

## Impact case study (REF3)

<b>Institution:</b> Ulster University		
<b>Unit of Assessment:</b> Allied Health Professions, Dentistry, Nursing and Pharmacy (3)		
<b>Title of case study:</b> ICS-5 Transforming Eyecare for Children with Developmental Disability		
<b>Period when the underpinning research was undertaken:</b> Jan 2000 - Dec 2020		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b>	<b>Role(s) (e.g. job title):</b>	<b>Period(s) employed by submitting HEI:</b>
Kathryn J Saunders Julie F McClelland Julie-Anne Little	Professor Senior Lecturer Senior Lecturer	1998–present 2004–present 2006–present
<b>Period when the claimed impact occurred:</b> 1st August 2013 - 31st December 2020		
<b>Is this case study continued from a case study submitted in 2014?</b> N		
<p><b>1. Summary of the impact</b>          Ulster research has transformed eyecare for children with developmental disability. Our research demonstrated that previously unrecognised visual impairments were prevalent among children with disability and that evidence-based eyecare delivered to children in special education settings conveys visual and educational benefit. The research has raised clinical and therapeutic best practice worldwide (<b>I1</b>, <b>I2</b>, <b>I4</b>), through provision of an evidence base for the assessment, diagnosis, management and communication of eye and vision problems experienced by visually vulnerable children. As a consequence, children with developmental disability have benefited from an increased recognition of their eyecare needs and more targeted eyecare from clinicians and educators. Our research enabled the commissioning of a nationwide in-school NHS eyecare service to comprehensively address the visual needs of <b>all</b> children in special educational settings in England (<b>I3</b>).</p>		
<p><b>2. Underpinning research</b>          Developmental disability refers to a diverse group of chronic physical and/or intellectual impairments that arise in childhood, such as Down syndrome, autism and cerebral palsy. Developmental disabilities affect nearly 53 million children worldwide (nearly 1 in 20 children in the UK). Our research has highlighted that visual problems in children with such disabilities are often diagnostically overshadowed by their primary systemic conditions, and that potentially treatable visual deficits may be overlooked to the detriment of quality of life and educational attainment.</p> <p>Between 2006 and 2018, with charitable and NI HSC R&amp;D funding, the paediatric vision team at Ulster University (Little, McClelland, Saunders) was the first to profile the visual characteristics of children with cerebral palsy (CP) (<b>R1</b>) and autism (<b>R2</b>) using large, population-based samples. Previous information on visual status in these groups was derived from clinical samples and was inherently biased. Our research demonstrated significantly increased prevalence of focusing deficits in both conditions (CP 58%; autism 19%) compared to typically developing children (5%). We identified a clear link between poor focusing and more severe motor impairment in CP, but also found significant visual deficits among the mildest cases.</p> <p>We found that, alarmingly, only 2% of children with CP whose focusing was impaired in 2006 had received appropriate recognition and management of this sight-impairing condition. Our research identified a clinical imperative for routine assessment of focusing in children with developmental disabilities, in order to mitigate visual impairment (<b>R1</b>, <b>R2</b>).</p> <p>Traditional clinical methods for assessing focusing are unsuitable for young children and those with impaired communication and/or understanding. Consequently, focusing in these populations has rarely been evaluated. To establish the clinical need for routine testing of focus in this</p>		

patient group, we validated and established the repeatability of an objective child- and clinician-friendly 'dynamic retinoscopy' technique for assessing focusing accuracy (**R3**). We published the first age-normative data for the technique in 2004, allowing clinicians to easily identify focusing deficits in children with or without developmental disability (**R4**). In collaboration with colleagues at Cardiff University we incorporated these research outcomes into a novel clinical tool for objectively measuring focusing accuracy: the Ulster-Cardiff Cube (UC-Cube).

