Paper

Multidisciplinary assessment of vision in children with neurological disability

Claire Lundy¹, Nan Hill², Clive Wolsley³, Myrtle Shannon⁴, Julie McClelland⁴, Kathryn Saunders⁴, Jonathan Jackson⁵

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ABSTRACT

Introduction There is no consensus as to the best method of assessing vision in children with neurological disability. There are a variety of tests and approaches that can be used. It is important to look at models of assessment that identify the visual diagnosis and provide appropriate feedback and explanation to parents, carers and educational professionals.

Methods This study reports on the results of comprehensive visual assessments of fifty children with neurological disability over a three year period. It focuses on the feedback from families and professionals after the assessment report was disseminated.

Results The majority of families and professionals strongly agreed that a specialist assessment was needed in this population. Parents and professionals particularly valued the written report which provided guidance on appropriate visual material including advice relevant to education.

Conclusion This study highlights the importance of specialist teams engaging with local child development services and indicates how partnership working can potentially be emotionally supportive as well as developmentally beneficial.

INTRODUCTION

There is no consensus as to the best method of assessing vision in children with neurological disability. There are a variety of tests and approaches that can be used.¹⁻³ It is therefore important to look at models of assessment that clearly identify the visual diagnosis which encompasses the ophthalmic diagnosis and visual characteristics and how to provide appropriate feedback and explanation to parents, carers and educational professionals doing so in a holistic way that takes into account the other medical diagnosis and specialist needs the child may have. In assessing the utility of such a service we not only need to look at the effectiveness with which a visual diagnosis is obtained after an assessment but also the perceived utility of such an assessment by those individuals caring for and educating the child. Evidence suggests that developmental intervention in the form of visual promotion may benefit even those children with severe or profound visual impairments.⁴ Studies show that children with visual impairment demonstrate delayed development in other areas due to the lack of visual stimulus. This may impact greatly on the child with other neurological difficulties.^{5;6}

Parents and carers have an important role in visual assessment. The visual skills inventory paper published in 2007 by McCulloch and colleagues found when parents were asked focused questions on their child's vision their responses correlated well with visual ability.⁷ This model provides practical assistance for clinicians trying to plan appropriate assessment tools and may result in a more efficient process. Parental involvement is also likely to heighten awareness of the child's visual abilities and may assist in preparing them

for a diagnosis of visual impairment. The assessment of visual acuity and function in the paediatric neurodisability population is a complex process, which may require testing by a number of professionals and using various strategies before a reliable conclusion can be drawn about the child's visual ability. There is little in the literature on communicating with families about a diagnosis of visual impairment. One team described various methods of meeting parental needs around this time using strategies such as a dedicated key worker.⁸ Studies demonstrate the widespread use of asking parents to provide information on their experience of health service provision for children with disabilities.⁸⁻¹¹ The use of questionnaires has been demonstrated to be effective and valid in a number of settings.^{8,11,12} This study reports parental and professional evaluation of a pilot visual assessment clinic with the use of some open ended questions and free text as a means of identifying areas of good practice or dissatisfaction.¹³

The pilot clinic focussed on visual assessment in children with neurodisability. Research on adults with learning problems showed they are fifteen times more likely to have a visual impairment than the rest of the population.¹⁴ Woodhouse

Correspondence to Dr Lundy

claire.lundy@btopenworld.com

Evelina Children's Hospital, Guys and St Thomas' NHS Foundation Trust¹, Community Paediatrics, Belfast Health and Social Care Trust², Department of Ophthalmology Royal Victoria Hospital³, Vision Science Research Group, School of Biomedical Sciences, University of Ulster⁴ Department of Ophthalmology Royal Victoria Hospital/Queens University Belfast⁵

demonstrated that the more severe the learning disability the more likely it was for visual acuity to be reduced, findings mirrored by the paediatric literature.^{1,15,16} The adult literature provides the basis for choosing tests of visual acuity that might be applicable in the neurologically disabled childhood population with numerous studies on testing techniques.¹⁵⁻¹⁷

