

# A Rapid Evidence Assessment of the effectiveness of educational interventions to support children and young people with multi-sensory impairment

Hodges, Elizabeth; Ellis, Liz; Douglas, Graeme; Hewett, Rachel; McLinden, Mike; Terlektsi, Emmanouela; Wootten, Angela; Ware, Jean; Williams, Lora

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## Document Version

Publisher's PDF, also known as Version of record

## Citation for published version (Harvard):

Hodges, E, Ellis, L, Douglas, G, Hewett, R, McLinden, M, Terlektsi, E, Wootten, A, Ware, J & Williams, L 2019, *A Rapid Evidence Assessment of the effectiveness of educational interventions to support children and young people with multi-sensory impairment*. Welsh Assembly Government.  
<<https://gov.wales/sites/default/files/statistics-and-research/2019-11/effectiveness-educational-interventions-support-children-young-people-multi-sensory-impairment.pdf>>

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SOCIAL RESEARCH NUMBER:

51/2019

PUBLICATION DATE:

14/11/2019

# A Rapid Evidence Assessment of the effectiveness of educational interventions to support children and young people with multi-sensory impairment

Mae'r ddogfen yma hefyd ar gael yn Gymraeg.

This document is also available in Welsh.

# A Rapid Evidence Assessment of the effectiveness of educational interventions to support children and young people with hearing impairment

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Full Research Report: Hodges, L; Ellis, L; Douglas, G; Hewett, R; McLinden, Terlektsi, E; Wootten, A; M; Ware, J; Williams, L,; (2019). *A Rapid Evidence Assessment of the effectiveness of educational interventions to support children and young people with multi-sensory impairment*. Cardiff: Welsh Government, GSR report number 51/2019. Available at: <https://gov.wales/effectiveness-educational-interventions-support-children-and-young-people-multi-sensory>

Views expressed in this report are those of the researcher and not necessarily those of the Welsh Government

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## Glossary

ALN	additional learning needs
BET	bodily emotional trace
BSL	British sign language
GEST	grants for education support and training
HI	hearing impairment
IDP	individual development plan
IEP	Individual education plan
JCQ	joint council for qualifications
QHS	qualified habilitation specialist
QToD	qualified teacher of the Deaf
QTVI	qualified teacher of children and young people with vision impairment
Moon	A tactile code based upon raised lines
MSI	multi-sensory impairment
NatSIP	National Sensory Impairment Partnership
PMLD	profound and multiple learning disabilities
REA	rapid evidence assessment
SLD	severe learning disabilities
TA	teaching assistant
UEB	unified English braille
VI	vision impairment

## **1. Introduction/Background**

1.1 The Welsh Government commissioned the University of Birmingham to undertake a rapid evidence assessment (REA) into the extent to which interventions to support learners affected by multi-sensory impairment are effective. The purpose of the review is to facilitate the planning and delivery of early, timely and effective interventions to support children and young people with multi-sensory impairment.

1.2 This is one of three REAs in the area of sensory impairment, which are related; the other two are:

- A Rapid Evidence Assessment of the effectiveness of educational interventions to support children and young people with vision impairment
- A Rapid Evidence Assessment of the effectiveness of educational interventions to support children and young people with hearing impairment.

All three were published by the Welsh Government in 2019.

1.3 The Additional Learning Needs and Education Tribunal (Wales) Act (the Act) received Royal Assent in January 2018. The Act introduces a new additional learning system, which has three overarching objectives:

- A unified legislative framework to support all children and young people with additional learning needs (ALN) from birth up to the age of 25, where they remain in education
- An integrated, collaborative process of assessment, planning and monitoring which facilitates early, timely and effective interventions
- A fair and transparent system for providing information and advice, and for resolving concerns and appeals.

1.4 The Act provides for a single plan – the individual development plan (IDP) – which will replace the range of statutory and non-statutory plans for learners with special educational needs or learning difficulties and/or disabilities.



- 1.5 The Act forms part of a wider package of reforms, which aim to transform the expectations, experiences and outcomes for children and young people with ALN. One key area of the transformation programme focuses on awareness raising, to facilitate those involved in the ALN system to better understand the evidence of good practice, what can be expected from interventions, the interventions most likely to be effective, and the role of professionals. This is to help inform expectations and the effective deployment of resources.
- 1.6 This report has been prepared for the Welsh Government and provides a synthesis of the findings of the REA. These findings are intended to inform the development of a document regarding evidence-based practice for practitioners and parents, to raise awareness amongst those engaging with young learners with multi-sensory impairment in educational settings about various interventions and their effectiveness.

### ***Population of children with multi-sensory impairment (deafblindness)***

#### *What is 'MSI'/deafblindness?*

- 1.7 There are many definitions and criteria in practical use for who might be included in the definition 'multi-sensory impaired' i.e. those who have both vision and hearing loss, or 'deafblind'. Different local authorities have used the term to describe different groups. However, the Department of Education and Science in 1989 outlined that deafblind children had combined vision and hearing loss and set out that they were:
- 'a heterogeneous group of children who may suffer from varying degrees of visual and hearing impairment.'
- 1.8 Quality standards in Educational Services for children and young people with sensory impairment (National Assembly for Wales, 2005) defined this group clearly as:
- 'Multi-sensory impairment or deafblindness is not defined in clinical terms but is regarded as any degree of dual-sensory impairment which has a significant adverse effect on the child or young person's ability to access education.'

1.9 The Social Services and Well Being (Wales 2014) Act regards people as deafblind if they

‘have sight and hearing impairments which in combination have a significant effect on their day to day lives.’

1.10 The Welsh Government Guidance for School Information Management (2017) defines it thus;

‘Pupils with multi-sensory impairment have a combination of visual and hearing difficulties. They are sometimes referred to as deaf blind, but may have some residual sight and/or hearing. Many also have additional disabilities but their complex needs mean that it may be difficult to ascertain their intellectual abilities’ (p12).

1.11 The terms ‘deafblind’ ‘multi-sensory impaired’ and ‘dual sensory impaired’ are frequently used interchangeably to describe people with a combined visual and hearing impairment which significantly affects their communication, mobility and orientation, and access to information. All three would, in accordance with the definitions above, include people who have some use of either vision or hearing or both, but where a combination of these impairments causes difficulties in addition and to a greater degree than that which would be expected of single sensory impairments.

#### *Causes of deafblindness and syndromes*

1.12 Multi-sensory impairment in children and young people can be, and frequently is, part of a wider spectrum of disabling conditions, including physical and medical disabilities, intellectual disability, social and emotional difficulties. However, it can also present as the sole primary disability (although it will often, of itself, cause difficulty with other areas of development). In children and young people, deafblindness can be as a result of a prenatal or perinatal injury or condition or as a result of a syndrome which results in impaired vision and hearing (congenital), or it can be acquired, either by trauma, illness or as part of a condition (acquired and/or degenerative). Sometimes a second impairment is acquired by a person who already had a single impairment, either of vision or hearing.

- 1.13 These each cause different effects and difficulties for the individual. Combinations of different degrees of visual and hearing impairment can have quite different effects which lead to quite different outcomes – e.g. for a young person who is severely sight impaired but has a moderate hearing loss to a child who is severely hearing impaired but has a moderate vision loss. There are differences in communication, experience, and understanding with people who have acquired deafblindness later, most particularly between pre-lingually and post-lingually deafblind learners. ‘Scoring’ for individuals in relation to severity is therefore not usually very helpful.
- 1.14 Deafblindness, that is, a combination of visual and hearing impairment which causes difficulty with communication, orientation and mobility, and access to information (DoH 1997, Aitken 2000), has a range of causes in the UK, including Wales. Most deafblind people have some remaining vision or hearing, though these provide a distorted picture.
- 1.15 Because of differences in definition, and counting, there is no reliable evidence for the prevalence of different causes but for example from an analysis of children on Sense caseloads (in England) (McKay 2019) for most deafblind learners the causes are not known (or not recorded); but the next most common causes were CHARGE syndrome, Usher syndrome, Down syndrome, prematurity, birth trauma, meningitis, Alström syndrome, and Bardet-Biedl syndrome (described in more detail below). These figures are unlikely to be definitive because it is much more likely that people with CHARGE would be referred to Sense than individuals with Down syndrome, for example. Examples of description of syndromes are as follows:
- 1.16 “CHARGE syndrome’s principal factors are with the eye, choanal atresia (when the nasal passages are blocked by bone or tissue), cranial nerve anomalies, and ear anomalies. They may have learning delay. It affects about 1 in 12,000 people in the UK” (Ellis and Hodges, 2015, p41).
- 1.17 “Alström syndrome affects the whole body, including with rod-cone retinal dystrophy, sensorineural hearing loss, obesity, insulin resistance, and type 2 diabetes mellitus, as well as a range of other issues. It is a life-limiting

disorder, which might affect 100 people in the UK“(Ellis and Hodges, 2015, p40).

- 1.18 “Usher syndrome (type 1, 2 and 3) is principally characterised by sensorineural deafness and progressive vision loss due to Retinitis Pigmentosa (RP). Initially peripheral vision loss occurs which is described as ‘tunnel vision’. The exact number of people affected is unknown but it could be as high as 1 in 7,000 people” (Ellis and Hodges, 2015, p42).
- 1.19 Hurler syndrome (mucopolysaccharidosis 1/H) is an enzyme deficiency which leads to progressive vision and hearing loss, developmental delays and difficulties with other organs (NORD 2017). It occurs approximately once every 100, 000 births (Moore et al., 2008).
- 1.20 Down syndrome is caused by an additional chromosome. While the most commonly recognised feature of Down syndrome is intellectual delay and disability, sensory impairments are common (Määttä et al., 2006) and it is likely that combined sensory impairments resulting in deafblindness are under-recognised in this population.

#### *Terminology*

- 1.21 This report uses predominantly the terminology ‘deafblind/deafblindness’ rather than multi-sensory impairment or MSI. While MSI is used in education, it is rarely if ever used in the literature in this area. The term ‘multi-sensory impaired’ is also frequently interpreted as meaning ‘having multiple disabilities including learning disability’ or confused with having a sensory processing disorder, as outlined below.

#### *Numbers and prevalence*

- 1.22 There are a number of different figures used for the incidence of multi-sensory impairment amongst children in the UK and in the countries of the UK, with different degrees of reliability.
- 1.23 School census data is frequently at odds with ‘on the ground’ data from support services, probably for the following reasons:
  - a) Schools do not understand the term ‘multi-sensory impairment’ and use it to describe students who they might consider have ‘sensory

issues' – often associated with autism, and do not use it to describe pupils with combined vision and hearing loss. This is despite guidance such as that of the Welsh Government (2017) which defines deafblind pupils.

- b) Specialist schools (e.g. for pupils with learning disabilities) record what is considered a 'primary disability' and do not include pupils who have both multi-sensory impairment and, for example, learning difficulties, or are blind, but also use hearing aids.

- 1.24 A 2010 Report from the Centre for Disability Research (Robertson and Emerson, 2010) estimated a figure of 22,000 deafblind children (0-19) across the UK, which by population could be estimated to be around 1,100 for Wales (assuming – for which there is no evidence – equivalence for Wales with the rest of the UK per head of population).
- 1.25 A figure gained by more informal questioning by Hodges of UK specialist teachers of deafblind children indicates a figure of around 1 in 4,000. This would be equivalent to roughly 232 children and young people 0-24 based on child/young people populations in Wales according to Public Health Wales Observatory (2011).

### ***Conceptual framework and targeted educational outcomes***

- 1.26 The educational history for deafblindness in the UK (and therefore Wales) is much shorter than that for vision impairment (VI) or hearing impairment (HI); it was only recognised as a specific educational difficulty in 1989 (DES, 1989). As a relative newcomer to the field of study (in terms of recognition across the world as a distinct and different disability) there is less of a developed field of conceptual understanding. Some particular features do however stand out.
- 1.27 Deafblindness in the UK is recognised as the effects of combined visual and hearing impairments on three essential elements of development and education (DoH, 1997) – these relate to difficulties with:
  - Communication
  - Access to information

- Mobility and orientation.

- 1.28 This functional definition demonstrates that deafblind children and young people have basic difficulties in learning in typical educational environments, which are nearly always predicated on accessing information through vision and hearing, or can be adapted to use one method to compensate for the other. In addition, many deafblind children work at levels significantly below their age-peers, with learning disabilities either additional to, or consequent on, their sensory impairments.
- 1.29 By definition, learners with deafblindness are also learners with hearing impairment and learners with vision impairment. Therefore to some extent all that applies to hearing impaired (HI) and vision impaired (VI) learners also applies to them. Nevertheless, there is recognition that hearing and vision impairments interact considerably such that common teaching and communication strategies adopted for either group will often not be appropriate for deafblind learners.
- 1.30 As related both to learning delay or disability, or the issues related to dual sensory impairment, many deafblind learners will need support throughout their lives. Nevertheless, for most young people with dual sensory impairment, educators will aim to develop the young person's sense of agency. That is educators aim to give them as much access to involvement with their world and the people in it as possible, and where appropriate to give them control (e.g. Murdoch et al., 2009). This will include the development of functional skills as well as formal curriculum access where this is appropriate.
- 1.31 The key thrust then of educational interventions is for educators to construct teaching approaches and learning environments which overcome the defining difficulties of communication, access to information, and mobility and orientation. Or presented a different way, educators seek appropriate ways to develop deafblind learners' ability to communicate, access information, and be mobile. Through these approaches, educators seek to maximise learner agency and independence (e.g. Aitken, 2000, Hodges, 2000, and Murdoch et al., 2009).

1.32 Recognising the centrality of establishing communication, access to information, and mobility and orientation in the environment, a distinction between ‘access to learning’ and ‘learning to access’ (e.g. McLinden and Douglas, 2014) can be used to describe educational approaches for deafblind children:

Learning to access:

- Learning to communicate
- Learning to access information
- Learning about space and learning to be mobile

Access to learning:

- Using communication to learn
- Accessing information to learn
- Movement as and for learning

1.33 While the distinction is helpful in drawing out the differences in educational approaches taken, it is important to recognise that it is the interaction between the two which is vital and provides the building blocks of education for deafblind learners:

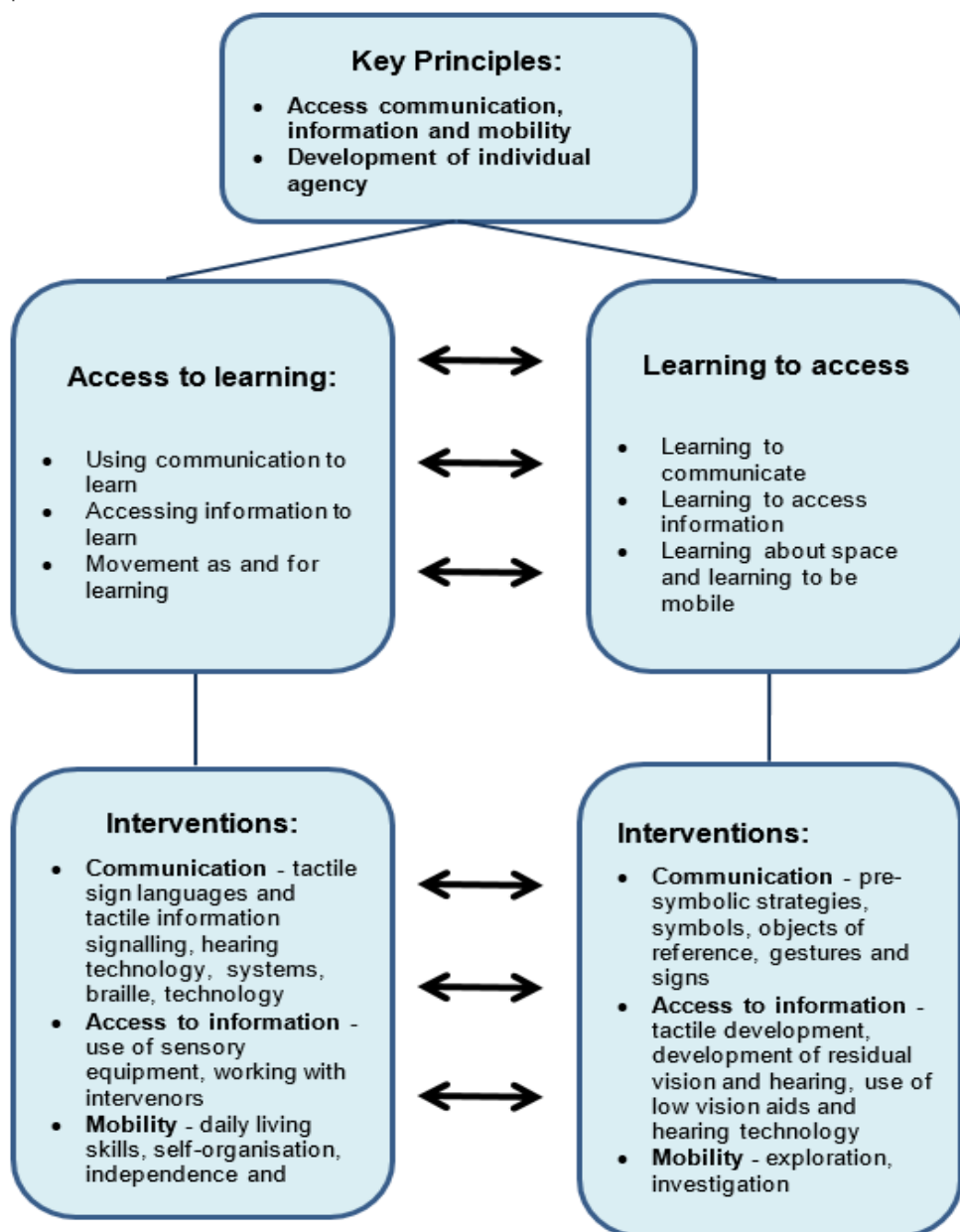
1.34 Learners need to learn to communicate, in order to communicate to learn – thus the building blocks of communication provide access to learning in other areas, which allows further learning in communication, and widening the range of learning and so on.

1.35 Learners need to find ways to access information, in order to use information to learn – learning to use and process information, through different means, likewise proceeds on parallel tracks, first finding the means of access which works for an individual, then using this to learn further skills to develop it, allowing access to more information which then allows further development of the skills to learn.

1.36 Learners need to become mobile, in order to use movement for learning – learning about their place in the world also provides access to a wider range of educational opportunities.

1.37 In many cases, the overall educational approach for a given learner will require finding possibly unique combinations of teaching strategies and drawing on remaining hearing, vision and tactile methods to support individual needs. Therefore, another key feature of educational approaches for deafblind learners is that they are centred around the individual needs of the given young person.

**Figure 1: Relationship between overarching conception in the field of deafblind education and how this links to targeted interventions and educational outcomes.**





1.38 In these terms, there are a range of more specific interventions related to each of the strategies. So interventions related to learning to communicate include pre-symbolic strategies, symbols, objects of reference, gestures and signs; while interventions related to using communication to learn include tactile sign languages and tactile information signalling, hearing technology, braille, and technology. Interventions related to access to information include tactile development, development of residual vision and hearing, use of low vision aids and hearing technology; while interventions related to using information to learn include use of sensory equipment, working with intervenors<sup>1</sup> and other support. Interventions related to learning about space and learning to be mobile include the development of concepts which enable exploration and investigation; while interventions related to movement as and for learning include daily living skills, self-organisation, independence and mobility.

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<sup>1</sup> Intervenors provide specialist support for deafblind people

## 2. Methodology

2.1 This document is a 'Rapid Evidence Assessment'<sup>2</sup> in line with the project outlined by the Welsh Government. It has followed, broadly, the trajectory of the parallel studies in vision impairment and in hearing impairment commissioned at the same time<sup>3</sup>. The methodology outlined below discusses the ways in which literature was systematically reviewed in relation to deafblindness. However, not unexpectedly, the outcomes of this review produced little evidence for 'interventions' which met the literature inclusion criteria outlined below. In order therefore, to provide a report which meets the overarching requirement of the REA – an examination of good teaching and educational support for deafblind learners – a range of other literature has been reviewed and included in the introduction and implication sections of the intervention summaries.

2.2 The design of the REA agreed with the Welsh Government is split into five stages:

- Stage 1: literature search and inclusion/exclusion criteria framework
- Stage 2: refining the search
- Stage 3: assessing the quality
- Stage 4: data extraction
- Stage 5: data synthesis/report production.

### **Stage 1: Literature search and inclusion/exclusion criteria framework**

2.3 The aim of stage 1 was to carry out searches using the databases and search terms specified in Table 1 below and to apply an inclusion/exclusion criteria framework. Following discussions in the evaluation steering group, it was noted that the specification for the REA was very broad in focus, seeking to look at interventions as a whole rather than focussing upon a specific type of intervention or targeted educational outcome (e.g. teaching reading). The REA was linked to all educational outcomes which the

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<sup>2</sup> As defined by the Government Social Research Rapid Evidence Assessment Toolkit. Available at [GSR REA Toolkit](#)

<sup>3</sup> A Rapid Evidence Assessment of the effectiveness of educational interventions to support children and young people with vision impairment

research team sought to simplify into thirteen broad educational strategies. This can be contrasted with other REAs undertaken in other disciplines which might seek evidence of the successful interventions in relation to much narrower target outcomes (for example in relation to ADHD, the focus may be linked to the reduction in particular defining behaviours).

- 2.4 Educational strategies were drawn from our initial conceptual work and captured broad educational areas and interventions associated with the education of people with a multi-sensory impairment, and related to the parallel works in vision impairment and hearing impairment. These are listed in Table 1 below.

**Table 1: Multi-sensory impairment educational strategies – summary descriptions of 13 educational strategies**

<b>Strategies</b>	<b>Description of the broad educational strategies</b>
Communication	Supporting the development of communication skills from <sup>4</sup> early pre-symbolic levels through to the use of early language and to signed and spoken communication. This includes the use of alternative and augmented communication systems.
Literacy	Supporting the development of skills which relate to reading and/or writing skills. This includes the development of early recording, the use of symbols, print, braille, and oral/aural access to text.
Mathematics and numeracy	Supporting the development of mathematical skill and numeracy.
Access to examinations	Assessment accommodations/modifications.
Mobility and Independence	Supporting the development of mobility and orientation from early exploration to specific mobility techniques, and the development of independence and living skills.
Cognitive skills	Supporting the development of a range of cognitive skills including conceptual development, agency, attention and perception, executive functioning, and tactile cognition.
Social and emotional functioning	Supporting development of social relationships (e.g. with peers) and management of behaviour.
Use of technology	Supporting the development of skills in using technology as a learning tool.
Vision and auditory training	Supporting the development of functional vision and hearing including the use of technology and low vision aids.
Teaching support	The use of teaching support; including intervenors
Teaching strategies	The use of teaching strategies to support learning, including adaptations, delivery options, hand under hand strategies, to provide scaffolded access to learning
Welsh and minority language	Approaches which are particularly concerned with teaching of children with a multisensory impairment in a dual-language and/or multicultural context.
Inclusion	The use of environmental adjustments, inclusive practice, peer, teacher, and parental training to support and enable the learning environment.

<sup>4</sup> Pre-symbolic levels refers to children and young people communicating through the use of direct, contextual means such as facial expression, vocalisation or gesture, without the use of any referents such as objects, pictures, speech or sign.

2.5 Searching the literature in relation to the educational strategies described above was operationalised as thirteen separate searches of several databases. Details of the search terms and procedure are presented in Annex B: Database sources and search terms. In summary:

### ***Databases***

2.6 The search was carried out in four databases: (1) EBSCO Education Databases, (2) PsychInfo, (3) Proquest Social Sciences and (4) Web of Science. Some additional hand searches were also carried out.

### ***Search structure***

2.7 Our broad search involved a series of searches with the following structure:

- Age (various terms to include research relevant to children and young people under the age of 25 years)
- Deafblindness
- Educational strategies (thirteen broad educational strategies – see above).

### ***Filtering by types of materials and relevance***

2.8 Further inclusion and exclusion criteria, most notably: literature from 1980 onwards, published in English or Welsh, and based in OECD countries. The date of 1980 was chosen as an approximate time scale when education practice in relation to disability started to more clearly reflect current practice (e.g. in England and Wales through the 1981 Education Act), in particular the acceleration of the creation of services in the UK which supported the education of children with sensory impairments in mainstream schools. However, *deafblindness (multisensory impairment)* was not recognised as a distinct disability in England and Wales until 1989.

### ***Number of sources identified (four databases)***

2.9 The sources (references and abstracts) generated after applying the above were collated in EndNote (a bibliographic data software package) and duplicate citations were removed.

**Table 2: Number of results from each database for multi-sensory impairment, plus totals after removing duplicates**

<b>Databases</b>	<b>Sensory field</b>	<b>Number of results</b>
EBSCO	Multi-sensory impairment	121
PsychInfo	Multi-sensory impairment	1,035
Proquest Social Sciences	Multi-sensory impairment	91
Web of Science	Multi-sensory impairment	432
<b>Total (removing duplicates)</b>	<b>Multi-sensory impairment</b>	<b>1,679</b>

### **Stage 2: Refining the search**

2.10 The aim of the second stage was to narrow the material down from the initial search to ensure the most relevant material was selected.

2.11 A separate Endnote database for each subject area was created. The sources in each Endnote database were scrutinised based on the inclusion and exclusion criteria regarding the relevance of the study through reference to the title and abstract of each source. More details are presented in Annex B: Database sources and search terms.

2.12 In addition to the review needing to cover the huge breadth of ‘interventions’, there is a related challenge of defining the term ‘intervention’ itself. The working definition of an intervention study was ‘studies which sought to describe the effect of some kind of educational approach upon a targeted outcome. These studies might be qualitative designs, controlled trials, or single subject designs.’

2.13 In order to contextualise this definition further, the specification for this work offers the following definition of the interventions of interest:

‘For the purposes of this research, an intervention is defined as SEP [special educational provision] as set out in the Education Act 1996 ‘education provision which is additional to or otherwise different from the education provision made generally for children of their age in maintained schools, other than special schools, in the area. For children aged under two, SEP is considered to be education provision of any kind’ (p11)

2.14 Our proposal also unpicked special educational provision further and made a distinction between:

- **Inclusive practice and differentiation:** ensuring that the child’s environment is structured to promote inclusion and learning throughout their education.
- **Additional learning provision:** supporting the child to learn distinctive skills in order to afford more independent learning.

2.15 Such a broad and inclusive definition of intervention is helpful in ensuring valuable evidence is included in this REA which is broad in scope. Nevertheless, such a definition is difficult to operationalise. The working solution agreed by the evaluation steering group was to make a distinction between the following categories of sources: (1) 'excluded/not relevant'; (2) 'good practice'; and (3) 'intervention'. All the sources in each Endnote database were categorised in this way. The table below outlines the criteria for this categorisation.

