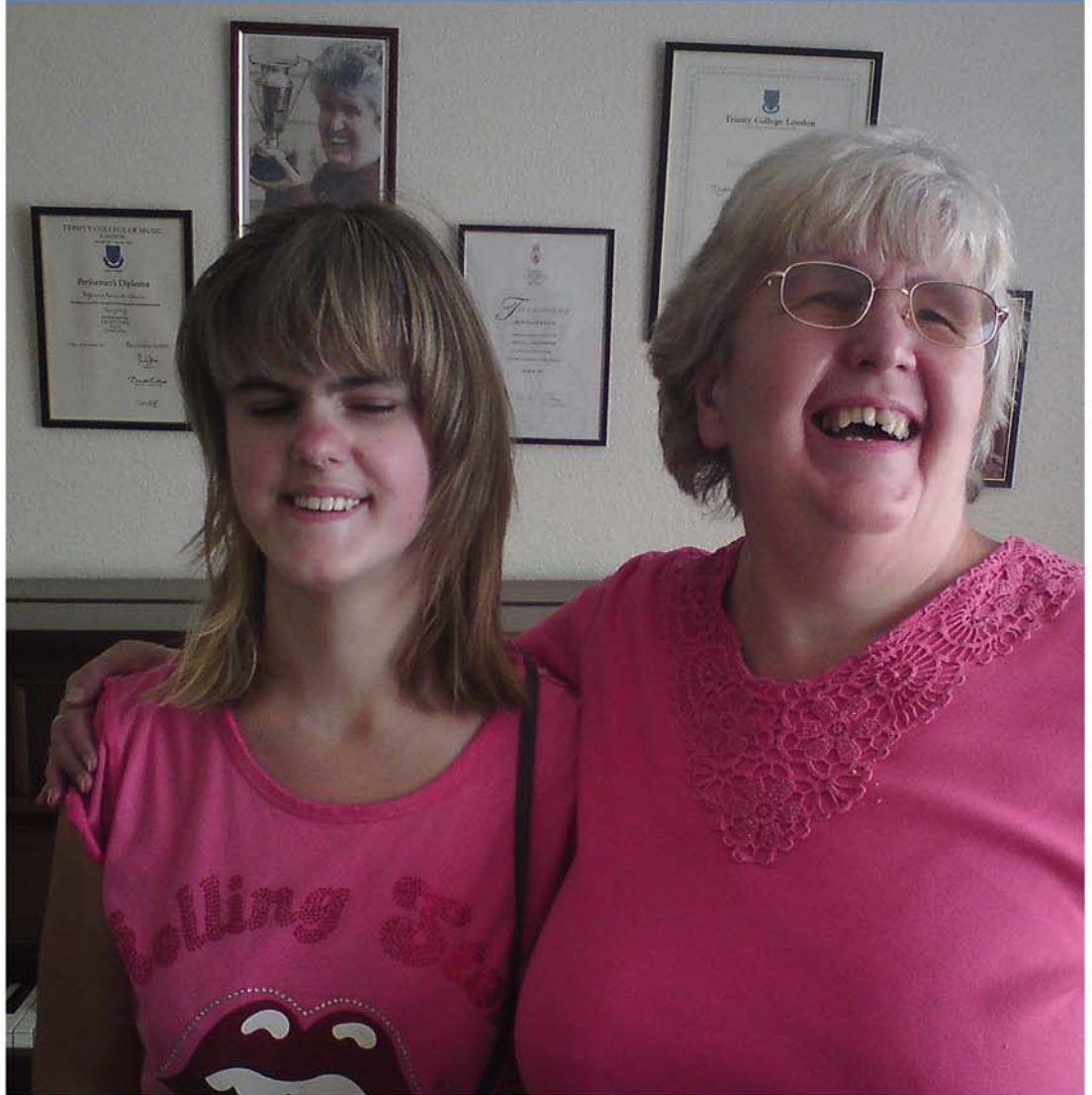


# Growing Up and Moving On



Service Provision for Children and Young People with Visual Impairment in Wales

Elaine Kelleher

## **Growing up and Moving On: Service Provision for Children and Young People with Visual Impairment in Wales**

This report was written by Elaine Kelleher, Rehabilitation Officer Visual Impairment for Bridgend County Borough Council, on behalf of Sight Support.

The author would like to extend her gratitude to the many people who were interviewed and provided information in the course of this research, young people, parents/carers and practitioners from a range of organisations.

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## **Foreword from Sharon Beckett, CEO Sight Support**

Sight Support is delighted to have been able to sponsor this excellent piece of research. We have long been concerned that sight loss is too often seen as exclusively something that affects older people, and excludes the very real needs of children and young people. For those at the beginning of their lives, sight loss may be something that will affect them for many decades to come and is likely to have a greater impact on their families and carers than may have been the case if they were adult at onset.

It is reassuring to see that despite sight loss profoundly affecting young people and their families, there are examples of very good practice and joint working. But we should not be complacent, and given that these children are the future for us all, we need to build on what we have and make sure everyone with sight loss has access to excellent timely broad-based rehabilitation and support. Furthermore, that support should be extended to their families and carers, and made available at many points throughout their growth and development.

