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Learning to Access: why we need a new UK specialist curriculum to enable equitable participation in education for children and young people with vision impairment

VIEW discussion paper

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## Summary

The aim of this paper is to start a discussion about the need for a national, UK specialist curriculum for vision impairment (VI) education that addresses the development and learning needs associated with blindness and partial sight and reflects the distinctive skills required by learners with VI.

The importance of a specialist curriculum is supported by the vision impairment education literature, and access to it should be seen as a right and entitlement for all children and young people with VI. However, it is evident that the current approach to educational provision for children and young people with VI is not working. In essence, children and young people with VI are being let down by an education system which fails to understand and prioritise their true needs.

The situation is not helped by the fact that there are several specialist curricula and outcomes frameworks for children and young people with VI being used in the UK, none of which has any statutory status. Having a range of curricula and outcomes frameworks can lead to a lack of clarity about what should be taught, when and by whom.

Given the widening differences in education policy and terminology relating to special education and disability across the UK, having a unifying framework that enables a consistent approach to the education of children and young people with VI is particularly important.

It is proposed that the new UK curriculum should have a clear conceptual framework based on the concept of ‘access to learning/learning to access’ (McLinden, Douglas, Cobb, Hewett and Ravenscroft, 2016) and an agreed set of outcomes and approach to intervention that guides professional practice in teaching and habilitation from early years through to higher education and/or vocational training.

## Introduction

The central premise of this paper is that there is a need for a national, UK curriculum to ensure that every child or young person with vision impairment (VI) – regardless of where s/he lives – receives an education that addresses the development and learning needs associated with his/her VI. The UK curriculum for VI education needs to acknowledge the developmental impact of blindness and partial sight and reflect the distinctive skills required by learners with vision impairment. It is proposed that the curriculum has a clear conceptual framework based on the concept of ‘access to learning/learning to access’ (McLinden Douglas, Hewett, Cobb and Ravenscroft, 2016) and an agreed set of outcomes and approach to intervention that guides professional practice in teaching and habilitation from early years through to higher education and/or vocational training. While the focus of this discussion paper will be on the ‘learning to access’ element of the model (i.e. those VI specific skills which are taught by specialists), it is important to acknowledge that there is also a role for ***all*** education providers to enable ‘access to learning’ for children and young people with VI by making ‘reasonable adjustments’ to the learning environment.

At present there are several specialist curricula and outcomes frameworks for children and young people with VI being used in the UK and internationally. Not surprisingly, given what is known about the developmental impact of blindness and partial sight, there is considerable similarity and overlap between these frameworks and their outcomes. However, having a range of curricula and outcomes frameworks (six are currently being used in England alone) can lead to a lack of clarity about what should be taught, when and by whom.

We know from the research evidence that children and young people who have access to the key elements of these curricula are much more likely than those who don’t, to achieve better long term outcomes in terms of making a successful transition to independent adulthood. The importance of a specialist curriculum is therefore supported by the vision impairment education literature, and access to it should be seen as a right and entitlement for all children and young people with VI. Given the widening differences in education policy and terminology relating to special education and disability across the UK (for example, in England legislation and terminology relates to ‘special educational needs and disability’, in Wales ‘additional learning needs’ and in Scotland to ‘additional support needs’) having a unifying framework that enables a consistent approach to the education of children and young people with VI is particularly important.

Through this paper, we aim to start a discussion about why a specialist UK curriculum for children and young people with VI is needed, what it should look like, who should deliver it, and what should be the key outcomes.

## The population of children and young people with VI

The estimated prevalence of childhood blindness and severe vision impairment in the UK is 0.2%; at least half of all children and young people with vision impairment have additional disabilities including many with complex learning and health needs (Cumberland, Pathai, Rahi et al, 2010; Vision2020 UK, 2015). Severe VI has a substantial impact on early childhood development, with vulnerabilities in the areas of motor skills, cognition, language, social communication and attention (Sonkson and Dale, 2002; Tadic, Pring and Dale, 2008). Vision impairment continues to affect learning and social relationships throughout childhood and into adulthood (Tadic, Pring and Dale, 2010; see also Keil, Fielder and Sargent, 2016). While the majority of childhood vision impairment is evident within the first year of life (Rahi and Cable, 2003), some conditions are of later onset, or cause progressive/deteriorating sight loss which can have significant educational and psycho-social impact (Tadic, Lewando Hundt, Keeley et al, 2015). Consequently, all children and young people with VI require specialist support to promote their cognitive development, communication, social and independence skills and to enable them to access the academic curriculum, and prepare them for life after school and into adulthood.

For babies and young children specialist support and intervention should first be provided in the family home (Dale and Salt, 2007). As children move into early years settings and school, specialist support will continue to be required in both mainstream and special school settings.

## Specialist curricula and outcomes frameworks for children and young people with VI

Specialist educational support entails not only supporting children and young people with VI to access the standard academic curriculum, but also ensuring that they are taught a range of independent learning, mobility, everyday living and social skills. In the UK, responsibilities for teaching these specialist skills tend to be divided between the Qualified Teacher for Children and Young People with VI (QTVI) and the Registered Qualified Habilitation Specialist (RQHS). The latter qualification was introduced relatively recently in 2009 and practitioners in this role may, at the present time, still be called Mobility Officers, O&M Instructors, Education, Children’s or Paediatric Mobility Officers or Mobility and Independence Specialists (HabVIUK, 2018).

Through initial analysis, five specialist curricula and outcomes frameworks for children and young people with VI have been identified that are being used in the UK as a whole, at present. In England there are six, plus an additional two frameworks designed to ascertain a child’s eligibility for, and allocate levels of, specialist support. This is not a definitive list as individual local authority education services, organisations, schools and consultants have developed their own frameworks. None of the curricula or outcomes frameworks are statutory in the UK. Only two (the ‘Expanded Core Curriculum’ (ECC) and ‘Developmental Journal for Babies and Young Children with Visual Impairment’ (DJVI) which are discussed in the following section) have formal status and are widely recognised by the VI education profession both nationally and internationally. As noted in the introduction, while there is considerable similarity and overlap between these frameworks, having this number can in itself lead to a lack of clarity about what should be taught, when, and by whom. The remainder of this section describes the history and content of the identified frameworks (including the two eligibility frameworks).