**Table 3: Working definitions of categorisation of sources**

<b>Category</b>	<b>Definition</b>	<b>Example</b>
<b>1. Excluded/not relevant</b>	The source is not linked to a relevant <i>educational</i> intervention or outcome (e.g. it is medical in focus), or the source does not provide an analysis of educational practice.	(1) Impact of cochlear implants upon functional hearing. (2) A survey of teacher preparation or parent attitudes not linked to educational practice.
<b>2. Good practice</b>	The source is linked to <i>educational</i> practice. While it does not provide evidence of an effect of that practice upon target outcomes, it provides evidence and rationale for the differentiated education provision.	The development of standardised and accessible assessment approaches (e.g. a reading assessment for braille readers).
<b>3. Intervention</b>	The source presents evidence of the effect of some kind of educational approach upon a targeted educational outcome(s).	The trial of a reading intervention to measure the effect upon children's reading performance.

### **Outcomes following stage 1 and 2**

2.16 The sources which were rated as ‘intervention’ or ‘good practice’ were grouped under each of the 13 educational strategies (plus 'other') (see Tables 4 and 5 below). The remaining sources were categorised as 'excluded/not relevant'.

**Table 4: Multi-sensory impairment interventions – number of sources categorised as ‘intervention’ under each of the 13 educational strategies (plus other).**

<b>Strategies</b>	<b>Rationale for categorisation under ‘intervention’ group</b>	<b>Numbers</b>
Communication	Studies describing the range of techniques to enhance communication through a range of means (most describing the same intervention).	12
Literacy	No further interventions were identified under this category (one is included in Communication above).	0
Mathematics and numeracy	No interventions were identified under this category.	0
Access to examinations	No interventions were identified under this category.	0
Mobility and Independence	Studies describing the effect of instruction/teaching/training to support independence and living skills.	3
Cognitive skills	A study describing the use of positive reinforcement for learning.	0
Social and emotional functioning	Studies describing techniques used to assist in behaviour and social interactions.	4
Use of technology	Studies about the use of technology – but these are all more than 20 years old and very unlikely to be relevant.	4
Vision and auditory training	No interventions were identified under this category.	0
Teaching support	No interventions were identified under this category.	0
Teaching strategies	Studies describing specific strategies used to enhance teaching. (and one which is also included in Communication above)	5
Welsh and minority language	No interventions were identified under this category.	0
Inclusion	A study with the inclusion of deafblind pupils socially.	1
<b>Total</b>		<b>29</b>



**Table 5: Multi-sensory impairment good practice – number of sources categorised as ‘good practice’ under each of the 13 educational strategies (plus other)**

<b>Strategies</b>	<b>Rationale for categorisation under ‘good practice’ group</b>	<b>Numbers</b>
Communication	Studies examining/exploring a range of communication methods, strategies, choices, teaching programmes and assessments which can support good practice.	53
Literacy	Studies examining/exploring some issues related to literacy and literacy teaching which support good practice	11
Mathematics and numeracy	No articles were identified directly relating to mathematics and numeracy in this category.	0
Access to examinations	One study which relates to changes to mass assessment methods. <sup>5</sup>	1
Mobility and Independence	Studies examining/exploring strategies approaches and abilities related to mobility and independence skills which support good practice.	18
Cognitive skills	Studies examining/exploring issues related to cognitive functioning, including executive functioning, theory of mind and academic skills which support good practice.	20
Social and emotional functioning	Studies examining/exploring a range of strategies, issues and individual studies related to behaviour and social emotional issues which support good practice.	26
Use of technology	Studies examining/exploring the use of technology in an educational setting to enhance learning which support good practice.	3
Vision and auditory training	No articles were identified directly relating to low vision training, low vision aids or auditory training in this category.	0
Teaching support	Studies examining/ exploring the way in which support staff (including intervenors) can help learning including intervenors in relation to improving practice.	7
Teaching strategies	Studies examining/exploring learning media assessments and learning helplessness which can support good practice.	2
Welsh and minority language	No articles were identified directly relating to Welsh and minority language in this category.	0
Inclusion	Studies examining/exploring the environment, strategies for support and social inclusion which support good practice.	9
Other	A range of other studies which examine/explore issues such as team working, parents, and planning or assessment which support good practice.	19
<b>Total</b>		<b>169</b>

<sup>5</sup> Mass assessment; the assessment of the general population of schools

### ***Inter-rater reliability – stage 2***

- 2.17 To offer greater rigour, all sources identified as interventions were reviewed independently by another team member. There was 97% agreement, and if disagreements were noted the sources were reviewed and if necessary re-categorised. One paper was removed from the ‘communication’ category as it was accidentally recorded twice in this category. A further 10% of the sources identified as ‘good practice’ were reviewed independently. There was 100% agreement. Total agreement across all independent reviews (N=61 sources) was 98%.

### **Stage 3 and 4: Assessing the quality and Data extraction**

- 2.18 The aim of stage 3 was to assess the quality of the identified research (and the protocol for checking the reliability of this assessment), while the aim of stage 4 was to extract the relevant information from the research articles/sources into a standard database.
- 2.19 In terms of quality assessment, the full text of articles which met the inclusion criteria for interventions (in stage 2 above) were viewed and assessed for relevance and robustness. They were subsequently excluded if they did not meet the inclusion criteria upon examination of the full text. The quality of the evidence was assessed (assigning a score of 1, 2 or 3) using the criteria described in Table 2 based on the following categories:
- Score of 1: where there was only impressionistic evidence of impact.
  - Score of 2: where there is modest evidence of impact.
  - Score of 3: where there is strong evidence of impact.

- 2.20 These criteria are drawn from a number of studies which have examined the evidence on ‘evidence based practice’ and assessment of REAs (e.g. Luckner et al., 2016; Houghton Carr et al., 2013; Collins et al., 2016; Bruce & Ferrell, 2016; Nelson et al., 2011).

To ensure the matrix was ‘fit for purpose’, four full text articles covering different methodologies were read and assessed using the matrix included in the inception report. Based on the rating of this sample of articles the matrix was further developed to the criteria presented in Table 6 (empirical studies) and Table 7 (literature reviews) below.

2.21 The combined score assigned to each article enabled the identification of the most relevant and most robust studies, and as such were scored highest. This provided an indication of the confidence placed by the project team in the evidence in the selected articles.

**Table 6: Matrix table to derive confidence in the robustness of EMPIRICAL STUDIES (Commonly experimental, trial and case study designs)**

<b>Components</b>	<b>Score 1: Impressionistic evidence of impact</b>	<b>Score 2: Moderate evidence of impact</b>	<b>Score 3: Strong evidence of impact</b>
<b>1) Objectives of study/hypothesis being tested</b>	No clear objectives (e.g. the effect of intervention on students 'outcomes is incidental/by- product of study).	General objective (e.g. investigation of school impact on intervention).	Clear specific objectives (e.g. investigation of effect of intervention on children's academic outcomes).
<b>2) Approach – quality of <u>outcome measures</u> (valid and reliable)</b>	Limited outcome measures – lack richness and depth (qualitative) or no evidence of valid/reliable measures.	Moderate quality outcome measures – offer some richness and depth (qualitative) or some evidence of valid/reliable measures (e.g. inter-rater reliability).	High quality outcome measures – offer high richness and depth including triangulation (qualitative) or clear evidence of valid / reliable measures including multiple variables.
<b>3) Approach – quality of the research <u>design</u> (appropriate structure)</b>	Design is limited, e.g. no baseline evidence.	Design is appropriate, but rigour is limited, e.g. no use of control or intervention group.	Design is high quality such as using a control and intervention group: either random assignment of participants to conditions or two groups equivalent before the intervention began. In qualitative designs, clear processes of extended periods of observation are recorded (e.g. in action research or case study work).
<b>4) Quality of the intervention</b>	The details of the intervention (independent variable) are not presented, or they are presented in very little detail. The intervention is not replicable.	Moderate quality - details of the intervention are presented, and it could be replicated. Nevertheless little or no rationale for the intervention is offered.	High quality - details of the intervention are presented, and it could be replicated. Rationale for the intervention is offered including theoretical and empirical underpinning.
<b>5) Implication for practice (ecological validity)</b>	Minimal implication on practice, e.g. the intervention in the study has no obvious/explicit link to educational practice, nor are these links made by the authors. Minimal or no discussion of	Moderate implication on practice, e.g. while the intervention was not carried out in a practice setting, there are clear	Strong implication on practice, e.g. the intervention was situated in practice (such as in the classroom, with classroom teachers); the authors explicitly make links

	the interpretation of the application of the study.	similarities and possibilities for transfer; the authors explicitly make these links.	to practical application of the intervention. No evidence of 'over-reach'.
<b>6) Sample size</b>	Small number of participants (e.g. n is less than 5 and reported as individual case studies).	Small sample sizes (e.g. studies based in only one or two educational settings), or the sampling/sample design does not account for bias/representativeness.	Large sample size allowing for calculation of effect sizes. The sampling/sample design accounts for bias/representativeness.
<b>7) Generalisability</b>	Results only apply to the specific participant/s of the intervention.	Results are representative for a specific group of the population.	Results are an accurate representation of the majority population.
<b>8) Evaluation – data reporting and analysis</b>	Descriptive summary/review of results only. Minimal or no analysis and evaluation of study data.	Beyond descriptive, but not extensive, account of the results. Moderate analysis and evaluation of study data.	Extensive account of the results. Extensive analysis and evaluation of study data.
<b>9) Evaluation – critical reflections on limitations of the study</b>	Minimal or no reflection on the limitations of the study.	Moderate reflection on the limitations of the study.	Extensive and rigorous reflection on the limitations of the study.
<b>10) Evaluation – Reporting of evaluation</b>	Unpublished, subject to no peer review.	Reported on websites or in grey literature. Some peer/external review described.	Reported in peer reviewed literature.
<b>Mean scores across all components (Max 30/10; Min 10/10)</b>			

**Table 7: Matrix table to derive confidence in the robustness of LITERATURE REVIEW articles**

<b>Components</b>	<b>Score 1: Impressionistic evidence of impact</b>	<b>Score 2: Moderate evidence of impact</b>	<b>Score 3: Strong evidence of impact</b>
<b>1) Objectives of the review</b>	No clear objectives	General objective made clear	Clear and specific objectives given
<b>2) Approach –search strategy rationale</b>	No clear search strategy outlining key words and sources. Minimal database search; no clear databases defined	Moderate search strategy outlining key words and sources.	Strong search strategy outlining key words and sources. Typified by a systematic review.
<b>3) Approach –rationale and breadth of search</b>	No clear rationale for the inclusion of the selected studies.	Moderate rationale for the inclusion of the selected studies. Limited or no searching of grey literature.	Robust rationale for the inclusion of the selected studies. Extensive database search, including publication bias mitigation through identification of grey/unpublished literature. Typified by a systematic review.
<b>4) Implication for practice (ecological validity)</b>	Minimal implication on practice, e.g. the intervention in the study has no obvious / explicit link to educational practice, nor are these links made by the authors. Minimal or no discussion of the interpretation of the application of the study.	Moderate implication on practice, e.g. while the intervention was not carried out in a practice setting, there are clear similarities and possibilities for transfer; the authors explicitly make these links.	Strong implication on practice, e.g. the intervention was situated in practice (such as in the classroom, with classroom teachers); the authors explicitly make links to practical application of the intervention. No evidence of 'over-reach'.
<b>5) Generalisability (of the conclusions of review)</b>	Results only apply to a specific sub-group of the population.	Results are representative for a specific group of the population.	Results are an accurate representation of the majority population.

<b>6) Evaluation – data reporting and analysis</b>	Descriptive summary review of results only. Minimal or no analysis and evaluation of study data.	Beyond descriptive, but not extensive, account of the results. Moderate analysis and evaluation of reviewed studies; limited synthesis.	Extensive account of the results. Extensive analysis and evaluation of study data; coherent synthesis.
<b>7) Evaluation – critical reflections on limitations of the study</b>	No or minimal reflection on the limitations of the review.	Moderate reflection on the limitations of the review.	Extensive and rigorous reflection on the limitations of the study.
<b>8) Evaluation – Reporting of evaluation</b>	Unpublished, subject to no peer review.	Reported on websites or in grey literature. Some peer/external review described.	Peer reviewed literature, including (a version of the review) presented in a peer reviewed academic journal.
<b>Mean scores across all components</b> <b>(Max 24/8; Min 8/8)</b>			

### ***Inter-rater reliability – stage 3***

2.22 A protocol for inter-rater reliability of scoring of the quality of studies is presented in Annex B: Database sources and search terms. Twelve of the studies were independently rated and the agreement level was 75%. There was disagreement in relation to three of the papers. All three were reviewed once more by quality rater 1 (QR1) and one paper was moved from strong to impressionistic evidence, one paper was moved from impressionistic to strong evidence, and one paper remained in the impressionistic category.

**Table 8: Inter-rater analysis for the quality scoring (N=12 studies)**

<b>Category</b>	<b>QR1</b>	<b>QR2</b>	<b>Agree?</b>	<b>Action</b>
Communication	1.5	1.7	1	
	2	2.1	1	
	2.2	2.1	1	
Literacy	2.75	2.75	1	
Mobility	2.1	1.6	0	Article: Luiselli (1988) QR1 review (1.8) moved to impressionistic evidence
Cognitive skills	1.3	1.4	1	
Social and Emotional	1.4	1.3	1	
	1.3	1.5	1	
Technology	1.7	2.4	0	Article: Mar and Sall (1994) QR1 review (2) moved to strong evidence
Teaching strategies	1.8	2.3	0	Article: Grisham-Brown et al. (2000) QR1 review (1.8) remains impressionistic evidence
	1.3	1.5	1	
Inclusion	2.1	2	1	
<b>Total (N)</b>			<b>9/12</b>	
<b>Total (%)</b>			<b>75%</b>	



#### **Data extraction – stage 4**

- 2.23 A predefined spreadsheet template was developed to facilitate recording of the most important details of each study on intervention to provide a comprehensive overview. This template (record) is summarised in Annex B: Database sources and search terms, and completed templates made available to the Welsh Government.
- 2.24 The analysis and discussion of the literature in this report also draws on a range of sources to support the understanding of the issue. This literature includes work with congenitally deafblind adults. While it is not possible to say, definitively, that this is relevant to deafblind children, when there is little other evidence it is useful to draw on this – and experience suggests it is relevant. The lead author is a very experienced practitioner (more than 30 years) and the only lecturer in Deafblindness in the UK, responsible for the only training programme for teachers of deafblind children in England and Wales. This unique position, means that for more than 17 years she has had access to a range of research undertakings by students – qualified practising teachers taking an additional specialist qualification, which are often, in this field, original work. It also provides access to accounts of practice in deafblindness from across England and Wales, in student assignments and portfolios, which furnish an in-depth understanding of current practice.

### **3. Characteristics of the evidence**

3.1 From the intervention studies we quality rated:

- 29 were 'interventions'
- 8 were rated moderate (2) to strong (3) quality
- 21 were rated impressionistic (1) to moderate (1.9)
- Communication is an area which has received most research attention in relation to intervention studies.

3.2 Tables 9-12 below summarise the nature of the 29 sources included in the REA. Table nine lists the quality ratings of the 29 sources of identified interventions. Of these, 19 had impressionistic-moderate quality ratings (8 in Communication, 3 in Mobility and independence, 2 in Technology, 3 in Teaching strategies). 10 had moderate-strong quality ratings (4 in Communication, 1 in Social and emotional functioning, 2 in Technology, 2 in Teaching strategies, and 1 in Inclusion).

**Table 9: Summary of quality rating ranges by strategy for the identified interventions (total of 29 sources)**

<b>Strategies</b>	<b>Quality Rating: Impressionistic – moderate (score 1-1.9)</b>	<b>Quality Rating: Moderate to strong (score 2-3)</b>	<b>Total sources</b>
Communication	8	4	12
Literacy	No additional sources		
Mathematics and numeracy	0	0	0
Access to examinations	0	0	0
Mobility and independence	3	0	3
Cognitive skills	0	0	0
Social and emotional functioning	3	1	4
Use of technology	2	2	4
Vision and auditory training	0	0	0
Teaching support	0	0	0
Teaching strategies	3	2	5
Welsh and minority language	0	0	0
Inclusion	0	1	1
Other	0	0	0
<b>Total</b>	<b>19</b>	<b>10</b>	<b>29</b>

**Table 10: Summary of the study designs (29 studies)**

<b>Design type</b>	<b>Count</b>
Systematic review	1
RCT or quasi-experimental study	2
Single case experimental design	26
Meta-analysis	0
Mixed methods	0
<b>Total</b>	<b>29</b>

**Table 11: Summary of national research settings (29 studies)**

<b>County</b>	<b>Count</b>
Netherlands	8
UK	1
USA	19
Other countries	1
<b>Total</b>	<b>29</b>

**Table 12: Summary age range (29 studies, age groups not mutually exclusive)**

<b>Age group</b>	<b>Count</b>
Pre-school	3
Primary years	9
Secondary years	3
16+	2
All age	5
All ages including adults (e.g. parents, teachers)	5
No age given	2
<b>Total</b>	<b>29</b>

3.3 The final list of 29 studies provides evidence within 7 broad educational strategy areas. In Table 23 below these appear as 31 articles because one is included in both of the categories of Communication and Literacy and one in both categories Communication and Teaching strategies. Nevertheless, within each of these strategy areas there were a range of different interventions. Table 13 summarises the nature of the interventions within the different strategy areas.

**Table 13: Summary of the interventions linked to each strategy area**

Strategy (number of studies)	Overview of the types of interventions identified
Communication (12)	<p>Eight interventions looked at promoting communication and interaction with educators, through the coaching of the educators in their interactions (Janssen et al., 2002; Janssen et al., 2003; Janssen et al., 2004; Janssen et al., 2006; Janssen et al., 2007; Janssen et al., 2011; Janssen et al., 2012; Martens et al., 2014).</p> <p>One intervention looked at the use of wait time when waiting for responses (Johnson and Parker, 2013).</p> <p>One intervention examined how the introduction of scents helped students make choices at mealtimes (Murdoch et al., 2014).</p> <p>One intervention explored how textured cards could be used to request food items (Murray-Branch, 1991).</p> <p>One literature review found that very little evidence exists regarding interventions and communication, however there is limited evidence on child-guided approaches and moderate evidence on systematic instruction for specific outcomes (Luckner et al., 2016).</p>
Literacy (1)	<p>One literature review found that most studies on literacy instruction for deafblind children are descriptive studies and that there is a need for intervention studies (including expressive and narrative) (Luckner et al., 2016). This was also included in the category above.</p>
Mathematics and numeracy (0)	N/A
Access to examinations (0)	N/A
Mobility and independence (3)	<p>Two interventions looked at how deafblind children may be taught to feed themselves (Luiselli, 1988 and 1993).</p> <p>One intervention looked at how a deafblind child might be taught to dress themselves (McKelvey et al., 1992).</p>

Cognitive skills (0)	N/A
Social and emotional functioning (4)	<p>Three interventions examined promoting communication and interaction with non-deafblind peers (Hunt et al., 1996; Mar and Sall, 1995; Romer et al., 1996).</p> <p>One intervention looked at strategies to increase self-regulation and promote classroom integration (Nelson et al., 2016).</p>
Use of technology (4)	<p>Three of the interventions looked at the use of microtechnology (microswitches, microcomputers) to support early stage communication particularly contingency awareness (Mar and Sall, 1994; Schweigert, 1989; Schweigert and Rowland, 1992).</p> <p>One intervention was based upon the use of colour CCTV to recognise object linked to photographs (Peck, 1995).</p>
Vision and auditory training (0)	N/A
Teaching support (0)	N/A
Teaching strategies (6)	<p>Two interventions (Alberto et al., 1983; McDaniel, 1984) looked at negative reinforcement/aversive actions (e.g. holding a disliked object, holding hands in a particular way) to produce positive actions or prevent problematic behaviours.</p> <p>One intervention looked at using contingent and non-contingent sensory reinforcement, and response interruption to prevent problematic behaviours (Sprague et al., 1997).</p> <p>One intervention looked at using response prompting to support preschool children to make choices (Grisham-Brown et al., 2000).</p> <p>One intervention looked at the use of wait time when waiting for responses (Johnson and Parker, 2013).</p>

	One intervention looked at the use of sound or light stimulus or both in the presentation of switch based stimuli. (Knight and Rosenblatt, 1983).
Welsh and minority Language (0)	N/A
Inclusion (1)	One intervention (Desrochers et al., 2014) examined the use of background music in the classroom to minimise problem behaviours.
Other (0)	N/A

### Overview of the evidence

- 3.4 The process of this review demonstrated the very limited range of articles which met the criteria for the typical REA process. In terms of peer-reviewed evidence from research, there was very little. An overview of the evidence is thus presented here, outlining the type of material found by the REA process and the subsequent steps to provide a more informed perspective on the education of deafblind learners.
- 3.5 The field of education in deafblindness is still young, with the recognition of this as a separate disability by the DfE in 1989 and by the European Union in 2004<sup>6</sup>. As it is also an exceptional field within a low incidence area (sensory impairment), the total numbers of involved practitioners and researchers is low. In terms of recorded evidence in the field of deafblindness, there is less still than in vision impairment or in hearing impairment.
- 3.6 There are two issues of particular significance which contribute to the low evidence base. Firstly, in vision impairment and in hearing impairment, research and writing is generally focused on individuals who have few, if any, additional disabilities. Quite often learners who do have other disabilities are deliberately excluded. In reading about research, it is reasonable to assume in vision impairment and hearing impairment that it will be about otherwise typically developing children, unless it clearly states otherwise. In the field of deafblindness, it is likely to be the opposite. Unless it is clearly stated, it is likely that the research concerns individuals who present as having a learning disability. For example, all the items (except one in the

<sup>6</sup> Declaration of the [European Parliament](#) on the rights of deafblind people was passed in Strasbourg on 1/4/2004.



Communication Intervention literature section) concern individuals with a learning disability, and one covers the full range of ability with a strong emphasis on multiple disability. It is, therefore, frequently difficult to work out whether it is the dual sensory impairments which are being addressed by an intervention, or the learning disability – and adaptations for sensory impairment may not be included. Indeed, an intervention may include a deafblind person in a group for research but this does not mean it is research aimed at deafblindness. However, a holistic picture of deafblindness means that this distinction does not make much sense in the real world in which both factors, deafblindness and learning disability continue to be both important to any individual.

- 3.7 Secondly, the very nature of the individuality of deafblind people, across a spectrum of levels of vision, hearing, combined hearing and vision, communication mode, presence or absence of other disabilities, not to mention age, gender, and school type, means that there is no opportunity to compare groups to reach conclusions. Studies are small scale, or single case studies and cannot be straightforwardly applied to a wider range of learners. However, large scale studies are largely impossible to undertake because: there are no groups of otherwise similar deafblind learners, particularly if children cannot be brought together and comparisons between otherwise diverse learners are not rigorous; even in quite a wide geographical area, only small numbers of learners will be eligible; definitions of deafblindness remain unclear and eligibility would need to be checked individually.
- 3.8 Therefore, smaller studies are the best evidence which is available. Consequently, such studies are also not replicable – undertaken with a learner with different abilities and impairments, they would not be the same study. Practitioners in this field need to be able to read research with an open mind, and think about interpreting and applying any outcomes to their own work with care and reflection. For this to be effective, they need to be well-trained and to have become practitioners who are able to reflect critically on their own work.

- 3.9 It seems then that the nature of the evidence in deafblindness is limited, and appears to be more impressionistic than robust. As Hartmann and Weismer (2016) say:
- ‘learners with deafblindness are a low- incidence and heterogeneous population, and validating instructional practices through scientific measurement is often not feasible given the variability among these learners.’  
(p463)
- 3.10 Some evidence which did meet the criteria for inclusion in the REA is quite dated. In the areas of teaching support for example, articles about negative reinforcement (that is, deliberately providing situations children did not like to prevent them from using certain behaviours) were included. These would not fit within the current climate of education in the UK, and indeed such research may not gain ethical approval if undertaken now. Some of the evidence on technology was also about equipment which would no longer be used (CCTV rather than video magnifiers for example). While principles from these articles may be generalisable to other situations, this must be done with caution.
- 3.11 One author (Janssen) as the main or second author dominates the literature, with eight out of 29 articles. Most of these are about the same intervention strategy (attunement). However, this author’s approaches, while sound, do not relate to all the relevant ground in the field of deafblindness and communication. While it is clearly valuable research, it cannot be taken as the only (or complete) route to follow, as there are many significant areas barely addressed in these articles.
- 3.12 This highly limited level of evidence, in relation to the criteria of the REA justifies our response to the discussion that follows. It therefore draws on wider evidence to ensure that this review of effective teaching for deafblind people, does present the best known advice. It considers a wider range of literature with the intention of providing some guidance from, and through, literature in relation to this important field.
- 3.13 The literature in the Intervention summaries presented in the introduction and implication sub-sections draws widely on:
- The ‘good practice’ articles found in the literature search for this study, which did not meet the intervention criteria, but have potentially valuable information/insight/ideas for the field. For example, they may be descriptive,

rather than about an intervention, or they may be about adults rather than children and young people.

- Books/chapters written by reputable authors in the field, many of them practitioners, who write about teaching and learning.
- A range of less formal literature, short booklets, reputable internet sites about deafblindness, articles from professional journals in the field which provide relevant information.

3.14 Occasionally, high quality student assignments, mostly Master's dissertations (many of them prize winners). These students are practitioners who are writing about current practice. Some of these are about areas which are not discussed or minimally discussed in relation to deafblindness in the wider literature. Other material includes examples from experience, drawn from the authors' or from students' work (assignments and portfolios). This wider inclusion has meant that although there are few evidence-based intervention studies, informed and competent practitioners have contributed to this review.

3.15 What this review does not draw on is the evidence already included in the parallel studies on vision impairment and hearing impairment – it is strongly focused on dual sensory impairment. However, of course, these other studies will provide additional evidence from which professionals can usefully draw. Information about, for instance, teaching braille, using hearing aids, or theory of mind, for vision impaired or hearing impaired learners will still be relevant even though it will need to be applied in a possibly different way for a deafblind learner.

### ***Reflections upon the type of available evidence***

3.16 The evidence available from the intervention studies (that is, meeting the criteria for inclusion in the Intervention category of the REA search) comprises only 29 articles (two articles occur in two categories). In seven of the 13 categories nothing was found at all. In two other areas, only one article was found. Further, 19 of the 29 articles provided only impressionistic to moderate quality of evidence, and 27 of the 29 articles were small sample case study designs. This reflects the nature of the population which means that comparisons between deafblind learners (and in particular control groups) are unlikely to be possible.