We would like to thank Lloyds TSB Foundation for their financial support, and Elaine Kelleher for her superb professionalism throughout the project. We'd also like to thank WCB for tying up the technical loose ends and publishing the report on our behalf. Most importantly we'd like to thank everyone who gave their time and expertise towards this work and particularly those families who took part.

Finally, we do believe this report gives a very real opportunity to make sure we can build on existing provision and ensure that in the future children and young people with sight loss can be given the very best start in life by working together – statutory and third sectors alongside parents and carers.

If you have an interest in this area and would like to be part of further such work please, please get in touch. It's their future, and our responsibility to protect it.

## Introduction

Anecdotal evidence suggests that some young visually impaired (VI) people may have a good level of education but lack independence and life skills needed to move onto the next phase of their lives. Reports from some individuals reflect that there is a lack of information about services and entitlements, lack of skills training and lack of support. These worrying reports led to the need for an in-depth exploration of what services are in place for VI children and young people, where gaps may lie in service provision and to highlight good practices which could be used to improve services in other areas of Wales.

This research scopes the nature and provision of services for children and young people with visual impairment in the community across Wales. It focuses on how mobility and independent living skills (habilitation) are provided by the relevant statutory agencies. It also looks at what VI services from all sectors are in place to promote social inclusion, and what opportunities are available to improve the confidence and self-esteem of visually impaired young people on their journey through childhood. The report brings together information primarily from surveys, interviews and discussions with practitioners in education, social care and third sector organisations as well as a small number of interviews with parents and young people.

For the purposes of this report, children and young people are defined in the age range 0-19 years.

Throughout this report the term 'habilitation' and 'mobility and independent living skills training' are used. These terms are interchangeable; the term 'habilitation' recognises the distinct needs of children with VI acquiring new skills as opposed to rehabilitation with adults, where the emphasis is on regaining skills and independence. A list of abbreviations used is also provided in Appendix 1.

A separate document gives a directory of services in each Local Authority across Wales.

## **Objectives**

The objectives of the research are to:

- Present a picture of what specialist VI services are in place for children and young people within each authority in Wales from both the statutory and non-statutory sectors and how these services link together;
- Present a picture of how VI specialist services are addressing the mobility, independent living and social skills needs of children and young people and to what extent;
- Provide recommendations based on findings.

## **Executive Summary and Recommendations**

*'The fear of not knowing what to expect was the worst. It was only by talking to another parent that I realised what support was available.'*

*'I didn't know that there were specialists in social services who provide independence skills'.*

*'Services were co-ordinated; Social Services did the home bit and had Rehab meetings with school. This is when it all came together for her.'*

*'He was registered in 2005 but it took 6 years to get a Registration Card. We didn't have a visit from social services'*

These quotes from parents illustrate how different their experiences of Specialist VI Services have been across the country. This research provides a directory of Specialist VI services across Wales for children and young people, from both the statutory and non-statutory sectors (see the separate document with this report). It focuses on specialist VI extra-curricular support provided by education, as well as specialist VI support by both social services and third sector, to meet the mobility, independent living and social skills needs of children and young people. Inclusion of VI specialist roles based in Adult Social Services draws attention to the individual nature of support which is available for VI children and young people in each authority.

Feedback from parents and visually impaired children and young people has highlighted the importance of independence, social interaction and support. Examples of good practice are emphasised and gaps in service provision across Wales have been identified.

The main findings relate to habilitation provision by education and social care which has been found to vary widely between authorities. In 18 authorities, mobility specialists in education provide mobility skills training to children and young people with VI in Wales. In the other 4 authorities this service is provided by Rehabilitation Officers Visual Impairment (ROVIs) based in Social Services. Mobility specialists in education incorporate provision of independence skills in their roles as much as possible. In 12 authorities ROVIs provide habilitation for children as well as providing rehabilitation for adults. In the other 10 authorities habilitation is not provided.

Examples of good communication across services are highlighted and recognition is given to innovative and collaborative working by determined individuals to improve services and promote sharing of information with the needs of the child or young person at the centre.

The remainder of the research highlight other factors which affect the mobility, independence and social skills development of children and young people. In particular the registration process (following receipt of the Certificate of Visual Impairment (CVI) in social services) for children and young people is not as robust as that for adults. 5 of 22 authorities do not offer an assessment of VI needs for children following receipt of CVI.

There is widespread concern amongst VI Practitioners that VI children and young people are not being offered an assessment of need by Disabled Children's Teams due to high access criteria.

The importance of specific VI social groups for VI children and young people is brought to light. Professionals in education, parents as well as children and young people themselves emphasised the huge benefits on many levels of having the opportunity to socialise with other VI children.



This report did not look specifically at transition but has flagged up the need for more detailed research into meeting the needs of young people with VI at this crucial stage in their lives. Each agency involved needs to plan and communicate effectively with each other as well as involving the young person and providing them with appropriate information.

