -3.00)
- Moderate Myopia (-3.10 to -6.00)
- High Myopia (over -6.00)

The average refractive error was calculated for each eye using an established technique referred to as the Best Vision Sphere (BVS). The results were fairly similar for paired Right and Left eyes, as presented in Figure 18.

![Figure 18: Refractive Error for each eye using Best Vision Sphere (n=617)](image)

The drawback with calculating refractive error using BVS is that a refractive error with a high astigmatic component can often be misrepresented as a low spherical error e.g. -4.00/+8.00\(\times\)90 gives BVS=0.00, whereas +4.00/+1.00\(\times\)90 gives BVS 4.50DS. The former is a more significant refractive error.

\textsuperscript{14} Emmetropia- no significant refractive error, Hypermetropia- long sightedness, Myopia- short sightedness
Therefore, in addition to BVS, the cylindrical component of the refractive error was also assessed according to the categories of astigmatic errors listed below.

Astigmatic Errors were also classified following the same classification system used by Dr Woodhouse in her 2000 and 2004 papers:

**Astigmatic Errors**
- No significant cylinder (0 to 1.00)
- Low Cylinder (1.25 to 3.00)
- High Cylinder (over 3.00)

The results for each eye presented in Figure 19, show that 39% (238/617) of patients had a significant (over 1.00DC) astigmatic error in at least one eye.

![Figure 19: Astigmatic Error of each Eye (n=617)](image)

**Near Acuity and Accommodation**

Presbyopia is the loss/reduction of accommodation (near focusing) that happens as we get older due to loss of elasticity of the crystalline lens. In the general population this typically happens at around 45 years of age. However some adults with learning disability such as Down’s Syndrome and Cerebral Palsy can have reduced accommodation or become presbyopic at an earlier age. Presbyopia is often ignored in adults with learning disabilities, perhaps because of the common use of the term ‘reading glasses’. If a person does not read, it may be that carers do not consider spectacles for other near tasks. Many adults with Down’s syndrome do read, and others will have jobs or hobbies that require good near vision, and as a result need ‘near’ glasses.

---

\(^{15}\)Astigmatic Error/Astigmatism is an optical defect in which vision is blurred due to the inability of the optics of the eye to focus a point object into a sharp focused image on the retina. This may be due to an irregular or toric curvature of the cornea or lens. It is corrected using a cylindrical lens.
There were 215 patients of ‘presbyopic age’, i.e. 45 years or older, all of whom would be expected to have reduced accommodation. Prior to the SVAC, 23% (50/215) had been given spectacles for near tasks (27 Single Vision near only, 16 Single Vision distance and near, 7 bifocal).

Following assessment at the SVAC, 31% (66/215) of the presbyopes were given a new prescription for near tasks (35 Single Vision near only, 26 Single Vision distance and near, 5 bifocal). This demonstrates that 16 patients who may benefit from a near correction had not previously been prescribed spectacles for near tasks.

Following the SVAC clinic 40% (85/215) patients of ‘presbyopic age’ were identified as potentially benefiting from a near correction (43 Single Vision near only, 33 Single Vision distance and near, 9 bifocal).

**Figure 20** shows the near visual acuity of presbyopic patients before and after SVAC Clinic.

![Figure 20: Near Visual Acuity of Presbyopic Patients before and after SVAC Clinic (n=215)](chart)

As illustrated in **Figure 20**, the number of patients able to access the small N5 size print or equivalent more than doubled (x2.2) following assessment at the SVAC clinic.
Prescription issued

Of the total SVAC population 36% (220/617) already had glasses and were using them prior to the commencement of the SVAC. A further 13% (83/617) had either worn glasses in the past or had been prescribed glasses in the past, but had never used them or had lost them. There was no evidence to suggest that just over half 51% (314/617) had ever had glasses.

Of the 397 patients who had no glasses when the SVAC clinic began 62% (246/397) had never been seen by an optometrist, 7% (27/397) had attended an optometrist within the last two years and 31% (124/397) indicated that at some point in time, prior to the last two years, they had received some form of eyecare which may have involved refraction and a spectacle check. Of those who had no glasses when first attending SVAC 35% (138/397) were prescribed glasses at the SVAC clinic.

Only 53% (117/220) of those who were wearing glasses at first visit were deemed to have had an adequate existing prescription. Two fifths of these patients, 41% (48/117) were prescribed new glasses due to the condition of their current pair. Nine (4%) of the 220 patients who wore glasses prior to the SVAC had at least one pair of glasses that they did not actually require. Of the spectacle wearers 31% (67/220) were deemed to have appropriate and serviceable spectacles.

Two hundred and eighty individuals (45%) of the total population (617) were issued with a prescription for glasses. Of the prescriptions issued, for a total of 310 pairs of spectacles (some patients having been issued with a prescription for separate distance and reading glasses):

- 206 were for SV\textsuperscript{16} distance
- 39 were for SV near
- 30 were for two pairs, one SV distance and one SV near
- 5 were for bifocals

Following completion of the SVAC clinic at all centres across the Northern Trust area, it was found that a total of 56% (347/617) of patients required some form of spectacle correction. Of these:

- 67 had an existing prescription which was deemed satisfactory and therefore were not issued with a new prescription
- 48 had no clinical change in their prescription, however required a new prescription due to the condition of their frame and/or lenses
- 85 who were currently wearing glasses, required a new prescription due to a clinical change
- 147 not using glasses were issued with a prescription for spectacles.

\textsuperscript{16} SV: Single Vision lenses- correct for only one distance e.g. distance or near
Only 19% (67/347) of those who should be wearing glasses already had a serviceable, satisfactory and up to date spectacle correction.

Figure 21 displays the type of spectacle correction recommended for all patients that required glasses following completion of the SVAC in the Northern Trust (categories include; those whose existing spectacles are serviceable and appropriate; those whose current glasses are inappropriate and need replacement; and individuals currently not using spectacles who it was felt could benefit from glasses).

![Figure 21: Type of Spectacle correction recommended for those who required glasses (n=347)](image)

It is difficult to determine exact guidelines for the prescribing of spectacles. At times significant glasses prescriptions were not issued for reasons such as, the patient was deemed to have a severe visual impairment, and a glasses correction would not provide visual improvement. In addition some patients may not have been issued with glasses as they may have been intolerant to glasses wear e.g. severe autism and issues with touch.