#### Expanded core curriculum (formal, but not statutory, status, internationally recognised)

In the US, these skills are grouped under the heading of the ‘expanded core curriculum’ (ECC), with nine outcome areas: compensatory or access skills, sensory efficiency skills (tactile, listening skills), use of assistive technology, self determination skills, social interaction skills, recreational and leisure skills, orientation and mobility skills and concepts, independent living skills, and careers education (Hatlen,1996; Sapp and Hatlen, 2010). The ECC is known internationally within the VI specialist education field, and is:

“…*a globally recognized prerequisite to the inclusion of students with vision impairment (those who are blind or have low vision) in schools… The ECC is not seen as an optional part of a vision impaired student’s educational program but an essential part that must be taught, compensating for experiences that are typically learned incidentally by sighted children through observing role models visually (…)* [refs]. *Without training in the ECC skills, students who are vision impaired have difficulty accessing the standard core curriculum or engaging in many of the activities that are basic to their well-being* (…) [refs].” (Opie, 2018, p76)

#### UK specialist/additional curriculum (descriptive, no formal status nationally or internationally)

In the UK five key areas of a specialist or ‘additional’ curriculum have been identified. Unlike the ECC the UK additional curriculum is not a formal curriculum or framework but a description of the skills that are generally taught to pupils with VI in the UK. These are: access to literacy (including braille), low vision training, ICT, mobility and independence, and social and emotional inclusion (Douglas, McLinden, McCall, Pavey, Ware and Farrell, 2009; McLinden et al, 2016).

#### Developmental Journal (DJVI) (formal, but not statutory, status nationally – and increasingly internationally – recognised)

The UK has a separate, research based developmental framework for addressing the particular developmental vulnerabilities of babies and very young children with severe or profound vision impairment, the Developmental Journal for babies and children with VI (DJVI). The DJVI, which was designed to be used jointly by parents and their key worker, provides a structured sequential guide of expected developmental steps in young children with VI aged 0–36 months. It has five areas of development: social and emotional development, communication, language and meaning, play and learning, movement and mobility, and towards independent self-care (Dale and Salt, 2007). The release of a new edition of the DJVI is planned (UCL, 2018). This follows findings from a recent, major, UK research study (Dale, Sakkalou, O’Reilly, Springall, Sakki, Glew, Pissaridou, De Haan and Salt, 2018) which are being used to update an intervention programme that provides a systematic framework for tracking and supporting vision and development of babies and toddlers with VI, and to inform new online training for health and education professionals (HEE, 2017).

#### Learner outcomes framework (no formal status, some recognition in England and parts of Wales)

More recently, in England, a new ‘Learner Outcomes’ framework which expands the five categories in the UK additional curriculum to create eight learner outcomes has been developed (NatSIP, 2016a). This was in response to legislation and a Code of Practice that emphasises the need to provide children and young people with special educational needs and disabilities (SEND) with support that will help them achieve the best possible educational and other outcomes and prepare them effectively for adulthood (DfE, 2015). The Learner Outcomes framework, in addition to listing the eight outcome categories, explains ***why*** each outcome is important, and ***how*** it may be delivered. The eight Learner Outcome categories are: learning to access, use of equipment, independence and negotiation skills, participation, meeting others, getting around, looking after him/herself, and life after school.

### 3.1 Habilitation outcomes and frameworks

#### Steps to Independence (descriptive: research findings and recommendations)

The development of the habilitation specialist practitioner role can be traced back to the publication of findings from the ‘Steps to Independence’ research (Pavey, Douglas, McCall McLinden and Arter, 2002). The study found wide disparities in the provision of mobility and independence education across the UK, with variations in criteria for eligibility for assessment and provision, in what was being taught, and in the depth to which it was covered. The findings indicated a “*need for a mobility and independence curriculum framework with agreed structure, boundaries and vocabulary*” (p29), and this is reflected in the first of the ten recommendations arising from the research, which was that VI education services should consider adopting the key concepts and skills set out in a proposed curriculum framework as the basis underpinning their provision. The proposed framework makes a distinction between **early and foundation** mobility and independence**,** comprising body and spatial awareness and social and emotional development,and **advanced** mobility and independence comprising travel skills and independent living skills. In so doing, it places an emphasis on early intervention in order to start embedding the learning of these skills from a very young age. This is reiterated in recommendation 6, which also refers to other groups of children: “[local authority] *mobility and independence policy documents should include explicit reference to the needs of, and educational provision for, pre-school children, children undergoing transition from school to post-school, children with multiple disabilities and a visual impairment, and children from a range of cultural and religious backgrounds*” (Pavey et al, 2002, p119).

#### Quality Standards for Habilitation (no formal status but widely recognised in the UK)

The evidence from Steps to Independence provided the impetus for Mobility21, a three-year, government funded project from 2007 to 2010. One of the outcomes from the project was the development of Quality Standards for the habilitation of children and young people with VI, which set out six learning outcomes for children that habilitation services should aim to achieve. These are: the maximum degree of independent living; the maximum degree of independent travel and mobility; emotional well-being, including self confidence and self esteem; the maximum degree of social inclusion; competence in the use of any specialist habilitation tools as aids to mobility and independence; and the ability to be able to assess risks and anticipate likely areas of personal difficulty in mobility and independent living (Miller, Wall and Garner, 2011). These Quality Standards form the basis of the Registered Qualified Habilitation Specialist (RQHS) course that was set up in 2009.

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#### NatSIP Vision Impairment Specific Independence Outcomes (no formal status, England only, not widely recognised)

In England, the National Sensory Impairment Partnership NatSIP (2016b) has also produced guidance on specific independence outcomes for children and young people with VI in four broad areas: achievements in keyboarding and braille; achievements in managing support needs; achievements in mobility (travel, orientation, safety); and achievements in independent living (dressing, cooking, social skills).