## Recommendations

1. Every VI child and young person in Wales should have access to a full habilitation service. In the current model of service provision, habilitation service needs to be improved as follows:
  - i. An increase in mobility services in education to ensure that every VI child and young person should have an assessment of their mobility needs. The mobility service should address mobility needs at school, in the child's home and in their local community.
  - ii. The creation of a Rehabilitation / Habilitation Officer post for children and young people on a regional level to provide a service in the authorities where there is no service provision (10 authorities in Wales). The post, possibly joint-funded between education and social care, needs to be based in Children's Services to increase awareness of the specialist needs of VI children and young people and to promote joint-working across services. The needs of young people of transition age 14-25 are greatest as current provision varies greatly from one authority to another.
2. Creation of a Transitions Officer for VI post based in North Wales to provide a similar level of support for children and young people as that provided in South Wales. The current RNIB Transitions Service is undergoing expansion with the potential recruitment of a part-time Transitions Officer for South Wales and an equivalent in North Wales.
3. Creation of regular VI-specific social groups for children and young people in each region. The data on VI children supported by Local Education Authority (LEA) in Table 4 provides a geographical spread of children and young people with VI.

## Measures which can be taken within current resources:

1. Highlight the findings regarding registration with Eye Clinic Liaison Officers (ECLOs). Equip ECLOs with information on entitlements of registration for children and young people and information on statutory and third sector services available in each authority. For example, the eye clinic in Singleton Hospital in Swansea sends CVIs to Swansea, Neath Port Talbot, Powys and Carmarthenshire. Service provision for children varies significantly for each of these authorities and the ECLO has a crucial role to play with providing information, particularly in authorities where a habilitation service is not provided for children and young people.
2. Working together to improve communication and partnerships, especially between education and social services leading to multi-agency working with young VI people ultimately achieving their potential for an independent life.
3. Where habilitation services currently exist for VI children and young people, VI specialists in education and social care need to meet regularly to discuss the needs and plan service intervention to provide continuity and improve outcomes for VI children and young people.
4. Where habilitation services for VI children and young people don't currently exist, improvement of the transition to adulthood process is required by prioritising the needs of visually impaired young people by Adult VI services. Identify one ROVI to take the lead on transition working whilst ensuring that protected time is allocated to ensure that other aspects of their job do not take priority over their role with young people.

5. Links need to be made at an early stage between VI services in education and Rehabilitation services in Adult Social Care to ensure the young person is aware of services available to them. Referrals should be made as appropriate.
  
6. Capitalise on resources already in place. For example, the Independent Living Skills Co-ordinator in Gwent Visual Impairment Services has developed a series of 'I Can Do It' leaflets, step-by-step guides for children, parents and Teaching Assistants to show them how to complete tasks such as using a microwave or tying laces.

# The Report

## Background

Statutory and non-statutory services for VI have seen many changes and developments in Wales over the past ten years.

Statutory Services for disabled children have been underpinned by the Children Act 1989<sup>1</sup>. Since the Children Act 2004<sup>2</sup> Local Education Authorities (LEAs) and Children's Services were brought under the same leadership with responsibility for both functions being held by the Director of Children's Services. In some areas, this has contributed towards the development of multi-disciplinary Disabled Children's Teams with professionals from education, health and social services providing integrated services.

Services in education for children and young people with VI are underpinned by the Statement of Educational Needs (SEN) Code of Practice for Wales (2002)<sup>3</sup> which sets out the statutory duty of educational settings to make provision for children's needs in education. In 2003/4 the Welsh Government carried out an audit of educational provision for children and young people with Sensory Impairment. The findings led to the Quality Standards in Educational Services for Children and Young People with Sensory Impairment<sup>4</sup> which sets out clear guidance for LEAs. The findings also led to the Welsh Government providing a grant for teachers to train as Qualified Teachers of the Visually Impaired (QTVIs). It was also identified that there was a shortage of Mobility Officers across Wales as only 7 LEAs employed a Mobility Specialist. University of Wales Newport developed a new course 'Mobility and Orientation in Education' and a grant was provided for students to undertake the training.

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<sup>1</sup> [www.direct.gov.uk/en/caringforsomeone/caringforadisabledchild](http://www.direct.gov.uk/en/caringforsomeone/caringforadisabledchild)

<sup>2</sup> [www.legislation.gov.uk/ukpga/2004/31/contents](http://www.legislation.gov.uk/ukpga/2004/31/contents)

<sup>3</sup> [www.wales.gov.uk/topics/educationandskills/publications/guidance/specialedneeds Scop](http://www.wales.gov.uk/topics/educationandskills/publications/guidance/specialedneeds Scop)

<sup>4</sup> [www.wales.gov.uk/topics/educationandskills/publications/guidance/qualitystandards](http://www.wales.gov.uk/topics/educationandskills/publications/guidance/qualitystandards)

In Social Services, various models of service delivery have developed in each authority. National Occupational Standards for Sensory Impairment<sup>5</sup> have been in place since 2008 to inform best practice for social care staff working with people of all ages with sensory impairment. Sensory Impairment (SI) or VI Teams traditionally worked with people from 'cradle to the grave'. Government policies have led to a move towards regionalisation, generic social work, early intervention and partnership working, particularly between Health and Social Care. In light of this, the role of some Specialist VI Social Workers has been altered to work with adults only, or the VI specialism has been lost completely to generic social work. Along with the dilution or dissolution of many SI Teams, some ROVIs have moved into therapeutic teams where there is a focus on Reablement and early intervention. On the other hand, a small number of sensory teams have been strengthened and the specialist nature of the service has been recognised.