**Binocular Status**

Binocular Status refers to the ability to use both eyes together and was assessed using cover/uncover and alternate cover tests or by looking at the corneal reflections.

A Tropia (Strabismus) is the term used to describe a squint (eye turn). This is when the two eyes are not directed towards the same fixation point and are therefore not properly aligned with each other.

Of the total population, 65% (403/617) were orthophoric (no tropia). Horizontal tropias were classified as shown – esotropia (one eye turns in) or exotropia (one eye turns out) or alternating (either eye turns in or out). Vertical tropias were classified as hyper (one eye looking up) or hypo (one eye looking down).
Figure 22 illustrates the prevalence of each.

Figure 22: Binocular Assessment (n=617)

Figure 22 shows that horizontal tropias are more common with 12% (76/617) of the SVAC population having an esotropia and 10% (63/617) having an exotropia. However the prevalence of any type of Tropia (Strabismus) was 34% (210/617).

Ocular Health Check Outcomes
The prevalence of Cataract in the SVAC population was 13% (82/617) although an additional 2% (8/617) of patients had previously had cataract surgery. Nystagmus 4% (25/617) and Keratoconus 2% (13/617) were other conditions associated with potential significant sight loss (Figure 25).
Table 7: Prevalence of Common Ocular Abnormalities within the SVAC Population

<table>
<thead>
<tr>
<th>Common Ocular Defects</th>
<th>Number of SVAC Population</th>
<th>Percentage of SVAC Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nystagmus</td>
<td>25</td>
<td>4</td>
</tr>
<tr>
<td>Blepharitis/MGD</td>
<td>35</td>
<td>6</td>
</tr>
<tr>
<td>Ptosis</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Keratoconus</td>
<td>13</td>
<td>2</td>
</tr>
<tr>
<td>Corneal Scarring-not Keratoconus</td>
<td>14</td>
<td>2</td>
</tr>
<tr>
<td>Early Cataract</td>
<td>61</td>
<td>10</td>
</tr>
<tr>
<td>Significant Cataract</td>
<td>21</td>
<td>3</td>
</tr>
<tr>
<td>IOL</td>
<td>8</td>
<td>1</td>
</tr>
<tr>
<td>Optic Atrophy</td>
<td>8</td>
<td>1</td>
</tr>
<tr>
<td>ARMD</td>
<td>5</td>
<td>0.8</td>
</tr>
<tr>
<td>Macular Other</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td>Diabetic Retinopathy</td>
<td>3</td>
<td>0.5</td>
</tr>
<tr>
<td>Retinitis Pigmentosa</td>
<td>2</td>
<td>0.3</td>
</tr>
<tr>
<td>Myopic Degeneration</td>
<td>4</td>
<td>0.6</td>
</tr>
<tr>
<td>Other Retinal Conditions</td>
<td>17</td>
<td>3</td>
</tr>
</tbody>
</table>

Referral
Of the total cohort 5% (31/617) were referred to an ophthalmologist, the reasons for referral are illustrated in Figure 23.

![Figure 23: Reason for Referral to Ophthalmologist (n=31)](image)

Only 1% (6/617) of the population was referred to their GP. A further 2% (12/617) were referred to a rehabilitation worker for practical advice and support due to their sight loss.
Day Centre Staff Questionnaires

Staff Details and Centre Coverage
A total of 36 Day Centre staff from across ten Day Centres responded to the questionnaire. Staff had over 420 years’ experience of having worked in day care, with an average of 11 years and a range of between two and 30 years.

Agenda for Change bandings, introduced in Northern Ireland in 2004, indicate the pay grades of staff. Of the 36 staff who responded, 2 did not provide banding details. Of the 34 who provided banding details, the majority 31 (91%) were in pay bands 3 to 5. One member of staff was management level (Band 7) and the other two were Band 6. Some staff worked with those who required intensive support or had challenging behaviours, whilst others worked with those who had mild learning disability or within mixed groups.

Level of involvement with the SVAC
Invited to comment on the level of involvement with the SVAC, the majority of staff indicated “at least some involvement” (15/36, 42%) or “involvement by most” (16/36, 44%). Only five Day Centre staff indicated that they were not involved with the SVAC with their group members. Of the 36 staff who responded, 15 (42%) attended training provided by the optometrists. Whilst one person was unable to recall if they attended or not, the remaining 20 staff had not attended.

Perceived level of awareness of eye problems pre and post the introduction of the SVAC
Day Centre staff were invited to rate their level of awareness and knowledge of “the visual impairment experienced by members” prior to the establishment of the SVAC.

Using a semantic\(^\text{17}\) differential rating scale 1-10 (with one representing a very low level of awareness and 10 representing a high level), results indicated that 20 staff (20/36, 56%) considered their degree of awareness was at the lower end, with a rating of between 1-5. The remaining seven staff who responded to this question (7/36, 19%) rated their awareness as high between 6-10. Nine staff did not provide an answer to this question. This question was repeated in order to invite comment on their perceived level of knowledge post the introduction of the SVAC. This showed an increase in knowledge with 29 staff (29/36, 81%) rating their knowledge at this stage as between 6-10. Two indicated a score of 1-5 and five members of staff did not respond to this question.

Thirty two Day Centre staff were able to provide an opinion on their perception of the manner by which the Optometrist carried out the eye assessment. Twenty eight

\(^{17}\) The Semantic Differential (SD) measures people’s reactions to stimulus words and concepts in terms of ratings on bipolar scales defined with contrasting adjectives at each end, for example, Good 3-2-1-0-1-2-3 Bad
(28/32, 88%) of those who responded to this question suggested it was carried out in a manner that suited members’ needs. The remaining four disagreed but no additional comment was provided.

**Perceived views on outcomes of SVAC**

A component of the evaluation was the extent to which Day Centre staff perceived that the outcomes of the SVAC balanced with the effort required for its smooth running, "Was it all worth it?". Day Centre staff were invited to express their views on this question on a semantic differential scale 1-10 with 1 representing “not worth it” to 10 “really worth it”. All 36 staff responded to this question and all rated positive outcomes of 5 or greater on the scale.

An additional outcome measure was the extent to which there were improvements in the wearing of glasses by Day Centre members. Response options were provided on a Likert scale\(^\text{18}\) from “decreased a lot” to “increased a lot”. Responses indicated a clear increase as reported by 29 (80%) staff. For 21 (21/29, 72%) of these staff they viewed the wearing of glasses to have increased “a little” whilst the other 8 indicated that the increase in wearing was “a lot”.