- 3.17 Of the 29 articles, five were written between 1980 and 1989, ten between 1990 and 1999, six between 2000 and 2009, and eight between 2010 and 2016. Of the older articles, two were about negative reinforcement (a process which would not be used today) and four were very strongly based on a behavioural strategy which is less used now. Three of these, although about deafblind learners, did not relate strongly to deafblindness. All four of the technology articles written about in the Intervention summary below (Mar and Sall, 1994; Schweigert, 1989; Schweigert and Rowland, 1992 and Peck, 1995) were written before 1996, making them considerably out of date.
- 3.18 Of the later articles (after 2000), eight were written by the same team, examining broadly the same intervention, through a range of different perspectives. One was a systematic literature review (appearing in two categories), and another appeared in both Communication and Strategies sections. Taking this into account reduces the number of different interventions written to just 22. Five are in the field of Communication, three in Mobility and independence, four in Social and emotional skills, four in Technology, five in Teaching strategies and one in Inclusion. Apart from the multiple articles written by Janssen and her partners (in 2002, 2003, 2004, 2006, 2007, 2011, 2012, 2014) there is no replication of studies, so most evidence remains from a single study.
- 3.19 Therefore, it is hard to use the intervention studies in order to draw conclusions. Even where there is good evidence of effect, this may not be applicable to new situations.
- 3.20 While there is most evidence about communication, this is not the only important issue for this field. Deafblindness is a complex disability, and it involves more than communication. Other issues which have significant cost implications (e.g. the deployment of intervenors, or the use of assistive technology for visual enhancement) also need researching, but have not been systematically investigated (though some small scale student projects have been done).
- 3.21 This evidence-base does not relate to the commitment and growing strength of the field. Practitioners, who may have little time for formal research, use other means to share information, and ideas, which are used by others to take and apply ideas, rather than exact plans. Therefore, single practitioner research (such as that done by students qualifying as specialist teachers) can be valuable to the field, alongside peer reviewed work in journals. There is a need for increased sharing and

networking to ensure that individual practitioners, who might be widely geographically spread, are able to benefit from each other's experience.

- 3.22 While the fields of vision impairment and hearing impairment are very important to this population, the approaches they describe are not always appropriate for deafblind learners. For example, while it is likely an assistive device will work in the same way for a deafblind learner as for a learner with a single sensory impairment, e.g. a low vision aid will magnify/clarify to the same degree, it is likely that this support will need to be delivered in a different way, and perhaps used with different materials. This might be seen, for example, in some of the good practice sources included in the discussion.

## 4. Intervention summaries

4.1 In this section, the findings for the different educational strategy areas are discussed in turn. For each, we present three sub-sections:

- Introduction
- Available evidence
- Implications.

Taking each in turn, the sub-sections have the following purposes:

4.2 The introduction outlines the educational strategy area. In the light of the minimal evidence from intervention studies, it then outlines the key issues and ideas in relation to this area and deafblindness.

4.3 The available evidence sub-section details each of the sources and articles identified through the REA. Where there is any evidence, this includes details of the intervention under investigation, what the researchers found, how they did this (methodology), and the quality of the evidence generated.

4.4 The implications sub-section draws on the evidence section (if there is one) and a wider range of literature and knowledge, as outlined above, to provide a reflection on the issue and the possible implications for educational practice.

4.5 This review is focused on deafblindness. However, it is associated with two parallel studies in vision impairment and hearing impairment. For each of the educational strategy areas, the issues associated with these, the evidence drawn from the intervention studies, and the implications of these have relevance to deafblind learners. The findings from research studies and the areas of good practice contribute very significantly to what is known in each of the areas, but these are not, in general included in this discussion below. As is emphasised by the conclusions, practitioners in deafblindness must *a/ways* interpret and apply research findings to the individuals they are working with because of the impossibility of generalisation from low incidence, highly diverse groups. This is true also of the literature relating to vision impairment/hearing impairment.

## **Communication**

### *Introduction*

4.6 It is recognised in most of the definitions of deafblindness that communication is one of the areas most affected by dual sensory impairment. It is the area about which most material relating to intervention studies was found and also about which most other good practice articles are related. There are chapters in all the key texts about communication, and books dedicated to this area. It is perhaps the most written about and arguably the most important of the issues and areas in relation to deafblindness. Certainly it is true that communication has a bearing on many, if not all, of the other areas in this search, as it affects literacy, mathematics, social behaviour, cognition, mobility and more (Janssen and Rødbroe 2007).

4.7 This review is based on seven areas related to communication. These areas are drawn from literature and from experience, as important to deafblind learners. They are;

- Accurate assessment for learners in respect of communication;
- Developing symbolicity – from concrete to increasing abstract expression;
- The use of appropriate modes and forms of communication;
- Developing vocabulary and function;
- Developing interaction – from early levels of work with a responsive adult to developing friendships;
- Approaches to the development of communication: shared construction, and structured activities;
- The use of amplification and hearing instruments.

### *Assessment*

4.8 Assessment is important for deafblind learners because their communication development does not necessarily follow typical directions and will not necessarily happen without additional support. Assessment can help determine, in some detail, what level of communication, what methods of communication and what functions of communication are currently used, and thus enable strategies and approaches to be determined. Without this, inappropriate levels or methods of communication which seem 'fashionable' or which are usually used in a particular educational setting, may be employed and the learner may be assumed to have intellectual difficulty if they make no progress. The Communication Matrix (Rowland, 2004) is

one of the most useful – based on work done with deafblind people and was used by Cascella et al. (2015), Dammeyer and Ask Larsen (2016), Bloeming-Wolbrink et al. (2015) and others, as part of studies examining the skills of groups of deafblind learners. The Callier Azusa scale (H) (Stillman and Battle 1985) helpfully divides communication into four areas: receptive communication, expressive communication, symbolicity, and interaction. These four areas all need to develop in order for communication to make progress.

- 4.9 Aitken (1995) also discusses the importance of assessing the environment – a systems sensitive assessment. No-one communicates alone and the communicative environment can determine the communication success of a learner. Just as German people naturally learn to speak German but not Portuguese and people in Portugal acquire Portuguese and not German, it is not reasonable to expect a deafblind learner to communicate in BSL (British Sign Language) or use symbols, if she is the only one in her environment using these systems (Wolff-Heller et al., 1995). As Bruce (2003) and Villas Boas et al. (2016) discuss, if staff communication is mostly in speech, and the learner cannot hear, then the learners are not understanding information, communicative initiative and much more. In fact, the communication environment is not always rich – Verleod et al. (2006) found that in an activity chosen for the likelihood of communication opportunities, only 2% of the time was in fact used for teacher-child communication.

#### *Symbolicity*

- 4.10 As Petroff (2001) outlines, about half of deafblind people do not manage to move into symbolic communication, that is, communication where a referent (a picture, object, spoken or written word, or sign) stands for the 'idea' – a thing, an act, an emotion etc. Bruce (2005) discusses the difficulty that many have in crossing the apparent barrier from pre-symbolic (context bound, concrete based communication) to symbolic forms. These are of course difficult because deafblind learners do not have the opportunistic learning available from a world full of visual and auditory communication – spoken words, sounds, pictures, text and more. Developing symbolicity requires (Bruce 2005) joint attention, which is particularly difficult if someone is using touch both to explore an object and then to talk (or 'listen' to someone else) about that exploration. The fact that the number of communication initiatives taken by emergent symbolic communicators appears to be linked to the success of transition to symbolic communication indicates that an unsupportive



environment (as above) can restrict the possibilities for communication development. In addition, there is some evidence of the link between mobility and movement and communication ability (Petroff 2001, Thelin and Fussner 2005, Peltokorpi and Huttunen 2008). Petroff suggests that deafblind people are broadly divided into two groups: those who do not use symbolic language and do not walk; and those who do use symbolic language and walk. Thelin and Fussner, studying children with CHARGE syndrome (see section 1.1) suggest that for learners with CHARGE at least, this is not related to general overall level of disability (because it wasn't linked, for example, to physical health) but they:

- 4.11 'hypothesize that, with the ability to walk independently, the individual may have a marked advantage in maximizing communication with self-positioning rather than depending upon the talker to identify the optimal location' (Thelin and Fussner 2005 p288).
- 4.12 The use of appropriate strategies and methods to match the level of symbolic understanding is vital. As McLarty (1997) says about the use of objects of reference (concrete tangible symbols) there is:
- 'significant confusion among practitioners who tend to invest the objects themselves with some special quality to communicate meaning to very disabled students.' (p13).
- 4.13 This approach means that objects of reference can be used as a panacea, which will provide communicative information, without regard to whether the learner can match this to a meaning.
- 4.14 Symbolicity then develops from concrete 'iconic' (Park 1997) to increasingly abstract formats (Rowland and Stremel Campbell, 1987; Deasy, 2009). That is, the use of referents which have a direct link to the item/activity/idea they are referring to, (such as a spoon for dinner, a photograph for jet ski-ing or a gesture for a direction) will develop into more abstract formats, such as a line drawing, a written or spoken word, or a sign. Of course, it is the case that many learners will cross boundaries with their communication, using different levels and a variety of methods (Casella et al., 2015; Deuce, 2015). Those developing more abstract communication will then move into recording (using text in print or braille, or BSL in video, or symbol-pictures) and into sentence construction. Dammeyer and Ask Larsen (2016) found that 17% of deafblind children in Denmark were using conventional sentences and 18% had no language delay. When appropriate levels

of communication are used; deafblind learners have access to learning; and they can use their skills to extend their learning. Until shared communication is established, learners cannot necessarily use means available in the classroom but unintelligible to them. For example, a learner who is not at a level to be able to sign, cannot gain information from signing in the classroom any more than they can from speech if they do not understand speech.

### *Forms of communication*

- 4.15 Authors in this field recognise the wide range of communication methods which are used for, and by, learners who are deafblind (e.g. Petroff, 2001; Bruce, 2005; Dammeyer and Ask Larsen, 2016; Pease, 2000; Miles and Riggio, 1999). These include but are not limited to:

#### ***Pre-symbolic forms***

Receptive: Cues – visual, auditory, tactile, situational

Routines, scripts

Gestures, sounds, tones of voice

Facial expressions

Expressive: Vocalisations

Body movement, body tone

Facial expressions

Physical actions (going to something, reaching for something)

Eye gaze

#### ***Symbolic forms (both receptive and expressive)***

Gestures

Concrete symbols- objects, photographs, pictures, symbol pictures, sounds

Signs

Speech

Tactile symbols

Text – print, braille (or Moon<sup>7</sup> or tactile equivalent).

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<sup>7</sup> Moon is a tactile code based upon raised lines.

- 4.16 Any of these may need to be adapted to support the learner's vision and hearing impairments, to make signs more visible, (Clark, 1998) to access them by touch, (NatSIP, 2015) or to amplify speech or access through touch. Graphic media (pictures or text) may need to be enlarged and adapted.
- 4.17 The intersection between the levels of symbolic communication and the modes of communication is significant. Signing may become tactually accessible when delivered through hands on sign but this does not necessarily make it appropriate for a deafblind person with poor vision. If they are not cognitively and communicatively able to access signing if they had good vision, using it tactily does not make it accessible. McLarty (1997) as above, explains that objects of reference do not of themselves hold the key to communication, as some seem to think. They are helpful when a learner has the cognitive and other communicative skills to learn to use them. Likewise, while tangible symbols can be highly successful means of providing information (Rowland and Schweigert, 2000; Rowland and Schweigert, 1989), they are a part of the communication hierarchy and require pre-requisite skills, such as one-to-one referencing and memory, and object permanence (Hodges and Pease 2002). The use of Tangible Symbols are taught through calendars (as below) and exchange systems.
- 4.18 The use of complex systems of communication can, however, also mean that individuals can become quite isolated from others, because the means of communication they use is not understood. Wolff Heller et al. (1995) discuss the difficulties when communication methods are not transparent in the community (such as braille or sign) and how this can be supported by labelling some materials at two levels (so a picture also has a written word) or by backing it up with alternatives, such as picture boards to ensure that they can be understood.

*Developing vocabulary and function*

- 4.19 There is less written about the important role of developing communication into different areas and increasing vocabulary. The basic levels of protesting, requesting, social and information are outlined by Rowland (2013). However, as Rowland and Stremel Campbell (1987) and Pease (2000) suggest, learners should not be limited to these. They also need to develop communication about asking questions, making comments, understanding a wider range of concepts and developing joint attention. Using only requests and imperatives does not constitute a real and meaningful access to language (Deasy, 2009). For individuals who

perceive the world only at close distance (either because of limited vision or because of tactile access), even the vocabulary they develop may be different. One young deafblind boy, for example, had the word 'necklace' in his early vocabulary (first 20 words) because this was the tactile, close experience he had of his mother. Bruce (2005) demonstrates the importance of linking words (spoken, signed, as graphics or in whatever format) to activities, objects and emotions (and more) to develop and increase understanding.

- 4.20 Bruce, Godbold and Naponelli-Gold (2004) show that most teachers in fact use directive language, physical actions and comments on actions. They rarely used comments on objects, greetings or labels. This can lead to distortions in language for the learner, who is not able to access a full model of typical human interaction through vision or hearing. Indeed, the adult's ability to control the vocabulary of a learner using concrete symbols (pictures, photos, objects) can limit the learner's own ability to develop ideas or to say what they want. Hodges and Pease (2002) contrast the first ten objects of reference for a deafblind child (which included 'clean teeth', 'physiotherapy' and 'toilet') and the first ten words in the vocabulary of a typically developing child.

#### *Developing interaction*

- 4.21 Several authors all describe the importance of developing an interaction between a deafblind learner and initially an adult (e.g. Wheeler and Griffin, 1997; Villas Boas et al., 2016; Hartmann, 2012; Pease, 2000). This is related to a 'dyadic' approach in which the learner and the adult take part together in an enjoyable activity, in exploring objects, or in movement (Writer, 1987; McInnes and Treffry, 1982) to develop an understanding of two people working together. Rødbroe and Souriau (1999) outline the importance of direct interaction, face to face (especially for young children) to overcome the barriers caused by vision and hearing impairment.
- 4.22 For those who are more able, the interaction necessary for friendships and social relationships is clearly important. Deafblind people are often missing the means to accomplish this interaction; they do not know for example that a person has come into a room and so cannot greet them (Bruce, 2005), and they are often able to communicate only with one person at a time (Rowland and Schweigert, 1993). Even for those who are competent and understand social relationships, navigating the appropriateness of these can be complex and difficult (Sirotkin and Kalyanova, 2009).

### *Approaches to the development of communication*

4.23 Bruce et al. (2016), Ferrell et al. (2014), and Bruce and Borders (2015) all describe three basic approaches to teaching communication to deafblind learners:

- Child led (shared construction)
- Systematic instruction (structured activities)
- Tangible symbols (see above).

#### *Shared construction*

4.24 One of the most important developments in the education of deafblind people is the approach of communication as being a shared construction between a deafblind person and another adult (e.g. Hart 2006). This is based on developing intersubjectivity, the recognition that the deafblind person and the other are both people, and that 'he's just like me' (Hart 2006). This process begins from a shared understanding between a parent and a child, as the child develops first in close proximity to the parent, attuning to the parent and becoming aware of themselves, the parent and then the wider world (Nafstad and Rødbroe, 1999). The process of attunement – gradually developing an understanding of the person's means and methods of communication at early levels, and two working together – leads to the ability to share in attributing meaning to various signals which can then become referential (Souriau, Rødbroe and Janssen, 2008). Hart (2010) describes this negotiation of meaning leading into the development of valuable, human interactions. Hartmann (2012) describes this process too (proto-conversations using sound, face, and movement). Daelman et al. (2004) and others, following, talk about the combination of the body and the emotional into a 'trace' (Bodily Emotional Trace – BET) which can become symbolic between two individuals to represent a shared activity. Hart (2008) describes further the ways in which deafblind people find gestures within events can be used to share with others what they have experienced – if only the partners are ready to understand. It is key that the partners are both receptive, and competent in understanding and in using different modes of communication: visual, sounds, or tactile means. Indeed, Hart (2008, 2010) considers that the barriers to communication for deafblind people are often the fact that their partners do not understand the means and modes they use naturally, rather than that deafblind people being unable to build up the pre-requisites to language.

### *Structured activities*

- 4.25 Structured activities designed to promote communication are described by Writer (1987), Pease (2000) and Wheeler and Griffin (1997) particularly in relation to the use of calendars. That is, using objects/pictures/text to represent activities and events which are part of a learner's day and using this to link symbolic cues and referents to the activity (as an approach to developing referential understanding). These calendars can support the development of symbolicity, through gradual progress from concrete to abstract means of communication. They can provide opportunities to talk about events with which the learner is certainly engaged. Language learning, cognitive skills and literacy skills merge as many learners will need text or symbol support to support language learning, and likewise will need understanding of concepts to develop language.
- 4.26 While Gothelf et al. (1994) describe choice making as largely absent from learners' programmes. Murdoch et al. (2014), 20 years later, describe this as now 'widely accepted'. Porter, Miller and Pease (1997) describe choice making as a strategy which is seen as effective to learners at early levels, and is one of the most widely used by teachers. Making choices is used as a teaching stimulus because it can link objects to activities, or to symbols, thus increasing the symbolicity. Choices usually also involve highly motivating rewards – choice of food is described by Gothelf et al. (1994), Murray Branch (1991) and Murdoch et al. (2014). Although making choices is so widely used, the theoretical basis often has not been thought through, considering the issues which need to be understood for choice to be effective, e.g. the ability to remember events, to weigh and balance options, to understand that 'choosing' one thing means another is rejected (Luckner et al., 2016; Hodges, 2003b; Hodges, 2008).
- 4.27 Pausing (or 'wait time') is also used as a strategy to promote communication. Hodges (2000) describes it as a means to encourage communication at early stages by pausing in an enjoyed activity to elicit a response from the learner, and Miles (2008) explains the importance of pausing to allow for the learner to take turns in an interaction. For more able learners it is important to ensure they have had time to process the incoming information, to form and think about an answer, and sometimes, simply to have a rest (Ayer 2010).

### *Hearing instruments*

- 4.28 One more key approach not much mentioned by authors is the use of amplification. Some learners will be so profoundly deaf that hearing instruments (hearing aids or cochlear implants) will make little or no difference to their perception of, and so production of, speech. For others it is an essential pre-requisite for their understanding and so for the development of language
- 4.29 Thelin and Fussner (2005) emphasise the importance of using hearing aids/cochlear implants. In their study of children with CHARGE syndrome, those who did not develop symbolic language were also not, or not successfully, using amplification. In contrast, some children with the same levels of hearing loss who did use amplification successfully developed symbolic communication. While the reasons for this are not yet known, it is an indication that hearing speech may increase the possibility of symbolic understanding (even if not by speech). Nevertheless, it should be noted that some children who did *not* use amplification still developed symbolic communication; therefore the relationship is not straightforward. In Thelin and Fussner's study, parents also considered that hearing impairment had the biggest effect on communication in their children.

### *Available evidence*

- 4.30 The first piece of evidence looks at enhancing the quality of interaction between deafblind children and their educators (Janssen et al., 2002). Four deafblind children, aged 6-9 years and their 14 educators took part in the experiment. The educators were trained to respond more appropriately to the children's interactive behaviours as well as to adapt to the context of the interactions in order to facilitate the occurrence of appropriate child behaviours. Examples of adaptations include: 1) offering communicative aids in an orderly manner; 2) offering choices; 3) removal of distracting stimuli; 4) removal of stimuli not wanted by the child; 5) attuning activities to the child's abilities; and 6) demonstration of appropriate interactive behaviours. In order to implement the interventions appropriately the educators were informed, consulted, trained, and given individual and group supervision. The findings show that it is possible to increase children's responsive communicative behaviours by training the staff who work with them to be more responsive. Furthermore, contextual adaptation (changing stimulus, or increasing motivation) can also help in the achievement of targets. Despite the small sample size, lack of generalisability,

and poor quality of the intervention this study provides moderate to strong quality of evidence, however it falls to the moderate end of the range.

- 4.31 The effects of an intervention program to foster harmonious interactions between deafblind children and their educators were explored by Janssen et al. (2003). Six congenitally deafblind children/young people (3 – 19 years old) were involved in the study along with 14 educators. The findings show that it is possible to increase children's responsive communicative behaviours by training the staff who work for them to be more responsive. Three stages to the implementation of the intervention were identified in order to increasing educator responsiveness - help the educator recognise the deafblind child's signals, attune their interactive behaviours to those of the child, and adapt the interaction context to facilitate the occurrence of target behaviours of the child. This study replicates the previous study (Janssen et al., 2002) but the training programme was adapted to make it more suitable for everyday practice and use in the home. However, no consideration is given as to whether things might have improved without the training. Overall, this study provides impressionistic to moderate quality of evidence. This is due to the small sample size, lack of generalisability and poor quality of the intervention and evaluation.
- 4.32 The authors of the previous two studies carried on their work exploring whether the intervention effects endure when enhancing the interactive competence of deafblind children (Janssen, et al., 2004). Four congenitally deafblind children (7-11 years old) were involved in the study along with 24 educators. The educators were trained to respond more appropriately to the children's interactive behaviours and also to adapt the context of interactions to facilitate the occurrence of appropriate child behaviours. Training was individual supervision consisting of observation and feedback and group supervision with video. There was a follow up period with no intervention. The results of the study showed that educators' appropriately responsive behaviour increased. For two of the deafblind children the frequency of their appropriate responses remained higher in the follow up phase when intervention ceased, but decreased when intervention stopped for two of the four deafblind children. Overall, this study provides impressionistic to moderate quality of evidence. This is due to the small sample size, lack of generalisability, poor quality of the intervention and lack of critical reflection on the limitations of the study.



- 4.33 In Janssen et al. (2006) they took a single child from their 2003 work (see Janssen et al., 2003) and using a case study method explored the application of a diagnostic intervention model to foster harmonious interactions between deafblind children and their educators. An interaction coach, who consults with and supervises the educators, was key in helping the educator to recognise the child's signals, attune his or her behaviour to those of the child, and adapt the interactional context to promote the occurrence of a particular child's behaviours. The findings of the study show that the child was more actively involved in interaction following these interventions. Overall, this paper provides impressionistic to moderate quality of evidence, scoring 'impressionistic' in the majority of the categories.
- 4.34 In Janssen et al. (2007) the authors demonstrate the use of the diagnostic intervention model in everyday practice and the effects of its application in two case studies using team interaction coaching. Two deafblind young people were central to the case studies. A five-step intervention protocol was introduced by two different interaction coaches (one for each participant). This protocol comprised: 1) determination of the question; 2) clarification of the question; 3) analysis of the interaction; 4) implementation of the intervention; and 5) evaluation. The intervention lasted 11 weeks for the participants and their educational teams. There were three team coaching sessions each, and three individual sessions with the first participant and six with the second. The authors claim that the interventions are 'successful for both cases' but in fact the evidence for one is very weak. The intervention appears successful for staff but not students. Once again, overall this paper provides impressionistic to moderate quality of evidence, scoring 'impressionistic' in the majority of the categories.
- 4.35 This work on fostering harmonious interaction was also drawn upon again in Janssen et al. (2011), this time with the case study of a congenitally deafblind five year old boy. Continuing with the diagnostic intervention model changes in the caregiver's turn-giving had substantial effects on the child's turn taking, regulation of intensity, and approving and disapproving answers. The interaction effects were less clear for the child. Overall, this paper provides impressionistic to moderate evidence of quality.
- 4.36 The fostering of affective involvement with deafblind young people was explored in Martens et al. (2014). In this case study a coaching intervention was used to measure affective involvement sharing emotions with four deafblind people and 16

communication partners. The results showed that the coaching improved the affective attunement of the individuals but not universally and not straightforwardly. This paper provides impressionistic to moderate quality of evidence.

- 4.37 In their 2012, study Janssen et al. reanalysed their data from their previous study (Janssen et al., 2003) to look at the duration of sustained interaction. There were six deafblind children/young people ranging from 3 – 19 years old. There were also 13 educators and three interaction coaches. The analysis involved re-watching and scoring interactions based upon the diagnostic interaction method for sequences of sustained interaction, the longest sequence, and the mean number of turns in a sequence. The length of interaction time was seen to increase as a result of the particular coaching method, however this was not an intended outcome of the intervention. The study did not provide adequate critical reflection on the limitations of the study and was not clear in its objectives, consequently overall this paper provides impressionistic to moderate evidence of quality.
- 4.38 The interventions had positive effects on sustained interaction across almost all the cases and eight interventions looked at promoting communication and interaction with educators, through the coaching of the educators in their interactions (Janssen et al., 2002; Janssen et al., 2003; Janssen et al., 2004; Janssen et al., 2006; Janssen et al., 2007; Janssen et al., 2011; Janssen et al., 2012; Martens et al., 2014).
- 4.39 The use of wait time (pauses) following directions, to allow a response was examined by Johnson and Parker (2013). Of the three children in their study, only one was deafblind (two had visual impairment and multiple disabilities); they were all under the age of eleven. The participants were presented with different objects (selected so as to be specific to their interests) and were asked to complete an instruction such as “play music” or “find rattle”. Either a 5, 10, or 15 second wait was given before prompting (physical or audible) if there was no response from the participant. If the correct action occurred within the wait time verbal praise was given. The results showed that wait time helped children engage. It appeared to be individual to children which time they preferred – the deafblind child preferred a longer wait. Despite the small sample size and lack of generalisability this study does provide moderate to strong quality of evidence.

- 4.40 Murdoch et al. (2014) examined how the introduction of scents helped students make choices at mealtimes. Three deafblind participants (aged 17, 14, and 7 years old), who were known to use olfaction and be able to make symbolic choices, were presented with up to three scented pictures to help them make dinner choices (pizza, fish and chips or curry). The results showed that the pupils were interested in the fragranced pictures and this did appear to influence their food choices, but this could be related to the interest of the fragrance rather than demonstrating it enhanced their ability to choose. However, the participants did appear more engaged and more secure in their choices after the introduction of fragrance. Despite the small sample size and lack of generalisability this study does provide moderate to strong quality of evidence.
- 4.41 Continuing with the theme of food, Murray-Branch (1991) explored how textured cards could be used by two deafblind teenagers to request food items. The textured cards gave choice making ability to two people who had none before. Furthermore, although not described as part of the intervention, the community aspect of this - in educational and recreational facilities, is considered to be important. It is also very portable. However despite the potential for such an intervention this study provides impressionistic to moderate quality of evidence.
- 4.42 A literature review found that very little evidence exists regarding interventions and communication, and that which does exist is generally very descriptive (Luckner et al., 2016). There is, however, some limited evidence on child-guided approaches and moderate evidence on systematic instruction for specific outcomes as well as moderate evidence of effectiveness of tactile approaches, such as touch cues, and tactile sign. The review itself is a solid piece of work and provides some evidence for the usefulness of child guided approaches, and the need for more systematic instruction, in communication. Overall, the review provides moderate to strong quality of evidence.

### ***Implications***

- 4.43 Learners who are deafblind need support to develop communication in meaningful ways. Communication supports access to information and mobility skills; and mobility skills and access to information skills support the development of communication. Support for communication development may be by providing additional access to a communication signal (e.g. by amplification of speech, or use of sign language) but for many individuals this of itself will not be enough. They will

need an interactive social environment, skilled partners and lots of opportunities for using and developing their communication.