In the non-statutory sector, key developments have taken place affecting services for children and young people with VI. As part of the Wales Eye Care Initiative the Welsh Low Vision Scheme has been in place since 2002 providing children and young people with low vision aids free of charge. The Children's Low Vision Project funded by the Welsh Government was set up in 2004 with the appointment of a Children's Low Vision Advocate. This project encourages multi-disciplinary working between professionals across sectors, supports children and young people to access services including low vision services in their local areas and promotes good practice with use of low vision aids. In 2009 'Reading with Confidence: A report on the provision of electronic pocket magnifiers for children with sight problems in Wales'<sup>6</sup> produced by Wales Council for the Blind led to the provision of pocket electronic magnifiers for children and young people through the Welsh Low Vision Scheme.

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<sup>5</sup> [www.ccwales.org.uk/qualifications-and-careers/nos/sensory-services](http://www.ccwales.org.uk/qualifications-and-careers/nos/sensory-services)

<sup>6</sup> [www.wcb-ccd.org.uk/files/reading\\_with\\_confidence.pdf](http://www.wcb-ccd.org.uk/files/reading_with_confidence.pdf)

## Recent Developments

As part of the UK Vision Strategy, the Wales Vision Strategy Implementation Plan 2010-2014<sup>7</sup> sets out a plan to deliver the outcomes set out by the UK Vision Strategy. These outcomes include delivering excellent support to people with sight loss and delivering inclusion, participation and independence for them. Objectives particularly relevant to children and young people include:

- Ensure timely and effective post assessment care of children with VI (objective 2.4)
- To maximise independence of children with VI (objective 3.1)
- Increase the number of blind and partially sighted people who have access to peer support (objective 3.2)
- Young people with VI have smooth transitions pathway from children's to adult services (objective 3.7)

In 2010 RNIB Cymru appointed a Transitions Officer with an all-Wales remit to provide support and guidance to young people aged 14-25 regarding options following school, support at University and in work and services in available in their local area. A Youth Ambassador Programme promotes VI role models who are in Further Education (FE) College, University or working, to speak to groups of VI students in schools. The Transitions Officer also works closely with employers to try and break down the barriers to employment for young people with VI.

An important development for young people with VI is the development of 'Beyond Vision', a specialist VI residential Learning and Employment Centre to be built in Neath Port Talbot College. This will be the first of its kind in Wales is envisaged to be completed in 2014.

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<sup>7</sup> [www.wcb-ccd.org.uk/wales\\_vision\\_strategy\\_contents.php](http://www.wcb-ccd.org.uk/wales_vision_strategy_contents.php)

On a UK level, in 2009 Guide Dogs removed the lower age limit for guide dog ownership enabling children and young people under 16 to become guide dog owners. This has impacted on the independence of a small number of visually impaired young people in Wales who have become guide dog owners at a younger age or who are currently in the process of applying for a guide dog.

The Quality Standards for Delivery of Habilitation Training (Mobility and Independent Living Skills) for Children and Young People with Visual Impairment<sup>8</sup> were devised in conjunction with Mobility and Independence Specialists in Education in 2008. They provide detailed guidelines backed by supporting evidence for assessment and habilitation training from early years to transition to adulthood. It is hoped that these standards will become statutory in the whole of the UK.

The impact of these standards is seen by Mobility Specialists in Wales who are members of the national professional body MISE – Mobility and Independence Specialists in Education. In light of developments to downgrade Mobility Specialists in some LEAs in England, MISE has recently voted to form a National Independent Body to standardize pay and protect the specialism. It is intended that Mobility Specialists will register as either Habilitation Assistants or Habilitation Specialists depending on their qualifications and experience.

The Graduate Diploma: Specialist Qualification in Habilitation and Disabilities of Sight (Children and Young People)<sup>9</sup>, a two year course to qualify as a Habilitation Specialist, is provided by the Institute of Education London. It is currently also being provided in two other Universities and there is possibility that it may be available in University of Wales Newport in the future.

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<sup>8</sup>

[www.rnib.org.uk/professionals/documents/qs\\_for\\_habilitation\\_work\\_with\\_children\\_and\\_young\\_people.doc](http://www.rnib.org.uk/professionals/documents/qs_for_habilitation_work_with_children_and_young_people.doc)

<sup>9</sup> [www.ioe.ac.uk/study/professionalDevelopment/PDI9\\_CYP9IM.html](http://www.ioe.ac.uk/study/professionalDevelopment/PDI9_CYP9IM.html)



In 2010 the University of Wales Newport established a Foundation Degree course in Rehabilitation (VI). This course is the first of its kind in Wales to train individuals to become ROVIs with the first graduates qualifying in July 2012.