One of the aims of visual testing is to establish how well an individual's visual system can resolve detail, this is known as their visual acuity. This is a quantitative measure and is usually tested using standardised charts e.g. Snellen with specialised printed targets called optotypes. In the paediatric population these standardized charts have been adapted to include symbols that are recognisable by young children. In young infants unable to identify symbols more opportunistic techniques are needed and tests of preferential looking were developed to try and gauge infant acuity. It is possible to measure the electrical response of the brain to visual stimuli. Visual evoked potentials (VEP) provide a non-invasive, objective measure of visual function which reflects the activity of the visual pathway from the retina to the visual cortex¹⁸ VEPs are generated using standardised flash and pattern stimuli and can be used to assess visual impairment and visual acuity in infancy. It is important to recognise that VEPs merely assess the integrity of the visual pathway. 'Seeing' implies resolution, recognition and conscious perception. Children with complex neurodisability are more likely to have conditions such as nystagmus, central scotomas and poor fixation as well as disorders affecting muscle tone and epilepsy. All these conditions can impair the VEP quality. making acuity assessments more difficult. Success rates vary with this form of visual testing from 50-91% in children with complex neurodisability. 1

Useful vision requires an ability to focus the eye through a field of vision and to detect variation of depth and colour. The ability to focus the eye (accommodation) can be assessed objectively using refractive techniques that do not rely on patient participation.¹⁹ Visual fields can be tested by conventional direct confrontation techniques or more opportunistic techniques such as Stycar balls.^{15,20,21} All of the techniques and tests described can be used to help build an impression of what a child with a neurological disability can see. The assessment process undertaken in the pilot clinic used a variety of tests administered by a team of clinicians experienced in the field of paediatric neurodisability. We report on the experiences of parents and professionals who used the service describing their opinions of the clinic setting, assessment process and the final clinical report.

METHODS

Setting

The pilot visual assessment clinic took place in Northern Ireland over a three year period from 2003-2006. The clinic took place in the Royal Hospital in Belfast. Dedicated facilities are present for paediatric visual assessment including acuity testing and retinoscopy. There is on site access to electrophysiological testing in the hospital. A multidisciplinary team approach was adopted for the pilot clinic. The team was lead by a senior academic optometrist, supported by two academic optometrists with expertise in the assessment of vision in children with neurological problems (JJ, KS, JMcC). Other team members included a paediatrician with expertise in neurodevelopment, an orthoptist, a teacher of the visually impaired (MS) and a clinical scientist with expertise in electrophysiology (CW). The role of the principal author (CL) was as an observer reflecting and reporting on the process.

The sample population consisted of 54 children. This was a convenience sample based on the total number of children seen within the period in which the clinic was funded. Children under the age of sixteen years who had a neurological impairment and a suspected visual impairment were eligible. All children recruited were resident in Northern Ireland and were under the care of a community paediatrician and/or in 'Special Education'. All children referred to the clinic were offered an assessment. All of the available parental and professional feedback was analysed.

METHOD OF RECRUITMENT

During 2003 letters describing the clinic were sent to all community paediatricians and paediatric ophthalmologists in Northern Ireland. They were invited to refer children with neurological disability in whom there was a concern about visual impairment. Particular emphasis was placed on recruiting children for whom the process for 'statement of special educational need' was either imminent or ongoing. All parents and referrers of children who attended the clinic were invited to participate in a follow up questionnaire.