4.44 Literature and the evidence from the REA provides some of the following points:

- As a starting point, assessment allows educators to provide appropriate communication at the right levels and in the right modes. Rowland's communication matrix is helpful, but it may need a skilled interpreter; and Dammeyer and Ask Larsen (2016) needed to create additional measures of communication mode, language level and vocabulary.
- Assessment of the communicative environment, for example, looking at 'pause times', 'opportunities' and 'functions' (Taylor Stremel and Steele, 2010), will help educators to adapt teaching and the environment to maximise communication.
- Examining the use of particular strategies within the environment, such as the use of materials in parts to ensure that learners must request more (Rowland and Schweigert, 1993) can make educators more aware of the need for these strategies.

4.45 Assessment leads on to ways of developing symbolicity. Ways of doing this from the literature include;

- Developing symbolic play (Bruce, 2005) to increase symbolic language.
- Moving from using objects as cues within a routine, gradually to a standalone referent and then reducing the object to a tactile symbols (Hodges and Pease, 2002).
- Using communication cues at one level and pairing them with symbols at the next level, to build the understanding of symbolicity. This also supports transparency in the wider community, so others can understand what is meant, e.g. partial objects actually represent, or (at a higher level) what braille means (Wolff Heller et al., 1995).
- Developing from the use of cues, concrete symbols into literacy through adapted recording using pictures, objects, video (especially for BSL) and written words (braille or text) (Crook and Miles, 1999).

4.46 The use of routes of communication which are appropriate for the deafblind learner is obviously important, taking into consideration visual, auditory/oral and tactile methods. The choice, and development of these methods can be supported by:

- At early levels, methods must be individualised to the learner (Hart, 2008; Hodges and Pease, 2002) not those favoured by school/institution policy. Cues initially need to be *part of a routine*, not abstract and unlinked to the event.
- Communication can be shaped from learners' natural responses; so that gestures can be turned gradually into signs (Souriau et al., 2008) or vocalisations into words.
- Signs in particular may need to be adapted for vision impairment (Clark, P, 1998) including non manual features<sup>8</sup> to be represented on the hands instead so they remain in view.
- Signs may need to be delivered in a tactile format (NatSIP, 2015; Watkins and Clark, T, 1991).
- Speech may need to be amplified or even accessed by touch (Tadoma method – e.g. Dammeyer and Ask Larsen, 2016; although this is now uncommon in the UK).
- Photographs, or symbols or other graphic media may need to be enhanced and adapted to be visually accessible – e.g. bigger, with anti-glare materials, less cluttered.
- Methods used may need to be adapted to meet changing circumstances, either as symbolicity develops (e.g. moving from pictures to text) or in response to changes in sensory function (Ellis and Hodges, 2013).
- Learning media assessments (McKenzie, 2007), although these are usually considered to be about *reading* access. Methods cannot be chosen solely by staff, or by the school/institution's policy. They must fit the individual.
- Staff confidence in using the methods is required to ensure that communication is natural and enjoyable (Dammeyer and Ask Larsen, 2016).

4.47 Teachers' assumptions (whether conscious or not) about learners' understanding can also mean that pupils do not receive appropriate communication. It needs to be within their symbolic level of understanding; highly abstract concepts for example, should not be represented by concrete methods. For learners who need concrete

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<sup>8</sup> Non-manual features are aspects of BSL which are not represented, usually, on the hands, e.g. shaking the head to signify a negative, or a mouth shape.

representations to process and develop communication, these can only be linked to concrete events/activities (McLarty, 1997; Rowland, 2013). It is important not only to use speech for learners who have little or no access to sound, or where this is distorted (Smithers, 2003). Communication partners need to use the right methods for the learner, and not to assume that the learner has understood them.

Dammeyer and Ask Larsen (2016) report that 22% of deafblind learners in their study were rarely or never understood. Communication partners need to talk (sign/communicate) at a pace which is understood and to use appropriate strategies, which do not only include directive actions. Bruce et al. (2004), Vervleod et al. (2006) and Smithers (2003) all show that this is not always the case.

4.48 Expanding vocabulary and function beyond the use of calendars and information systems is vitally important for cognitive development and mental wellbeing. This should include:

- Opportunities to share memories, tell jokes, and greet new friends, even with limited vocabulary and language. Educators can be much too directive (Bruce, 2005).
- Appropriate choices of vocabulary, based on the individuals' needs rather than being controlled by a member of staff. This is particularly the case for people using concrete based systems, or some technological systems (Hodges and Pease, 2002).
- An understanding of the perceptual perspective of a deafblind individual (Hart, 2006), and their own wishes and requirements in this context (Gibson, 2005).
- A vocabulary which includes comments, descriptions, and emotions, not only imperatives, in their communication mode. Deasy (2009) describes the pitfalls if this does not happen.
- Opportunities to explore new vocabulary (including, where appropriate handling objects or experiencing activities) before these are introduced into teaching (Monaco and Mamer, 1999). This enables the building of conceptual understanding (Bruce, 2005).
- Widening the horizons of deafblind learners who cannot experience such things as 'sky' or 'volcano' or even 'burning' through touch.
- Using words (spoken, signed, symbols, text) to describe emotions. Although only available to those with some abstract understanding, emotions are very

real to learners. Being able to describe how they feel is very important in terms of mental health, and managing behaviour.

4.49 Skilled communication partners are key to successful development of communication. Janssen and Rødbroe (2007) demonstrate the importance of strategies which support this. The evidence from the intervention literature shows the benefit for training and support for the communicator (Janssen et al. 2002, Janssen et al. 2003, Janssen et al. 2004). Being a good communication partner includes:

- Giving lots of opportunities within the learning environment. Vervloed et al. (2006) found that only 2% of a teacher's time was engaged in substantial communicative engagements with a particular child, even when working 1-1. Smithers (2003) identified longer periods of interaction with the pupil she studied, although these interactions were not always directed in accessible formats or about a wide range of issues.
- Staff who are appropriately trained to recognise communication attempts from learners and to respond in the ways that they understand (Villas Boas et al., 2016).
- Not only using speech (Villas Boas et al., 2016). While natural speech helps in many instances to make a communication interaction flow smoothly for the staff member, it should not be expected that learners can benefit from it. They may not be able to hear it or understand it.
- Efforts to ensure that deafblind learners, or deafblind learners with their peers, are able to interact with each other. The multitude of communication methods can lead to confusion and there is some evidence that using multiple sensory inputs may not be helpful.

4.50 Successful interactions with learners at early stages are likely to include (Hart, 2008):

- A good relationship between learner and partner.
- Physical closeness.
- A natural narrative which includes moments of excitement or surprise (something to talk about).
- A shared exploration or use of objects to which both are attending and which both communicate about.

4.51 These strategies can be used:

- In, and through, any activity which is useful to the learner (Rødbroe and Souriau, 1999).
- Through naturally occurring activities/events, which gives both more opportunities, and more motivation (Pease 2000, Brady and Bashinski, 2008)
- In motivating, and shared learning. For example, Gibson (2005) outlines his work climbing with two deafblind men as they develop their signed, gesture and picture vocabulary together.

4.52 Attunement is the process of understanding the communication attempts of the learner and to be ready to respond to them. Attunement is central to the communication partner approach (Janssen et al. 2002, Hart 2003, 2008). Attuned partners use the learners' cues as to pace, space and other factors (Dammeyer and Ask Larsen, 2016). The gradual coming together of expectations and willingness to be ready to meet the deafblind learner on their own ground is a key factor of the success of early communicative interactions. Rødbroe and Souriau (1999) discuss the importance of responding to the contribution, but also acting as a challenge and presenting new and different responses to progress communication.

4.53 Intensive interaction (Nind and Hewett, 1994) is an approach frequently used in practice and mentioned as a key strategy for developing interactional understanding for deafblind people (e.g. Hart, 2008; Hodges, 2000). However, its emphasis on eye contact and imitation of vocal and physical sequence does mean that it needs to be applied with care for learners with deafblindness.

4.54 In terms of more structured activities, the value of calendars is emphasised by several authors. Calendar systems can:

- Develop security (through an understanding of predictability) and then to help build understanding of sequence (Deasy, 2009).
- Help individuals to progress in the use of symbolic means of communication. They may begin by using two referents to describe what will happen now and next, and move to recording for much longer periods, such as a week's planning or diary. This can be an entrance to more conventional literacy (Crook and Miles, 1999).
- Progress from intentional communication using daily picture cues, to understanding weekly events, and record keeping (Murdoch et al., 2009).



- Understand days of the week as key events can be linked to this understanding (Pease, 2000).
- The use of calendars can then develop into a conversation (Blaha and Moss, 1997) or into a diary or record, which can then be shared and discussed (Crook and Miles, 1999). This can include nouns, verbs and adjectives, thus extending the scope of language.

4.55 Language learning, cognitive skills and literacy skills merge as many learners will need text or symbol support to support language learning, and likewise will need understanding of concepts to develop language. This is particularly the case in practising for real life community situations, such as shops and cafes (Castro and Miles, 1999).

Choices can:

- Be structured to support the development of both symbollicity and intentionality.
- Be very motivating, and can reinforce agency and self-esteem (Olson 1999). It is not often considered that it is also hard work (Hodges, 2003b).
- Help to develop the use of more abstract referents. Murdoch et al. (2014) used food smells on cards (this was complex and difficult to reproduce) and Murray Branch (1991) used tactile referents. Both had some success.

4.56 Pauses can support the development of intentionality and decrease passivity:

- Increasing the time staff wait for a response can encourage initiative and pass control to the learner (Johnson and Parker, 2013).
- Pauses provide opportunities for interaction and for non-directive activities (Miles, 2008).
- Pauses also decrease anxiety and demands on the learner, so allowing them to dictate pace (Ayer, 2010).
- Pauses can help overcome dependence on only responding to staff/parent initiatives.

4.57 Finally, it is important to remember that the quality of amplification or assisted hearing may be a key component of success. While out of the scope of this review, this emphasises the importance of accurate audiological assessment and accurate prescription of hearing instruments, which is known to be difficult in people with multiple disabilities (e.g. McCracken et al., 2008). The significance of hearing which

affects not just speech but language (Thelin and Fussner, 2005) means that educators must take very seriously setting up programmes to encourage hearing aid use and support those who find it initially difficult.

## **Literacy**

### *Introduction*

- 4.58 That traditional reading will be potentially difficult for deafblind people is almost axiomatic – they may not be able to see a printed word properly, nor to hear it when pronounced (and may not know it) (Ingraham and Andrews, 2010). Due to the difficulties for deafblind people in developing communication, many never in fact achieve any functional literacy. Some, however, do in either print or tactile means. As outlined above in Section 3.1 in the overview of the evidence, there were a number of areas where no evidence which met the criteria for inclusion in the Intervention studies was found. Literacy was one of these; there is no identified research evidence evaluating the success of any particular strategies relating to the development of literacy in deafblind learners.
- 4.59 In the area of deafblindness in particular, there is much debate about what *literacy* actually implies. Watson et al. (2004) recognise the development of formal literacy (such as *reading* and *writing*) as developing through much earlier forms of communication (the use of objects, of picture symbols and of deliberate communication in other ways). They write about sensory impairments in general but most of their examples are from deafblind people and were generated by the experience of professional attendees at a workshop exploring these issues. McKenzie (2009a) also describes the limitation of expectation for deafblind learners when they are described as non-readers rather than emergent readers. Perkins School (for blind and deafblind students, in the USA) supports the website Paths to Literacy<sup>9</sup> that includes a strand entirely about deafblindness, which recognises that language and concept development are the foundations of literacy. They also recognise other possible routes to literacy, such as through listening and dictating in the new ‘multi-media world’ (Hatlen, 2004).

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<sup>9</sup> [Paths to Literacy](#)

- 4.60 A variety of approaches for literacy are described by authors including the use of storytelling, and making literary classics (e.g. Park, 2004 on Genesis) accessible through the format of rhyme, rhythm and through vibration and multi-sensory stimulation. Access to ‘literature’ – stories and rhymes – through the means of ‘sensory stories’ is also a regular part of the education of many deafblind pupils, particularly those in schools for children with severe or profound learning disabilities (Park, 2007; Fuller, 2012; Marion in Sense Blog, 2016; Grace, 2015; Murdoch et al., 2009; also seen on the deafblindness Paths to Literacy blog).
- 4.61 While there is no research material on sensory stories specifically in relation to deafblindness in academic literature, experience in schools, (including from students’ research), shows that it is one of the most widely used curriculum experiences for pupils with severe or profound learning disability and deafblindness.
- 4.62 A second important strand which is present in many schools (particularly where working with children with learning disabilities) is the use of morning circle/meeting in which learners are frequently part of activities which involve the printed word for names of classmates, days of the week, and weather (McKenzie 2009b). As well as seen in McKenzie’s work, this is also supported by the writing and shared experiences of multiple students on their experience as teachers in classrooms.
- 4.63 There is, therefore, a strong argument that for deafblind learners in particular, literacy and communication are particularly strongly intertwined (Watson et al., 2004; McKenzie 2009a). There are forms of communication which are embedded in literacy – such as the use of the deafblind manual alphabet (Ingraham and Andrews, 2010), although some would consider that the use of a single letter, e.g. for a name sign, is not alphabetical but rather a form of signing. For deafblind learners in particular, the use of text (in braille or print) or other literacy formats such as picture symbols can be vitally important in backing up spoken words which may not be heard properly. The same can be true for the use of subtitles or captions for visual media (Ingraham and Andrews 2010). Indeed, for some, reading has been used as a route to communication (rather than the other way round) as in Thorley et al. (1991) where a young person exposed to large print words was able to express himself although he could not use sign. Watson et al. (2004) also give an example of a learner communicating through a print medium even giving meaning to a string of letters he invented which does not exist in the English language – as if he were using ‘babbling’ like a typical infant and creating neologisms – but in text. Thus the

skills of recognition, sequencing, and memory which are part of reading are, in fact, part of the basic communication skills which are assumed to come 'first'. As Ingraham and Andrews (2010) point out, the 21<sup>st</sup> century world *does* require communication through text based media perhaps even more than any previous generation –SMS messages, social media, email, and more. The two have been embedded as people say they have 'spoken' to someone when what they did was email or text.

- 4.64 In addition, all this points to the importance of knowing how best individuals who are deafblind can access literacy. Even assuming that this might mean access to 'print media' rather than the complexity of embedded communication, the use of visual, tactile and auditory methods or combinations of these might each be appropriate for any one individual. As Ingraham and Andrews's study (2010) shows, deafblind readers use different routes to reading. McKenzie (2009b) describes the importance of a learning media assessment and that this may be different to that required for a vision impaired learner; using parameters such as visual access, hearing access, communication mode, conceptual development, and other difficulties to reach a decision. McKenzie's (2007) research showed that, in fact, most deafblind learners in her study had not had any assessment which showed how they might access reading and writing, (possibly because of the complexity) and that this was likely to mean they wouldn't get the best support for learning (McKenzie 2009b).
- 4.65 McKenzie also found that there were (in the USA) few targets set on IEPs (individual education plans) relating to literacy for deafblind learners in her study. Whether this is the same in the UK, or in Wales, is unknown.
- 4.66 The importance of life stories and memories for deafblind people who are not literate in typical ways must be recognised, because ability to reminisce and remember with others is an important human characteristic. There has been little work on records, diaries or otherwise recording memories for deafblind people, although some has been done using objects, photographs and others (e.g. Hodges, 2003). Scrapbooks, photo displays and more can be particularly important for helping people remember and understand who they are.
- 4.67 Of course some deafblind students do become effective readers, in either print or tactile media, or indeed expert readers. These students will continue to be affected, in particular, by the limitations of their experience which means there are concepts and ideas which they have not heard about. However, for them, reading may

actually be a support to their learning, as a medium in which they *can* be equal or near equal with others (though their reading speed is likely to be slower as with many learners with vision impairment). They can find out, from reading, about many issues which have not otherwise come to their experience.

- 4.68 There is no known literature about the effect of hearing impairment on learning to read for people with vision impairment. These effects would include issues such as the use of phonics, which can be restricted by hearing impairment, particularly where a learner cannot lip read. Phonics, although a method recommended and sometimes stipulated in schools may not be a useful approach for deafblind learners. Even the use of braille (Unified English Braille – UEB) can be problematic because for a profoundly deaf learner there are rules for the use of contracted braille which rely on understanding how a word sounds or is segmented – e.g. beautiful can include the contraction ‘be’, but be-auty would not. These rules may not be understood by someone who cannot hear the sounds. As with deaf and hearing impaired readers, it may be that written language needs to be expressed more straightforwardly, for instance using fewer embedded clauses and no use of double negatives. Such adaptations are not usually required for learners with vision impairment. These are even more crucial for deafblind learners, who may have less understanding of the world around them. Lack of vocabulary (because of lack of experience) is likely to limit their access to literacy considerably. In combination with vision impairment then, this will mean that literacy skills are more difficult to develop and take longer, and need more support.

*Available evidence*

- 4.69 Luckner et al. (2016) conducted a literature review which found that most studies on literacy instruction for deafblind children are descriptive studies and that there is a need for intervention studies, including both expressive and narrative literacy skills. It is suggested that literacy should be promoted through diaries, schedules, story boxes and experience books. There is moderate evidence of the effectiveness of tactile approaches, such as touch cues, and tactile signs. This study provides strong quality of evidence particularly in relation to its implication for practice, generalisability, and overall evaluation.

## ***Implications***

- 4.70 Literacy can open doors – for some deafblind people it can lead to further development of knowledge and understanding, and allow them to continue an education. But for others it is also important for a range of practical things such as keeping shopping lists and diary schedules. It is also a vital way of keeping in touch with others, through letters, text messages, or cards. It is particularly important in helping people to understand who they are and their own history. Literacy can take a variety of forms and formats and these formats should be chosen carefully to make the most use of skills and abilities as, well as helping learners to make use of all they can.
- 4.71 To help to achieve literacy for deafblind learners, the following implications are drawn from literature and experience:
- Literacy education should begin early for deafblind students, whether or not they are ‘ready to read’ (Watson et al., 2004). This can include the use of sensory stories, calendars, and being ‘read’ to in voice, or sign (for rhythm, motivation, and experience of books). Reading needs to be talked about (McKenzie, 2009b).
  - Environments should be arranged to support literacy (McKenzie and Davidson 2007) and this can be by providing labelling, and opportunities to scribble in print and braille, (McKenzie 2009b).
  - Stories can be told using books, objects, musical instruments, songs and voice output communication aids (Murdoch et al., 2009). This will aid emergent literacy and reinforce concepts and communication.
  - Personalised and individual books can be developed from photograph or audio material recording events in which learners have taken part, and labelled with text (or symbols) to develop reading skills (Murdoch et al., 2009). Learners whose experience is limited may not be able to relate to more typical story books.
  - Younger or earlier readers may need support for *developing* the concepts which they then read about – for example, finding out about playgrounds, shops and so on in order to be able to read books about them or to learn about things they cannot see, such as such as roofs, rainbows and unicorns.

- Calendar work can be developed by linking to text (or symbols) to support literacy (Crook and Miles, 1999). This can be moved into writing home school books together and to developing recording skills and supporting memory, a very important skill (Bruce et al., 2008).
- Even emergent readers (who are not accessing print) might need targets relating to developing literacy, which should be recognised as a route to wider knowledge and understanding, and perhaps a way of learning more language.
- Learning media assessments will support staff in finding the best routes, print, braille, or auditory/oral means for accessing text (McKenzie, 2009a and 2009b).
- Those who are reading texts will need support from large print, video magnification, or braille. Braille is especially important for some deafblind readers, unable to access through screen reading software for example. They will need to understand their own needs and how to use assistive technology.
- Readers should be able to make choices which include using multiple means of access (Watson et al., 2004; McKenzie, 2009a and 2009b). Ingraham and Andrews (2010) participants used braille, scanning and screen reading, large print, video magnification and sign language interpretation.
- More able readers will need access to meta-skills, such as skimming, using indexes, recognising titles and subtitles – skills which other readers acquire without help.

4.72 Given the heterogeneity of deafblindness, the different levels of vision and hearing, and the different combinations of these, their range of experience, the presence of other disabilities (or not), the different communication modes which may be used (speech, sign or others) and of course the range of ages, no prescribed route can be set out for developing into literacy for deafblind learners as a whole. Each learner will be on a particular and individual journey, which will need to be carefully tailored to them, and account for their particular access needs. Literacy can be a route *to developing* a vocabulary and a language and, thus, it is crucial that possible routes are explored. This does not mean that every deafblind learner will learn to read, but that the potentials of this should be investigated.

- 4.73 Good assessment is crucial towards working out this route. This might, for instance, begin with using photographs to using pictures labelled with words, to using pictograms and onto text for shopping lists. Or it might be using increased fingerspelling leading to links to braille. The use of strategies from vision impairment and hearing impairment will support this but they have to be used as appropriate to an individual's dual impairments. Some strategies used for hearing impaired learners depend on the use of visual strategies which would not be appropriate, and some for vision impaired learners use auditory strategies which likewise would not be appropriate.
- 4.74 The route to literacy is not straightforward but, individually and skilfully supported, it can be accessed, and be a route of access, for deafblind pupils.

## **Mathematics and Numeracy**

### *Introduction*

- 4.75 There was no evidence in particular about teaching deafblind learners mathematics or numeracy and it is important firstly to discuss why this is the case. The strongest focus in the development of education of deafblind people has long been on communication (e.g. Rødbroe and Souriau, 1999) and it is certainly arguable that it is not possible to work on maths until communication has been established.
- 4.76 In relation, then, to the teaching of mathematics, there are some reasons why deafblind learners may have particular issues with mathematical learning. One of these is the difficulty with incidental learning, because those who have solely vision impairment constantly hear the language of maths (counting, time, shape, money and measurement) and those who are solely hearing impaired are presented with varied opportunities for exploring it – room and bus numbers, coins, clocks, and tape measures and scales. Deafblind learners do not have access, or have limited access to these concepts unless they are deliberately directed to them. With a major focus on communication, this may not be done in a structured pattern.
- 4.77 In fact, mathematics is mentioned only rarely at all in literature about deafblindness. In the 1997 document Curriculum Access for Deafblind Children, (Porter et al., 1997) particular strategies were discussed in relation to communication (e.g. signing, choice making, objects of reference, speech) but the only mentions in relation to maths were from a case study example in which strategies of physical prompting, guiding, modelling and imitation were seen, none of which were



particularly related to maths. The only article found relating directly to maths teaching was Galvão et al. (2018) about accessing a regular plane geometry class through adaptation and did not discuss issues about mathematics in general.

- 4.78 In fact, the concrete nature of much of the early learning in maths – counting, shape, simple measurement, and money, might make learning easier for deafblind learners in this area, if there were more evidence about how to do it. These are essential characteristics of daily life and independence. Corbett (2016) discussed the knowledge of congenitally deafblind adults about time (through a questionnaire to staff), including the use of calendar systems, and concluded that in fact most of the deafblind people the staff knew had little access to systems which enabled them to tell or understand time. Interestingly even here the focus was primarily on communication.
- 4.79 Early mathematical learning is, for course, deeply embedded in daily living skills. While topics such as weighing, money and time are clearly essential for such higher level skills as shopping, cooking and scheduling, at earlier levels, important concepts such as sorting, categorising and shape are involved in washing up, laying a table and sorting clothes from a dryer.
- 4.80 The Victoria School MSI curriculum (Murdoch et al. 2009) links early stage maths to conceptual development and responses to routines and changes. The latter links to patterns and anticipation and prediction.

#### *Available evidence*

- 4.81 As outlined in section 3.1 no evidence meeting the criteria for Intervention studies was identified through the REA

#### *Implications*

- 4.82 Diminished vision and hearing have an effect on incidental learning which means that mathematical concepts are not typically presented through life in the same way to learners with vision and hearing impairment. Because of this they will need to be deliberately brought to the attention of learners. In many cases visual and auditory enhancements may be needed, for example, louder talking scales, hi-contrast, e.g. yellow and black rulers, or microwave dials with brighter coloured numbers.

#### 4.83 Mathematical experiences could include:

- Counting
  - ‘counting’ to two, and recognising more than two by using two hands – e.g. holding a toy in each hand, but there are more on the table.
  - counting routines through activities even at early levels (as parents count steps for young children), including numbers higher than three.
  - opportunities to count, measure and manipulate using tactile, concrete methods, e.g. using hand measure, (a handful of flour, a hand’s length of string, a finger to measure a full cup).
  - matching fingers to items (one finger on each item to five) to build understanding of quantity and the signed language for counting.
  - using simple supports such as a pound coin holder to assist in practical situations even when change is not understood.
  - using concrete supports such as ice cube trays, cuisenaire rods<sup>10</sup> or linking blocks to build understanding of one to one correspondence and numbers. These concrete experiences build concepts and support mathematical learning (Deuce 2015).
- Measure
  - measuring e.g. cooking ingredients by cupfuls, spoonfuls rather than use of vibrating kitchen timers, talking scales, microwaves with dial (not button displays because the turn of a dial can be felt and marked) as appropriate in practical activities.
- Early Mathematical concepts
  - supporting one to one correspondence by natural opportunities e.g. each cup goes on a particular hook and there are only five, or every pair of shoes has a place in the shoe hanger).
  - supporting categorising (sorting) by labelling drawers or cupboards with the item inside (e.g. sorting clothes) (Nietupski and Hamre-Nietupski, 1987).

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<sup>10</sup> Cuisenaire rods are a concrete support to mathematics development, comprising a set of rods in different lengths to facilitate concepts of addition, subtraction, multiplication and division.

- Language and skills
  - the use of mathematical language, including measure, time and shape as well as numbers, and addition and subtraction (adding or taking away) in practical situations to encourage understanding, for example in matching biscuits to people and seeing how as they take them the number goes down.
  - use of time as linked to numbers (e.g. 'afternoon' is 1 o'clock).
- Shape
  - using objects which fit and don't fit into others – biscuits into plastic tubs – can help understand shape.

4.84 For those working at higher levels of learning, the same issues will arise as for learners with vision impairment and hearing impairment. Learners may need tactile learning methods, the complex codes of braille maths, or may need support for the development of terminology for mathematical concepts and calculations. They may well have less exposure to knowledge and understanding of mathematical concepts and need additional support. However, the fact that some higher maths skills are 'absolute' and are not about individual evaluation, and therefore to some extent do not require social understanding or great amounts of reading may support mathematical study for some individuals.

### **Access to examinations**

#### *Introduction*

- 4.85 Examinations are a stressful time for all students but students with deafblindness have to manage a range of issues over and above simply whether they have learned their material and can produce this evidence. They may have to manage additional time (which, although of course it can be absolutely necessary, makes examinations longer and can be very stressful in itself), and staff supporting them, and the rigour of exams meaning that people behave in different ways (see Horvath et al., 2005). This can be much harder for a deafblind pupil to understand.
- 4.86 As discussed by Horvath et al. (2005) each deafblind student presents a unique challenge to an examination system because of the combined levels of vision and hearing, and the best and most accessible formats for access to learning. While examinations may be related to a particular subject (e.g. history or English language) the papers may unconsciously expect and require a level of general

knowledge and understanding about the world which is much harder for a deafblind person to acquire. This is because a deafblind person may need all learning brought to their attention and not have access to the incidental learning from conversation, TV and other media. An example of this (from practice) is a deafblind learner who found a National Curriculum English assessment about fairgrounds very difficult because she had no direct experience and little incidental learning so was unable to write an essay about this. Similarly, a candidate at higher levels might not be able to compare a historical approach to an otherwise well known and publicised news event, such as the election of Donald Trump and the discussion of 'fake news'.