Both LEAs and Social Services are on the crux of some fundamental and radical legislative changes to models of service as part of the Government's five year plan 2011-2016<sup>10</sup>.

In Education, the Welsh Government is developing 'a coherent pattern of services led by consortia of local authorities to provide multi-agency services based on the needs of the learner as close as possible to their home'<sup>11</sup>. It is clear that a collaborative model for developing educational services is in progress with the establishment of a total of four consortia across the whole of Wales<sup>12</sup>.

The current (June-Oct 2012) Welsh Government Consultation Document; 'Forward in partnership for children and young people with additional needs'<sup>13</sup> outlines the proposed changes to Special Education Needs and emphasises a shift in service provision for children with 'additional needs', moving away from the education service taking the lead to full partnership working between education, health and social services.

Pathways are being developed for each additional learning need, setting new standards for Additional Learning Needs (ALN) provision<sup>14</sup>. As part of this RNIB Cymru has led the development of The Visual Impairment Pathway<sup>15</sup>, a pathway which sets out a best practice model of service provision for children and young people using a 4-tiered model of provision.

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<sup>10</sup> [www.wales.gov.uk/legislation/programme/5yearplan](http://www.wales.gov.uk/legislation/programme/5yearplan)

<sup>11</sup> [www.wales.gov.uk/publications/accessinfo/decisionreports/education](http://www.wales.gov.uk/publications/accessinfo/decisionreports/education)

<sup>12</sup> Central South Consortium Newsletter March 2012

<sup>13</sup> <http://wales.gov.uk/consultations/education/senframeworkconsultation/?lang=en>

<sup>14</sup> Irene Allen – Additional Needs and Inclusion Division, Welsh Government, speaking at RNIB Showcase Event, 9 March 2012

<sup>15</sup> [www.rnib.org.uk/aboutus/contactdetails/cymru/cymrumedia/Pages/Cymru\\_VI\\_pathway](http://www.rnib.org.uk/aboutus/contactdetails/cymru/cymrumedia/Pages/Cymru_VI_pathway)

It was developed by a group of professionals, mostly from LEAs and the Pathway is due to piloted in Carmarthenshire (2012).

Although the focus of the Pathway is on educational services, central to the model is the involvement of a ROVI trained to work with children and young people or Habilitation Officer. Currently, there are no qualified Habilitation Specialists in Wales; Guide Dogs have created a Trainee Habilitation Specialist post in Wales who is currently undertaking the Graduate Diploma in Habilitation.

The Pathway strongly advocates inter-agency working. When a child or young person with a visual impairment has been identified a multi-agency assessment will take into account the educational, social, emotional and independence needs of the children and young people, with that individual at the centre of the process. Instead of a statement, an Individual Development Plan (IDP) will be used to draw up an Action Plan with the involvement of the children and young people and his or her carers.

The Visual Impairment Pathway encompasses the children and young people from birth to age 25 in line with the current reform to the existing system of statements for children and young people with SEN. The aim of the IDP is for a more person-centred, adaptable and accessible (it is web-based) system resulting in a quicker and more appropriate tool which meets the holistic needs of children and young people.

In social care, The Welsh Government White Paper 'Sustainable Social Services for Wales: A Framework for Action' 2011 set out priorities for action which includes 'services for people with a sensory impairment being delivered regionally'<sup>16</sup>. This has led to the Social Services (Wales) Bill Consultation Document in March 2012 which also proposes an integrated delivery of services for adults and children, a 'family-focused social services'<sup>17</sup> and also integration across social services, education services and Local Health Boards. One of the other priorities of significance is improving transition to adulthood for disabled children with complex needs.

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<sup>16</sup> <http://wales.gov.uk/docs/dhss/publications/110216frameworken.pdf>

<sup>17</sup> <http://wales.gov.uk/docs/dhss/consultation/120312consultationen.pdf>

## **Parents' and Young People's Views**

Partially due to time constraints, only a small number of parents and young people's views are provided. 13 parents living in 5 different authorities across Wales were interviewed either by phone or in person to get a flavour of their experiences of VI services, both positive and negative. Included amongst the discussion topics are some of their views. The nature of their positive experiences varied greatly whereas the theme of their negative experiences can be summarised by two issues:

1. lack of communication
2. lack of support at time of diagnosis

5 young people aged 17-19 attending Neath Port Talbot College were interviewed as part of this research. Their views are discussed under a separate heading.