Utilising long-standing relationships with stakeholders including clinicians, parents and educators, we tested the degree to which those groups recognised the effect of visual impairment on a child's ability to access educational material. We revealed discrepancies among clinicians' understanding of a child's visual status and needs, the knowledge held by parents and teachers, and the information included in statutory documents relating to the child's educational, health and social needs (Education Health and Care Plans (EHCPs)). We measured these discrepancies for the first time (2010–13) by comparing information held in clinical records and EHCPs of children with developmental disability (**R5**). 43% of clinical records documented significant visual impairment by World Health Organisation standards, but these educationally and socially relevant impairments were not acknowledged in 67% of the corresponding EHCPs, allowing visual impairment to go unsupported in the classroom. Parents and teachers reported that they routinely received only oral information about a child's vision and that where written information was provided, it was invariably technical in nature and not translatable to the child's circumstances or need for support.

Building on this evidence with funding from Action Medical Research, between 2016 and 2019 we (i) worked with service users and other stakeholders to co-design and test a semi-standardised 'Vision Report' proforma for translating visual assessment outcomes into actionable 'plain English' written information for non-clinical audiences and (ii) researched the visual and educational benefits of accessible in-school eyecare (incorporating the Vision Report and the UC-Cube) for children in special educational settings. Our research demonstrated that unmet visual needs are common among children in special education settings (45% with at least one unmet visual need). Using evidence-based methodologies, the research also measured for the first time the visual, behavioural and educational benefit of delivering in-school eyecare (**R6**). We found that in-school vision assessment and reporting significantly improved children's classroom engagement (less time spent 'off-task') and visual status (unmet visual need reduced from 45% to 18%). Furthermore, parents and teachers agreed that the in-school eyecare service conferred benefit to students (83%), that they understood and acted on the Vision Report (88% found 'information useful on a daily basis'; 33% found out 'something new about the child's vision'), and that the implementation of the in-school eyecare service resulted in positive change to the education setting (88% of teachers made classroom modifications following receipt of the Vision Report) (**R6**).

### 3. References to the research

The following outputs have been published in the international scientific literature following a rigorous peer-reviewed process.

**R1.** McClelland JF, Parkes J, Hill AE, Jackson, AJ, and Saunders K. Accommodative dysfunction in children with cerebral palsy: a population-based study. 2006. *Investigative Ophthalmology and Visual Science*, 47(5):1824–30. doi:10.1167/iovs.05-0825

**R2.** Anketell PM, Saunders KJ, Gallagher SM, Bailey C and Little JA. Accommodative Function in Individuals with Autism Spectrum Disorder. 2018. *Optometry and Vision Science*, 95(3):193–201. doi: 10.1097/OPX.0000000000001190

**R3.** McClelland JF and Saunders KJ. The repeatability and validity of dynamic retinoscopy in assessing the accommodative response. 2003. *Ophthalmic and Physiological Optics*, 23(3):243–50. doi: 10.1046/j.1475-1313.2003.00113

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**R4.** McClelland JF and Saunders KJ. Accommodative lag using dynamic retinoscopy: age norms for school-age children. 2004. *Optometry and Vision Science*, 81(12):929–33. doi:10.1097/01.OPX.0000147681.94971.28

**R5.** Little JA, Saunders KJ. A lack of vision: evidence for poor communication of visual problems and support needs in education statements/plans for children with SEN. 2015. *Journal of the Royal Institute of Public Health*, 129(2):143-8. doi: 10.1016/j.puhe.2014.12.009

**R6.** Black SA, McConnell EL, McKerr L, McClelland JF, Little JA, Dillenburger K, Jackson AJ, Anketell PA and Saunders KJ. In-school eyecare in special education settings has measurable benefits for children’s vision and behaviour. 2019. *PLoS ONE* 14(8): e0220480. doi: <https://doi.org/10.1371/journal.pone.0220480>

Infrastructure Equipment grant for Vision Science Research group	The Wellcome Trust, Infrastructure Grant	Hudson, Saunders, Anderson, McKeefry.	GBP113,250	2000-2002
Accommodation in Cerebral Palsy	The College of Optometrists	Saunders	GBP34,615	2000-2003
Optometry research on children with complex vision needs	Health and Social Care Research and Development (HSC R&D) (HPSS RRG 4.4)	Saunders	GBP14,215	2003-2006
Vision and Visual Function in Autistic Spectrum Disorder (ASD); developing an evidence base for the eyecare profession	NI HSC R&D office, Public Health Agency, Doctoral Fellowship Scheme	Little, Saunders	GBP159,915	2010-2014
A Clearer Vision: Improving stakeholder’s understanding of the nature of vision and visual function in the presence of complex neurological problems	NI HSC R&D office, Public Health Agency, Knowledge Transfer Funding	Saunders	GBP96,394	2010-2013
Poor Visual Health and Unmet Visual Need in Special Schools	Action Medical Research	Saunders, McClelland, Little et al.	GBP189,315	2016-2019