- 4.87 Other issues which are of significance for those taking exams may include the fact that through their learning journeys their needs may change (the issue of changing eyesight for learners with Usher Syndrome for example and the difficulties with change itself which this poses – Ellis and Hodges 2013). As the measure for acceptance of alternative access arrangements by the JCQ – Joint Council for Qualifications is that the modifications represent their 'normal way of working' (JCQ, multiple instances), this can present problems for learners who are constantly adjusting font size or who now require more time than previously to read text.
- 4.88 For many deafblind pupils in the UK, including Wales, procedures for standardised testing of this sort will not be relevant. Their achievements, while still of value, may be affected by multiple disabilities and intellectual impairments which mean they will not access public examinations.

*Available evidence*

- 4.89 No evidence meeting the criteria for Intervention studies was identified through the REA.

***Implications***

- 4.90 In practical terms, access to examinations in the UK is clearly laid out in the JCQ guidelines, unlike in the USA and Horvath et al.'s study (2005) where these could be individually negotiated. Nevertheless, individual pupils will need individual packages within the guidelines. These provisions are, of course, also those referred to in the parallel studies on deafness and on vision impairment and those discussions will be applicable for individual learners. However, for deafblind learners undertaking exams, they will likely require unique and individualised

packages of support, such as for example, braille and hands on BSL. Access may require a range of adjustments, as allowed by the JCQ. This might include:

- Different ways of presenting print materials (in different size fonts, in braille, with adapted diagrams).
- Use of modified language, or BSL a using a reader and or scribe (including a live reader to allow for listening examinations to be lip read).
- Having rest breaks, and having extra time (JCQ 2017).
- Use of assistive technology, including laptops.

4.91 Where specialist teachers of pupils with MSI are not available, the lead teacher (either Qualified Teacher of the Visually Impaired or Qualified Teacher of the Deaf QTVI or ToD) who is working with the learner may ensure accommodations are available which relate to that disability, but fail to see or understand requirements for the combined difficulties (see Horvath et al., 2005 for this issue in the USA).

4.92 It is also very important to teach learners to understand and be able to articulate their needs for support for assessments and exams. Once they have moved on to college or university, for instance, they will need to be responsible for asking for what they need (Ellis and Hodges, 2013). Testing and assessments will of course continue from school into any further education or training which deafblind people undertake.

4.93 The key message from this area is the importance of individualised packages of accommodations for examinations, and that these are discussed and related to what the person needs and wants – there is no purpose in an accommodation if the learner does not want to use it. Young people, therefore, should be involved in choosing how to access tests and assessments so that they learn to be able to choose good methods for accessing public examinations when they come. Given that they are also very likely to need longer for examinations themselves, and that the revision, preparation and learning for them will also take longer, they may need flexibility about the timescale for exams, with the opportunity to take some in subsequent years and not all at once.

## **Mobility and independence**

### *Introduction*

- 4.94 Mobility and orientation is one of the key areas identified in the definition of deafblindness; that combined vision and hearing impairment will cause difficulties in relation to mobility. Despite this, however, there is very little indeed written about mobility and orientation for deafblind people, especially children and young people, and even key resources such as McInnes (Editor) *A guide to planning and support for individuals who are deafblind* (1999) and Aitken Buultjens, Clark Eyre and Pease (editors) *Teaching Children who are Deafblind, Contact, Communication and Learning* 2000) do not include chapters on mobility and orientation. Parker (2012) found one significant author in her search for single subject designs and this author (Lancioni, 1980) has mostly written about adults. For some authors no clear distinction is made of what is important for learners with vision impairment and those who are deafblind – for example, in '*Innovative program design for individuals with dual sensory impairments*' (Eds Goetz, Guess and Stremel Campbell, 1987) the chapter on teaching orientation and mobility skills contains only a very few words on deafness (Gee Harrell and Rosenberg 1987), despite the fact that McInnes and Treffry (1982) indicate that much of the information about mobility for people with vision impairment is not applicable to deafblind people. They outline the key needs of deafblind (as opposed to vision impaired learners) including lack of auditory cues and difficulty in communication about and within the environment.
- 4.95 Because of differing levels of vision and hearing impairment, deafblind learners are likely to have divergent paths to developing skills in this area. The lack of auditory clues (so important for learners with vision impairment) and the difficulties in communication with people in the community, and with those teaching mobility skills, will have significant effects on deafblind people learning to manage their mobility and independence in the wider world (Gense and Gense 2004). Gense and Gense describe the difference between working on orientation and mobility skills with a visually impaired student and a deafblind student as being primarily related to communication and language.
- 4.96 For many deafblind people balance may also be a significant issue given that the balance senses are housed in the same basic apparatus as hearing senses (the semi-circular canals in the inner ear) and can sometimes be affected by the issues that cause deafness. Balance is a particular issue for learners with Usher

syndrome and balance and proprioceptive senses for learners with CHARGE (e.g. as described by Lieberman et al., 2012 and Brown, 2011). Other issues which may affect the development of physical skills include additional physical difficulties, limited opportunity or motivation to play in typical environments or take part in physical activity (Lieberman et al., 2003).

4.97 In relation to independence, while this is an acknowledged goal in some writing (e.g. Sauerberger, 1993 about adults) there is some writing connected to the mobility and orientation discussions (e.g. Phillips et al., 2013). There are a number of articles related to basic training such as feeding and using the toilet which are based on techniques for people with severe disabilities but not necessarily very specific to deafblind children (e.g. Lancioni 1980). One important area is the level of organisational skill that deafblind young people require – the abilities to get access to what they need (e.g. ask for materials in the correct sizes, hand over an FM system, be guided to where they need to go). The deafblind learner is almost never (even in a school for the deaf, or provision for the vision impaired) in a deafblind friendly environment, because an additional set of adaptations needs to be put in place. They need to learn to self advocate. Without developing skills in independence, the support they might be provided, e.g. by an intervenor becomes merely direction and control. Venn and Wadler (1990) described a situation which can be seen in schools nearly 30 years later, where deafblind students were rarely without direct supervision, and were unable to begin, maintain or complete activities without prompting or direction. Strategies need to be put in place to pass over as much control as possible.

4.98 Bruce and Parker (2012) discuss the significance of deafblind people learning to advocate for themselves, because there are many obstacles to their understanding of the world and how to work within it. As they suggest, this kind of self-advocacy can never be begun too early, with learners learning about themselves as independent individuals and how to ensure that they are included and listened to.

*Available evidence*

4.99 Luiselli (1988) examined specific behavioural feeding interventions for two individual deafblind children with multiple disabilities. The intervention for the first participant involved a physical prompt (elbow tap) to encourage focus on the task when self-feeding. The intervention for the second participant was designed to encourage more variety in food choices – when a new food was tasted a desired food (an M+M

sweet) was given. The interventions were designed to be administered by care staff at lunch time rather than teachers. The results from the first case study show that the intervention was moderately to highly effective, especially when the wait time before the physical prompt was shortened. With the second study, a wider range of foods were consumed, however this appears to be dependent on the sweet still being given - there was no maintenance period. Due to the small sample size, lack of generalisability, and limited critical reflection on the limitations of the study it only provides impressionistic to moderate quality of evidence.

- 4.100 The training of self-feeding skills in two deafblind children with multiple disabilities was explored by Luiselli (1993). The first study examined the effectiveness of a six step teaching program for self-feeding with a spoon and the second examined the effectiveness of an intervention which sought to refine the self-feeding skills of a child with interfering behaviours. The interventions utilised the well-established techniques of prompting, prompt fade, and positive reinforcement. The interventions were highly effective in both cases for these two individual participants – training effects were achieved quickly and easily maintained, and were readily adopted by parents in the home environment. Although only providing impressionistic evidence in relation to sample size and generalisability, overall the study provides moderate to strong quality of evidence.
- 4.101 McKelvey et al. (1992) examine a guided approach to teach self-dressing skills to an 11 year old deafblind girl with multiple disabilities. Manual guidance was used to teach the student how to put on socks, top, and shorts. The participant was taught the whole sequence for putting on a particular item, rather than a step-by-step approach. The evidence suggests that this was highly effective for this particular student. However due to the limitations relating to sample size and generalisability as well as the quality of the outcome measures and the research design, and the data reporting and critical reflections on the limitations of the study this paper only provides impressionistic to moderate quality of evidence.

#### *Implications*

- 4.102 Mobility and orientation is a key area requiring education and support for deafblind learners. Unfortunately it is often underestimated as an issue of importance, particularly for learners who are not going to become independent walkers. The focus on 'mobility skills' as requiring the use of particular techniques for ambulant travellers and for using long canes may have influenced learners into considering



that it is not important for other learners. Learners with deafblindness who are wheelchair users, including those who will not be able to use any travel skills themselves, also need to learn about their position in space, the layout of the world and the properties of their own bodies and movement.

4.103 With little evidence then on mobility and orientation, the following need to be considered:

- Mobility should be considered as a key goal for deafblind learners – it is distinct from motor skills and requires special consideration because of deafblindness (Aitken, 2000; McInnes, 1999). Practitioners report that learners especially those at early levels, are unlikely to have goals in mobility and orientation.
- Mobility needs to begin early – teaching a learner about their body, about space, exploring (McInnes and Treffry, 1982) and then learning where objects are, reaching for them (Gense and Gense, 2004). This needs to include laterality, direction and position (Cratty and Sams 1968).
- Massage, physiotherapy, and swimming can support mobility and orientation goals.
- Environments should support learning; through for example consistent place names in schools (e.g. one agreed name in speech, sign or symbol for a room, not ‘cooking, food tech, or kitchen’). Environmental audits should make routes clear and mobility safe (Naish et al., 2003). Places should be distinguished by key features (e.g. swimming pool smells, hall echo) – classrooms may all initially be much the same.
- Formal mobility techniques such as cane use can be taught even to young learners (Scott, 2015, about vision impaired young people) and even for wheelchair users (Gense and Gense, 2004). Wheelchair ‘buffers’ can be used to support trailing for someone using both hands to propel their own chair (Gense and Gense, 2004). Teaching methods may need to be adapted according to individual communication needs, but experience shows that formal language is not pre-requisite. Qualified habilitation specialists (QHS) should be involved for teaching specific skills (e.g. long cane use).
- Control should be given to and shared with the learner for any guiding (including pushing wheelchairs) as soon as possible (Langham, 1999), for example, indicating when they want to begin, rather than just being pushed

off (Thomas, 1987). Consistent routes will develop skills such as pointing in the correct direction at corners can also be included.

- Structured travel training should begin with teaching individual, naturally occurring routes rather than general principles (Gee et al., 1995; Gee et al., 1997).
- Particular approaches may be needed for deafblind learners, not depending so much on listening, using adapted canes, and adjusting communication – they may need communication before a route rather than during it (Marx, 2004; Joffe, 1999). They may need to be taught to listen – e.g. in particular using directional sounds (Phillips et al., 2013). They will need to learn how to manage in the community, for example by using cue cards (Sauerberger, 1993).

4.104 In terms of developing independence, the following will be supportive:

- Deafblind learners can be given responsibility as soon as possible for putting away materials when they are finished (even if only into a 'finished' basket) and in so far as possible, to fetch and then put away their own materials.
- More able and older learners will need to learn to manage their own equipment - hearing aids, assistive devices and so on. This includes asking for help when needed.
- Learners who cannot manage these things for themselves may be able to learn to ask for help with them (can you get... could you fix...) even by simple pointing or gesture. Autonomy is possible with limited physical skills, it is planning, initiating, implementing and completing, which is needed (Okbøl, 2014).
- Learners need to understand their own needs, asking for help, and reviewing what is working for them –for example, how much support they need, whether the lights are bright enough, will help them develop agency and independence (Bruce and Parker, 2012; Phillips et al., 2013).

4.105 This can all build the ability to advocate for themselves, and to learn, perhaps later in life, to manage support staff (e.g. as they may need to do at college). McInnes (1999) for example, describes the intervenor not as the eyes and ears of the child, but the taxi driver, telephone operator and tourist information centre (relating to mobility, communication and access to information) which are under the direction of the deafblind person, rather than directing them.

## **Cognitive skills**

### *Introduction*

- 4.106 The development of cognitive skills in deafblind learners is interesting from a psychological perspective; could it be expected that people with distorted and restricted access to vision and hearing would learn in the same way as other children? (Diderot 1999). In fact, development of the ability to learn from and act on the environment is reflected in one of the key difficulties caused by deafblindness - a lack of access to information. As with other areas there are strong relationships with hearing impairment and vision impairment.
- 4.107 The areas which are likely to be of particular significance include:
- Experiential learning and concept development
  - Development of a sense of agency (an ability to make changes in the world by action)
  - The link between language and learning
  - Attention, perception and memory
  - Tactile cognition
  - Executive function difficulties.
- 4.108 Deafblind learners are less able to learn from the environment around them and to understand that their actions have an impact on it. They are, therefore, much more likely to develop into passive learners and to lack the creative initiative for curiosity and enquiry. Their difficulties with communication and mobility will also interact with their difficulty in developing concepts of the world and their ability to understand it. As a deafblind person, their learning relies more on direct experience, and is related to the interaction of their bodies with the world (embodied cognition – Deasy and Lyddy, 2006). Because they have more limited experience (related to their difficulties with mobility, and communication) they are less likely to be able to make sense of, and integrate, learning presented in an abstract way. This further limits their understanding, and therefore, their developing learning.
- 4.109 Intellectual achievement (typical development in cognitive terms) can be linked with levels of sensory impairment. Salem-Hartshorne (2011) notes that for individuals with CHARGE syndrome, intellectual capacity is related to the degree of vision impairment. This is not necessarily causal as it could be the case that the two

effects occur together (e.g. time and extent of brain development in utero) rather than an effect of vision loss.

### *Experiential Learning*

- 4.110 Aitken (2000) points out how lack of sensory input deprives deafblind children of the ability to learn patterns and predictability in their environment. They may not learn easily about cause and effect, pattern and structure, or agency because they are not able to perceive the effects of their actions, to see the repetition in the environment or to see that it is them who are affecting the environment (Aitken 2000). Deafblind people are, almost axiomatically, deprived of typical interaction with the environment. They cannot use their vision, or their hearing, to learn incidentally and experientially from the environment (Monaco and Mamer 1999). Lack of experience leads to limited concept development, in particular, difficulty with abstract concepts, which are also related to language learning (Geenens 1999). As McInnes and Treffry (1982) outline, it is not necessarily the processing ability that is damaged, but the input mechanism.

### *Sense of agency*

- 4.111 Problems with agency are reported by authors such as Marks (1998) who outlines that because deafblind learners cannot observe persistence and self initiation in others, they may be less likely to take control of situations themselves, instead becoming passive in response to learning opportunities. He identifies the dangers of lack of motivation and persistence, dependence on prompts, manipulation by adults when the learner does not initiate and a history of failure. To reverse these he outlines the importance of high expectations by staff, appropriate sensory stimulation, predictable environments, and ensuring the possibility of success. The sense of agency is also outlined as significant by Reed and Addis (1996) (although they are discussing now very dated technology) in developing an understanding through the use of switching systems and is supported as one of the key curriculum requirements for deafblind children in the Victoria School MSI curriculum (Murdoch et al., 2009).

### *Language and Learning*

- 4.112 The use of language to describe and express ideas and concepts which cannot be seen can be an effective compensation for people with vision impairment. However, deafblind learners are significantly more at risk because frequently their

language is delayed and restricted. Geenens (1999) describes difficulties with language as the “primary limiting variable” for deafblind learners. The difficulty with language also means that deafblind learners may appear not to be developing in typical ways and thus others relate to them as if they have a learning disability, and this further limits their potential (Geenens 1999).

- 4.113 Bruce describes ‘a reciprocal relationship’ between cognition and language, (2005, p234) which means that without language, cognitive skills are delayed. Pizzo and Bruce (2010) link this to difficulty in accessing the environment, because deafblind learners do not have the experiences, or do not have them repeated often enough to allow the development of conceptual labels. This is linked to the ability to use representation in symbolic play in early years, which also allows cognitive skills about the world to be developed. The skills of object permanence, cause and effect, categorisation and imitation are also linked to the development of language (Deasy, 2009). Without an understanding that one referent links to one meaning, symbolic language cannot be established (Rowland and Stremel Campbell 1987). Discrimination between symbolic referents is a necessary pre-requisite of language and imitation drives the production of expressive language through gradual shaping (Bruce 2005). This mutual development means that the vulnerability in relation to communication delay has a significant impact on cognitive skills, although the two are so linked that it is not possible to say which is which.

*Learning skills (including perception, and memory)*

- 4.114 The work of Henricson et al. (2016) indicates that difficulties in the areas of learning skills, in particular perception and memory may be related to deafblindness itself (and not only because many deafblind people have additional learning disability). Both people (adults) with Usher and Alström syndromes demonstrated lower levels (than control groups) of Theory of Mind<sup>11</sup>, although the additional disabilities associated with Alström may well have caused their still lower levels (Frölander et al., 2014; Henricson et al., 2016). They also demonstrated difficulties with verbal reasoning and problem solving capacity in the deafblind adults. Subtests demonstrated difficulties in working memory, and verbal reasoning.

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<sup>11</sup> The ability to attribute mental states to other people

- 4.115 To some extent of course, difficulties with cognitive skills are affected by vision and hearing disabilities – causing problems with speed of processing reading for example (Henricson et al., 2015). Similarly, Bruce (2005) describes the difficulty deafblind learners have in developing links between referents and what they refer to, through the processes of understanding that they are different and separate from the world around them. The difficulties caused by deafblindness- e.g. that they only have experience of parts of objects or activities, link to the further difficulties in aspects such as joint attention. Without this it is hard to further, and to develop, understanding which might lead to the development of symbolic understanding.
- 4.116 Most children learn a great deal through imitation; they learn both deliberately when told 'do this' and also incidentally. Much of this learning is inaccessible to the deafblind learner (Miles and McLetchie 2008) who needs imitation to be brought to them, and to be able to touch and feel. They may need to be taught subsequent, rather than concurrent, imitation.
- 4.117 Narayan et al. (2010) reported that the parents and teachers of the deafblind children they studied considered the children more 'creative' than the parents and teachers did of children with learning difficulties. While they give no further explanation, perhaps this creativity is a way of solving problems and difficulties which children with deafblindness demonstrated, to overcome the restrictions of their deafblindness, thus demonstrating higher levels of understanding than they might otherwise be credited with.

#### *Tactile cognition*

- 4.118 There is little known about how cognition which is based on tactile perception is activated, implemented and interpreted. Although touch as a sensory mechanism is a basic part of our perceptual mechanism and is part of everyone's experience, (Hart, 2010) the conscious use of touch, or indeed the understanding of its contribution to sighted hearing people is little recognised. As a main, or significant means of building learning and developing cognitive skills, even less is known. A theoretical background to the complexity of tactile processing and its use in providing specific, multi-source information is given by Nicholas, (2010). Specific processes include tactile short term, working and long term memory, tactile attention, the ability to acquire new information. However, little of the research involved in his discussion was carried out with deafblind people. Ask Larsen and Damen (2014) recognise the 'sequential and fragmented' nature of touch based

processing, unlike the 'simultaneous and holistic nature' of visual processing for example (both p13). It is not known how this might relate to the nature of the building of cognitive skills; but it is unlikely to be irrelevant.

- 4.119 While there is evidence (e.g Janssen et al., 2007) that deafblind people may have more tactile perception than people with no vision problems, the difficulties of encoding information, in particular for memory, are indicated. Memory is a vital process in learning and where it is limited, it will have a potentially profound effect on learning processes. Whether better tactile memory can be taught is unknown. Janssen et al. showed tactile memory is no more advanced for deafblind people than it is for people artificially without vision through using sleepshades. However, Nicholas (2010) outlines a case study of a deafblind person with a better tactile memory, and Nicholas and Koppen (2007, cited in Hart 2010) described a faster response to a tactile recognition task. Arnold and Heiron (2002) describe faster tactile recognition, spatial memory and recall for matched deafblind and sighted hearing peers. However, these individuals and those in Nicholas and Nicholas and Koppen (cited Hart 2010) almost all had acquired deafblindness (bar one in Arnold and Heiron). How this might apply to congenitally deafblind young learners is unknown, but these studies may indicate the benefits of practice. Nicholas concludes that tactile encoding was more efficient in deafblind people (2010). With such contradictory evidence it is hard to be clear about what might be expected from a young person whose main access to learning is through touch.
- 4.120 As Geenens (1999) discusses, the perceptual access for a deafblind person might take longer, and this might limit both the range of things they can have access to and also the number (Narayan et al., 2010). Deafblind people are not able to perceive things as fast as a sighted hearing person, who may be able to listen to the names of plants (rose, marigold etc) of 15 pictures in 5 minutes, and learn them, while the tactile access to both the materials and communication means the deafblind person might only be able to access three in the same period (Monaco and Mamer, 1999), and it takes longer to explore and recognise an object than for a sighted hearing person (Nicholas 2010). Even using remaining vision, and hearing, this will be a more complex and tiring process.

### *Executive functioning*

- 4.121 Executive function difficulties are reported in learners with particular syndromes associated with deafblindness; Frölander et al. (2015) mention them for learners with Alström syndrome but there is much more written about learners with CHARGE syndrome. CHARGE is significant as the biggest known cause of deafblindness in the current child population in the UK (Deuce 2015). Nicholas (2005) initially reported on an individual with CHARGE who showed significant executive function difficulties, and Hartshorne et al. (2007) follow up by describing the difficulty children with CHARGE had in executive functioning; and this was strongly related to those learners who were deafblind. They were not able to respond appropriately to situations, they could not monitor or control their own learning effectively. Lasserre et al. (2013) also found cognitive problems for children with CHARGE whether or not they had additional learning difficulties, in particular sequential processing and selective attention.
- 4.122 While it is clear, then, that executive function difficulties are present in people with certain syndromes of deafblindness, there is no clear evidence as to how these relate to sensory impairments – are they subsequent to them, as in dual sensory impairment creates the conditions for executive functioning problems, or additional to them, as in, created by the same root cause but having no causative relationship.

### *Available evidence*

- 4.123 No evidence meeting the criteria for Intervention studies was identified through the REA

### ***Implications***

- 4.124 Deafblindness creates the most extreme conditions for the development of cognitive skills. Without well-functioning vision and hearing, the learner is very limited in the ability to initiate, carry through and act on their thinking. It is not surprising therefore that deafblind learners frequently have cognitive difficulties. Particular approaches can help to mitigate these difficulties but they will not overcome them. The fundamental links between communication, mobility and orientation, and access to information and the difficulties created for learning in deafblind people are clear, so any strategies which build on these can perhaps be expected to be relevant.



4.125 There is not much evidence directly about building cognitive skills, but the following areas are likely to be relevant:

- Building a secure understanding of the world, through routines, structures and predictability, rather than a random experience of stimuli (Aitken, 2000; Hodges, 2000). Structure can be built into the curriculum (Murdoch et al., 2009). This builds a mental framework for other concepts (Miles and McLetchie, 2008).
- Repetitions to encourage learning; often through using natural opportunities and infused targets (Hodges, 2000). Helmstetter and Guess (1987) echoed by Hodges (2000) recommend a 'matrix' to provide frequent opportunities to practice skills. Overlearning (frequent practice until a skills becomes automatic) is recommended by Monaco and Mamer (1999).
- Opportunities for concrete experience, backed up by pre and post teaching sessions (see Teaching strategies below). They may also need support for concept learning which others acquire incidentally, through language. Learners with CHARGE in particular, may need concrete reminders of sequences and rules, through, for example, symbols (Deuce, 2015).
- Ability to take control of learning, whether this is through switch technology at early levels (e.g Reed and Addis, 1996) or through the ability to design and execute a plan for example to fetch dinner from the canteen (Okbøl, 2014). Agency is a key goal of the Victoria School MSI curriculum (Murdoch et al., 2008).
- High expectations should support learners who struggle with access, rather than assuming these are related to additional learning disability (Geenens, 1999; Marks, 1998).
- Hand under hand strategies, as outlined in Teaching strategies below, are key to ensuring that pupils who need tactile methods to learn can learn in the most effective way.
- All their learning needs to be delivered in accessible formats matched to sensory needs, and often at a very close distance (Miles and Riggio, 1999).
- Symbolic play, cause and effect, categorisation and imitation may have to be taught rather than being acquired incidentally. All are key to cognitive development (Narayan et al., 2010).

- As soon as is feasible, metacognitive skills such as the ability to recognise their own difficulties should be taught and developed (though this requires some language skills). This will enable deafblind learners to take more control of their own learning (McKenzie and Davidson, 2007; McKenzie, 2009). This might be as simple as review of whether they did well, or whether their amplification is working (Phillips et al., 2013). Ingraham and Andrews (2010) describe the importance of more developed skills.
- Fatigue needs to be managed (Monaco and Mamer, 1999; Wahlqvist et al., 2013) by reducing output (how many sums are needed to demonstrate understanding?), input (how many pages need to be read?) and by providing breaks. Using diminished vision and hearing requires concentration, and if accompanied by balance difficulties, as for learners with Usher and CHARGE may be overwhelming (Ellis and Hodges, 2013; Deuce, 2015).

## **Social and emotional functioning**

### *Introduction*

- 4.126 Social and emotional skills are clearly linked to communication; and within this group two main strands were acknowledged, social relationships (e.g. with peers) and behaviour. A third strand, managing progressive conditions was not in the research but is important for a significant group in the deafblind population.
- 4.127 For deafblind learners, isolation and difficulty in friendships are important themes in descriptions of their social learning (Hersch, 2013a; Sall, 1999). Kamenopoulou (2012) outlined the difficulties pupils in mainstream secondary schools had with unreciprocated friendships, bullying, incomplete or misunderstood communication. Ellis and Hodges (2013) show that the boundary between friendship and support is difficult for deafblind young people to navigate and understand. Are truly mutual friendships possible when young people have to be 'taught' to be friends, as advocated e.g. by Haring et al., (1995)? Davies (2017a) outlines the tendency of peers to 'mother' the deafblind child rather than engage in reciprocal friendships. Other relevant factors are poor understanding of the needs of deafblind people, environments which were unsupportive and the deafblind individuals' previous unsuccessful or inadequate social experiences (Kamenopoulou, 2012). Kamenopoulou also demonstrates that factors such as significant amounts of support from a person, (e.g. 1-1 support from a TA), while essential for learning, can isolate an individual from peers. For example, no-one passes notes to the

classmate with a member of staff sitting with them. Opportunities to leave a session five minutes early to facilitate travel between classes may interfere instead with typical social opportunities (Kamenopoulou, 2012).