**Most appropriate location for members to have eye assessments**

Day Centre members were provided with the opportunity to have their eye assessments undertaken (many for the first time) within a familiar environment. The question was posed to staff, from their perspective, as to where they perceived was the most appropriate location to conduct a visual assessment. Thirty two staff responded to this question; of these 13 (13/32, 41%) state their perception was that members should be encouraged to use their local optometrist. This is a positive response as further analysis revealed that 8 (8/13, 62%) of the 13 staff also perceived that members viewed the SVAC positively and 7 (7/13, 54%) considered that carers also viewed the service positively. Encouragement to use local optometry services is not adversely impacted upon by experience of the SVAC, but rather the opposite. Of the 32 staff who responded to the question on best location, 10 (10/32, 31%) indicated that “the SVAC was the only way to ensure that members obtained a visual assessment”. In addition 9 (9/32, 28%) staff indicated that they did not think that carers would “take members to the local optometrist”.

**Additional Comments**

In the design of the questionnaire it was important that staff were given the opportunity to provide any additional comments on the service. Eighteen (18/36, 50%) took the opportunity to do so. A review of the comments revealed a number of

---

\(^{18}\) Likert Scale is a psychometric scale commonly involved in research that employs questionnaires. Likert scales usually have five potential choices (strongly agree, agree, neutral, disagree, strongly disagree) but sometimes go up to ten or more. The final average score represents overall level of accomplishment or attitude toward the subject matter.
themes both positive and negative, though negative comments were fewer by comparison.

Below is a thematic analysis of comments received.

**Negative**

**Increased workloads**
Comments that were more negative in tone centred on two issues:
1. The time-consuming nature of the service and particularly its impact on staff resources, resulting in increased workloads.
2. More family members and carers should have been involved, particularly during the appointment. (Possibly this implication being, it would free up staff time and resources.) For some, however, the comment on resources was accompanied by the comment that despite this the service was “still worth it”.

One member of staff compared the SVAC less favourably with a previous experience of another service provided by an independent provider.

**Positive**

**Quality and skill of staff**
Positive comments were articulated in relation to both the skill and manner in which the optometrist delivered the service. In particular, the acute awareness by the optometrist of the various types of behaviour expressed by members was perceived as “impressive”. The use of different and appropriate methods and materials for assessment was also viewed positively. The attitude of the optometrist, in particular encouragement offered to members to wear their glasses, was specifically highlighted. It was also suggested that encouragement would be likely to have a lasting impact on members, allowing them to be better prepared to use local optometry services rather than the SVAC. However, there was an acknowledgement that for some the SVAC would remain necessary, especially for those with more complex needs.

**Independence and quality of life**
The improvement in members’ independence as a result of receiving glasses was noted by a number of staff. Previously it was suggested that members would have needed more assistance to do some relatively straightforward tasks around the Day Centre. In the absence of the SVAC a number of staff suggested that members would not have had the opportunity to have their eyes tested and glasses provided where this was necessary. Consequently the SVAC “gave members back their independence which was theirs” in the first instance.

---

19 Thematic analysis is used in qualitative research and focuses on examining themes within data. This method emphasizes organization and rich description of the data set. Thematic analysis goes beyond simply counting phrases or words in a text and moves on to identifying implicit and explicit ideas within the data.
Worthwhile service
Some additional general comments were provided indicating that the service was worthwhile and should have been provided sooner and more frequently. Its replication across other centres in Northern Ireland was suggested by some staff as a necessity.

Focus Groups
A total of six clients consented and participated in the focus group (see Methodology) which was held in Ballymena on Thursday 11 April 2013. The full transcript of the discussion is attached to the audit report as Appendix 11.

All six clients were already known to eye care services, five having previously attended a local optometry practice and the sixth being under current review in the hospital eye service. Also of note is the fact that a domiciliary eye care provider had previously carried out eye examinations within the day centre and three clients had availed of this service. This resulted in five of the six clients having been prescribed spectacles, with four clients wearing them on a regular basis. This combination of factors may have resulted in the focus group being non representative of the SVAC population.

Every client interviewed felt the eye examinations were a positive experience, with no negative comments noted. No concerns or anxieties were expressed about the examination and the testing procedure.

The clients all recognised the importance of having their eyes tested. They commented that the eye examination “helped you to see” and was also necessary “just in case you had problems”. In response to the question, “Do you think all people in the centre should get their eyes tested?” the answer was a unanimous yes. None of the six clients participating expressed a preference for having their eyes tested within the day centre or at an optometry practice. They did, however, say that it was “nice and handy” to get your eyes checked at the day centre.

Of the four clients who wore spectacles, they were able to inform the interviewer that their eyesight was good when wearing spectacles. They all chose to wear their spectacles full-time and had selected the frames with the help of family members. Comments included “all good when you wear them” and the glasses “helped you to see TV and play pool”.
Findings in Relation to set Criteria

Criteria 1
Ensure that day centre attendees are accessing eye care services (100%)
Of all eligible clients attending day care facilities within the Northern Trust Area 66% (617/941) were assessed by SVAC staff and an additional 15% (138/941) were seen either, by a local optometrist, or at a low vision clinic. The overall percentage of clients now in receipt of eyecare services is thus 80% (755/941). This contrasts markedly with the finding that, prior to the introduction of SVAC services, only 40% (248/617) of those who ultimately received SVAC services were aware of ever having received eyecare services. Of those who had previously received eyecare services only 36% (132/369) had received services within the two year period prior to the introduction of SVAC. Future plans are to review available information on those who are not accessing eye care services and identify both needs, and ways to encourage access, among this group. Consideration needs to be given to ways in which the current level of uptake of eye care services can be maintained.

Criteria 2
Measure the high prevalence rate of visual problems amongst adults with learning disabilities
The prevalence of visual impairment, as determined from data relating to those for whom accurate information on vision status could be gathered, following assessment at the SVAC, was 10.8% (58/537).

Following completion of the SVAC clinic at all the centres in the Northern Trust, it was found that a total of 56% (347/617) required a spectacle correction. Concerning ocular pathology, 34% (210/617) of the SVAC population were found to have a squint whereas 13% (82/617) were found to have cataract. These figures are significantly higher than those that would be found in the general population.