Within each outcome category, specific tasks are described, against which the child or young person is assessed according to four levels of skill achievement: 0 = Skill not yet introduced; 1 = Skill introduced; 2 = Skill in progress; and 3 = Skill established. While the guidance is specific on assessment criteria for some of the outcome measures (e.g. assessing the pupil’s keyboarding skills at the end of Key Stage 1), for others it is far less so. For example, at the end of Key Stage 3, under ‘Social Skills: understanding and empathy’ the outcome is simply for the pupil to [have] ‘*understanding and empathy towards peers with different needs*’ (NatSIP, 2016, p33).

#### Guide Dogs habilitation programme (no formal status, specific to Guide Dogs practitioners in the UK)

Guide Dogs, which has a UK wide team of habilitation specialists makes use of a range of programmes and resources developed in the UK, US and Australia, and has specified skill areas detailed in its ‘Movement Matters’ habilitation programme.  For young children aged 0-5, the service is organised around the DJVI and Oregon programme and what are known as the MISE checklists (derived originally from Texas School for the Blind and Visually Impaired’s Teaching Age Appropriate Purposeful Skills (TAPS) programme) (personal communication with Mike England of Guide Dogs).

### 3.2 Eligibility assessment frameworks

In addition to the specialist curricula and outcomes frameworks previously described, NatSIP has developed two frameworks that are intended to be used by local authority VI education support services as tools to help guide decision making when allocating levels of specialist support to individual children and young people.

#### NatSIP Habilitation Eligibility Framework for Scoring Support Levels (no formal status, England only, not widely recognised)

Building upon the Quality Standards, which provide a broad set of underpinning principles for specialist education services in providing habilitation support to children and young people with VI, in England, NatSIP has developed a framework to help guide decision making when allocating such support. The focus of the framework is mobility and independent living skills and according to the guidance document, *“the criteria it uses cover the seven extended criteria as defined by the International Classification of Functioning, Disability and Health – Children and Youth Version (World Health Organization 2007)”*. These are listed as: early movement (fine and gross motor skills); sensory development and functioning (hearing, vision, touch, taste, smell, proprioception, kinaesthetic, vestibular, haptic); concepts (body, spatial and environmental awareness); social and communication skills (including keeping safe); independent living skills (organization skills, personal hygiene, money, dressing); orientation; and general mobility (NatSIP, 2016c. p10). For each of the seven criteria, the child is scored according to a professional judgement about his/her level of need. This is described in very general terms, with the scoring ranging from a) *The learner has age appropriate* [specified skills or understanding] (zero score), to f) *The learner requires a structured longer-term programme of assessed interventions to develop* [specified skills or concepts]*, appropriate to age and ability, delivered and monitored by an RQHS (in conjunction with other key professionals**), reinforced by the family* (a score of 10).

#### NatSIP Eligibility Framework for Scoring Support Levels (no formal status, widely recognised in England and much of Wales)

NatSIP has also developed an eligibility framework to assist local authority sensory services in the decision making process when allocating levels of support to children and young people with VI. Similar frameworks have been developed for hearing impairment (HI) and multi-sensory impairment (MSI). NatSIP emphasises that although the framework is, “*designed to provide the basis for a fair allocation of available resources,* ***it relies on professional judgement and should only be used as part of a full assessment by a qualified specialist SI teacher***” (NatSIP, 2017, p4). The framework has ten criteria: degree of VI – distance; degree of VI – near; additional factors relating to VI (e.g. whether recent onset, fluctuating condition); impact of the VI on language and communication development and on access to learning and the curriculum (particularly English, mathematics and science); development of habilitation skills; training and mentoring requirement; transition support (i.e. change of placement); support for effective use of specialist equipment by learner and key staff; physical learning environment; impact of the child or young person’s (CYP’s) VI on personal, social and emotional learning; additional factors relating to family support (e.g. acceptance of VI; family speaks English as an additional language; LA as corporate parent); and multi-agency liaison/role (including safeguarding).

Scoring for the criteria relating to the child’s vision uses standard visual acuity and reading format measures. For the other eight criteria, the child is scored according to a professional judgement about the impact of the VI on the criterion concerned, and/or level of need of the child and those supporting him/her. As with the habilitation framework, the descriptions are given in quite general terms. Scores can range from 0 to 10 in relation to the particular criterion. When added together the total score (maximum of 100) is then translated into a category of support, which is primarily expressed in number of VI service visits according to a support allocation matrix.

### 3.3 Summary of specialist curricula and outcomes frameworks

To summarise therefore, across the UK there is a multiplicity of outcomes and frameworks for children and young people with VI, but no consensus on which to use or how to use them. To illustrate this point, ~~a~~s can be seen from the table in Appendix A, there is considerable overlap in the outcomes that each curriculum/framework aims to achieve for children and young people with VI, although some of the outcomes do not directly map onto each other.

This issue is discussed further in section 6, which proposes a new model for specialist VI intervention in the UK.

## Why are these outcomes important?

As McLinden et al (2016) have observed, regardless of the terminology used the notion of an ‘additional’ or ‘expanded’ curriculum is clearly linked with the broad notion of independence. In both the US and the UK, better long term outcomes have been found in terms of successful transition to independent adulthood for young people with VI who received good instruction while at school in skills that enabled them to function independently, compared to those whose support continued to be provided to them directly (Sapp and Hatlen, 2010; Capella McDonnall, 2011; Wolffe and Kelly, 2011). This is known as the ‘access to learning/learning to access’ model (Douglas and Hewett, 2014) which is discussed in more detail in section 6.1.