- 4.128 A second strand concerns issues around so called challenging behaviours, that is, things which learners do which challenge the systems around them and may include aggression, self-injury, repetitive behaviours and a range of other issues (Hartshorne and Cypher, 2004; Murdoch, 2000). For children with CHARGE syndrome there are associated a number of behavioural characteristics such as hyperactivity, obsessive compulsive disorder, and behaviours typical of autistic spectrum disorder (Hartshorne and Cypher, 2004). Such behaviours can pose difficulties for deafblind people themselves, and for their families and peers and the environment and community (Dammeyer, 2011 in regard to Denmark). Hartshorne and Schmittel (2016) spell out many reasons why this may be so; including difficulties with attachment and empathy (based on bonding and observation) with friendships and peer rejections, and self-regulation and monitoring and with family stress. Deafblind people may be especially likely to adopt such behaviours because of difficulties with communication, leading to frustration and lack of independent control. Issues such as parental stress, and problems with bonding and attachment are also more likely to lead to challenging behaviours (Hartshorne and Schmittel, 2016). Some behaviours may also be a response to sensory deprivation or sensory processing deficits which mean that a learner either provides a different source of stimulus or self regulates between over and under stimulated states (Hartshorne and Salem Hartshorne, 2011).
- 4.129 Some issues which are seen as unwanted behaviours (such as self-stimulation, eye poking, or body movements) can be interpreted by staff unfamiliar with deafblindness in one way, while when looked at from the perspective of a deafblind person can be highly functional. Goode (1994) describes examples where such behaviour was interpreted as being indicative of learning disability rather than of problem solving. In other cases it may be communicative, when other means of communication have failed. There may be issues with depression or anxiety caused by deafblindness; although these are very poorly documented, in particular in relation to children and young people. But it would not be surprising if isolation, boredom, lack of friends and lack of control affected mental health (Hersch, 2013a).

4.130 The issue of progressive conditions, in which deaf people may lose vision, or visually impaired people lose hearing, or others may lose vision and hearing gradually, is a very significant one in relation to deafblindness. One of the largest populations of deafblind people under 60 in the UK is of people with Usher Syndrome, where (in most cases) individuals are congenitally deaf and develop visual impairment usually beginning in their teens (Dammeyer, 2012). Other conditions include Leber's Congenital Amaurosis, where people with congenital blindness lose hearing later in life, and conditions where people gradually lose both senses, such as Alström syndrome or Hurler syndrome.

4.131 For people with Usher syndrome, Ellis and Hodges (2013) found that the lack of predictability regarding the rate and extent of their vision and/or hearing loss, and the nature of living with change presented as much difficulty as the ongoing impairment itself. Information about progression could be difficult for young people as reported by Ellis and Hodges (2013):

'I felt sad and shock (sic)' (Dima, 15, Type 1 Usher) (p54).

However, others would not change it:

'I'm used to how I am.... I'm OK' (Jess, 15, type 3 Usher) (p58).

4.132 Danermark and Möller (2008) describe this as a lack of ontological security. Ellis and Hodges (2013) found that many individuals with Usher were able to manage their difficulties, and that most people they talked with were optimistic about some aspects of their lives. In completing a self-image profile, the young people (14 – 20 years old) that they spoke with, did agree that they worried a lot, and would like to worry less. However, they saw themselves as friendly, helpful, fun to be with and did not pick only negative characteristics for themselves (Ellis and Hodges, 2013).

#### *Available evidence*

4.133 Hunt et al. (1996) explored the creation of socially supportive environments for primary aged children with multiple disabilities including deafblindness. The three participants, of whom only two were deafblind, took part in a three part intervention. Part one included giving information to classmates about their peers' communication system and the equipment they use, part two included the identification and utilisation of various media that could serve as the basis for interactive exchanges between students, the final part involved ongoing facilitation by educational staff through use of a 'buddy' system, arrangement of activities,

prompting, interpreting etc. Results showed that the interventions were effective in producing positive changes in the nature of interactive exchanges between the student and others in general education settings. The interactions did not always necessarily increase but a greater sense of 'balance' between participants was noted. Interactions with paraprofessionals and the students on whom the research was focusing did not decrease as predicted, but there was evidence that there was a decrease in assistive interactions. Overall, the intervention provides moderate to strong quality of evidence in promoting interactions between those with multiple disabilities including deafblindness and their peers. It scores highly in its use of triangulation and the critical reflection on its limitations, however it falls short due to the small sample size and lack of generalisability.

- 4.134 Promoting communication and interaction with non-deafblind peers was also explored in a case study of three participants by Mar and Sall (1995). Two of the participants had severe developmental delay, the third did not but was described as 'socially immature'. The intervention programmes were highly individualised but all involved three components. The first involved team meetings of the child's parents, teachers, teaching assistants, school administrators and service providers to identify the child's needs, opportunities, and to establish intervention goals. The second component 'educator support' had four levels of intervention 1) providing informational support, 2) promoting the use of adapted materials, equipment and environments, 3) training sessions, 4) modelling interaction techniques. The third component 'parent support' had three levels of intervention 1) providing information resources, 2) supporting parents, and 3) networking with other parents. Data was collected on the perception of parents and educators as to the range of opportunities for social involvement, and at the end of the study they reported recognising more such opportunities. A measure of activities which involved peers was also undertaken and staff or parent actions to support these increased. A count of the number of 'friends' in the social networks of the children showed decreases in numbers. There is therefore little data related to change for the deafblind children, but only to the support offered. Due to these difficulties as well as the small sample size, lack of generalisability, poor approach and evaluation, the study only provides impressionistic to moderate quality of evidence, with the overall score much closer to impressionistic than moderate.

- 4.135 Romer et al. (1996) explored the effect of peer mediated social competency training on the type and frequency of social contacts with students with deafblindness. The study involved three deafblind students and eight peers – the participants aged from 10 years to 18 years old. Initially, three peers received training in social interaction skills, including communication and social skills determined appropriate for each of the three deafblind students. After mastering these skills they then trained their peers in the use of these skills in order to interact with the deafblind students. The results show that there was an increased amount of time for deafblind students in social interaction with peers, but this is marginal and not well reported - not measured beforehand. Due to the small sample size and lack of generalisability, as well as unclear objectives and a poor approach and evaluation, this study provides impressionistic to moderate quality of evidence, with the overall score much closer to impressionistic than moderate.
- 4.136 Strategies to increase self-regulation and promote classroom integration for a 5 year old deafblind student were explored by Nelson et al. (2016). The intervention comprised of three components 1) provision of meaningful activities (e.g., providing opportunities for choice, using favoured materials, involving the child in preparation for the activity, the activity itself, cleaning up and transition to the next activity, and following the child's lead, 2) anticipatory strategies (e.g., object cues, verbal cues, schedule or calendar systems), and 3) calming strategies (e.g., reflecting the child's emotions to him by saying phrases such as 'You look angry,' holding his hand, or providing vibratory toys). The interventions did decrease challenging behaviours and increased participation in school activities. Dysregulated behaviours lessened when activities were made more meaningful and developmentally appropriate, when environmental needs supported, choices offered, and hand-over-hand manipulation decreased. This is a solid study which thinks a lot about the implications for practice and the limitations of the study. It highlights the importance of highly specialised and individualised support for these young people, however the interventions would be difficult to replicate as the sample size was extremely small. Overall, this study provides moderate to strong quality of evidence.

## ***Implications***

### *Social relationships*

- 4.137 Most people, as adults, remember their friends and the school community as the permanently important aspects of school. Social relationships are, therefore, very important, in relation to quality of life and happiness (Haring et al., 1995) and the evidence shows that these are difficult for deafblind learners.
- 4.138 While some very organised strategies to increase social inclusion have been carried out, there is little evidence as to whether these actually improved the lives of deafblind people, from their own perception (e.g Mar and Sall, 1995; Romer et al., 1996). Evidence from some of the intervention studies and other literature suggest that strategies to help deafblind learners manage their social relationships include:
- Training for peers. This might include using communication methods, providing adapted materials, and modelling (Hunt et al., 1996; Mar and Sall, 1995; Romer et al., 1996).
  - Having buddy arrangements (Hunt et al., 1996). The reduction of ‘helping’ behaviours and increase of ‘friendship’ behaviours would be an important aim (Davies, 2017a; Ellis and Hodges, 2013) .
  - Helping peers to take the lead; either in passing on their increased understanding (Romer et al., 1996) or through using their knowledge of what young people actually **want** to talk about – making more formalised training less useful (Haring et al., 1995).
  - Providing deliberate, structured activities to support friendship building (Deuce, 2015) such as friendship tables, structured games at play times, and other supports (Correa-Torres, 2008b).
  - Managing the physical environment; Möller and Danermark (2007) found that lighting, labelling and transport were key to young people’s social inclusion.
  - Managing the support of teaching assistants and intervenors, so that they facilitate rather than limit interaction; considering the impact of academic support on social relationships.
  - Staff attitudes to recognising the importance of friendships and finding ways to facilitate it (Sall, 1999). Staff will need also to manage the competing priorities between friendship and study.

4.139 In the writing about social relationships, most of the material is about including deafblind people with a learning disability in mainstream schools, and these discuss the teaching typically developing students the skills to interact with a deafblind person (e.g. Correa-Torres, 2008a and 2008b; Haring et al., 1995). Kamenopoulou (2012) writes about pupils in mainstream with mainstream capabilities alongside peers. Given though that in the UK there are many deafblind pupils in special schools for people with learning disability, who are part of peer groups with disability, there is nothing published about these peer relationships. They should not be ignored. Davies (2017a) in her Master's dissertation wrote about Nic, 11 years old, whose number one goal was to have friends, but found this difficult. Davies explores this idea in the context of being able to play together (and later went on to create a 'play club' to foster these relationships, Davies, 2017b). Hartshorne and Schmittel (2016) also recognise the importance of play, as a means of developing and creating opportunities for social interaction. Current educational practice however, as Davies outlines, does not leave much room for 'play' even for those who are functioning at early levels, once they have reached 6 or 7 years old.

#### *Managing behaviour*

4.140 In terms of managing behaviour, strategies are recommended as approaches to dealing with the challenges posed by 'difficult' behaviour. These are mostly based on behavioural techniques, using strategies such as accurate description and recording of the behaviour, teaching alternatives, providing motivations, and working together (e.g. Haring et al., 1995; Bridgett, 1999; Sisson et al., 1993). These are fundamentally the same as those which might be recommended for other people with learning disability. Even these, however, are not simply straightforward. Miles and Riggio (1999) describe how eliminating behaviours seen as a problem can cause substantial further difficulties, leaving a deafblind person with no way to communicate (for example pain) and this, of course, could equally be applied to having no stimulation, and no way to regulate their emotional/physical state.

However, strategies which do provide some links to deafblindness include:

- Being responsive to the needs of the individual (Nelson et al., 2016) and understanding their perspective. Deafblind learners are frequently fatigued, and unreasonable demands should not be made.
- Investigating reasons for behaviours, which may be functional, rather than simply aiming to eliminate them (Murdoch 2000).



- Teaching and supporting understanding of emotional understanding and regulation (Hartshorne and Schmittel, 2016), and providing language models to help them discuss this (Nelson et al 2016).
- Managing the environment, in terms of secure places, structures and routines, to build social relationships and understanding (Hartshorne and Schmittel, 2016). Learners can later move to wider environments.

4.141 In terms of the well-being of young people with progressive conditions, little is known about the implications of this in respect of deafblindness:

- Truth is important – e.g. learners told Ellis and Hodges (2013) that they wanted clear information in their preferred communication format –although they then might prefer to forget it.
- Adaptations for changes are likely to be effective only when the young person is ready – e.g. as Ellis and Hodges (2013) found for learning braille or using a cane.

## **Use of technology**

### *Introduction*

- 4.142 Technology within the modern age can provide a range of specialist resources and strategies which were not available before computers. Of course, technology changes rapidly and articles written before the last five years or so may have only the most general application to current use and availability, but as stated by Warren Horn and Hill, (1987) technology does have the potential to be used to increase independence, allow access to things which were impossible and assist in inclusion. Although written in 1987, this seems as useful now as then, as a general statement of what might be assistive.
- 4.143 Technology can be a powerful assistance for some deafblind people in gathering information, in communication and in orientation and mobility. Ms Haben Girma, a disability rights lawyer, who used assistive technology in a widely publicised conversation with Barack Obama in 2015 (BBC 2015), or another lawyer, Mr Riku Virtanen (D'Costa 2009) provide good role models and examples.
- 4.144 Hartmann and Weismer (2016) describe models which outline the value of technology within curriculum practices, emphasising that it should be seen as a way of participating increasingly, rather than of value by itself.

- 4.145 While there is little written in particular about highly technological devices, some used with people who have either vision impairment or hearing impairment will have similar benefits for deafblind people (Loeding 2011), however this is not the case for all. Of course, much technology used for people with serious vision impairment depends on the use of sound (daily living equipment such as talking scales, sonic devices to support mobility and most importantly computer access through screen readers and similar devices). This may not be accessible straightforwardly to deafblind people – it is not usual to find that assistive devices can be significantly varied or altered in pitch, volume or speed. Southern and Drescher (2005) describe some issues which remain current; small text on devices and subtitles; low level audio warnings; lack of tactile marking; low contrast; incompatibility with communication choices such as BSL (British Sign Language). Some devices will have a headphone jack and where this is used it may be possible to link the output directly to a hearing instrument, but this is not always so. The way in which many vision impaired people use rapid recorded speech for reading is not likely to be accessible to deafblind people. The increase in the use of software through voice and speech, which makes technology much more available to sighted hearing people and to vision impaired people (see e.g. Douglas, McLinden and Hewett 2018) can actually exclude and isolate deafblind people who currently can use braille, or braille technology to access information and resources that may become available only in speech.
- 4.146 Likewise, people with hearing impairments use technology to produce visual output instead of auditory output and this may not be usable for deafblind learners. For example, flashing bells for change of lessons, the use of subtitles and closed captions on videos or TV, and the use of sign language interpreting via video link may all be of very little use to deafblind people. However, technology which improves the reception of sound, such as FM systems (radio aids) induction loops and headphones will support those who use hearing instruments and have useable hearing. FM systems can provide access to learners who also have significant additional disabilities. Even then, there are some disadvantages for deafblind pupils. When using a loop system, the teacher's voice sounds clear and very close to the pupil. A fully sighted pupil is aware visually that the teacher is not in fact near them, and will reply accordingly, but this information may not be available to a child who has vision impairment.

- 4.147 A range of computing technologies are discussed by authors in the field, such as the use of a videophone to increase social engagement (Emerson and Bishop 2012) and the use of braille to text phone by Loeding (2011). A number of authors (e.g. Carrera et al., 2017 and Chang et al., 2002) have used technology to create vibro- tactile communication devices although these usually seem to be primarily for the challenge of making an effective device rather than the practical use which might ensue – they do not, generally, for instance, use an already recognised communication system for deafblind people. Other than the vibro-tactile aid which alerts to sound, there are no current widely recognised uses of vibro-tactile devices for meaning. However, vibration can be used instead of sound in terms of daily living devices such as a doorbell, fire alarm, liquid level indicator (Loeding, 2011) but there is little ability to discriminate between vibrations so it acts primarily as an alerter rather than carrying information.
- 4.148 For many learners who have additional learning disability, technology to support the development of vision and hearing, such as light simulation equipment, as used in sensory rooms, and electronic instruments, such as drum machines, which can be used to give control to carefully pitched sounds can be very valuable (there is some further discussion in ‘Vision and Auditory training’ below). Communication technologies using voice output communication devices are also widely used in classrooms for learners with severe learning disabilities although it does not always appear that much thought is given to the aspects relating to ability to hear the outputs, or see the choice mechanisms. Devices using communication symbols, text and even objects can be used to bridge a gap to a spoken voice output.

*Available evidence*

- 4.149 There is evidence to support the use of microtechnology (microswitches, microcomputers) to support early stage communication particularly contingency awareness (Mar and Sall, 1994; Schweigert, 1989; Schweigert and Rowland, 1992).
- 4.150 Mar and Sall (1994) indicated that students with deafblindness including those with severe to profound cognitive disabilities, could achieve individualised communication goals through the use of microcomputers and other technological resources. Analysis of intervention goals and activities revealed that, for students with nonsymbolic, nonintentional forms of communication, increasing social attention and contingency awareness was of primary concern. However, although they conducted pre and post testing there was no longer term follow up of the

effects of the intervention. Furthermore this paper was focused on a single case study, which although part of a larger 26 participant study, meant that these results were not generalisable to a larger population. Therefore, this study only provided impressionistic to moderate quality of evidence on the use of microcomputers.

- 4.151 Similarly, Schweigert and Rowland (1992) report their findings of a small (three participant) case study reviewing the development of the use of microswitch technology for nursery aged children, as a means to interact with people or to communicate and to use this microtechnology to establish awareness of social contingencies. (This is the use of microswitches to communicate, rather than to activate toys or computers). Integral to this was the use of Early Communication Process (ECP) as an instructional sequence to identify the different components to communication. The paper provides an interesting review of the processes and use of ECP but the details of the intervention in relation to the use of microtechnology are not always clear, and there was no rigorous pre and post testing and no inter-observer reliability. The study also identifies that participants often had a lot of medication which meant less than optimal learning conditions. Ultimately, ECP provides a systematic approach to communication instruction for a group of children who may not acquire the most basic communication skills without prolonged and intensive intervention, however the evidence of the role of technology to support this is limited. Overall, this study provides impressionistic to moderate quality of evidence.
- 4.152 Although only a single-case study Schweigert (1989) compares the effectiveness of social (caregiver's voice) and non-social stimuli (warm air on arm) in a contingency learning task for a particular child - when the participant activated a switch they received one of the stimuli. Social reinforcement was an effective feedback condition to a non-social response for this participant. The study uses appropriate baseline and post testing. Some anecdotal evidence from classroom practice suggested there might be a longer term effect, though this was not measured. Therefore, this study is seen to provide moderate to strong quality of evidence.
- 4.153 Peck (1995) explored the use of colour CCTV to help students recognise objects linked to photographs. Unfortunately, the claims of the author - that the use of colour CCTV created an immediate relationship and provided good reinforcement – were not evidenced in the article. Consequently this paper, scoring impressionistic

in the majority of categories, only provides impressionistic to moderate quality of evidence.

### ***Implications***

4.154 There is no doubt that technology can support and assist deafblind people, but it is not an answer to all problems and it can only be a means to an end, not a goal in itself (Hartmann and Weismer 2016).

4.155 In order for technology to be used effectively to meet learners' needs:

- It must be individualised to them, matched to hearing and vision levels, and to their competence and familiarity with it (Bruce et al., 2008).
- The deafblind learner needs to have control over the process; be involved in choosing it, or choosing to use it, and must be in control of the way it works. They must be comfortable with it and understand how it works, how to use it – and how to get others to use it (e.g. staff), which requires social competence (Hartmann and Weismer, 2016).
- Many young people will have found their own way to adapt and use equipment and these should be respected and celebrated (Ingraham and Andrews, 2010).
- It must be designed to be used to include and assist, as it can feel that equipment isolates and stigmatises the user (Hersch 2013b).
- Teachers need to consider how to include technology within their teaching – e.g. to make a goal to 'compose' rather than 'write' a story so that learners using assistive technology do not need differentiation (Hartmann, and Weismer, 2016).
- Teachers need to infuse the using of technology into sessions – an ecological approach, such as outlined by Nietupski and Hamre Nietupski (1987) can help to make technology use part of many activities.
- Teachers need to analyse the situation, environment aims and delivery to allow for and develop the use of technology – so that the pupil both learns to access, and is having access to learning through the assistive devices.
- Using technology for well defined aims, supports both teachers and learners (Schweigert and Rowland 1992, Mar and Sall 1994).
- At early stages, it can be used to teach agency and control for learners who do not usually get a directly accessible response from the environment,

because of vision and hearing difficulties (Reed and Addis, 1996). It also supports independence from adult direction if switches provide a reward.

- It should be arranged to provide a range of highly variable and motivating rewards; music, lights, sounds, even smells and fans which can be tailored to the individual needs of deafblind people. It can also help to *develop* residual vision and hearing if rewards are well chosen.
- Careful use of voice output and similar technological communication aids can support communication development. This might begin with an individual using a device with one recorded word or phrase to more complex technology which allows a pupil to compose phrases e.g. to record their work. These systems need to be flexible and be based on individual need.

4.156 The use of technology within sensory rooms is discussed in the section on low vision aids.

4.157 There is little research on the use of vision or hearing technology with congenitally deafblind people (Wittich et al. 2016) and as seen above, there is a poor evidence base overall within any articles. In particular, there is little which spans the (apparent) divide between pupils with and without cognitive impairments, for example, in the use of video magnifiers, speaking technology and even FM systems for those who have multiple disabilities. The wide availability, for example, of tablet devices which could photograph and enlarge might make aspects of learning other than reading (which they may never be able to do) much more accessible to those with learning disabilities. However, there is no advice about how to develop or use these skills for this group.

## **Vision and auditory training**

### *Introduction*

4.158 The development of perception (the ability to become aware of sensory information from visual or auditory systems) is a particularly important part of learning for deafblind young people. With no easy sense to rely on given their combination of vision and hearing impairment, any improvement of visual or auditory perception, or enhancement of it by the use of aids is obviously important.

4.159 While some would assert that the main sources of information for deafblind people are movement, touch and airflow (along with vibration smell and taste, Rødbroe and Souriau 1999), there is considerable evidence that learners use either vision or

hearing or both and indeed most deafblind learners have remaining vision and hearing (Hodges, 2004; Deuce, 2015). Thus, the enhancement of vision and hearing is mentioned as significant in the Victoria school MSI Curriculum (Murdoch et al., 2009).

- 4.160 Many education settings assume that multi-sensory practice must be the way forward but there is little researched evidence for this. Knight and Rosenblatt (1983) investigated the use of single and multi-modal stimuli (in fact during assessment) and concluded that using both visual and auditory stimuli together might not be the best way forward as children appeared to be unable to process both simultaneously (which suggests that a 'multi-sensory approach' needs to be properly evaluated). This is further discussed below, in 'Teaching Strategies'. In addition, it is important to recognise that for an individual, even if their vision is quite poor, use of that vision is their preferred sense and their mostly likely channel for learning (Hodges 2004, Ellis and Hodges 2013). This means that visual training and enhancement may be the most useful route for learning, even if high magnifications are needed.
- 4.161 There was no research evidence or even good practice in relation to the use of low vision aids or to low vision training for deafblind people. Of course, most of the information relating to low vision training for vision impaired pupils will apply equally to deafblind learners, except of course where this might be through the use of an auditory function, but there may be distinct differences.
- 4.162 Firstly of course, more technologically focused low vision aid (LVA) equipment such as video magnifiers frequently use audio output as well, which may not be accessible to deafblind learners (though there is no known research about how accessible these computer technologies are). Secondly however, increasing the visual accessibility may increase the visual demands on the learner's system (they can now see it rather than ignore it, but they have to concentrate very hard to do so, thus meaning they can no longer concentrate on accessing using listening simultaneously).
- 4.163 The use of sensory rooms (also called multi-sensory rooms, white rooms, vision stimulation rooms) is widespread for learners who are deafblind, but there is little written to examine what the key uses should be, although both visual stimulation and relaxation are often talked about in professional circles (while not in relation to deafblindness, Pagliano, 1999 and Hirstwood and Smith, 1996). These facilities

have a significant role in terms of visual training for learners with profound and multiple learning disabilities (PMLD) and severe learning disabilities (SLD), at least in terms of time and investment from, for example, schools. There is no published intervention evidence as to how successful they are. Hodges (2000) discusses the use of sensory room equipment such as bubble tubes, or visual stimulation computer programmes to help pupils learn to use their vision. However, Mount and Cavet (1995) warn that such specialist environments can be assumed to do the teaching automatically, and that no planning or recording is needed. This is has also been seen in student experience – lack of coherent policies for these rooms and lack of targets, assessments and plans for deafblind learners (Hyndman, 2008).

- 4.164 Auditory training, although even less considered in the literature, is likely to be as important. Just as pupils need to learn to use their vision effectively, they need to learn to use their hearing effectively.

*Available evidence*

- 4.165 No evidence meeting the criteria for Intervention studies was identified through the REA.

***Implications***

- 4.166 There is little research on which to base implications, which considering the widespread use, acceptance of, and the significant cost of sensory room equipment is quite surprising. The implications for teachers of the use of visual and auditory training and aids include:

- Using vision and hearing together (or multi-sensory learning) which is often assumed to be best practice, may in fact not be the best approach (Knight and Rosenblatt, 1983).
- Individual preferences should be respected, even if vision is considered to be poor, if the learner prefers to use visual means, this should be supported (Hodges, 2004).
- Specialist aids to vision such as ultra violet light, video magnifiers and additional lenses will enhance access to text and artefacts for many learners including those with multiple disabilities (Hodges 2000) but they need to be taught to use them.
- Screen magnification software, video magnifiers and similar devices will help more able learners to access text, but they need to be taught to manage



them effectively. It can be difficult to understand how to navigate round a document when only a part can be seen at once, for example, and then to understand how to synthesise a whole.

- Learners will also need support to learn to listen, including using and tolerating hearing aids, cochlear implants and FM systems. FM in particular can support perceptual development and access to learning (Phillips et al., 2013; Mathes, 2016).
- Learning to listen must be promoted and supported also as a social tool – ensuring listening in groups for example and at break times (Mathes, 2016).

4.167 The sensory perception of deafblind learners needs to be developed; they are unlikely to develop the effective use of their vision and hearing without support. While deaf children with good vision realise through their visual interactions that something is happening in the environment that they don't have access to (and likewise vision impaired children can be directed through language to attend, perceive and recognise) deafblind learners cannot use either sense effectively to promote the other.

### **Teaching support**

#### *Introduction*

4.168 Deafblind learners will almost inevitably need support, because teaching is mostly delivered through the senses of sight and hearing. Fundamentally, they will need support for the three key difficulties they will have; communication, access to information and mobility and orientation.

4.169 More or less since the GEST grants (Grants for Education Support and Training – a scheme offering Government money for supporting particular projects) in relation to deafblind children in England (1992-5) the role of specialist TA support for a deafblind child has been recognised as that of an intervenor – defined by the Canadian Deafblind Association (no date) as someone who:

“mediates between the person who is deafblind and his or her environment to enable him or her to communicate effectively with and receive non-distorted information from the world around them” (no page number) (The concept of Intervenors originated in Canada)

4.170 The educational intervenor, as someone who provides access to learning as outlined above, has become a key role for deafblind learners across the UK. In Wales, it is recognised that for deafblind children:

"Unlike those who have no sight or no hearing, children who have dual sensory impairment are unable to receive a flow of information.... They need systematic support to learn and progress.... The services of a qualified intervenor are essential in order that learning can occur".