#### 4. Details of the impact

**Significance and Reach:** Our research has shaped clinical best-practice guidance worldwide and improved the ability of clinicians to provide appropriately targeted care (**I1**, **I2**). Our research has triggered commissioning of new NHS eyecare services for children with developmental disability in England (**I3**). Furthermore, by providing clinicians with ‘plain English’ communication tools to enable effective reporting of children’s visual strengths and weaknesses to key supporters and educators, we have ensured that the findings from clinical assessments achieve maximum impact (**I4**).

#### **I1: Clinical knowledge and best practice have changed, enabling alleviation of visually-impairing focusing deficits in children with developmental disability.**

Our research is recognised and utilised nationally and internationally by educators, therapists and health professionals. Our research outcomes highlighting the prevalence of sight-impairing visual deficits among children with CP and autism, and those validating an accessible method to diagnose poor focusing in children with developmental disability, have been used in key international eye and healthcare texts (**C1**; **R1**, **R3**, **R4**). The outcomes are also incorporated into national and global clinical guidance, such as that issued by the College of Optometrists, whose members comprise over 12,000 of the 14,000 optometrists registered in the UK (**C2**; **R2**,

**R6).** North America's leading professional organisation for optometrists, the American Optometric Association, which represents over 44,000 members, cites our work (**R3**) in its clinical practice guidance (**C2**) when identifying dynamic retinoscopy as a key assessment in paediatric eyecare.

Our research outcomes (**R1, R3, R4**) are used in the Brien Holden Foundation's Global Optometry Resources, an open-access curriculum curated to facilitate the implementation, delivery and advancement of optometric education in developing countries, and reflected in the curricula of the College of Optometrists' Professional and Higher Professional Certificates in Paediatric Eye Care (**C3**).

Since 2013, the number of children issued with bifocal spectacles (the primary means to correct focusing deficits) has increased by 24% in UK NHS practice (**C4**). This change in eyecare practice in line with our research has enabled a greater number of children to experience better vision.

Our research is also used by Public Health England and third-sector organisations to inform and empower parents and other stakeholders. Public Health England's 'plain English' guidance on reasonable adjustments for eye care for people with learning disability links to Ulster's Vision Report (**R6**), hosted by SeeAbility. In addition, the UK's leading organisation promoting education, training, advancement and development of people with special/additional support needs, the National Association of Special Educational Needs (nasen), includes our research (**R5**) in its stakeholder resources (**C5**).

**I2: Successful commercial development of a research-supported tool (UC-Cube) provides a means by which clinicians can identify focusing deficits.**

In 2010 we translated our research outcomes (**R3, R4**) into a novel commercial tool for assessing focusing accuracy. Commercialised to prioritise clinical uptake through a not-for-profit agenda, the UC-Cube provides clinicians with an accessible, objective method to quantify, diagnose and manage focusing difficulties in patients unable to communicate effectively and to contextualise outputs against our research-derived normative data. Manufactured and distributed in collaboration with Cardiff University and PAVision Ltd, the UC-Cube's global sales (approximately GBP20,000) to practitioners and researchers, including in UK, Ireland, Sweden, South Africa, Antigua, India and the United States, have embedded the tool in clinical training programmes, hospital and primary eyecare services and specialist services for children with learning difficulties across the world. In a survey of NHS paediatric eyecare clinicians who introduced the UC-Cube into their practice, 92% agreed or strongly agreed that using the UC-Cube benefitted both their patients and their practice. Clinicians reported specifically that the UC-Cube improved detection of focusing deficits and treatment of near visual impairment (**C6**).