In the US, longitudinal studies have shown that young people with VI whose schooling included key aspects of the ECC (e.g. braille, assistive technology and mobility) were more likely as young adults to have ***meaningful*** outcomes, such as employment, post secondary training, and engagement in social activities (Wolffe and Kelly, 2011). The authors also found significant relationships between the use of assistive technology and young people’s social skills and social interaction, suggesting that its use enhances social interactions: “…*there were significant relationships between being invited to social activities with friends and both knowing how to use and using a computer for homework and school assignments, for playing games, for accessing the Internet, for e-mail or instant messaging, and for taking part in chat rooms. Assistive technology was integral to these relationships…to [enable young people to] access computers. These findings are notable because they expand on the relationships that were already established by this study that related the use of assistive technology to increased performance in several other areas of the ECC that were also indicative of successful employment and post secondary training outcomes*” (Wolffe and Kelly, 2011, p348)*.* An analysis of longitudinal study data, Capella McDonnall (2011) found six factors that predicted whether a young person with VI would be in employment. These were: early work experience, number of work experiences, having a post secondary educational qualification, independent travel skills, and good peer social skills. Having difficulties with transport made it less likely that they would be in employment. The authors suggested that one benefit of multiple work experiences was that this increased and strengthened young people’s social networks making it more likely they would hear about job opportunities.

Similar findings have been obtained in the UK, where important insights about the longer term impact of educational policy and practice have been obtained through a longitudinal study of around 80 young people with VI as they have made the transition from school and moved into early adulthood (Hewett, Douglas and Keil 2015, 2017). Study participants, reflecting on their experiences of school, identified a number of ways in which support could have been improved, such as: more training to develop their independent living skills, more opportunities to learn to self-advocate, better support in lessons, better preparation for independent learning and development of independent study skills, better inclusive practice in schools, and more practical support for making the transition into a new setting (Hewett et al, 2017).

In developing the Learner Outcomes framework (NatSIP, 2016) the eight outcome categories were used to consider how young people with VI assessed, in retrospect, the support they had received at school and the extent to which it had prepared them for the transition to adult life. These were the young people who were consulted for the original learner outcomes project, and the participants in the longitudinal transitions research. A common theme running through these young people’s reflections is that there are important benefits to acquiring independent learning, living and mobility skills from an early age. Skills learnt from an early age become embedded, younger children are perhaps less self- conscious than adolescents, and there are fewer demands from the academic curriculum. The importance of understanding their own sight condition and support needs, and having the skills to self advocate was also apparent. Not surprisingly, being made to feel different was also an issue for many of the young people, and one of the barriers to inclusion was having a teaching assistant (TA) with them all the time in class.

The following quotes taken from Keil, Hewett, Douglas, Cobb and Clery (2018) help to illustrate these points:

*“I think all in all I was supported really well in school…and I did have a teaching assistant in some classes, but...they would...keep their distance, so you knew that they were there for you if needed them, but they weren’t kind of in your face, which is good.”*

*“Most of the time because I had a learning support assistant with me, I always seemed to feel like the one who stuck out”*

*“…I don’t really remember learning [to use assistive technology] because it’s been so long…But I think that’s a good thing…so when school actually got important around GCSEs, I wasn’t struggling with technology because I had been doing it for so long. I think it’s definitely helped me, because I have never had to worry about it, because I learnt it from such a young age.”*

*“[Specialist teacher] was very good at helping me to organise what I wanted to say to my teachers – to prepare for meetings with teachers, make sure I had precise questions, how to organise my thoughts.”*

*“[Mobility training]…was very helpful, it boosted my confidence, even now when I don’t know where I am going I do feel more confident because I know I can do it if I concentrate.”*

*“…I got [mobility training] quite late…Most other children had it from primary school onwards. I don’t know why I didn’t get it earlier…I just wish I’d had it sooner, I would have felt more comfortable travelling independently. I’m still a bit on edge, though it’s getting better.”*

*“…I was 16 and…I could make myself a cup of tea and that was about it!”*

*“It frustrates me that I am 19 and I don’t know how to cook or clean. I got to know the washing machine but that’s because it’s three buttons and I memorised which buttons to press.”*

We can see, therefore, that this is not simply an academic discussion about abstract theory – ‘learning to access’ has real implications in terms of outcomes for children and young people with VI, both in their everyday lives and their future prospects. It is notable that analysis of the Labour Force Survey (LFS) has found that the employment rates for young people with VI aged 16-25 in the UK are lower than those of their age peers (25.6% vs 54.0%), and the difference is not accounted for by the higher proportion of VI students in education. Overall, in 2015 only 62% of young people with VI aged 16-25 were in education or employment compared with 80% of the general population of 16-25 year olds (Hewett, 2016). It is worth noting that the young people identified as VI for the LFS analysis were those whose ***main*** long standing health problem or disability was a seeing difficulty, and is therefore likely to exclude young people whose VI was in addition to other complex needs or disabilities. In essence, children and young people with VI are being let down by an education system which fails to understand and prioritise their true needs.

## Problems and challenges

Despite all the evidence supporting the need for a specialist VI curriculum with specified outcomes, there is evidence that in England, where mainstream schools are judged on how well their pupils attain academically, provision for pupils with VI is at increased risk of being focused on short term benefits such as ensuring that they have their learning materials in accessible formats, rather than taking a longer term perspective and teaching them the skills they need to become independent learners. According to feedback from specialist teaching services, finding a way to fit the additional curriculum, including mobility and everyday living skills, into the school day – especially at secondary school level, which is dominated by the academic timetable – presents another challenge. This runs counter to the statement in the DfE National Curriculum framework that, “*The national curriculum is just one element in the education of every child. There is time and space in the school day and in each week, term and year to range beyond the national curriculum* specifications” (DfE, 2014, para 3.2).

The situation is not helped by the fact that the majority of TAs who provide in-class support for pupils with VI are recruited and employed directly by schools, and specialist education services may have little control over their training and deployment (Keil, 2016). This is a cause for concern as evidence relating to other SEN groups has found that the way TAs are deployed in schools impacts on pupils’ progress, independent learning and inclusion (Blatchford, Russell and Webster, 2012; Radford, Blatchford and Webster, 2011; Webster, Blatchford and Russell, 2012). Examples of TA support that leads to negative outcomes for pupils includes asking lower quality questions and supplying answers, which have been found to have a negative impact on pupils’ independent learning (Blatchford et al, 2012, Radford et al, 2012, Webster et al, 2012), and reducing interactions between the pupil and their teacher and classmates, affecting both learning and inclusion (Webster and Blatchford, 2013; see also Radford, Bosanquet, Webster and Blatchford, 2015). These findings have particular significance for pupils with VI who are at risk of being ‘over-supported’ if the role and training of TAs supporting them is organised around an ‘access to learning’ rather than ‘learning to access’ approach. In addition, having a vision impairment makes social interaction difficult and if support from a TA acts as a barrier to interactions between a pupil with VI and his or her peers this will be to the detriment of inclusion. Yet as guidance on how TAs can work effectively with pupils with VI makes clear, the TA role is to: raise the achievement of blind and partially sighted pupils narrowing any attainment gap with other children; enable the inclusion of blind and partially sighted pupils in school activities; and encourage independent learning (NatSIP, 2012, p5).