(National Assembly for Wales, 2005 p14)

4.171 The use of intervenors has, therefore, become a very significant approach to including deafblind learners in educational environments which were not designed for them, so they can have access to learning alongside other pupils. As such, an important element of learning, it is very disappointing that no systematic research has been carried out on the benefits or otherwise of this level of support. A very limited study of pre-school children receiving intervenor services at home – so not easily generalisable to school – did suggest some measurable benefits (Watkins et al. 1994). However, the value of this level of support is also challenged by findings such as Blatchford et al. (2011) who suggest that 1-1 TA support can reduce independence, may be related to reduced attainment, (though this study is about mainstream schools and is not about deafblind children). Kamenopoulou (2012) also mentions the increased distancing which may isolate deafblind learners when a TA is closely involved. However, Alborz et al. (2009) suggest that well trained TA staff working towards clear goals may support literacy skills (once again this study is not about deafblind children). A number of authors have recognised the importance of appropriate training for intervenors in the UK (e.g. DfE, 1995; Boothroyd and Rose, 2015a; Boothroyd and Rose 2015b), it may be the case that intervenors are involved in this more precise and particular delivery, as is shown by the description of the support role given below.

4.172 Evidence from practice, including student projects and investigations suggests that the presence of an intervenor provides access to educational experiences which are otherwise denied to a child. However, from the USA (where the situation is undoubtedly different), Rafalowski-Welch and Goetz (1997) indicate a number of possible issues, such as confusion over the role of intervenors because of a lack of job descriptions, difficulty with balancing the intervenor's input with that of the class

teacher, and lack of appropriate qualifications for intervenors. While these are not documented in UK research, they are recognised in practitioner discussions.

- 4.173 The value of the support of specialist teachers for deafblind pupils is not researched, however, it is mentioned in a number of sources. Porter et al. (1997), for example, mention that classroom teachers found the support of specialist teachers very helpful in learning about appropriate teaching strategies, and that teachers mostly found out about such strategies on mandatory qualification training. Moss and Hagood (1995) outline how deafblind learners do (and don't) learn and why a specialist teacher is needed, because they cannot learn from seeing as other hearing impaired children do, or from someone telling them as other vision impaired children do. McInnes (1999) outlines why deafblind learners require specialists in deafblindness, describing as 'errors' such practices as combining experts from other fields, who may predominantly use compensatory strategies relying on the intact other sense. He goes on to emphasise that success in Canada (where he is writing) is dependent on high levels of training in the specialist field of deafblindness. McLetchie (1995) also writes about the importance of well prepared teachers with recognisable competencies. Specialist teachers are recognised in the Additional Learning Needs Code for Wales (Welsh Government, 2018), where it is recognised that staff in schools may not have the expertise to teach deafblind pupils and a qualified specialist may need to be involved. A key role for such qualified staff is, of course, to work with others who might support the child, including an intervenor (e.g. Staffordshire et al., 1995).
- 4.174 The support given is likely to include the roles which are outlined by NatSIP (the National Sensory Impairment Partnership, 2012) and Boothroyd and Rose (2015a) that they should:

- Provide additional or alternative communication (e.g. sign interpreting, use of symbols or objects of reference).
- Adapt or recreate materials to be accessible in other formats (large print, tactile, braille).
- Read/scribe or otherwise to support text access.
- Adapt the environment for vision and hearing, and for mobility.

- Provide support/alternatives for hearing (including ensuring resources are available, clean and working, facilitating group working, using Ling sounds<sup>12</sup> to check hearing aids).
- Provide support/alternatives for vision (turning on lights, providing auditory/signed description, ensuring equipment such as video magnifier is available and working).
- Support the development of vision through specialist programmes (such as visual perception through light stimulation to imitating and copying).
- Support the development of hearing through specialist programmes (such as teaching responses to sound and vibrotactile understanding).
- Support/supplement teaching by preview and review sessions (e.g. a chance to feel the ingredients before making playdoh or going through the vocabulary about volcanoes).
- Provide sighted guide when required (giving appropriate cues when moving a wheelchair, direct guiding on a trip out of school).
- Support additional curriculum work which may not be required by other learners in their setting (such as touch typing, learning to use a cane, tactile development sessions).

4.175 Alongside this, supporting staff will be developing skills in the young person such as:

- Enabling independence and self advocacy, including planning.
- Facilitating access to peer groups and peer activities, including clubs.

4.176 Further, supporting staff will be working alongside other professionals by contributing to monitoring progress, sharing in assessment activities, and assisting with planning (Boothroyd and Rose 2015a). In addition, they may provide other supports which the learner needs in relation to learning, or personal care, because they are already in a close working relationship (Watkins, Clark and Barringer, 1994).

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<sup>12</sup> The Ling sounds are six speech sounds (ah, ee, oo, mm, ss and sh) which span the range of speech frequencies in English and can, therefore, be used to check a consistent access to sound by school staff or parents.

### *Available evidence*

4.177 No evidence meeting the criteria for Intervention studies was identified through the REA.

### ***Implications***

4.178 It is highly likely that deafblind pupils in education will need forms of personal support, from specialist teachers, and from teaching assistants and/or intervenors. The benefits of providing this support can, it is presumed, outweigh the possible disadvantages, especially where this support is provided by well trained and resourced staff. The dangers of over supporting pupils can, however, be very significant in terms of their self-determination and can mean that pupils become unable to initiate and develop independent learning (Marks, 1988).

4.179 Teachers, intervenors and others working to support the child will want to consider the following:

- The importance of providing access; modifying and adapting delivery (NatSIP, 2012). This includes providing accessible materials but also ensuring the learner understands what is happening in class, repeating words out of access of the microphone, or what other pupils are getting into trouble about (if all other pupils in the class know). This is different for many individuals than the scaffolding approach which is the general TAs role – access, not support.
- The importance of providing access to social situations – which requires careful facilitation, perhaps role play, peer teaching, and so on. This also includes teaching and providing opportunities to practise and consolidate life skills in natural situations; travel, buying lunch, carrying messages, washing face and hands and so on.
- Providing a learning framework in which the learner can flourish as independently as possible, as described by Haakma et al. (2017) as having structure, autonomy and relatedness (this has been shown to raise achievement – Haakma et al., 2017).
- A clear understanding of job roles by all, who has which responsibilities (Rafalowski-Welch and Goetz, 1997). Sometimes all decisions are left inappropriately with an intervenor because there is no understanding of the individual roles of team members. This includes the roles of mobility

specialists and others, and the responsibilities of managers (SENCOs and others).

- The importance of training for all (Haakma et al., 2017; Boothroyd and Rose, 2015b) and especially for those with intervenor roles (Boothroyd and Rose, 2015a). Specific training for specialist teachers is recognised by the Welsh Government in co-operation with the English Department for Education in relation to Mandatory Qualifications.
- A consistent role for MSI specialists from pre-school to the transition to adult services (National Assembly for Wales, 2005).

4.180 There is little further guidance about successful strategies for specialist support; about how specialist teachers can support class teachers, and about how TAs or intervenors can support deafblind individuals. This is surprising given the financial implications of the number of specialist staff in support. However, given that with poor vision and poor hearing, all pupils will require access support, and many will also require scaffolding support, the role of supporting staff continues to be essential.

### **Teaching strategies**

#### *Introduction*

- 4.181 Conventionally, education is delivered primarily through visual and auditory means. Spoken words, pictures and demonstrations form the key parts of teaching, including in special schools for children with learning disability. Learning in ways which do not require vision and hearing necessitates different, and adapted means of doing so. Because learning is so difficult for children and young people who cannot see and hear reliably, additional strategies are needed to enable and reinforce learning.
- 4.182 Amongst the strategies needed are support (as outlined above) but also a range of other techniques for communication, for concept development, for sensory access and for providing independence and agency to learners. Among these are strategies which are supportive in general terms to people with learning disabilities but these are needed in relation to the implications of sensory impairment for deafblind learners.

- 4.183 A number of authors describe a range of strategies. Porter et al. (1997) outline the strategies which teachers in their study used with their deafblind pupils. They divide these into pedagogic strategies and organisational strategies. In pedagogical strategies they outline those which focus on an outcome (fading, prompting); those which provide access for learners at an early stage (e.g. routines, cause and effect); strategies using non-symbolic communication (eye contact, signal behaviours), those which use formal communication (writing, signing) and those which are about agency (choice making, negotiation, exploration). In organisational strategies they discuss visual access and development, auditory access and development, modification of materials or tasks, structures and physical positioning. Gee (1995) also looks at strategies for a deafblind child in a mainstream class, including the use of technology, involvement with peers, pre-teaching and infusion of a literacy skill (e.g. learning braille) within a class activity.
- 4.184 Murdoch et al. (2009) in the Victoria School MSI curriculum, list a range of strategies (they use the word 'approaches') which underlie the implementation of the curriculum. These include consistent routines, emphasis on stability of staff, response to all actions/behaviours as if they were intentionally communicative, and following the child's lead as to pace in a flexible format.
- 4.185 Downing and Eichinger (1990) discuss a range of strategies for ensuring the deafblind learner has appropriate access. This includes adaptation for sensory impairment, (ensuring visual access - they barely mention auditory access), promoting residual senses, tactile input, and natural routines. A range are mentioned by Hodges (2000), including burst pause teaching, use of routines, additional tactile information, and infused aims.
- 4.186 The use of multi-sensory learning (stimulating as many sensory channels as possible) has become common in schools for children with complex needs, in formats such as sensory stories or multi-sensory greetings. There is, however, some evidence that this may not be the most useful strategy for learners with sensory impairments. Knight and Rosenblatt (1983 – see below) supported by other studies such as Lane (1996) (with vision impaired children) and Biederman et al. (1994) (with vision impaired children) suggest that the use of a single sensory input at any one time may be the most effective system.

- 4.187 One practice which has become increasingly common as a particular strategy is hand under hand (rather than hand over hand) prompting and guidance. This perhaps began from Nielsen (writing about blind children) who describes taking hands of vision impaired children as similar to covering the eyes of sighted children (1996) but was particularly emphasised by Miles (1999) and Miles and Riggio (1999) as a less invasive strategy which helps deafblind learners to maintain initiative, independence and control. As Marks (1998) discusses, since learned passivity and dependence is a very significant limiting factor for deafblind learners, any strategy which may limit these is a key learning tool. Furthermore, a range of strategies have been mentioned also above; including *intensive interaction* and *calendars (Communication) use of concrete and experiential learning (Cognitive Skills) using technology (Technology)*.
- 4.188 The available intervention based literature is mostly focused on using behavioural techniques to teach particular skills. While this clearly has a place and a maintained value in the field, it is not representative of the strategies currently in use for teaching deafblind learners.

*Available evidence*

- 4.189 Alberto et al. (1983) looked at the use of negative reinforcement to condition a response in a deafblind 7 year old with multiple disabilities. The negative reinforcement (holding an ice cube) was used to direct the young person to the use of blowing air on the arm as a positive reinforcer. From this, the participant began to be able to use a microswitch with fan. This was their first example of usable skill. Due to the severe limitations of the study relating to all the rating criteria except the objectives of the study and the reporting of the evaluation, the study only provides impressionistic to moderate quality of evidence, with this score falling towards the impressionistic end of the scale. Furthermore, this method of teaching, using deliberately aversive stimuli, would no longer be considered appropriate.
- 4.190 Reducing self-stimulatory mouthing behaviours in three deafblind children with multiple disabilities was explored by McDaniel (1984). Two of the participants were 4 years old, the third was 7 years old. The interventions were individualised for each of the three participants. For the first participant when she sucked her fingers they were removed from her mouth and a firm 'no' was said and her head was shook by grasping her chin and turning her head from one side to the other. In the second phase of the intervention when the participant touched a toy she received a positive



reinforcement (small amount of apple sauce or yogurt). For the second participant when he bit himself he was given an aversive taste (lemon juice). In the second phase of the intervention his nails were painted with a nasty tasting substance used to reduce nail biting. For the third participant, when he sucked his fingers there was the introduction of an aversive taste (lemon juice), a 'no' and the headshake used with the first participant, and a strong tap on the back of the hand. The interventions appeared to be successful in these individualised case studies but there was no variable testing, inter-rater reliability, idea of how long behaviour changed after 'treatment' etc., and as with the study above, the use of deliberately aversive stimuli would no longer be considered appropriate. Overall, the study provides impressionistic to moderate quality of evidence.

- 4.191 The use of contingent and noncontingent sensory reinforcement, and response interruption to prevent problematic behaviours in two deafblind participants with multiple disabilities was explored by Sprague et al. (1997). One was aged 9 and the other 20 years old. The study looked at four conditions to detect whether a particular type of reinforcement was more predictive of problem behaviour. In the 'play' condition the participants were presented with a preferred toy, as well as praise for interacting with the items. In the 'alone' condition there was no praise or play materials. In the social condition the play materials were provided but following stereotypy or self-injurious behaviour attention was provided with the phrase 'Please don't do that.' In the demand conditions, participants were asked to participate in a task and praise was given for task-related behaviour, and a 10 second pause (demand cessation) provided contingently on the performance of problem behaviour. The analysis and evaluation of the study is poor. Consequently, reporting the results is difficult. However, an enriched sensory environment with sensory stimuli in the modality preferred by participants and matched to their self-stimulatory or self-injurious behaviour was reported as the most effective way of reducing 'problem' behaviours. Due to the difficulties mentioned above and the small sample size and lack of generalisability the study is rated as providing impressionistic to moderate quality of evidence.
- 4.192 The use of response prompting to support four preschool deafblind children with multiple disabilities to make choices was examined by Grisham-Brown et al. (2000). Activities were introduced with an object cue, a task request was provided and time was given for the child to respond, the response was identified as correct or

incorrect, and the appropriate consequence was provided. Correct responses received verbal and tactile praise while incorrect responses were ignored. Using response prompting procedures within an embedded skill approach was found to be effective in increasing performance on basic skill instruction for three of the four students. In addition, this study demonstrated that paraprofessionals can reliably implement these procedures when skills are taught concurrently within preschool activities. Overall, this study provides impressionistic to moderate quality of evidence.

- 4.193 The use of wait time when waiting for responses was examined by Johnson and Parker (2013). The teaching strategy (and evidence) has already been discussed within 'Communication', but it has clear relevance in term of teaching strategies too. As already noted, the results showed that wait time helped children engage. It appeared to be individual to children which time they preferred – the deafblind child preferred a longer wait. Despite the small sample size and lack of generalisability this study does provide moderate to strong quality of evidence.
- 4.194 The final piece of evidence in this category looked at the use of sound or light stimulus, or both, in the presentation of switch based stimuli (Knight and Rosenblatt, 1983). An experimental approach was used with eight randomly chosen deafblind children with multiple disabilities and intellectual impairment. Although originally aimed at improving audiological assessment the procedure investigated the use of dual and single stimulus (light/sound) responses to a child's action. In all cases, it found that discriminative and selective abilities were inhibited by the presentation of both sound and light, and were better in the single sensory mode. Overall, the study provides moderate to strong quality of evidence.

### ***Implications***

- 4.195 The intervention literature, as noted above, does not generally outline current good practice in the field of deafblindness. Instead, experience and expert opinion suggest a range of other strategies as being fundamental to good practice.

The following are drawn from the wider literature and from practice experience:

- Learners need to feel secure (Hodges, 2000; drawing on Jacobsen et al., 1993). Jacobsen et al. describe a sense of security as a first, necessary step to allow for other learning, because insecurity 'drains all energy' (p13). Murdoch et al. (2009) outline 'strategies of familiarity and routine', without which learners at early stages of

development will withdraw and perhaps be upset. For more able learners, Danermark and Möller (2008) develop the idea of ontological security as being necessary to personal development.

- Use appropriate sensory channels. For some learners this will be visual, for others auditory, or tactile, or even vibration and airflow (Rødbroe and Souriau, 1999). Hodges (2004) demonstrates that teachers are not always clear which are the most appropriate for individuals. Using mirroring in senses other than vision may be possible (Nelson and van Dijk, n.d).
- Use single or multi-sensory input as based on individual evidence of efficacy (Knight and Rosenblatt, 1983; Lane, 1996; Biederman et al., 1994). This may be included in a learning media assessment.
- The use of additional tactile input – although Downing and Eichinger (1990) recognise the limitations of this. Learners may need to touch materials to back up their vision or their learning from listening. In any case, the use of concrete media to support learning will support deafblind learners, (as shown by Deuce, 2015, about learners with CHARGE syndrome, and outlined in the section on ‘Cognitive Skills’ above).
- Use of hand under hand methods, which respect individual dignity and allow the pupil to develop independence (Miles, 1999). If this level of support is not needed, then staff should not intervene.
- Embed learning into real tasks and natural situations. This might be learning motor skills in a cookery session (lids off jars, stirring) or learning to read to access postcards from home, visual skills in a music session, mobility teaching on a route the pupil wants and needs to learn or providing communication supports within a playground (Downing and Eichinger, 1990; Hodges, 2000; Nietupski and Hamre Nietupski, 1987; and Bruce et al., 2008).
- Find and use activities (especially ones which can be shared with peers without sensory impairments) which do not require vision or hearing (Downing and Eichinger, 1990) such as cooking, carrying messages or skating.
- Use pre and post teaching – providing opportunities for learners to experience language, explore artefacts, and ask questions, outside the main ‘teaching activity’ (NatSIP, 2012; Monaco and Mamer, 1999). This may include repeating audio-visual materials from classes. In mainstream subject based classes, knowledge can be assumed which deafblind learners have not acquired incidentally, and in schools for children with complex needs, they

may need more experience of an activity or of materials than is available in the session.

- The importance of time; both pausing to allow the pupil to respond (Johnson and Parker, 2013; Hodges, 2000) but also allowing them to work at a pace which is likely to be slower than other learners (Rafalowski-Welch and Goetz, 1997).
- The importance of breaks – but not just at breaktime. Fatigue is a recognised problem for deafblind learners, and everything also takes longer (Rafalowski-Welch and Goetz, 1997). Playtimes or break times, are unstructured, often less supported and the demands are even greater than in sessions. Learners may need a break after break.

4.196 Finally, it is essential that staff use and respond to pupils' communication methods, even if these are different from the ones that they wish the pupil to learn. Deafblind people use a wide range of means to communicate, from gaze and body movement, to speech, sign, print and braille. Without rapid responses to communication attempts from pupils, they may learn that their communication is ineffective and cease making the effort. The environment needs to be responsive to their efforts.

4.197 Given the highly individual nature and exceptionality of deafblind people, there are no strategies which can be recommended for all pupils (Bruce et al., 2008). Nelson and van Dijk (n.d) discuss the importance of being guided by the individual pupil, following the pupil's lead and responding to their initiatives. While they write within the context of assessment, it can be seen that teaching should follow these principles too. This includes allowing the learner to choose the materials, pace, and activities, and the adult adapting to the motivations and interests of the learner.

## **Welsh Language Provision**

### *Introduction*

4.198 Based upon Welsh Government figures, in 2017-18 approximately 16% of pupils in Wales are taught through the medium of Welsh, and significant numbers of additional pupils have some of their lessons taught through the medium of Welsh (StatsWales, 2018a). Based upon Welsh Government figures, in 2017-18 there were very few pupils with multi-sensory impairment in Wales taught through the medium of Welsh. StatsWales (2018b) records the total figure recorded as zero,

although this reflects numbers being rounded to the nearest five (and some individual local authorities do record numbers of “greater than zero but less than five”). StatsWales (2018b) also records in 2017-18 there were a total of 178 pupils with multi-sensory impairment in Wales across all provision (which contrasts with the 1,100 estimate presented earlier in this report).

- 4.199 People who are deafblind are born into families with a variety of linguistic backgrounds; e.g. those who speak English or Welsh, those who use British Sign Language (and/or its Welsh variant), and those speaking minority languages in Wales. While the numbers of children with multi-sensory impairment are low, it is still very important to consider implications of this linguistic background for their educational provision.
- 4.200 Multi-sensory impairment is a low incidence disability and this has associated challenges in terms of educational provision (e.g. specialist training of staff, availability and distribution of accessible resources). These challenges are likely to be multiplied in the Welsh-medium context which does not benefit from the greater availability of English-medium resources and English-speaking specialist trained staff. While no figures are kept for this, there are few Welsh speaking qualified MSI teachers.
- 4.201 Here we draw upon the clear links with analyses offered in the parallel REAs carried out in the areas of vision impairment and deaf education<sup>13</sup>. As in deaf education, communication is a key factor defining the effect of deafblindness on individuals and therefore the language environment is important. Firstly, it is clearly recognised that deafblindness can have a significant effect on individuals’ feelings of isolation and exclusion (e.g. see Hersch, 2013a). It follows that where a common language cannot be found, this further reduces the opportunities for communication through methods such as electronic typing to braille or fingerspelling. Secondly, the availability of support can be affected by the availability of professionals trained to deliver Welsh language provision. For example, BBC (2013) described difficulty in recruiting an educational interpreter for BSL in Welsh medium to support a deaf child (not deafblind); this would be even more problematic for some communication systems used by deafblind people. This has an impact not only on children directly

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<sup>13</sup> Douglas, G., McLinden, M., Ellis, L., Hewett, R., Hodges, E., Terlektsi, E., Wootten, A., Ware, J. & Williams, L. (2019). A Rapid Evidence Assessment of the effectiveness of educational interventions to support children and young people with vision impairment. Welsh Government.

but also on the support available for families, in particular in relation to a very low incidence disability. Even so, some materials do exist, e.g. Early Support materials for parents have been produced in English and Welsh<sup>14</sup>.

- 4.202 Appropriate Welsh-medium resources in *print* for young people with low vision is unlikely to have any particular challenges for this group as this would be based upon available resources for most others who are taught through the Welsh-medium. Nevertheless, more challenging may be the availability of specialist multi-sensory impairment-specific materials in Welsh (including materials specific to deaf and vision impairment education), e.g. Welsh braille, speech-based technology (and associated applications), and tactile diagrams (with braille labels).
- 4.203 Another area of likely concern is the availability of Welsh language screen reader technology. While this appears to have improved significantly in recent years, the integration of the technology with mainstream technology may be limited (e.g. in touch typing training software).

*Available evidence*

- 4.204 No evidence meeting the criteria for intervention studies was identified through the REA.

***Implications***

- 4.205 No educational interventions in relation to multi-sensory impairment education in the Welsh language were identified through the REA. The broad principles and interventions identified in the REA are not language specific. However, many interventions do require specialist resources and specialist staff who communicate in the appropriate language. Most materials about deafblindness are not available in languages other than English and to some extent Spanish (especially in the Americas). In the USA, Correa-Torres and Durando (2011) carried out a survey to assess the perceived training needs of specialist teachers (in this case, of students with vision impairments) who work with students from culturally and linguistically diverse backgrounds. In the context of their study this was non-English speaking, and often Spanish-speaking. They noted the need for providing training for the teachers, including concerns about lack of appropriate teaching resources, how to work with families, how to work with interpreters, and practicum opportunities during training. Furthermore, the findings “highlight the need to recruit individuals from

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<sup>14</sup> [Children In Wales: Multi Sensory Impairment Information for Parents](#)

culturally and linguistically diverse backgrounds” (p531). A similar survey across Wales may prove useful in identifying specific training and resource needs in relation to children with multi-sensory impairment taught through the medium of Welsh (and/or in a Welsh speaking context).

- 4.206 Some deafblind people (from experience) learn to manage in multiple languages – using more than one native sign language or spoken language. Nevertheless, given the difficulties in communication inherent in being deafblind, it must be presumed that this is not easy. Individuals already frequently use non-standard means to communicate (e.g. home signs, individualised objects of reference, and the use of braille abbreviations in fingerspelling) and using these in more than one language environment might reduce still further their ability to communicate with a wider public (e.g. making photographs more complex by labelling in more than one written language). For others however, the use of a communication system which transcends the distinctions between spoken languages or signed languages – such as symbols – could actually make their communication more transparent.
- 4.207 With these issues in mind, we informally explored this with specialist teachers (including Welsh-speaking teachers) concerned with sensory impairment in two services in Wales. The issues raised tended to focus upon vision impairment and deaf education more specifically (and they are listed in the relevant REA). Nevertheless, the issues raised reflect the broad themes identified in the previous discussion, i.e. concerns about availability of educational resources in Welsh, and implications of having relatively few specialist professionals trained to deliver provision in Welsh.

## **Inclusion**

### *Introduction*

- 4.208 There are no reliable numbers as to how many deafblind pupils are included, or not, in mainstream schools in Wales, England or the UK. Practitioners have conversations about how to manage these situations in professional forums and at conferences, but there is little focused guidance on inclusion. Even ‘inclusion’ is a complex term as it may be interpreted as relating to deafblind learners in mainstream schools and it may be interpreted as deafblind learners, with their particular needs, in generic or other specialist schools.

- 4.209 Of the relevant literature, most relates to the United States, where there has been a strong movement from some practitioners to include any deafblind pupil, with or without additional difficulties in a local school, which they argue can effectively and efficiently provide an appropriate education (e.g. Downing and Eichinger, 1990). Downing and Eichinger point out that social partnerships may be more easily formed and social skills taught in environments where most pupils have typical communication patterns. While it is certainly true that pupils with poor communication skills may not be very good communication partners, this does not address the issues of pupils who use sign language and may benefit from a signing peer group.
- 4.210 Inclusion can only be effective if learners' sensory access is ensured. This may involve changes to the environment, to resourcing and the provision of support. It is important however to ensure that adapted environments do not make the learner dependent on adaptations and so unable to cope in the community or wider world (Prickett and Welch, 1995).
- 4.211 It will never be possible for the learner to be exactly the same as others. Almost the definition of deafblindness suggests that they will need additional explanation and experience of concepts, flexible support for communication, adaptations and equipment for sensory access, and additional time – both because of fatigue and for specialist skills they need to learn. In fact, pupils may be included only up to a point; they may be in the same class as pupils with other needs but they may not spend much time with them, in fact they may spend more time being taught differently for example, being taught with different materials or outcomes or taught 1-1 by an adult but with little interaction with other pupils.
- 4.212 Hartmann describes Universal Design for Learning (2011) as a way of allowing multiple means of access both by the materials and artefacts used, the ways of using the learning materials for output and the motivation to stay involved. This can mean that enhanced visual materials, alternative communication methods, and tactile means can all be included.
- 4.213 The social elements of inclusive practice are at least equally important, and to the individual perhaps more important. Friendships and social activities are often remembered longer than studied subjects in school. Correa-Torres (2008a) found that most social experiences for deafblind individuals in her study were with adult staff. Kamenopoulou (2012) found that in mainstream secondary schools, pupils



were isolated and felt different. Even where they shared communication methods Kamenopoulou's participants (2012) still found it very difficult indeed to make friends in mainstream secondary schools. This was put down to the school environment, and the fact that they were unable to cement friendships because of mobility and travel difficulties, so that they spent out of school time with families, or alone.