Visual assessment tools were chosen on the basis of the team's particular expertise with certain tests and on reports in the literature that demonstrated reliable methods of assessing visual ability in young children and adults with neurological impairment.^{22,23}. The assessment was individualised to meet the needs of the child. For each child a full medical and ocular history and functional visual assessment was obtained. A parent /carer was always present. In order to provide additional information a visual behaviour questionnaire was sent to families prior to attendance at clinic which provided a preliminary baseline of the child's visual ability. This was supplemented by a discussion with the carer during the clinic setting as to the child's current visual behaviour at home and at school where appropriate. Each individual recorded their assessment findings. Following a round table consultation a consensus was reached on results to be included in the report. The clinical report summarised some of this information in 'lay' terminology. Recommendations on size, colour, contrast and type of visual material were presented as part of the report. The report was reviewed by the whole team before dissemination to families and professionals. This method of reporting visual information to families and professionals has been used by other specialist low vision clinics.²⁴ A list of the visual assessment tests and techniques is provided in Table 1. An analysis of the visual assessment process and results obtained will be reported in a further paper.

This paper focuses on parental and professional satisfaction with the specialist visual assessment clinic visit and report. Satisfaction data was obtained by administration of a brief 5 point Likert scale questionnaire- Strongly Agree to Strongly Disagree. This was based on similar questionnaires in the research literature and adapted by the clinic staff.²⁵⁻²⁸ The Likert scale questionnaire was composed mainly of 'closed' statements.^{8,11,24,29} There was also free response. Two questions

asked for a rating on the usefulness of the clinic both at the beginning and the end of the questionnaire. Key questions were the accessibility of the clinic, the appropriateness of the clinic environment for children with neurodisability, the helpfulness of clinic staff, the ability to ask questions during the consultation, clarity of the report and if it was useful on a day to day basis. There were two sections for free response one rating the most beneficial and least beneficial aspects of the clinic and one question on the clinic overall. The parental questionnaire was administered by one of the clinic team by telephone. The professional questionnaire was returned by post. Sample questions included: 'I think there was a need for this service', 'the report was meaningful and relevant (it aids my practice)' a further question examined if they had acquired new information about their patient. Copies of the questionnaires are provided in Appendix 1.

RESULTS

All of the available parental and professional responses to the follow up questionnaire were analysed. A total of fifty children were seen at the pilot special visual assessment clinic. Four additional children failed to attend their appointment. The age range was from 0.6-15.9 years with an average of 5.7 years. Twenty nine were female. A total of 34 parental questionnaires were completed by telephone. Forty one health professionals responded to the follow up questionnaire in writing.

MEDICAL CONDITIONS IN THE CLINIC POPULATION

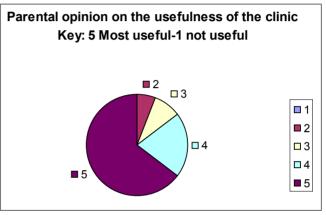
The most prevalent condition in the clinic population of fifty children was cerebral palsy (CP). There were seventeen children with quadriplegic cerebral palsy and five children were described as having hemiplegic cerebral palsy (see Table 2). Severe epilepsy and epileptic encephalopathy were the next most common cause of a neurological disability. Other conditions included congenital brain malformations and retinal disorders.

INFORMATION INCLUDED IN THE CLINICAL REPORTS IN THIS POPULATION

A complete visual assessment including acuity, refraction and visual fields was undertaken in the majority of children (31/50). Four children with mild or moderate impairment did not have visual field testing performed, one child was noted to be poorly co-operative and no reason was given for the other three cases. Formal assessment was not possible in 15 children identified as having either severe or profound visual impairment. Thirty three (66%) children were given advice on visual ability specific to their education needs. Twenty (40%) were affected by a severe or profound visual impairment and required advice about non-visual methods of education. Six (12%) children with moderate impairment received similar advice, two children in this moderate group were below the age of two years and a further two children did not receive advice as the relevant professional was not present at the clinic. Seven (14%) children with mild visual impairment benefited from advice for school, this mainly consisted of recommendations on materials, toys, size of print/objects and distance for working. This was also an opportunity for the clinic professional to recommend if the child would benefit from regular input from a specialist teacher of the visually impaired.