Pressures from the academic curriculum can also restrict access to habilitation support. Pavey et al (2002) observed that competition for space in crowded timetables often meant withdrawing pupils from (non-academic subject) lessons, or causing them to miss their break times in order to provide mobility training. “*It seems ironic that some of the lessons (and social times) which provide opportunities for including mobility and independence in mainstream education are sacrificed, even if for well intentioned reasons. For example, break times are important opportunities for children to socialise and interact with peers, and food technology may give opportunities to cover some aspects of independent living skills”*(Pavey et al, 2002, p70).

The nature of habilitation support provided can also be highly variable across schools and LAs. In a Freedom of Information (FOI) request sent to all 152 local authorities in England in 2015, a ‘*patchwork of habilitation provision’* was found, with the percentage of children and young people who had received habilitation in the past six months ranging from 64% in some areas to only 2% in others. The study also found that some LAs did not fully understand the concept of habilitation and the range of everyday living skills that it covers, tending instead to think of it in terms of mobility training, such as learning the route to and from school. Some local authority officials failed to grasp the concept of mobility entirely, confusing it with provision of transport to school, as this quote from the report illustrates: *“…a lot of the young people in our area are taken to and from school so there has been the argument that this is providing mobility…*”.(BCUK, 2016, pp12/13). These findings echo some of the findings from the Steps to Independence study 14 years earlier, which had observed that: “*different providers support different areas of the curriculum – e.g. many focus upon aspects of travel, but less upon independent living skills. Similarly, there also appears to be variation in the depth with which a given curriculum area is covered…*” (Pavey et al, 2002, p29).

Similar issues have been found outside the UK. In Australia, findings from case studies of seven young people with VI led to the observation that: “*The impact of poor delivery of the ECC on student well-being is highlighted by the many heartfelt comments made by the participants regarding their sense of isolation, of not belonging …It was apparent that participants were unable to be strong advocates for themselves…”* Opie (2018, p179).

In their review of how the ECC was both perceived and implemented by specialist teachers in the USA, Sapp and Hatlen (2010) observed that although teachers regarded the ECC as critical for students’ success, in everyday practice they tended to spend most of their time concentrating on the academic curriculum rather than teaching the ‘essential skills’ of the ECC. Training courses were not equipping teachers with the in-depth skills and knowledge needed to teach the ECC. For example: “*It is not enough for teachers to know that students with visual impairments may have deficits in social skills: they must know how to assess their students’ social skills and provide targeted instruction for the areas of deficit*” (Sapp and Hatlen, 2010, p343).

In relation to the TA role, McKenzie and Lewis (2008) found that many of the ‘paraprofessionals’ (i.e. TAs/support staff) in their study said that they needed more training in various aspects of the ECC. Of concern was the finding that over a third of paraprofessionals were providing direct instruction in skills in the ECC to students with VI. Possible explanations were: a lack of clarification about the roles of specialist teachers and paraeducators causing a blurring of the lines between direct teaching and teaching support; teachers employed on a peripatetic basis delegating important teaching tasks to paraeducators who spent more direct time with students; and the *“current system-wide emphasis on meeting state academic standards may persuade the teachers that their most important duty is to support students’ academic success, and, as a consequence, they assign other instructional duties to paraprofessionals*” (McKenzie and Lewis, 2008 p468).

## A new model for specialist intervention

It is evident that the current approach to educational provision for children and young people with VI is not working. Many of the problems appear to be the unforeseen consequences of the introduction of a succession of national government policies which have led to a fragmented, ‘postcode lottery’ of provision across England and the UK (e.g. see Keil, 2016). The situation is not helped by the fact that – as discussed in section 3 – a number of specialist curricula and frameworks have been developed, none of which has any statutory status.

There is an urgent need to bring together these components/outcomes into a single, UK specialist curriculum under a unifying, conceptual framework.

It is essential that this curriculum is appropriate for all children and young people from 0-25, and that specialist support is provided in a range of settings starting, for early years children, in the family home, where supporting parents/carers to care for, and play with, their child can play a significant role in facilitating the child’s development. This point is made clearly in the Quality Standards: “*Starting a habilitation programme early in life will enable good practice to become established from the outset and avoid the development of bad habits or practice which would then need to be modified at a later stage…It is particularly important at this stage, when the child is mainly in the home environment, that the significant role of parents or carers is fully acknowledged. In this regard all work should be carried out in partnership with parents/carers…*” (Miller et al, 2011, p16). Developing a new unified curriculum will clearly involve drawing upon components of existing frameworks discussed earlier in this paper (see also appendix A). There is also scope for developing new ones. For example, in a project currently underway in Gwent in Wales (see Hughes, 2018) two additional outcomes to the eight Learner Outcomes are being suggested. These are: transition (i.e. into new settings at all age phases), and wellbeing. The argument for adding wellbeing to the eight learner outcomes is the ‘fit’ with existing legislation. In Wales, wellbeing is an integral part of the new Additional Support Needs (ALN) legislation, while in Scotland wellbeing indicators (SHANARRI) are contained within legislation around Getting it Right for Every Child (GIRFEC). In England, while the SEND Code of Practice does not have specific wellbeing indicators, para 1.25 states that education providers should, “…*promote positive outcomes in the wider areas of personal and social development*….” (DfE, 2015, p25)