Criteria 3
Ensure that, where appropriate, spectacles are prescribed (100%)
Every patient who would benefit from, and tolerate, a spectacle correction was issued with a spectacle prescription, thus achieving the set target of 100%. Of the total population 45% (280/617) were issued with a new prescription for glasses. The prescriptions issued for individual pairs of glasses (310) were:
• 66.5% (206/310) for SV Distance only
• 12.6% (39/310) for SV Near only
• 9.7% (30/310) for both SV Distance and Near
• 1.6% (5/310) for Bifocals
Criteria 4
Ensure that onward referral is initiated for treatable ocular pathology (100%)
Every patient identified as having treatable ocular pathology was referred onwards, thus meeting our target of 100%.
5% (31/617) of the population were referred to an ophthalmologist for:
  • Suspect Glaucoma 36% (11/31)
  • Cataract 16% (5/31)
  • Keratoconus 13% (4/31)
  • Other 36% (11/31)

Criteria 5
Maximise co-operation rates through the utilisation of appropriate assessment techniques (86%)
a) Vision check
b) Spectacle Check
c) Eye Health Check
  • 93% (575/617) of all patients were able to co-operate with VA testing. Of the 7% (40/617) who could not perform conventional tests, a functional visual test was carried out e.g. hundreds and thousands.
  • 83% (509/617) were able to fully co-operate for retinoscopy. Only 2% (12/617) of adults could not co-operate at all for retinoscopy. The rest were able to either partially co-operate (10%, 59/617), or had a retinoscopy reflex that was unusable due to pathology (6%, 36/617).
  • 61% (378/617) of adults fully co-operated for ophthalmoscopy. However a further 27% (166/617) were only able to partially co-operate. Only 3% (19/617) were unable to co-operate in any way. Pathology restricted ophthalmoscopy (limited or no view) in 8% (51/617) of cases.
  • 64% (395/617) of all eye examinations were completed in one visit. The majority of patients, 94% (580/617) had their assessment completed over two visits. (580/617).
  • A range of visual assessment techniques were utilised, these included:
    ➢ Crowded letter naming or matching tests (Keeler Log MAR test) - 49% (303/617)
    ➢ Crowded picture naming or matching tests (Crowded Kay Pictures) - 26% (159/617)
    ➢ A Preferential looking test (Cardiff Acuity Cards at one metre )-15% (94/617)
    ➢ Other tests - 10% (61/617)
Criteria 6
Ascertain if the Special Visual Assessment Clinic has improved quality of life for those who accessed the service

Comments from the patient focus group included:

- Clients said that having had the opportunity to be part of the SVAC Service it had: “helped me to see”; “was important”; “helped me see the ball when playing football”; “helped me to see people”; “helped me see my work” and was useful “just in case you had problems”.
- When asked what was the best thing about getting their eyes tested, the response was “being able to see good”.
- When asked how they felt about wearing glasses, patients reported “all good when you wear them” and “eyesight not good when you don’t wear them”.

Presentation
Preliminary findings from this audit demonstrate that visual function improved following assessment at the clinic. These results were presented to the Northern Trust, which resulted in secured permanent funding being made available for this service. However, we now need to ensure the service is available throughout Northern Ireland.

Following the presentation of preliminary findings to the Western Trust, discussions have commenced between optometry and learning disability services to establish a similar service.

We now need to consider the provision of eye care services to children with learning disability. The Belfast Trust is currently undertaking an audit funded by GAIN to evaluate joint orthoptic/optometric assessments in Special Schools.

Final results will be presented to both optometric and learning disability professionals in 2016. It is envisaged that results will be published in a peer review journal to ensure distribution to a wider audience. Discussions will continue with the HSCB regarding the importance of commissioning appropriate eye care services for both adults and children with learning disabilities.
Recommendations

1. Continue to ensure a high uptake of eye examinations among adults with learning disability.

2. Identify reasons of non-attendance for eye examinations and consider methods to reduce this.

3. A process to encourage spectacle wear should be developed with the support of day care workers and those involved in the care of the client.

4. Prior to commencing eye examinations, staff/carers should prepare clients for assessment e.g. utilising an eye examination preparation booklet and showing a photo of the optometrist to the patient beforehand. This will help to alleviate any fears they have about the process and this can increase co-operation rates.

5. Staff familiar with the SVAC Service should identify those clients who may benefit from engagement with a local optometric provider and a pathway for referral put in place.

6. Adults with severe and profound learning disability and challenging behaviour should have access to eye care services such as the SVAC with the equipment, skills and experience needed to provide high quality eye care to this sector.

7. Those who specialise in the delivery of eye care services to those with learning disability should engage with the local optometric professionals to ensure all practices provide eye care for those deemed suitable and if they cannot, refer the patient to a specialist service that can.

8. Raise awareness of the SVAC Service to those involved in the care of adults with learning disability e.g. GPs and learning disability services to improve access of eye care for all adults with learning disability.

9. Extend the SVAC service to cover the Western and Southern Trust areas.

10. Given that a significant proportion of visual problems among adults with learning disability presented in early childhood, regular eye examinations should be carried out from an early age with a dedicated service for children attending special schools.
References


Appendices
### Special Visual Assessment Clinic Referral Form

<table>
<thead>
<tr>
<th>Name</th>
<th>Day Centre</th>
</tr>
</thead>
<tbody>
<tr>
<td>DOB</td>
<td>Contact Name</td>
</tr>
<tr>
<td>Address</td>
<td>Relationship to Client</td>
</tr>
<tr>
<td>Postcode</td>
<td>Contact Address</td>
</tr>
<tr>
<td>Tel No.</td>
<td></td>
</tr>
<tr>
<td>GP Name</td>
<td>GP Surgery</td>
</tr>
</tbody>
</table>

**Have you ever attended a hospital eye clinic?**
- Yes / No / Don’t know (Please circle)
- *If yes, please give details*

**Have you ever seen an optician?**
- Yes / No / Don’t know (Please circle)
- *If yes, when and where?*

**Have you ever worn glasses or contact lenses?**
- Yes / No / Don’t know (Please circle)
- *If yes, when do you wear them?*

Please describe any concerns you have regarding your vision e.g. difficulty seeing TV, walking around etc.