RESULTS OF THE PARENTAL FEEDBACK QUESTIONNAIRE

This questionnaire was administered by telephone following clinic attendance. A total of 34 parents were available to respond to the questionnaire. Satisfaction data was based on a 5 point Likert scale questionnaire- Strongly Agree (5) to Strongly Disagree(1). See Appendix 1. The majority responded that the clinic visit was useful. This was asked at the beginning and end of the questionnaire. Parental response was not significantly different depending on the timing of the question. Twenty nine (85%) graded it as Agree (4) or Strongly agree (5) initially. Thirty give this response at the completion of the questionnaire. Two (5%) parents rated the usefulness as Poor (1 or 2).



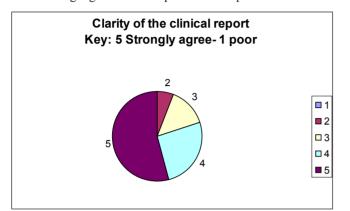
Thirteen (38%) families reported they did not receive any information describing the clinic prior to attendance. Of those who did receive information 17 (50%) rated it as Agree (4) or Strongly agree (5). Thirty one (91%) parents expressed a high degree of contentment with the explanation give by the clinic staff when they arrived for the appointment. Thirty three (97%) families rated the staff as being as helpful as possible. Thirty two (94%) families reported they had the opportunity to ask questions during the clinic visit.

Accessibility was a major problem for 11 families. Twenty four of the 34 respondents described parking access as 3 or less. The main comment made when asked was the lack of disabled access parking.

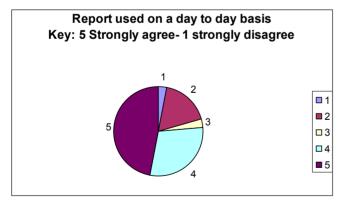


The clinic environment was rated as three or less by 17 (50%) families. Free text responses in the 'other comments' section of the questionnaire described it as a 'boring environment for non-visual patients' and that the room used was 'small... stuffy....overcrowded'.

As described a standardised clinic report was generated after every clinic attendance. This was sent to parents and the professional who referred the child. Responses were analysed using the Likert scale and also free comment. Thirty one (91%) of 34 parents rated the report as Useful (4) or Very useful (5); one parent stated it was poor. Twenty eight (80%) reported it was written in a way that could be understood, but seven (20%) felt this was not the case. In the free text responses these parents described the report as 'too technical' and the language should be 'plain and simple'.



Parents were asked to respond freely regarding the most beneficial and least beneficial aspects of the report. The responses were coded for analysis. Benefit appeared to be mainly due to the perceived usefulness of written information to be shared with professionals and the use of the report as a meaningful summary of a detailed visual assessment. Overall there were 25 comments around this theme. Five (15%) parents commented on the benefit of specific advice in relation to equipment or educational aids and three found the comments on promoting visual development helpful. Six (18%) described the technical nature of the report as not beneficial. Two (6%) parents felt the report was not detailed enough. The majority (76%) of parents felt the report contained information that was useful on a day to day basis.



Responses about the most beneficial aspects of the clinic generated four themes: Approachable and helpful staff, knowledge about the child's visual status, advice and equipment and no benefit. There were 19 positive comments based around the theme of knowledge and visual assessment and 8 comments on the approachable and helpful staff. Six parents(18%) commented positively about the additional benefit of detailed and advice about visual promotion and the supplying or recommendation of appropriate equipment. When asked to comment on what was of least benefit, the

majority of parents reported nothing negative. A small number of parents found the distance and parking problems to be detrimental, others commented on the late timing of appointments and unsatisfactory clinic environment. One parent commented on the technical nature of the assessment and four reported they would have liked more detailed advice following the assessment. One parent felt the assessment was inaccurate.