### 6.1 Access to learning/learning to access: a conceptual framework

McLinden et al (2016) propose that while the literature makes a strong case for a distinction between a ‘core’ (academic) and ‘additional’ or ‘expanded’ curriculum, it is important to recognise that the ‘core’ and ‘additional’ curricula are not completely independent of each other, but rather, they overlap and intertwine. Indeed, the skills involved in the specialist, ‘additional’ or ‘expanded’ curriculum are fundamental to being able to access the core academic curriculum. As a way of conceptualising this relationship, McLinden et al note that a dual view of ‘access’ has been developed, which makes a distinction between ‘access to learning’ and ‘learning to access’ (Douglas, McLinden, Farrell, Ware, McCall and Pavey, 2011; McLinden and Douglas, 2014). Drawing upon the concept of ‘***progressive mutual accommodation***’ taken from Bronfenbrenner’s Ecological Systems Theory (Bronfenbrenner, 1979, 2005), the dual access model describes a progression whereby over time, the emphasis gradually shifts from support being provided directly to the child/young person, to their acquiring the skills enabling them to function independently. Table 1 gives examples of the strategies that might be used to support a child or young person in two areas of learning. A key role of the VI specialist is to manage this process by ensuring that the environment is structured to promote learning, as well as to ensure that appropriate skills are taught McLinden et al, 2016).

**Table 1. Strategies used to support ‘access to learning’ and ‘learning to access’**

|  |  |  |
| --- | --- | --- |
| **Curriculum area** | **‘Access to learning’ support strategies** | **‘Learning to access’ support strategies** |
| Reading and writing | Provides curriculum materials in child’s preferred format | Teaches the skills required to access the curriculum through the use of assistive technology |
| Getting around | Trains peers, teachers, and other staff in sighted guide techniques | Teaches mobility and orientation skills needed to learn to navigate a new environment |

A broad conceptual framework to underpin a specialist VI curriculum could be provided by the access to learning / learning to access model. McLinden (2018) has described how this approach can promote an ethos of empowerment for the child/young person, which in term should support their independence: “*Promoting an ‘ethos of empowerment’ should ultimately support the development of longer term independence outcomes that ensure children and young people with vision impairment can exert their ‘power’ through expressing* ***personal agency*** *in order to influence their environments and ultimately help to shape their own future*” (McLinden, 2018, slide 3). For a more in-depth exploration of ***personal agency*** in relation to the transition of young people with VI into higher education, see Hewett, Douglas, McLinden and Keil (2018).

Integral to the model is the concept of inter-dependence, and while the emphasis in this paper is on the role of specialists in teaching the child ‘learning to access’ skills, the importance of also providing an appropriate and accessible environment (enabling ‘access to learning’) should not be forgotten. In Britain, this is enshrined in legislation under the Equality Act (2010) which requires education providers to make ‘reasonable adjustments’ to the learning environment. Reasonable adjustments for a pupil with VI will vary according to individual circumstances, but could include providing reading materials in braille for a blind pupil or changing the lighting in a classroom for a partially sighted pupil.

### 6.2 Integrating the ‘specialist curriculum’ with the academic curriculum

There are several examples in the literature, of how elements of the additional curriculum can be integrated into the general academic curriculum, with pre-teaching in certain skills and concepts provided by the VI specialist and reinforced or embedded through the general curriculum. Examples provided by Sapp and Hatlen (2010, p344) include: “working in groups (social skills), learning about different jobs (career education), reading a map (O&M), and managing money (independent living skills).”

Pavey et al (2002) describe ways in which many of the VI education services in their study tried to incorporate independent living skills within the school day without having to remove the child from any classes. Examples include teaching the child how to dress/undress before and after PE lessons, teaching eating skills at lunch breaks, and food preparation skills (such as making tea, toast, using a microwave) within food technology classes. This approach enables the habilitation provision to be, “*explicitly related to, reinforced by, and overlapped with the broader school curriculum”,* which, as the authors observe, “*will make mobility and independence relevant to the child…”*, as in this example: “*The Mobility & Rehab Officer tries to relate mobility lessons to activities that the child is doing in other subjects – like Geography (looking at Africa – so went to place where they could touch an animal, etc), and Maths (handling money*)” (Pavey et al, 2002, pp59/60).

On a similar note, Davis and Hopwood (2002) describe inclusive practice they had witnessed in primary school settings, which provided opportunities for the child to use the skills he or she was developing, “*out of class, in the main classroom or more widely in the school. Sending the child with a message for another teacher elsewhere in the school, for example, or sending him or her to collect the register could reinforce mobility and orientation skills*”.

In addition to these examples from the literature, ways of integrating the specialist with the mainstream curriculum have been practised in schools for many years but it is only recently that VI services and training providers in the UK have started to formally develop schemes and guidance for doing so. For example, in Wales Gwent Sensory and Communication Support Service has been exploring ways of integrating the 8 learner outcomes with the standard school curriculum. This has included looking explicitly at how the outcomes relate to the Wales Foundation Phase Framework (Beta, 2015) and the Digital Competence Framework (Learning Wales, 2018). Other examples of recent initiatives are in Doncaster, Sheffield, Birmingham and Norfolk, and by an independent training provider Positive Eye, which includes materials for pupils with complex needs (<https://www.positiveeye.co.uk/>). These are exciting initiatives, but there is scope for further work in drawing together and evaluating all these different approaches. As it is less clear how outcomes such as self advocacy and negotiation skills, social interaction skills, meeting others, and life after school can be integrated and who takes responsibility for delivering them, further work in this aspect of the specialist curriculum is also needed.

It is also important to note that while it is helpful to be able to demonstrate ways in which the VI specialist curriculum can be integrated with existing, mainstream curricula, this must not be allowed to undermine the importance of the VI specialist curriculum as a discrete entity. Access to a specialist curriculum and discrete teaching in these skills should be seen as a ***right*** for children and young people with VI that should be protected, and not just something to be squeezed into the standard education curriculum.