## **Discussion**

### 1. Habilitation Provision across Wales:

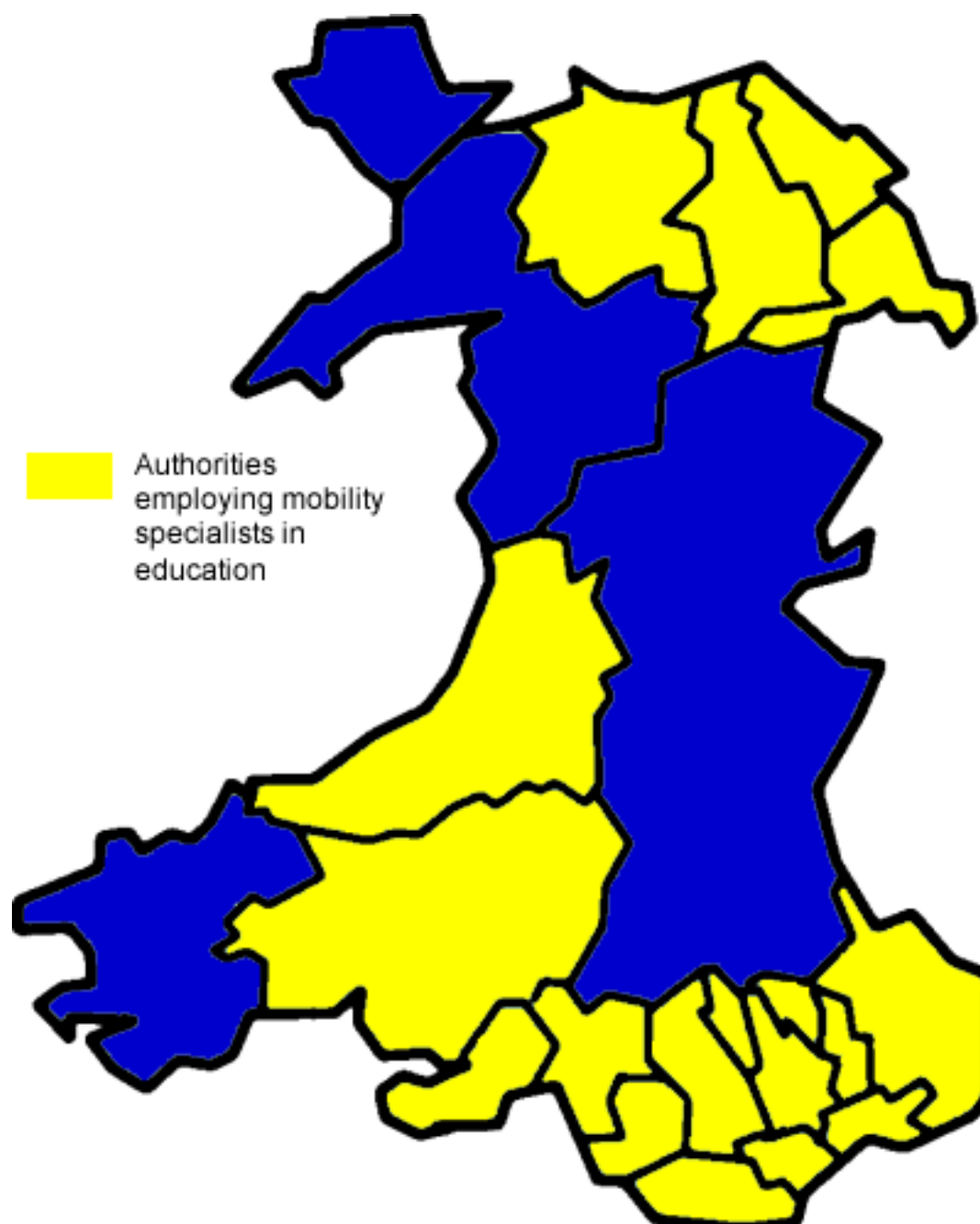
Various models of habilitation skills provision for children and young people with VI exist across Wales as evident from the Directory of Services.

Education:

GVIS is the only regional specialist service providing a service across five LEAs and has the resources to provide a Family Support Worker and Independent Living Skills (ILS) Co-ordinator. These posts are unique in Wales with the ILS Co-ordinator being a full-time post including school holidays. It is also the only service to provide after-school clubs (organised by the ILS Co-ordinator) which run on a weekly basis. These clubs provide an opportunity for peer support (Objective 3.2 of Wales Vision Strategy) and development of independence and social skills in a safe and supportive setting.

GVIS also employ a mobility assistant who works under the guidance of the Mobility Specialist.

Map 1.



Map 1 illustrates that 18 of 22 LEAs employ qualified Mobility Specialists in education. In the other 4 authorities, ROVIs working in Adult Social Services either on contract from the third sector (Anglesey and Gwynedd) or directly employed by the authority (Powys and Pembrokeshire), deliver habilitation to children and young people with VI in educational settings as well as at home and in the community.

This model of integrated working ensures consistency of service provision as the ROVI is the only professional providing a full habilitation service both in educational settings, at home and in the community. Excellent communication, collaborative working and information sharing between education and rehabilitation service needs to be in place to ensure delivery of a quality service.

The impact of the development of the Mobility and Orientation Course in University of Wales, Newport is clearly visible across Wales. Of a total of 14 mobility specialists currently practising in Wales, 8 completed the Mobility and Orientation Course since the course commenced in 2007. In Pembrokeshire, an LSA undertook training as a Mobility Specialist but moved on shortly afterwards and mobility and orientation has since been carried out by a ROVI in Social Services.