The final section where parents were asked to comment freely generated seven themes:

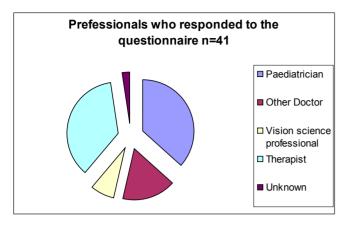
- Staff
- Knowledge and information
- Visual equipment
- Negative responses around travel and appointment timing
- Technical report
- Lack of information regarding follow up arrangements
- Parental distress during and following the appointment

Parents valued the honesty and approachable nature of the clinic staff. The use of informal and non-medical terminology was welcomed. Parents reflected positively on new knowledge acquisition and commented on how this affected their ability to work with their child at home and also communicate meaningfully with health professionals especially about visual equipment which may be beneficial for their child. The clinic population was primarily composed of children with neurological difficulty, the majority of whom had mobility problems. Six (18%) families reported that the late afternoon appointments, distance to the clinic and parking was a negative experience. Overall there were a range of comments about the technical aspects of the clinical report. Five (15%) parents commented on the benefit of specific advice in relation to equipment or educational aids and three found the comments on promoting visual development helpful. Two (6%) parents felt the report was not detailed enough.

Five (15%) parents commented on the lack of clarity regarding a follow up appointment. Four (12%) parents commented on the impact of being told a child had a severe visual impairment. One (3%) parent reported the difficulty of hearing this news from unfamiliar professionals and how it was not an accurate assessment. Another described the stress of the detailed assessment in an overcrowded clinic room she felt this was difficult for her as a parent and 'daunting' for a child.

HEALTH PROFESSIONAL'S RESPONSE TO THE CLINIC QUESTIONNAIRE

There were a total of 41 responses to the written questionnaire that was sent out to professionals with the clinic report. Most professionals listed their name and professional group in their response. Responses were coded in a Likert scale 5: strongly agree, 1: strongly disagree.

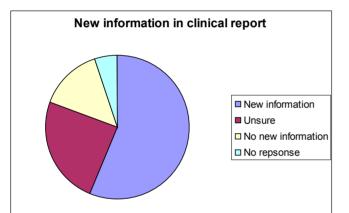


NEED FOR THE SERVICE

The majority 90% (37/41) of professionals were in strong support of the need for this service. Twenty six (63%) were confident it did not duplicate existing services, although eight respondents were unsure.

PROFESSIONAL SATISFACTION WITH THE CLINIC REPORT

Thirty two (78%) professionals felt the reports were meaningful, relevant and aided their practice. Interestingly, 23 (56%) stated the reports contained previously unknown information.



The majority of professionals (62%) agreed that parents would find the report useful. Four (10%) were unsure and two (5%) felt parents may find it unhelpful. There were few free text comments and therefore the development of themes was not possible. One paediatrician commented that the detail in the report was very helpful. Therapists from a range of backgrounds stated they had found it useful for preparing therapy sessions and treatment plans.

DISCUSSION

The structure and feedback from a specialist assessment is particularly important in children with neurological disability. There are implications for the length of the appointment, the information gathered beforehand, professionals present and feedback afterwards. A detailed referral document is helpful in reducing the amount of time spent going over history which is familiar to the family and the local team. Sending out questionnaires and letting the family know the structure of the appointment could be helpful prior to clinic attendance. Inviting a local professional to attend is common practice

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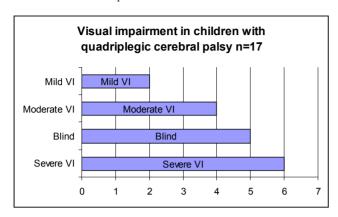
in many paediatric neurodisability clinics although this is dependent not only on parental consent but also on space.