**Cause of Learning Disability** (Please tick)
- Downs Syndrome
- Cerebral Palsy
- Autism
- Other please specify
- Unknown

**Family History of Eye Problems e.g. glaucoma**
- Further details

**Medication** (Please list)

<table>
<thead>
<tr>
<th>Cause of Learning Disability</th>
<th>General Health,</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Please tick)</td>
<td>(Please tick)</td>
</tr>
<tr>
<td>Downs Syndrome</td>
<td>High Blood Pressure</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>High Cholesterol</td>
</tr>
<tr>
<td>Autism</td>
<td>Epilepsy</td>
</tr>
<tr>
<td>Other please specify</td>
<td>Heart Problems</td>
</tr>
<tr>
<td>Unknown</td>
<td>Diabetes</td>
</tr>
<tr>
<td></td>
<td>Other, please specify</td>
</tr>
</tbody>
</table>

**Communication:**
- (Give Details e.g. gestures, signing etc)

**Challenging Behaviour:**
- ☐ Yes ☐ No (Give Details)

**Hearing Difficulties:**
- ☐ Yes ☐ No  Give Details

**Mobility Problems:**
- ☐ Yes ☐ No (Give Details)

Thank you for taking the time to complete this form.
Special Visual Assessment Clinic Consent Form

Patient to complete:

I __________________________ (patient’s name) consent to having an eye examination at the Special Visual Assessment Clinic.

Signed _______________________ Date ______________ 

OR

Carer to Complete:

(To be signed by a person close to the patient if the patient is unable to consent)

I __________________________ (carer’s name) believe that it is in best interests of __________________________ (patient’s name) to receive a visual assessment.

Relationship to patient __________________________

Signed _______________________ Date ______________ 

If you would like to be present for the assessment, please tick ☐

The eye examination records may be used for education, audit, research and for monitoring public health. This information is gathered anonymously from the records and used in order to help improve services. If you do not wish this information to be used for this purpose, please tick ☐

If you do not wish to attend the Special Visual Assessment Clinic, please tick your reason(s) below:

☐ I attend a local optometrist regularly and am happy with the care received
☐ I have no visual concerns
☐ I believe that co-operation for the eye examination will be difficult to obtain
☐ Other, please specify __________________________
Appendix 3

Eye Examination Preparation Booklet

Example 1

You will be asked to wear special glasses. The glasses are heavy but you don't have to wear them for long.

The optometrist will put different windows in the special glasses. This will check if the windows improve your eyesight.

Example 2

The optometrist will shine a light into your eyes, using special torches. This is to find out if you need glasses and if your eyes are healthy. The light can be quite bright but it doesn't take long. The optometrist will need to move very close to you, with their face near to your face. This is so they can see right into your eyes.
Dear Carer/Parent

The Special Visual Assessment Clinic (SVAC) is a service in the Northern Trust that provides eye examinations for adults with learning disabilities. This is provided by optometrists from the Belfast Health and Social Care Trust, free of charge.

The clinic takes place in the day centre. The examination tests are adapted to enable even those with a severe learning disability or communication difficulties to have an eye examination.

Regular eye examinations are important for everyone to check if glasses are needed and to ensure that eyes are healthy.

We are now starting this clinic at Adult Centre. We would like to encourage you to use this service. If you would like an assessment over the next few months, please complete all sections of the enclosed form and return it to the centre.

If you have any queries, please do not hesitate to contact us at Adult Centre on Tel Number

Yours faithfully

__________
Manager
## Special Visual Assessment Clinic
### First Visit

<table>
<thead>
<tr>
<th>Patient Details</th>
<th>Name</th>
<th>Location</th>
<th>Date</th>
<th>DOB</th>
<th>Day Centre Attended</th>
<th>Gender</th>
<th>Male</th>
<th>Female</th>
<th>Contact Name</th>
<th>Address</th>
<th>Relationship to Patient</th>
<th>Postcode</th>
<th>Telephone No.</th>
<th>Postcode</th>
<th>GP Name</th>
<th>GP Surgery</th>
</tr>
</thead>
</table>

### History

<table>
<thead>
<tr>
<th>GH</th>
<th>FH</th>
</tr>
</thead>
<tbody>
<tr>
<td>GH</td>
<td>Cause of learning disability</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Medication</th>
<th>Hearing</th>
<th>Communication</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Social History</th>
<th>Living circumstances</th>
</tr>
</thead>
</table>

### Occupation/Activities

| Any further problems/visual concerns |

### Action

<table>
<thead>
<tr>
<th>Optometrist Advice</th>
<th>Review</th>
</tr>
</thead>
</table>

### Refraction

<table>
<thead>
<tr>
<th>Name</th>
<th>DOB</th>
<th>Test used</th>
<th>Name</th>
<th>Refract</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unaided Vision</td>
<td>Distance</td>
<td>Near</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retinoscopy</td>
<td>WD</td>
<td>L</td>
<td>R</td>
<td></td>
</tr>
<tr>
<td>Reflexes</td>
<td></td>
<td></td>
<td>Time</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Subjective/Gives</th>
<th>R</th>
<th>L</th>
</tr>
</thead>
<tbody>
<tr>
<td>R VA</td>
<td>L VA</td>
<td></td>
</tr>
</tbody>
</table>

### Further Investigations

<table>
<thead>
<tr>
<th>DCT</th>
<th>Ocular Motility</th>
<th>IOP (Icare)</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>NCT</td>
<td>Pupil reactions</td>
<td>Visual Fields</td>
<td></td>
</tr>
<tr>
<td>NPC (cm)</td>
<td>Colour Vision (CV plates for infants)</td>
<td>Contrast Sensitivity</td>
<td></td>
</tr>
</tbody>
</table>

### Ophthalmoscopy

<table>
<thead>
<tr>
<th>External Eye</th>
<th>Media</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disc</td>
<td></td>
</tr>
<tr>
<td>Vessels</td>
<td></td>
</tr>
<tr>
<td>Macula</td>
<td></td>
</tr>
<tr>
<td>Fundus</td>
<td></td>
</tr>
</tbody>
</table>
# Special Visual Assessment Clinic Review

<table>
<thead>
<tr>
<th>Patient Details</th>
<th>Date</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td>Location</td>
<td></td>
</tr>
<tr>
<td>DOB</td>
<td>SVAC No.</td>
<td></td>
</tr>
</tbody>
</table>

## History & Symptoms

## Ocular Examination

## Action

| Optometrist Advice |  |

## Further Referral | Review
SVAC Letter: X

Letter to: Carer/Parent

Copy to: GP and Adult Centre

X was seen at the Special Visual Assessment Clinic at Adult Centre on 13.10.10 and again on 27.10.10 for an eye examination.