### Allocating specialist support

If we agree that access to the VI specialist curriculum should be seen as a right for all children and young people with VI, then an important consideration is the decision making process for allocating this support. The NatSIP eligibility framework discussed in section 3.2 was developed to promote good practice in the allocation of support, but there is evidence that at service level it has a number of limitations. In a survey of all LAs in England, Keil (2016) found considerable variation in LAs’ use of the eligibility framework, resulting in a lack of standardisation across the country. The findings showed that while most LAs referred to the framework to determine a child’s eligibility for VI service provision or to allocate levels of support, this was often in conjunction with other criteria and/or services differed in the minimum score used to trigger entitlement to VI service support. A minority appeared to using the framework as a way to justify rationing of VI service provision. Several used a banding system or locally developed criteria in preference to the NatSIP framework.

A meeting convened by VIEW in late 2017, which brought together eight VI managers/ heads of VI/sensory services to explore the way in which VIEW might support heads of service in managing their caseloads, gathered evidence suggesting that, “*although the Eligibility Framework is a useful tool in helping heads of service/VI managers manage their caseloads it does not always represent the everyday experiences of managers and their teams on the ground, supporting children and young people with a vision impairment due to conflicts and challenges such as staff training, staffing levels, funding issues, travel times and volume of work*” (Ellis, 2018, p2).

Another weakness of the NatSIP eligibility framework is that while it (rightly) emphasises the importance of professional judgement, stating clearly that it “***should not be interpreted and applied as a rigid set of criteria***”(NatSIP, 2017, p4) no guidance is provided to inform such judgement. In an effort to address this problem, VIEW commissioned a review to compare the NatSIP eligibility and VI learner outcomes frameworks. The review found the eligibility framework easy to use, with the ten criteria setting out some of the key issues that must be taken into consideration when planning support for a child with VI. The framework was also seen as advantageous over the VI learner outcomes in that it provides an indication of the level of support required. However, disadvantages were that a slightly reduced or increased score could move a child into a different category of support which may not reflect the reality of his/her experiences; linked to this finding, the criteria themselves are not nuanced enough to “*always allow for a deep understanding of the [child or young person’s] wishes, needs and experience”*, and while the framework indicates the level of support likely to be needed it says nothing about the ***nature*** of that support. The report concluded with four recommendations for further empirical work building on the findings of the review, including:

*“Lastly and most importantly, the production of a tool which brings together the advantages of the eligibility framework (simplicity, ease of use, caseload management) with a focus on outcomes as identified by the VI learner framework but with inbuilt measures of success in order to focus thinking, learning, and behaviour*” (Ellis, 2018, p18).

Notably, work is well underway by the Gwent Sensory and Communication Support Service in Wales to develop an Intervention Tool, which uses the eight learner outcomes, plus two additional outcomes, as a framework for heads of VI services to allocate caseloads. A programme of intervention towards VI specific outcomes is devised by a QTVI or Habilitation Specialist. If an outcome is long term, it is broken down into a series of interventions with review points by the specialist at set points after each short term intervention/step. The skill before and after intervention is scored demonstrating progress as skills develop. A strength of this approach is that it puts the child/young person at the centre and assesses the level of specialist support needed to enable him/her to achieve each outcome. By focusing on the learner outcomes, it is consistent with the concept of a specialist VI curriculum. The next stage in the development of the Intervention Tool will be to evaluate it as it is piloted within the Gwent service.

### Who does what?

As was seen earlier in this discussion paper, the habilitation specialist has a key role to play in the delivery of the specialist curriculum, and in addition to the Quality Standards for Habilitation, NatSIP has developed a separate set of VI independence outcomes and a habilitation eligibility framework. Likewise, for babies and early years children there is the DJVI with specific, research based VI outcomes. While the central premise of this paper is that there is a need for a single, UK specialist VI curriculum with clearly defined outcomes, in developing this curriculum it will be important to identify the relative roles of the key specialists – i.e. the QTVI and habilitation specialist - in delivering the different elements of the curriculum and to clearly differentiate between what elements are delivered directly by the VI specialist, and what can be undertaken by others, such as a TA or class teacher, under the direction of the allocated specialist. As noted in section 6.1, a focus on the role of the VI specialist in teaching ‘learning to access’ skills does not exempt mainstream teachers and education providers from their responsibility to provide an accessible learning environment. From this perspective, part of the role of the QTVI and habilitation specialist may be to provide advice and guidance on how to make the necessary adjustments.

Another consideration is specialist training and professional development. As previously noted in section 5 of this paper, Sapp and Hatlen (2010) emphasised that all specialist teachers of learners with VI need to be proficient in the skills and knowledge that are related to each area of the ECC. We need to consider whether there are currently any gaps in specialist knowledge and training for staff in the UK. Teaching social skills is one particular area where there may be both a lack of specialist training, and a lack of clarity about whose responsibility it is to deliver this aspect of the curriculum. For babies and toddlers with VI, arguably, all practitioners providing support need to undergo specialist early years training such as the Health Education England (HEE) training that is based on findings from the Optimum VI research. These are issues that may be explored further in the forthcoming (early 2019) review in England of the mandatory qualification (MQ) for teachers of children and young people with VI.

Training and supervision of TAs may be seen as a particular weakness in the current model of VI education provision, especially in England where, as discussed in section 5, the majority are now employed directly by schools rather than by VI services. Yet there is no national standard governing the work of TAs who support the learning of children and young people with VI in any part of the UK. While there is published guidance on the effective deployment of TAs supporting pupils with VI (NatSIP, 2012) this has no statutory status, and there is no clearly defined career structure, qualification level or training pathway for them. By comparison, there is much greater clarity about the role of the h**abilitation assistant** (HA), who *“works under the direct supervision and responsibility of the [habilitation specialist] HS. HAs support individual children and young people* to practice *their habilitation skills and strategies: this may be inside and/or outside of school or other educational settings. They also contribute to the monitoring of habilitation progress* (HabVIUK). Similarly, in Health, the role of assistant occupational therapists and physiotherapists for example, is clearly to work ***under the supervision/guidance of a qualified therapist*** (e.g. <https://www.rcot.co.uk/about-occupational-therapy/become-an-occupational-therapist/become-ot-support-worker> and <https://www.myworldofwork.co.uk/my-career-options/job-profiles/physiotherapy-assistant>). An important part of developing a specialist VI curriculum must therefore be to clarify the roles and responsibilities of those professionals who are involved in delivering it.