**I3: Eyecare services for children with developmental disability in England are transformed.**

Our research outcomes (**R5**) have been used by campaigners as evidence of the need for improved eyecare services for children with developmental disability. SeeAbility, the oldest disability charity in the world and one of the largest in the UK, successfully used our research outcomes to lobby for the funding and implementation of a national evidence-based eyecare service for children in special education settings (**C7**). In 2018, as a direct result of our research activity, Professor Saunders was invited to join a Department of Health project board tasked with designing and implementing a new evidence-based eyecare service for children with learning disability. Our work demonstrating the measurable benefit of in-school eyecare to children in special education settings (**R6**) provided key evidence needed to commission this targeted and accessible in-school eyecare service for all (over 110,000) children educated in special schools in England. Our evidence-derived validated tools, the UC-Cube and Vision Report proforma, are embedded in the service specification of this new nationwide service (2019) (**C8**). The NHS England and NHS Improvement Programme Manager for Optical Services Commissioning acknowledges the pivotal role Ulster research outcomes played in the commissioning and design of the service:

*“The starting point for every new NHS England programme is the need to evidence positive outcomes for patients. This was a significant obstacle for the special school eyecare programme because the evidence simply didn’t exist until the research was undertaken by Ulster University. Ulster University’s research not only helped to secure internal traction for the programme, but has informed our work throughout, contributing validated tools with which to optimise the delivery and impact of the service.” (C8).*

**I4: Research-derived resources enable clinicians to communicate the visual needs of children with developmental disability and help parents and teachers to ensure that those needs are met.**

Our Vision Report proforma (R6), co-designed with service users, industry, education and health stakeholders, is promoted by Public Health England (C5) and embedded in NHS England’s service specification for in-school eyecare (C8). The Vision Report equips parents, teachers and other key supporters of children in special education settings with clearer understanding of children’s visual needs and, when integrated into EHCPs, ensures that appropriate support is in place to allow children to participate fully in the educational curriculum and enjoy the benefits of improved vision and better care.

The Vision Report proforma is one of the most downloaded resources offered by SeeAbility (C5) and is also available from the open-access Ulster Vision Resources (UVR) (R1-R6; C9). The UVR curate research-based support tools for professionals, parents and lay people. These tools have been accessed by over 161,000 users across 75 countries since 2014. Google analytics provides evidence of consistent use/re-use by visitors from Africa, Asia, Europe, America and Australia (C9). The Royal National Institute of Blind People and the College of Optometrists promote the UVR to parents and carers of children with visual impairment and to optometrists providing eyecare for patients with learning disability (C10).

**5. Sources to corroborate the impact**

**C1.** List of key international eye and healthcare texts published post-2000 and in print 2013-2020, evidencing use of our research.

**C2.** The American Optometric Association’s most recent professional guidance (2017), which uses Ulster research to support good practice; and, AOA webpage material evidencing member numbers. The UK’s College of Optometrists’ Guidance for Professional Practice, which was revised utilising our research (revision period 2019-2020); and, its ‘Report and financial statements for the year ended 30 September 2020’, evidencing member numbers.

**C3.** Global curricula currently available for optometric training, which utilises our research outcomes to support clinical training and practice (Brien Holden Foundation’s Global Optometry Curriculum; College of Optometrists Higher Qualifications).

**C4.** General Ophthalmic Services NHS data analysis (2013-2018), evidencing increased bifocal prescribing.

**C5.** Public Health England (PHE) and third-sector organisations use our research to inform and empower parents and other stakeholders. PHE 2020 and nasen 2018 resources. Section 13.3 of the PHE resources links to our Vision Report hosted by SeeAbility (‘Quick Action Fact Sheets and Forms’/‘The Results of your Child’s Eye Test’).

**C6.** Analysis corroborating the benefit conferred by the UC-Cube to patients and eyecare practitioners and UC-Cube sales 2013-20.

**C7.** SeeAbility (2018), ‘Children in Focus – A Clear Call to Action’.

**C8.** Testimonial from NHS England NHS Improvement Optical Services Commissioning Programme Manager and NHS England service specification for in-school eyecare.

**C9.** Ulster Vision Resources webpage and Google Analytics evidence of the global use of UVR tools.

**C10.** RNIB (Looking Ahead guide for parents, 2014) and the College of Optometrists’ Professional Practice Guidance (Examining patients with learning disability, revision period 2019-2020) direct parents and clinicians to our research-derived resources.