His unaided distance vision measured 6/15 (about half way down the opticians letter test chart) in both the right and left eye.

At near, he can read N5 size print unaided. This is very small print, similar in size to that found in the classified advertisements section of the newspaper.

X has astigmatism (the front of the eye is more similar in shape to a rugby ball than a football) in both eyes. When this is corrected with glasses there is an improvement in his vision to 6/9.5 in both the right and left eye. This is about two thirds of the way down the opticians letter test chart and is a fairly good level of vision. Therefore a prescription for distance glasses was issued. I recommend that he wears these glasses full-time.

X has an eye turn (squint) that causes either eye to turn inwards (alternating esotropia). However, it is likely that this is longstanding and should cause him no visual problems.

His pupils react normally to light and his colour vision is normal.

I was able to view the retina (the layer at the back of the eye) and this appeared healthy.

I would recommend X has another eye examination in 2 years time.

If you have any queries do not hesitate to contact me on 028 9063 4205.

Yours sincerely,

Paula McElduff
(Specialist Optometrist)
Special Visual Assessment Clinic Day Centre Staff Survey

Dear Colleague,
As the Special Visual Assessment Clinic (SVAC) currently has temporary funding, it is important for us to evaluate the service and assess its impact. We then hope to try and secure permanent funding for the service. We would be very grateful if you would spend a few minutes completing the following questionnaire. Please tick the answer you feel best describes your opinion.

Thank you for your time!

1. Before the SVAC began, did you feel there was a need for this service in the centre?
   - Strongly agree ( ) Agree ( ) Neutral ( ) Disagree ( ) Strongly disagree ( )

2. Did you attend the staff training session given by the optometrist?
   - Yes ( ) No ( )
   - If yes, did you find the training session helpful and informative?
     - Strongly agree ( ) Agree ( ) Neutral ( ) Disagree ( ) Strongly disagree ( )
   - If yes, please answer the following question:
     a) Did you feel the optometrist’s communication with the client was good?
        - Strongly agree ( ) Agree ( ) Neutral ( ) Disagree ( ) Strongly disagree ( )
     b) Did you feel the optometrist carried out the clinical tasks in a manner appropriate for a patient with a learning disability?
        - Strongly agree ( ) Agree ( ) Neutral ( ) Disagree ( ) Strongly disagree ( )

3. Did you attend an eye examination with a client during the time the SVAC was running in the centre?
   - Yes ( ) No ( )

4. Of the clients who were prescribed glasses at the SVAC, do you feel glasses wear has been successful?
   - Strongly agree ( ) Agree ( ) Neutral ( ) Disagree ( ) Strongly disagree ( )

5. Did you find the client reports/information letters distributed after the assessment helpful?
   - Strongly agree ( ) Agree ( ) Neutral ( ) Disagree ( ) Strongly disagree ( )

6. Do you feel the day centre is a good environment for this clinic to be carried out in?
   - Strongly agree ( ) Agree ( ) Neutral ( ) Disagree ( ) Strongly disagree ( )

7. Do you feel there are advantages for clients being seen in the day centre rather than in a local optician’s practice?
   - Strongly agree ( ) Agree ( ) Neutral ( ) Disagree ( ) Strongly disagree ( )

8. We appreciate that the running of the clinic has been dependant on support and time from day centre staff. Do you feel this additional work has been worthwhile?
   - Strongly agree ( ) Agree ( ) Neutral ( ) Disagree ( ) Strongly disagree ( )

9. Do you feel the clinic is successful and clients benefit from accessing this service?
   - Strongly agree ( ) Agree ( ) Neutral ( ) Disagree ( ) Strongly disagree ( )

10. Do you feel the attitude of clients towards their experience of the SVAC has been positive?
    - Strongly agree ( ) Agree ( ) Neutral ( ) Disagree ( ) Strongly disagree ( )

11. Do you feel the attitude of parents/carers towards their experience of the SVAC has been positive?
    - Strongly agree ( ) Agree ( ) Neutral ( ) Disagree ( ) Strongly disagree ( )

12. Has your level of awareness of visual problems increased following the SVAC?
    - Strongly agree ( ) Agree ( ) Neutral ( ) Disagree ( ) Strongly disagree ( )

13. Do you have an example of a client who has benefited from this service?
    - Please give details of visual concerns, glasses issued, any differences in behaviour since starting glasses wear, improvements in quality of life etc.
      ........................................................................................................................................................................
      ........................................................................................................................................................................
      ........................................................................................................................................................................
      ........................................................................................................................................................................
      ........................................................................................................................................................................
      ........................................................................................................................................................................

14. Do you have any suggestions of ways to improve the service?
    ........................................................................................................................................................................
    ........................................................................................................................................................................
    ........................................................................................................................................................................

15. Do you have any other comments?
    ........................................................................................................................................................................
    ........................................................................................................................................................................
    ........................................................................................................................................................................
    ........................................................................................................................................................................

Appendix 8
Appendix 9

Hello, my name is Nickie,
I am from Downpatrick and I work with people like you.

I am doing a study.
A study is a way of finding things out.

Do you want to be in the study?
This information sheet tells you about the study.
It helps you to decide if you want to be in the study or not.

This is what we want to find out?
We are trying to find out about your views on the Special Visual Assessment Clinic that was held here at the centre. We would like you to be involved in the programme and tell us what you thought of having your eyes tested at the centre.

What will you have to do?
We would like you to attend a focus group at the centre. We hope to find out what you thought of the Special Visual Assessment Clinic through a focus group interview that will last about 1 hour.

We would like to video the day so we have an accurate record of how the programme was delivered and your views.

We will ask you to be in our study.
You can say “yes” or “no”.

Why do we want you to find out?
Finding out about this will help us to make changes to the Special Visual Assessment Clinic service to support you and others like you.

Then we can tell others about it.
You can decide if you want to say “yes, I want to be in the study”.

If you want to be in the study, you must sign your name on a special form called a consent form.

If you find it difficult to write, someone else can help you.

What happens if I say “no”?
If you don’t want to be in the study, that’s okay.

You will still get the same eye care.
Nickie will NOT contact you again.

What happens if I say “yes”?
You will be able to take part in the focus group with Nickie at the centre.