#### *Available evidence*

- 4.214 Desrochers et al., (2014) examined the use of background music in the classroom to minimise problem behaviours for a single participant. In this case both standing up and stereotyped behaviours limited the pupil's readiness to learn and these both decreased when background music was played. This study was rated overall as providing moderate to strong quality of evidence. Results suggest that background music may be a viable intervention to improve an individual's behaviour during assessment. However, further research is needed to investigate the generalisability of this finding and clarify the conditions under which music is most effective.

#### ***Implications***

- 4.215 Deafblind learners will present significant challenges to educational systems. In mainstream schools they require access to learning through adaptation and social relationships are difficult and sometimes require adult facilitation. In special schools for individuals with learning difficulties, where there is often a significant reliance on visual alternatives, in particular for communication (signs, symbols, schedules, etc.) they will need specialist accommodations. In special schools for the visually impaired or the hearing impaired, they will be unable to use the sense on which most others rely as effectively and, once again, may find barriers to learning and social skills.
- 4.216 Among the recommendations for inclusive practice from the literature are:
- The importance of appropriate support for an individual. The intervention from Desrochers et al. (2014) would not be appropriate for all.
  - An appropriate environment (Möller and Danermark, 2007), which includes lighting, labelling, hearing technology such as loop systems, and more. It is important that children and young people do not become so dependent on these that they cannot function in the wider community (Prickett and Welch, 1995). The environment needs to be safe for mobility (Rikhye et al., 1989).

- A shared communication environment where staff and peers frequently use the same communication methods as the deafblind learner (be that sign, symbol or speech). Interpreting may be required (If the learner is at pre-symbolic levels, there need to be partners who can try to understand them).
- A recognition of the person as they see themselves (e.g. some with acquired deafblindness may consider themselves 'deaf' and not consider visual impairment,) while ensuring that their needs are met (Möller and Danermark, 2007).
- Availability of resources in appropriate formats and/or use of magnification (Hodges, 2000; Rikhye et al., 1989): where possible resources to be arranged so that they are available to the whole class and do not simply 'pick out' the deafblind learner (e.g. Galvão et al., 2018 in their provision of resources for plane geometry).
- Enabling participation through Universal Design for Learning by using multiple means of access (visual, auditory, tactile), multiple ways of engaging with materials, and multiple routes of output (text, photograph, video etc). This can help keep individuals motivated and engaged (Hartmann, 2011).
- The importance of pace, and time. Deafblind learners are inevitably slower at reading, processing and need additional time for handling items (Rafalowski-Welch and Goetz, 1993). They may need additional time for travel. They may need decreased demands (fewer sums completed, less requirement to take part in assembly) to ensure their participation, while still completing necessary understanding.
- Facilitation of social relationships. This may be through peer training, using buddies (Correa-Torres, 2008b; Romer, White and Haring, 1996) or through facilitation e.g. of group work in class (Rowland and Schweigert, 1993).
- Professionals must work together including visiting specialists, class teachers and professions allied to medicine. A key worker can facilitate liaison (Rafalowski-Welch and Goetz, 1993).
- Family, and where possible, the pupil, should be included in decision making.
- All staff need training (Rafalowski-Welch and Goetz, 1993), possibly at different levels.
- Preparation is essential – for moving into a school, in respect of specialist events (such as trips) and for every session in terms of adaptation. This should focus on preparing the learner to be independent, to socialise and to learn.

4.217 Inclusion, where a pupil is 'not only served, but well-served, in programmes which protect their unique service needs while supporting full membership in the life of the school' (Rafalowski-Welch and Goetz, 1993 p 4) is a balancing act between the needs of the class, the abilities and attitudes of staff and the needs and wishes of the pupil.

## 5. Conclusions

- 5.1 A conceptual framework for the education of deafblind learners is presented in the introduction which outlines the twofold nature of learning to access and access to learning. An individual needs to have both fair and optimised access to the learning available at school and to learn to use this access themselves to increase their independence and learning. The interaction between these two is at the heart of education for deafblind learners. There are three key barriers to learning for deafblind learners: communication, access to information, and mobility and orientation. Each of these interacts with each of the other. Development in one area is likely to have a positive impact on the other areas: increases in communication help to increase access to information; increased mobility helps increase communication; and thus for each of the combinations of these three areas.
- 5.2 The REA was undertaken with reference to the conceptual framework, searching for evidence in these broad approaches. Evidence was sought and ideas were discussed in the Section 4 – Intervention summaries. In this section, we offer overarching themes, reflect upon the nature of evidence available, and consider the implications for educational practice in Wales.

### **Assessments and educational specialists**

- 5.3 Assessments were broadly excluded from the intervention review because of the definitions of the areas investigated for the REA. They have however been included to some extent within the introductions and implications section, with particular reference to the sections Communication, Literacy, and Teaching Strategies. While it is typical to think of assessments as related to pupil progress, they are in fact much more than this. Assessments are key to good teaching because they provide decision making information about the strategies needed (e.g. about levels of communication, about inclusion, and about learning media). In relation to measuring learners' progress, in deafblindness, this is a complex area. As outlined in the sections on Cognitive Skills; a summative assessment may not show what a learner is capable of, but only what they have experienced. That experience is limited by deafblindness. McInnes and Treffry (1982) state that;

‘some or all of the input systems have been damaged, but the processing mechanism has not.’ (p5)

- 5.4 While this is not true for all deafblind learners, the point is made that any deafblind learner encounters barriers of their sensory impairments to accessing experience and learning. Assessment, therefore, needs to be not only of *what is learnt* but also of *how learning takes place*. This can indicate important factors such as speed of learning, ability to generalise, problem-solve and integrate learning within current skills (Hodges 2004). A dynamic assessment of how someone learns may be more indicative of ability – with all the limitations of that term – than any summative assessment could ever be
- 5.5 Assessments which examine the systems and availability of access are also important to this group of learners. Without opportunities being made which are suitable for deafblind learners, they cannot be expected to learn.
- 5.6 In terms of early years progress, there is no developmental journal specific to deafblindness. However, both the Developmental Journal for Babies and Young Children with Vision Impairment (Dale and Salt, 2007), and the Deaf Babies and Children Development Journal (Council for Disabled Children, 2013) can be useful if interpreted by a skilled professional. They are probably most appropriate for learners who do not have an additional learning disability. The Development Journal for Children with Multiple Needs (Council for Disabled Children, 2013) can also be very helpful and was written deliberately to include learners with deafblindness (though it is not specific to them).
- 5.7 In terms of general developmental assessments, the *Callier Azusa scale G* (Stillman 1974) while well known in the field and specific to deafblindness is based in an educational context not always relevant to deafblind people 45 years later and in the UK. *Child Guided Strategies, the Van Dijk Approach to assessment* (Nelson et al., 2009) outlines an approach to assessment through following a child’s own activities, but without a prescriptive scale. Some use the *Victoria School MSI Curriculum profiles* (Murdoch et al., 2009) as an assessment tool, but Murdoch is quite clear that it is a curriculum rather than an assessment;

‘The Profiles are criterion-referenced assessments, linked to the MSI Unit Curriculum, not generic developmental measures.’ (p105)

- 5.8 Communication assessments have already been alluded to (see Communication, in Intervention summaries). The Callier Azusa scale H (Stillman and Battle, 1985) usefully outlines four areas which need equal development: Expressive and Receptive language, but also Reciprocity and Symbolicity which are areas likely to be of particular interest in deafblind learners. The Communication Matrix, while not written only for deafblind learners is particularly directed towards them (Rowland, 2004) and is an extremely helpful tool for examining communication levels and methods.
- 5.9 Functional visual and hearing assessments (complementary to clinical assessment) help educators to understand the residual skills of vision and hearing, to enable deafblind learners to both develop and apply those senses and to adapt appropriately for missing sensory information. Southwell in *Assessing Functional Vision in Children with Complex Needs* (2003) provides a useful outline for assessing vision (although this is not specific to deafblindness). Nelson and La Payette's *Routine-Based Functional Hearing Screening for Young Children Who are Deafblind* (2003) provides some advice for examining hearing, and Petroff et al. (2003) provide a useful framework in *Functional Assessment of Sensory Status of Children who are Deafblind* for drawing together information about both hearing and vision for deafblind learners.
- 5.10 Finally, systems sensitive assessment, as outlined in section 4.1 above, is especially important in relation to deafblind learners. This might include audits of both the visual and the hearing environment such as *How acoustically friendly is your classroom* (McGinn, no date) or Naish et al.'s (2003) *Exploring access* (neither of these are specific to deafblind learners). Albin and O'Neil's (1994) *Positive Environment Checklist* is a useful way of looking at responsive communicative environments (though again, not specific to deafblindness). Taylor et al. (2006) draw on curriculum, assessment, communication, social relationships, and assistive technology to look at the whole environment of the learner in their *Classroom Observation Instrument for Educational Environments Serving Students with Deaf-Blindness*.
- 5.11 Deafblindness is complex: the range and combination of levels of vision and hearing difficulty; the presence or not of other disabilities; the difficulty of disentangling which apparent difficulties are caused by additional disability and which are due to deafblindness (e.g. cognitive or motor delay) requires educators who are skilled and

reflective. No research paper, however robust, or good practice article, can give a definitive answer to questions about appropriate strategies for a given individual. As outlined earlier in the report, most of the empirical evidence is of very small sample sizes and narrow ranges. The specialist in deafblindness needs to be able to understand the research process, to interpret the ideas as they might apply to their own situation, and to apply them to the individuals they are working with. The consequences of a combination of vision and hearing impairment means that specialists in vision impairment or in hearing impairment as single fields, or even a combination of those specialists working together, is not sufficient for the individual with dual sensory impairment (McInnes 1999). From specialist training in deafblindness, educators can draw on skills in assessment, environmental management, pedagogy and resources to build effective programmes, deciding in each case on the appropriate approaches and having the skills to implement them. This will include drawing in the expertise of others to enhance and support, including: educational audiologists, habilitation specialists, intervenors, low vision specialists, teachers of the vision impaired and the hearing impaired, and professionals allied to medicine (Speech and Language therapy, Occupational therapy, Physiotherapy), and of course the knowledge of parents and young people.

- 5.12 Since 1989 teachers in Wales and England have achieved Specialist Qualifications in Deafblindness (MSI). These provide a Mandatory Qualification (MQ) which recognises the unique blend of skills and knowledge required for providing for deafblind learners.

### **Implications for Wales**

- 5.13 The Additional Learning Needs and Education Tribunal (Wales) Bill was passed by the National Assembly for Wales on 12 December 2017 and became an Act on 24 January 2018 after receiving Royal Assent. This will create the legislative framework which aims to improve the planning and delivery of additional learning provision, through a person-centred approach to identifying needs early, putting in place effective support and monitoring, and adapting interventions to ensure they deliver desired outcomes (Welsh Government, 2018).

5.14 The transformed system seeks to:

- Ensure that all learners with ALN are supported to overcome barriers to learning and achieve their full potential.
- Improve the planning and delivery of support for learners from 0 to 25 with ALN, placing learners' needs, views, wishes and feelings at the heart of the process.
- Focus on the importance of identifying needs early and putting in place timely and effective interventions which are monitored and adapted to ensure they deliver the desired outcomes.

5.15 The Act requires that learners with ALN will have a single plan – the individual development plan (IDP). This will replace the current range of statutory and non-statutory plans for learners with special educational needs or learning difficulties and/or disabilities.

5.16 The new emphasis of the legislation is to bring about many changes, but fundamental will be the attention to the support of learners with ALN up to the age of 25 years, and a focus upon targeting services to deliver *outcomes*. Drafts of the ALN Code of Practice place great emphasis upon targeted outcomes, including reference to developing young people's *independence* as part of accessing a broad and balanced curriculum.

5.17 The conceptual framework for the education of deafblind people presented in this report aligns with this policy transformation – the emphasis upon equal access to education ('access to learning') balanced with development of individual agency ('learning to access'). The framework presented, and the associated thirteen educational strategy areas, offers a vocabulary for identifying the needs of, and educational approaches for, deafblind children and young people. The analysis of available evidence through the REA identifies very little evidence of the effectiveness of many of these approaches, through the intervention focused articles/writings. Nevertheless, it is argued that educational practice demonstrates the general value of many of the approaches. However, it is commonly the case that such evidence does not provide precision of what works, when, and with whom. In many cases, there is a complete absence of evidence. Two implications of this are: (1) more research evidence is needed, and (2) practitioners must design broad interventions based upon the evidence and practice available, and then modify and adjust that intervention based upon assessment of progress.



## Annex A - Bibliography of evidence

### Communication

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## Annex B: Database sources and search terms

### Stage 1: Literature search and inclusion/exclusion criteria framework

The aim of stage 1 was to carry out searches using the databases and search terms specified below and to apply an inclusion/exclusion criteria framework.

#### Databases

In the inception report it was stated that seven databases would be searched to identify the literature. Following advice from the subject-specialist librarian at the University of Birmingham and discussion with the funder, it was decided to complete searches within four of those databases. The reasons for inclusion or exclusion of each database are provided in the table below:

**Table 14: REA stage 1 databases**

Included?	Database	Rationale for inclusion/exclusion
Searched	<b>EBSCO Education Databases</b>	Provides a platform on which a search can be undertaken across five important databases in the field of education – British Education Index (BEI; Child Development and Adolescent Studies; Education Administration Abstracts; Education Abstracts and ERIC (an American education database).
Searched	<b>PsychInfo</b>	Provides abstracts and citations to the scholarly literature in the psychological, social, behavioural and health sciences.
Searched	<b>Proquest Social Sciences</b>	A social sciences database platform which includes databases also contained within EBSCO Education Databases, but also some additional relevant databases.
Searched	<b>Web of science</b>	Added following Inception Meeting.
Not searched	<b>Education Research Abstracts not searched</b>	This database does not allow sophisticated searches (combination of searches). The subject specialist librarian advised that the sources included in this database would have already been retrieved by the searches within the other comprehensive databases (particularly EBSCO).
Not searched	<b>Medline (including CINAHL plus) Medline- not searched</b>	This database is included in the Web of Science database.
Not searched	<b>Science Direct:- not searched</b>	The subject specialist librarian advised us that the sources included in this database would have already been retrieved by the searches within the Web of Science database.

A number of other generic databases and known websites were identified in the Inception Report. These hand searches have not yet been performed as a high volume of sources were identified by the searches described above.

### *Search structure*

Our broad search involved a series of searches with the following structure (the detailed search terms follows in the next section):

**[Age] AND [Sensory Impairment X 3]**

**AND**

**[Educational strategy]]**

### *Search terms*

An asterisk was used for truncation in some of the databases for quicker searching: for example, "visual\* impair\*" would find instances of "visual impairment" as well as "visually impaired", and "child\*" found articles with "child" and "children" as well as other possible variations of the word.

#### **Age (using Boolean operator OR)**

Child\* OR student\* OR pupil\* OR pre-school OR "post school" OR transition OR kindergarten OR youth OR "young people" OR teenagers OR adolescent\* OR "early years"

#### **Sensory impairment: Multi-sensory Impairment (using Boolean operator OR)**

"Multi-sensory impair\*" OR "multisensory impair\*" OR MSI OR "Dual-sensory impair\*" OR Deafblind\* OR "Usher Syndrome" OR "CHARGE syndrome"

## **Educational strategy**

The thirteen strategies listed below were be searched for individually (each using Boolean operator OR), and repeated with some adjustment for each sensory impairment group.

### 1) Communication

*Auditory OR Oral OR Sign OR "Sign bilingual" OR "Cued Speech" OR "Visual phonics" OR "Manually coded sign systems" OR "Objects of reference" OR "Calendar systems" OR "Voice output" OR "Haptics" OR "social haptics" OR "Adapted signing" OR "Smell cues" OR "On body signs"*

### 2) Literacy

*Reading OR Writing OR "Metacognition and reading Comprehension" OR "Emergent literacy" OR Phonology OR "Phonological awareness" OR "Phonemic skills" OR "Visual phonics" OR Vocabulary OR "Syntactic Knowledge" OR Braille OR "\*Large\* print" OR "Modified print" OR Print*

### 3) Mathematics and numeracy

*Numeracy OR "Math\* problems" OR "Math\* concepts", "visual spatial abilities" OR quantity*

### 4) Access to examinations

*Exam OR Examination OR "Assessment accommodation" OR "Access arrangements"*

### 5) Mobility and Independence

*Habilitation OR mobility OR independence OR ILS OR "independent living skills" OR "daily living" OR "activities of daily living" OR orientation OR O&M OR M&I*

### 6) Cognitive skills

*Cognition OR Play OR "Theory of Mind" OR "Visual attention" OR Perception*

### 7) Social and emotional functioning

*Social OR Emotional OR Assertiveness OR Resilience OR "Self concept" OR "Self-worth" OR "Deaf identity" OR Friendship OR Behaviour OR*

*Interpersonal OR "Well being" OR "Peer training" OR "Peer awareness"  
Buddy OR "Circle of friends" OR "Self advocacy"*

8) Use of technology

*"Cochlear implant" OR "Hearing aids" OR "FM systems" OR "Acoustics ICT"  
OR Computer OR "Mobile technology" OR "Assistive technology" OR  
"Enabling technology" OR "Access technology"*

9) Low vision training

*"Low vision therapy" OR "Low vision device" OR LVD OR "Low vision aid"  
OR LVA OR "Visual skills"*

10) Teaching support

*"Learning Support assistant" OR LSA OR "Teaching Assistant" OR TA OR  
"Communication Support worker" OR Intervenor*

11) Strategies

*"Co-active movement" OR "Preparation of teaching materials" OR "Audio  
description" OR "Subtitle" OR "Enlarged print" OR "Simplified language"*

12) Welsh and minority language

*Catalonia OR Catalan OR Basque OR Brittany OR Breton OR Frisian OR  
Welsh OR Gaelic OR Irish OR "Minority ethnic" OR "Minority language\*" OR  
bilingual OR "dual language"*

13) Inclusion

*Acceptance OR Rejection OR Modification OR Learning styles OR Pre-  
teaching OR "post teaching" OR "School environments" OR "Person centred  
learning"*

*Filtering by types of materials and relevance criteria*

In each of the four databases the 'filter' setting was used to enable us to select only the types of materials under the 'inclusion criteria'



**Table 15: Types of materials – inclusion and exclusion criteria**

Inclusion criteria	Exclusion criteria
Peer reviewed academic journals	Websites not hosted by a recognised organisation as determined by the reviewers. Decision making will be documented.
Professional journals	Personal blogs
Expert opinion*	Personal opinions of interventions (presented online)
Students' work, PhD and Masters dissertations	Newspapers

Note \* expert opinion must be written and published by a professional body or reputable publisher, and the author has considerable experience in the field. This will be determined by the reviewers and decision making will be documented.

An additional filter was used to enable us to select the materials under the relevance inclusion criteria.

**Table 16: Relevance – inclusion and exclusion criteria**

	Inclusion criteria	Exclusion criteria
Date	1980 onwards*	Older than 1980
Language	English or Welsh	Any other language
Geographical location**	International	No exclusion
Population age	0-25	25 onwards

\* *date 1980* – this date was chosen as an approximate time scale when education practice in relation to disability started to more clearly reflect current practice (e.g. in England and Wales through the 1981 Education Act) - , in particular the acceleration of the creation of services in the UK which supported the education of children with vision impairment in mainstream schools. The time period also reduces the search results while still including evidence from approximately the last 40 years.

\*\* Location – the focus of the search was agreed to be research undertaken in OECD countries but this was not an available search criteria in. This criteria was therefore applied in stage 2.

## *Stage 2: Refining the search*

The aim of the second stage was to narrow the material down from the initial search by offering a detailed consideration of each source to ensure the most relevant material is selected.

A separate Endnote database for each subject area was created. The sources in each Endnote database were scrutinised based on the inclusion and exclusion criteria regarding the relevance of the study. Although the 'location' filter in each database (stage 1) assisted in selecting sources only from OECD countries, the sources were further scrutinised (reading the abstracts) for geographical location

In terms of relevant to the aim of the study, this is defined as the extent to which educational interventions are effective (or not) for sensory impairment with the purpose of improving targeted outcomes. Where research is related to technology, this technology should be current and has not been superseded by new technology/approaches which means the intervention is no longer relevant. Also, to be relevant the intervention should not be *solely* about a medical intervention (e.g. cochlear implant operation or cataract surgery), nor solely about the provision of a technical aid (e.g. hearing aid or low vision aid), but should be about the educational intervention around this. Furthermore, while interventions should have an education focus they should be additional to or different from those provided as part of, for example, a school's usual differentiated curriculum and strategies.

It was also noted that many articles generated in stage 1 were not relevant – particularly in visual impairment were studies incorporating alternative meanings of key terms were initially identified (e.g. "blind marking").

### *Initial sorting of materials for each sensory field*

Following discussions with the funder, it was noted that the commissioned sensory REAs were very broad in focus, rather than focussing upon a specific type of intervention or targeted educational outcome. All three REAs were linked to all educational outcomes, which the team sought to simplify into thirteen areas (see search terms in section Annex B: Database sources and search terms). This can be contrasted with other REAs undertaken in other disciplines which might seek evidence of the successful interventions in relation to much narrower target outcomes (e.g. in relation to ADHD, the focus may be linked to the reduction in particular defining behaviours).

In addition to the point about breadth of the review, there is a related challenge of defining the term 'intervention'. Our working definition of an intervention study was outlined in the proposal as studies which sought to describe the effect of some kind of educational approach upon a targeted outcome. These studies might be qualitative designs, controlled trials, or single subject designs.

In order to contextualise this definition further, the invitation to tender offers the following definition of the interventions of interest:

For the purposes of this research, an intervention is defined as SEP [special educational provision] as set out in the Education Act 1996 'education provision which is additional to or otherwise different from the education provision made generally for children of their age in maintained schools, other than special schools, in the area. For children aged under two SEP is considered to be education provision of any kind. (p11)

Our proposal also unpicked special educational provision further and made a distinction between.

- (1) Inclusive practice and differentiation: ensuring that the child's environment is structured to promote inclusion and learning throughout their education.
- (2) Additional learning provision: supporting the child to learn distinctive skills in order to afford more independent learning.

Such a broad and inclusive definition of intervention is helpful in ensuring valuable evidence is included in these REAs which are broad in scope. Nevertheless, such a definition is difficult to operationalise. The working solution was to make a distinction between the following categories of sources: (1) 'excluded/ not relevant'; (2) 'good practice'; and (3) 'intervention'. The table below outlines the criteria for this categorisation.

**Table 17: Working definitions of categorisation of sources – (1) 'excluded/not relevant'; (2) 'good practice'; and (3) 'intervention'.**

Category	Definition	Example
<b>1. Excluded/not relevant</b>	The source is not linked to a relevant <i>educational</i> intervention or outcome (e.g. it is medical in focus), or the source does not provide an analysis of educational practice.	(1) Impact of cochlear implants upon functional hearing. (2) A survey of teacher preparation or parent attitudes not linked to educational practice.
<b>2. Good practice</b>	The source is linked to <i>educational</i> practice. While it does not provide evidence of an effect of that practice upon target outcomes, it provides evidence and rationale for the differentiated education provision.	The development of standardised and accessible assessment approaches (e.g. a reading assessment for braille readers).
<b>3. Intervention</b>	The source presents evidence of the effect of some kind of educational approach upon a targeted educational outcome(s).	The trial of a reading intervention to measure the effect upon children's reading performance.

Based upon these working definitions all the sources in each Endnote database were categorised into (1) 'excluded/not relevant'; (2) 'good practice'; and (3) 'intervention', and this is reported upon in the sections which follow.

### *Inter-rater protocol and scores*

An inter-rater reliability check was performed based on the following protocol:

1. Quality rater 1 (QR1) to identify 25 % of articles from each category (13 categories). If necessary round up the number of papers e.g. 25% = 2.75, rate 3 papers. The selection of the articles to be given to Quality Rater 2 (QR2) is based on the following criteria:
  - Only one article by author in each category.
  - A variety of methods when possible. If the category includes interventions with a range of methodology, select a sample different designs of interventions (e.g. trials, case study etc.)
  - A range of scores. If possible the selected articles should reflect the range of scores given (i.e. 1, 2, 3)
  
1. Quality Rater 2 (QR2) to rate each selected article blindly
  
2. The total mean scores from each rater are entered in two columns in excel (QR1, QR2)
  
3. Calculation of inter-rater agreement (percentage)
  - The scores from the two raters will be entered into columns in excel (QR1 and QR2).
  - Agreement will be calculated based on the two scoring categories (1- 1.9: impressionistic to moderate evidence, 2-3 moderate to strong evidence)
  - The agreement of the two raters will be entered in a third column. When the scores of the two raters agree on these two scoring categories (i.e score is anywhere between 1-1.9 or between 2-3) then a score of 1 will be given. If the scores of the two raters are in a different scoring category (e.g the first rater scores 1.6 and the second 2.5) then a score of 0 will be given in the third column.
  - The number of agreement ( i.e the number of 1s) will be added and divided by the number of the articles that were rated by both raters and multiplied by 100.

Example is given below:

A	B	C
<b>QR1</b>	<b>QR2</b>	<b>Agreement (1-1.9 and 2-3)</b>
1.9	2.3	0
2.1	2.6	1
2.3	2.1	1
2	1.8	0
2.3	2.3	1
1.3	1.4	1
2.4	2.5	1
2.8	2.6	1
	<b>Average (sum divided by the number of articles rated)</b>	<b>0.75</b>
	<b>Percentage of agreement 75%</b>	<b>75%</b>

4. In the above example 8 articles were rated, for 6/8 articles there was agreement on the scores (in the same category of 1-1.9 or 2-3). The agreement was 75%.
5. Discussion between the two raters where there is no agreement in their scores (a score of 0 was given in the agreement column). In this case, the raters need to discuss and reach a conclusion on the score that will be assigned to each article. This will be discussed by looking at the individual components' score.
6. After rating QR2 to read the 'extracting info' section and to add or amend text as necessary.

#### *Stage 4: Data extraction*

A predefined spreadsheet template was developed to facilitate recording of the most important details of each study on intervention to provide a comprehensive overview. This template (record) includes the following details (fields) for each article:

- Title and authors with full reference or web address
- Funder of the research study
- Authors' affiliations
- Welsh specific data
- Theme of the intervention linked to the educational outcomes ( 13 categories)
- Methodology – including aims, objectives, sample size etc.

- Participants including the following details:
  - Sample size
  - Age group covered
  - Gender
  - Ethnicity
  - Socioeconomic data:
  - Details related to the characteristics of the participants with specific sensory impairment (e.g. degree of sensory loss)
- Design of the research and intervention details:
  - The nature of the intervention/independent variable under investigation.
  - Case study; Action Research; Longitudinal study; Trial; Control trial; Single subject design
- Pre and post measures
- Data Issues – Quality and Limitation
- Key findings summarising the effectiveness of the intervention
- Author’s conclusions and recommendations covering the key messages from the article
- Confidence scoring of robustness of the articles (see below).
- OTHER comments – any other reviewer comments which may support the writing upon the report as a whole and/or synthesising the findings (e.g. noting opinions about the applicability – or otherwise – of the findings in the opinion of the reviewer, which were not reported by the original authors).