One parent commented:

*'When the Learning Support Assistant (LSA) in school came on board having trained as a mobility officer we got continuity'*

Conwy is the only LEA employing a Mobility Specialist full-time, including school holidays. All other Mobility Specialists work term-time only. Working school holidays allows the Mobility Specialist in Conwy the flexibility to provide advanced travel mobility skills (train and bus travel) during the holidays as well as being able to incorporate independent living skills into the role more effectively.

A worrying issue arose; that visually impaired children and young people are not always assessed by a qualified Mobility Specialist. Other education professionals working with a child in school or home environment may not identify any problems with mobility skills but those particular environments are familiar to the child.

In an unfamiliar environment mobility skills can differ greatly. Children often follow their peers in movement and action, however when they are left to make their own decisions this can highlight concerns which other professionals may not recognise or they may not have access to carrying out assessments in less familiar environments.

The Quality Standards in Educational Services 2005 Wales<sup>18</sup> state that:

‘Every support service should have access to a Mobility Officer who should support provision for children and young people with visual impairment and multi-sensory impairment by:

- Assessing their mobility capabilities and needs;
- Agreeing, implementing and reviewing mobility training programmes to be conducted in and around the school, their home area and beyond;’

For pre-school children, access to a mobility specialist varied greatly between authorities. In some authorities, QTVIs provide support and guidance for parents/carers and the Mobility Specialist is a point of contact until the child starts school. In other areas, a referral is made to Mobility Specialist or a joint visit with QTVI takes place and Mobility Specialist works with the child on skills such as concept development, body awareness and spatial awareness.

The majority of Mobility Specialists interviewed agreed that they have a lot of flexibility within their roles and they undertake mobility skills both in the local community and allocate some time to work on advanced travel skills if appropriate as a child becomes more independent. It can be a challenge to find the extended time needed during the school day to undertake bus and train travel.

A need for more time to work on advanced travel skills was expressed or for opportunities for skills learned to be consolidated and practiced over the school holidays.

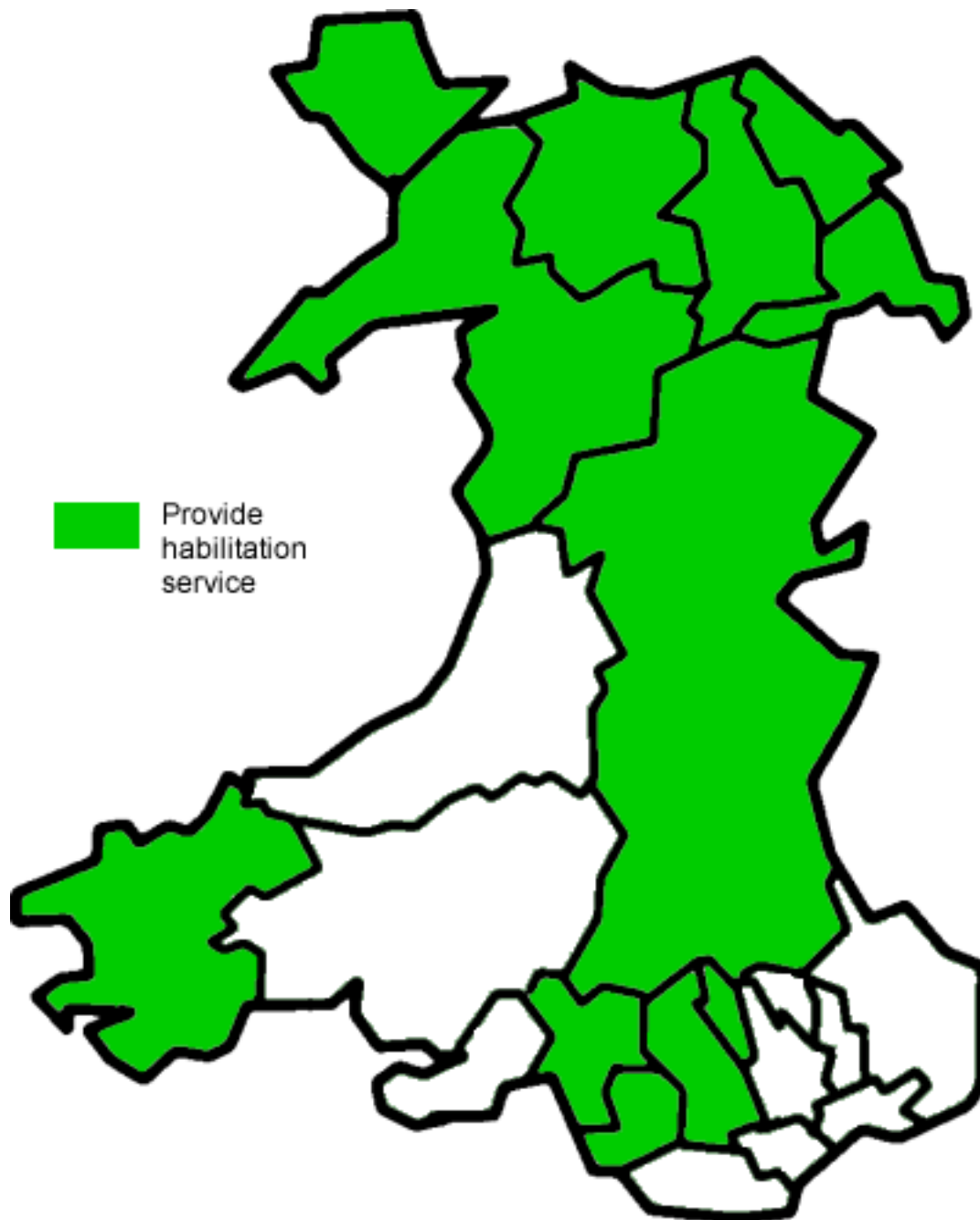
A minority of Mobility Specialists are not able to work with children in their home and local community areas. They are restricted to providing mobility training in the school environment or home to school route only. Outdoor mobility training is vital and, although skills can be transferred, route training specifically related to a children's social setting is invaluable. Being released from timetable is crucial as social skills and confidence are also part of education and school life, which is taken for granted with regard to sighted children. For Mobility Specialists this concept is often difficult to get across to schools which, by their nature, are heavily curriculum based.