What will Nickie do after the event?
Everything you tell Nickie and her work colleagues is private.

They will not let anyone know who talked to her for this study.

Nickie will go and write down everything she found out when she spoke with you.
She will write down what you said and put all the words on a computer.

Writing things down will help Nickie to understand.

Only the other people in her study team will know what Nickie has written about you.

Only Nickie and her team will read your words. Nobody else will be able to see it.

However, if you tell us that someone is hurting you or you are hurting somebody, we will have to pass this information on. But we will tell you if we are going to do this.

When we have finished, we will tell others what we have found out and we will make a report.

We will write down what we have found out.
If you like, we will give you the paper so you can read what we found out.

We may write what you say in a magazine or a report.

No one will know that it was you who said it.
We won’t tell anyone your name.
We will use a pretend name instead.

Can the study upset you?

Most people will not be upset by the study. But thinking about your eye sight and how it affects your life might be sad and if you feel upset you can leave the meeting at any time.

You must have someone (a carer, family member or friend) who you can talk to about this. You can also talk to Nickie and others after the meeting if you want to.

You or your carer can phone Nickie if you want to know more about the study.

Nickie’s phone number is: 028 90 60 7746
Her email address is:
Nickie.boyes@southeasterntrust.nihsni.net
Appendix 10

Consent form (Phase 2)

I say it is OK for Nickie from Downpatrick to spend time with me for her study.

I have seen the information sheet about the study
I understand what it says and I know what it is about.

I know how the study is being carried out.

I know why the study is being carried out.

I had a chance to ask questions about it.

I agree to be in the study  YES □  NO □

If I do not want to be in the study anymore, I do not have to.

I can tell Nickie if I do not want to be in the study at anytime.
It is my choice to stop or take part.

I know if I stop I will still get my eyes tested.
Nickie will not let anyone know who is in this study. She may write what I say and what I do but no one will know it was me.

I can phone Nickie if I want to know more about the study.
Nickie’s phone number is 028 0260 7746.

My signature ____________________________ Date ____________________________

______________________________ ____________________________

Nickie’s signature Date
Focus Group Questions and Answers:

Date of focus group – Thursday 11th April 2013

Location of focus group – George Sloan Adult Centre, Ballymena

Present: Individuals – RC, WD, IW, DMcC, WH and JL

Interviewer – Nickie Boyes

Other – Day Care Worker

Agreement Provided to Tape Record: No

Do some Warm Up Exercises to recall eye test

Did you ever have your eyes tested at local opticians?

Yes – 5 had previously attended a local optometry practice. One other client is currently under review within the hospital eye service. Optomise (domiciliary eye care provider) had previously carried out eye examinations within the day centre which 3 clients had availed of.

Explore views on this? If yes, explore if this was a good experience?

Yes – it was a good experience but no further details forthcoming.

Going back to the eye test that you had at the Resource Centre, who asked you if you wanted to get an eye test?

(Clients slightly confused about question – interviewer felt that the clients were used to being told what was happening, rather than being asked.)

Probe: Manager, Staff at Centre, Other or did you ask yourself to get it done?

Staff, home and mother were the 3 responses. DCW confirmed that all clients had received a letter home regarding the service. No-one asked for the eye test themselves. However, the DCW did say that centre staff had requested an assessment on 2 of the 6 clients interviewed.

How did you feel about getting your eyes tested?

Probe: Happy, Unhappy, Didn’t mind one way or other.
All 6 said good and happy.

Explore further.

Despite prompting, no further thoughts forthcoming.

Did you think it was a good idea to get your eyes tested?

Probe: Yes, No, Didn’t mind one way or other.

All 6 said yes.

Explore further.

Two clients said that it “helped you to see”. One client said it was “important”. Another client said to “see the ball when playing football”. A further client mentioned that it “helped to see people”. Some-one else stated that it helped you see your “work”. The final comment was “just in case you had problems”.

Were you worried at the thought of getting your eyes tested?

No worries about equipment or test. (Impression of interviewer was that they all enjoyed it due to the one-to-one attention.)

Explore further.

No further comments from clients.

About the eye test

Do you remember Paula who tested your eyes?

Yes, all 6 clients remembered who Paula was.

At the eye test, how did Paula carry it out?

Comments from clients – showed pictures, matching letters, put a light in / shone a light into their eye, looked at letters, stood very close (comment from autistic client), put on glasses and put in windows.

What was the best thing about getting your eyes tested? What was the worst thing?

“Enjoyed different tests” and “being able to see good”.

There were no negative comments.

For those who wear/got glasses

(5 of the 6 clients had already been prescribed spectacles before the SVAC appointment, but 1 doesn’t wear. The 6th client was found not to require glasses.)
When wearing glasses is eyesight Good, Poor, OK?

Good for those wearing spectacles.

When not wearing glasses is eyesight Good, Poor, OK?

For the client refusing to wear his glasses, he states that he can see the same with glasses on and off.

Before you got glasses were there things that you could not do?

No comments – people couldn’t remember back to when they didn’t wear glasses.

Explore what these things were.

N/A

Make a list of things you could not do.

N/A

About Glasses

Do glasses help you see?

Close Up

Far away

For the 4 clients who wear glasses, they wear them full-time. The client prescribed glasses, but not wearing, had them prescribed for distance.

Who if anybody helped you to pick them?

Two mummys, 1 brother-in-law and 1 unsure.

Were the glasses your own choice?

Yes.

How do you feel about wearing glasses?

“All good when you wear them”. “Eyesight not good when you don’t wear them”.

Do you ever forget to wear them?

If yes, who has to remind you to wear them?

4 clients wear glasses all the time. Another client needs to be prompted to wear them by his mother and day care staff.
Who cleans the glasses?

No comments.

Have your glasses ever got lost or broken?

One client reported breaking his glasses. He told his mum and he now has spare glasses. Another client who plays football has a different pair of glasses for football. The client who refuses to wear his glasses keeps them in a box in his bag.

Going back to the list that you made earlier about the problems with seeing to do things, explore if having glasses and being able to see helps you do any of these things now?

N/A

List things.

N/A

What’s the biggest difference that the glasses have made to your life?

“Help you to see”. One client mentioned that it helped you to see TV and play pool. (Difficult question for this group of clients as those wearing glasses were long-term spectacle wearers.)

Best thing – see above.

Worst thing – no comments.

General views on sight and eye tests

Does being able to see better, help you to do things on your own?