TABLE 1

- Retinoscope
- Full aperture lenses
- 2. Accommodation
- 3. Pupillary reflexes
- 4. Eye contact
- 5. Nystagmus
- 6. Ocular posture
- 7. Pursuit movements
- 8. Saccadic patterns
- 9. Stereopsis
- 10. Colour vision (where appropriate)
- 11. Acuity Tests:
 - Logmar
 - Snellen
 - Kays
 - Keeler
 - Cardiff cards
 - Sheridan Gardiner
 - LH cards
 - Techniques included:
 - Crowded letters
 - Single letters/symbols
 - Preferential looking
- 12. Electrophysiology Visual evoked potentials
- 13. Assessment of strabismus
- 14. Visual field testing
- 15. Developmental review

Four parents commented on the distressing impact of being told their child had a severe visual impairment by a new team. This reflects the ongoing difficulties experienced by many families in coming to terms with the diagnosis of a neurological disorder.8 This may be adversely affected by the number of consultations and specialists seen in order to obtain a coherent diagnosis.¹⁰ Baird et al demonstrated that these expressions of dissatisfaction are often associated with parental depression.9 However, comments in this study highlighted the value parents place on open and honest consultations that provided detailed knowledge and recommendations on how to work with their child. Research has shown that parental satisfaction is dependent upon the amount of medical language used, interpersonal skills of the professionals and the amount of information exchanged.¹¹ It would appear that the format of this pilot clinic and the subsequent report was noted to be helpful by the majority of parents. Comments on the testing environment and technical detail in the reports should be considered for future clinic design. Professionals who referred children also appeared to value the summary report which was shared with them. The majority identified that it contained previously unknown information and provided useful advice on how to progress with the child's visual management. Clinicians commented how the clinic supported their local Child Development Team by allowing therapists to devise realistic and appropriate programmes.

TABLE 2Visual impairment in children with CP



The importance of the history and examination by an appropriately trained medical professional was valued by families and seemed to provide useful contextual information for the interpretation of visual tests. The inclusion of a specialist teacher of the visually impaired allowed the team to consolidate the visual findings in terms of relevance to education and home environment. It also facilitated recommendations on suitable visual materials. The inclusion of these two team members appears to have heightened parental and professional satisfaction in terms of the content of the consultation and the summary report. As previously discussed parents are often supported by a large number of local professionals. Good communication between clinic staff and local teams resulted in accurate and valued assessments. It is likely that the addition of a local team member to the clinic team at the time of consultation may have provided further helpful background information and contributed to putting families at their ease. ^{10,30}

A specialist clinic for children with neurodisabilitywhat is important to families

- Appropriate facilities
 - Parking
 - Level access
 - Suitable changing and hoisting facilities
 - Appropriate play materials and information
- Experienced professionals
 - Knowledge of community teams and educational system
 - Confident practitioners in the relevant assessment process
 - Links to specialist professionals for further evaluation
 - Skills in providing verbal and written feedback to families and local professionals
 - Invitation to local professionals to attend for joint assessment
- Clear follow up arrangements
- Provision of support after diagnosis
- Advice on how to access appropriate developmental and educational material

LIMITATIONS OF THIS STUDY

The pilot clinic format was devised by a group of professionals who work regularly with children with neurological disability and their families. Their aim was an exploration of the potential need for a specialist service. This resulted in an open and fluid approach to the development of the clinic assessment techniques and report writing over the three year study period. This was responsive to the needs of the clinic population and the feedback from families and professionals. but as a result meant that there was less standardisation of clinical documentation and assessment techniques than would be found in a research clinic setting which usually has a strict protocol. The follow up questionnaires provided useful positive feedback reflecting the support of local teams for such a specialist service. It would have been preferable to use a recognised validated scale.¹² Ideally the questionnaire administered to parents should have been carried out by an independent person. There was no agreed protocol for the time period for administration and this too may have affected the responses as they are dependent on recall of the clinic consultation and the report.³¹ Similarly there was a lack of protocol for following up non-respondents in both the parental and professional groups. This resulted in an incomplete data set.2

CONCLUSION

The numbers in this study are small. However, the affirmative responses of parents and professionals when asked if the service provided them with new and useful information supports the recommendations of other researchers who have demonstrated that specialist expertise is needed in assessing vision in children with neurodisability.^{32;33}

The authors have no conflict of interest.

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