### The role of specialist education settings for learners with VI

The discussion so far has focused primarily on access to the specialist VI curriculum for children and young people in mainstream and special school settings where specialist support is provided by the local authority VI service. It is important though, to consider where the VI special school or college fits into the picture as this type of provision is a key element of the overall education ‘offer’. Aside however, from their role as a direct provider of education for those pupils for whom non VI-specialist settings in mainstream or special schools has proved unsatisfactory, there is the potential for the VI special schools to provide leadership in developing certain aspects of both the specialist ***and*** academic curricula. While it is acknowledged that there are likely to be fewer/different challenges to delivering a specialist VI curriculum in the mainstream school context, VI special schools can still have much to offer to the wider sector as well as to the individual learners to whom they provide direct teaching and support. This applies to VI special schools designated for pupils with VI with, and without, additional complex needs.

## Policy context

In terms of the policy context in, the outcomes of the specialist curriculum are consistent with the principles underpinning key legislation in England, Scotland and Wales. These include the Children and Families Act 2014 and the Special Educational Needs and Disability (SEND) Code of Practice in England, the Supporting Children's Learning: Code of Practice (revised 2010) and Children and Young People (Scotland) Act 2014 in Scotland, and in Wales the Additional Learning Needs (ALN) and Education Tribunal (Wales) Act 2018. For example, in England the SEND Code of Practice emphasises facilitating development as well as longer term independence outcomes in preparation for adulthood. One of the principles underpinning the Code of Practice is to:

*“…support the child or young person, and the child’s parents, in order to facilitate the development of the child or young person and to help them achieve the best possible educational and other outcomes, preparing them effectively for adulthood… [in order to support] successful preparation for adulthood, including independent living and employment*.” (DfE, 2015, pp19,20)

While the long term aim is to provide the child/young person with the skills needed for a transition into independent adulthood, it is important that the specialist curriculum is recognised as covering ***all*** ages from 0-25. As noted in 6.2, in Wales the Gwent VI service is looking at how the eight Learner Outcomes link to the Wales Foundation Phase Framework, which is the statutory curriculum for all 3 to 7-year olds in Wales, and the same can be done in relation to early years outcomes frameworks in England and Scotland.

Linking the specialist curriculum to government policies may be helpful but this is also about ***equality*** and ***equity***. For this reason, it is argued that the new model for specialist intervention should be a ***statutory*** part of education provision for children and young people with VI in the UK.

## What’s in a name?

In the USA and internationally – including in the UK – the term ‘expanded core curriculum’ (ECC) is widely recognised. In the UK, the term the ‘UK additional curriculum’ was used to describe the five key areas of a specialist or ‘additional’ curriculum which may be seen as a UK equivalent to the ECC. There are problems with both of these titles: some argue that the word ‘additional’ implies something that is ‘added on’ and by implication therefore, takes lower priority to what is considered ‘core’, while the ‘expanded core curriculum’ makes no direct reference to vision impairment, and is unlikely to mean much to people who are not specialists in VI education. It also fails to acknowledge the specialist skills and knowledge required to teach this curriculum. In one VI service, the term ‘extended core curriculum’ has been adopted, as, “… *the word ‘additional’ frightened school staff as they haven’t the time to deliver the standard curriculum let alone an additional one. Presenting it as ‘expanded’, or ‘extended’ in the case of our service meant everyone was focused on integrating the [pupil’s] development of the ECC into the standard curriculum. We decided on ‘Extended Core Curriculum’ but this clearly has the same implications as ‘expanded’”* (personal communication)*.*

An alternative title that has been suggested – and which has been used throughout this discussion paper - is ‘specialist VI curriculum’. While some people object to ‘specialist VI’ on the grounds that this marginalises learners with VI, others have argued that the specialist element of the provision ***must*** be emphasised in order to get its importance across to managers and officials who have no knowledge of VI education, but who nevertheless make budgetary decisions about resource allocation.

There are yet others who argue that rather than a ‘curriculum’, we should be arguing for a new UK ‘framework’ for VI education, setting out the key outcomes but leaving it to providers to decide how best to achieve them with individual learners. Getting the right balance between being too prescriptive and too vague is clearly essential in ensuring that this new initiative has a meaningful impact on the children and young people it is designed to support.

Whatever the final title, it is essential that the new curriculum reflects the fact that childhood VI requires specialist provision that supports development and learning from birth to early adulthood. It should also reflect the diversity of the VI child population in terms of needs and abilities, with an emphasis on outcomes that are framed in the language of independence and empowerment. There is clearly the need for a sector wide discussion to ensure that the title accurately describes this new, UK model of support and provides a common language that speaks to educators across all four devolved nations, in whatever setting they work.

## Conclusion

The aim of this paper was to start a discussion about the need for a specialist VI curriculum that addresses the development and learning needs associated with blindness and partial sight. The ‘access to learning / learning to access’ model provides a clear conceptual framework for the new curriculum. Existing international and UK curricula provide a comprehensive range of outcome categories, which should now be brought together under a single, UK specialist curriculum framework.

Secondly, there is a need to provide greater clarity about professional roles. This will require identifying which elements of the curriculum should be delivered directly by the QTVI, which are the responsibility of the habilitation specialist, and what aspects can be provided by others (such as TAs) under the supervision/guidance of a qualified practitioner. The development of an associated training pathway and qualification system for TAs should also be seen as a key part of this stage.

The curriculum/framework should be operationalised by drawing together and evaluating the excellent work that is already being done in individual VI services across the UK in: developing specialist VI curriculum content; finding ways to integrate it with the standard academic curriculum; and constructing intervention tools that link pupil progress towards agreed outcomes to allocation of specialist support. The final product would be a set of resources available to all VI services and VI special schools across the UK to select from, according to individual needs and circumstances.

Finally, it is proposed that in the interests of equity and equality, and to ensure that ***every*** child and young person with VI – regardless of where s/he lives – receives an education that addresses the development and learning needs associated with his/her VI, the VI sector works with government to ensure that the new curriculum is given statutory status.

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