No responses to this question – clients appeared to have difficulty understanding question despite rephrasing.

If they do things on their own explore:

What things do they do and how they feel about this?

Again, no responses.

Does good eyesight help you to make choices?

Explore for example what to wear, where to go, sports/leisure, what to eat etc.

Again, didn’t understand the question (due to being long-term spectacle wearers.

Do you think that all people with learning disability should get their eyes tested?
(Interviewer rephrased to “Do you think all people in the centre should get their eyes tested?”)
Yes, No or No strong feelings.
All said yes.

Explore.

No further comments.

Do you think it is a good idea to get your eyes tested at the Day Centre?
Yes, No or No strong feelings.
All said yes.

Explore.

It was “nice and handy” and “nice people come here to do the tests”.

Where would you rather get your eyes tested?
Day Centre or Local optician.

Patients had no preference as to where they had their eye test carried out.

Anything else that they want to tell us?

On prompting, clients said it would be good to see the test equipment beforehand but DCW felt this would have been of no benefit. Two clients recalled having eye drops and it was stingy (this could perhaps be what they feel is the worst part of the test). One client had his mum attend the eye test with him and he “felt more comfy with her there”.

None of the clients were aware of how often they should be getting their eyes tested.

Thank you for your help with this.
## Table 8: Causes of Learning Disability in the “Other” Category for Figure 2

<table>
<thead>
<tr>
<th>Learning Disability Cause</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accident motorcycle</td>
<td>1</td>
</tr>
<tr>
<td>Albright Syndrome</td>
<td>1</td>
</tr>
<tr>
<td>Angelman Syndrome</td>
<td>1</td>
</tr>
<tr>
<td>Bad febrile convulsion</td>
<td>1</td>
</tr>
<tr>
<td>Birth trauma</td>
<td>1</td>
</tr>
<tr>
<td>Brain damage</td>
<td>4</td>
</tr>
<tr>
<td>Brain damage at birth</td>
<td>3</td>
</tr>
<tr>
<td>Brain injury</td>
<td>2</td>
</tr>
<tr>
<td>CDLS</td>
<td>1</td>
</tr>
<tr>
<td>Childhood illness</td>
<td>1</td>
</tr>
<tr>
<td>Chromosomal abnormality</td>
<td>1</td>
</tr>
<tr>
<td>Chromosomal defect</td>
<td>1</td>
</tr>
<tr>
<td>Cocktail Syndrome</td>
<td>1</td>
</tr>
<tr>
<td>Cohens Syndrome</td>
<td>1</td>
</tr>
<tr>
<td>Congenital Rubella</td>
<td>1</td>
</tr>
<tr>
<td>Cornelia de Lange Syndrome</td>
<td>1</td>
</tr>
<tr>
<td>Cri du Chat Syndrome</td>
<td>3</td>
</tr>
<tr>
<td>Dandy Walker Syndrome</td>
<td>1</td>
</tr>
<tr>
<td>Dementia/Alzheimers</td>
<td>2</td>
</tr>
<tr>
<td>Eastman Bixler Syndrome</td>
<td>1</td>
</tr>
<tr>
<td>Encephalitis</td>
<td>1</td>
</tr>
<tr>
<td>Fragile X Syndrome</td>
<td>2</td>
</tr>
<tr>
<td>Global developmental delay</td>
<td>1</td>
</tr>
<tr>
<td>Huntingtons Chorea</td>
<td>1</td>
</tr>
<tr>
<td>Hyperglycemia</td>
<td>1</td>
</tr>
<tr>
<td>Hypoxia at birth</td>
<td>1</td>
</tr>
<tr>
<td>Klinefelter &amp; brain damage</td>
<td>1</td>
</tr>
<tr>
<td>Left liver enlarged</td>
<td>1</td>
</tr>
<tr>
<td>Lack of oxygen at birth</td>
<td>2</td>
</tr>
<tr>
<td>Lactosaemia blood poisoning</td>
<td>1</td>
</tr>
<tr>
<td>Laurence Moon Bardet Biedl Syndrome</td>
<td>1</td>
</tr>
<tr>
<td>Marinosco Sjogren Syndrome</td>
<td>1</td>
</tr>
<tr>
<td>Meningitis @ 3/52-Hydrocephalus</td>
<td>1</td>
</tr>
<tr>
<td>Mental health</td>
<td>1</td>
</tr>
<tr>
<td>Microcephaly</td>
<td>1</td>
</tr>
<tr>
<td>Muscular Dystrophy</td>
<td>1</td>
</tr>
<tr>
<td>Myotonic Dystrophy</td>
<td>1</td>
</tr>
<tr>
<td>Neo-natal Meningitis</td>
<td>1</td>
</tr>
<tr>
<td>Neurofibromatosis</td>
<td>1</td>
</tr>
<tr>
<td>Part of an extra chromosome</td>
<td>1</td>
</tr>
<tr>
<td>Phenyktoneturia</td>
<td>1</td>
</tr>
<tr>
<td>Prader Willi Syndrome</td>
<td>2</td>
</tr>
<tr>
<td>Rare genetic disorder</td>
<td>1</td>
</tr>
<tr>
<td>Reyes Syndrome</td>
<td>1</td>
</tr>
<tr>
<td>Condition</td>
<td>Count</td>
</tr>
<tr>
<td>-----------------------------------</td>
<td>-------</td>
</tr>
<tr>
<td>Road accident</td>
<td>1</td>
</tr>
<tr>
<td>Rubinstein-Taybi Syndrome</td>
<td>2</td>
</tr>
<tr>
<td>Septo-optic Dysplasia (SOD)</td>
<td>1</td>
</tr>
<tr>
<td>Smith-Magenis Syndrome</td>
<td>1</td>
</tr>
<tr>
<td>Spina Bifida</td>
<td>3</td>
</tr>
<tr>
<td>Sturge Weber Syndrome</td>
<td>1</td>
</tr>
<tr>
<td>Tuberous Sclerosis</td>
<td>1</td>
</tr>
<tr>
<td>Vaccine Damage</td>
<td>1</td>
</tr>
<tr>
<td>Van Reekhaws Disease</td>
<td>1</td>
</tr>
<tr>
<td>William’s Syndrome</td>
<td>3</td>
</tr>
<tr>
<td>Wolf Hirschorne Syndrome</td>
<td>1</td>
</tr>
</tbody>
</table>