This problem is shared by ROVIs providing mobility training in education who can find it more difficult being based outside the education system. In one case a totally blind child attending a Special School was not released from playing football in order to undertake mobility training as the Head Teacher deemed mobility training as 'pointless'.

In general, Mobility Specialists incorporate independence skills training as part of their programmes as much as feasible, working closely with Teaching Assistants. Issues relating to Independent Living Skills such as food preparation, hygiene, and personal care in school are usually addressed by a Teaching Assistant or Learning Support Assistant with advice and/or support given by the Mobility Specialist, ROVI or QTVI as needed.



Map 2.



### Social Services:

55% (12 of 22) of authorities offer a full habilitation service for children and young people by a qualified ROVI which is illustrated in Map 2. In the other 45% ROVIs work with adults only. This was reflected by experiences of parents in two authorities where the Rehabilitation service is provided strictly to adults only. Speaking of her visually impaired son, one parent shared:

*'Without the education service he would have had no support'*

In some authorities, certain aspects of habilitation are provided for children if identified through receipt of CVI or referral from education.

Most ROVIs work within adult Social Care teams. The qualification required to become a ROVI enable ROVIs to work with both adults and children, although child development is not a core component of the course. There is currently no post-qualifying training course on working with children available to ROVIs in the UK. Two ROVIs hold the post-qualification Advanced Certificate in Education (ACE) for working with children, a post-qualifying course provided by the Guide Dogs organisation in the past. Only one is currently working with both children and adults.

For the 18 ROVIs working with children (as well as adults) in statutory services in Wales there is a general consensus that a top-up course is needed in child development and VI. One ROVI agreed strongly, suggesting that it could be a role the Welsh Rehabilitation Officers Forum (professional body for ROVIs in Wales) could take on board. Feedback highlighted a need for ROVIs, with additional training to work with children, or Habilitation Specialists to be employed to work exclusively with children based in Children's Services. Implementing this on a regional basis would make a significant difference to outcomes for children and young people in some authorities, but may not be feasible in other Authorities due to current models of service delivery.

Appropriate training, assessment tools and professional support for ROVIs providing habilitation for children is needed. For those who work closely with education, it is evident that the support from education professionals enables ROVIs to develop their skills when working with children. One ROVI commented:

*'We liaise and work jointly with education. The support from education gives me the confidence to work with children and build on my skills and experience'*

The following concerns relating to habilitation skills provision were highlighted by both Mobility Specialists in Education and the ROVI profession:

- In school, there is a lot of pressure on accessing the curriculum and it can be difficult to find the time to provide a holistic service which also incorporates advice, guidance and support for parents/carers
- The pace of cooking skills in mainstream school is so fast that children and young people with VI struggle to keep up.
- Young people who attend out of country placements, for example RNC Hereford, come back to the authority and no longer have the support in education. They may not be aware of the existence of a rehabilitation service, especially in the 10 authorities where a full habilitation service for children is not offered.
- Young people who leave school to attend Further Education College, either sixth form or to pursue another course no longer receive support from their LEA and rely on support put in place by individual colleges. A number of ROVIs indicate there isn't a robust referral process from colleges to rehabilitation service.
- Some children and young people need habilitation training during school holidays, for advanced travel skills, reinforcement of routes or independent living skills. In 10 areas of Wales this service is not provided.

Despite developments of the profession, Mobility and Independence Specialists in Education (or Habilitation Specialists) are currently employed by LEAs as Mobility Specialists with a remit to provide mobility training to children and young people. It is vital that QTVIs and Mobility Specialists work in collaboration with ROVIs in Social Services where services exist to ensure VI children and young people have the specialist intervention they need. Where habilitation services don't currently exist, they need to be developed on a regional basis in line with the legislative changes proposed in the Welsh Consultation Document regarding children with additional needs and the Social Services Bill.

## 2. How services link together – Communication

The ethos behind The Children's Act 2004 is to promote co-ordination between multiple official entities to improve the overall well-being of children. It is crucial to be able to share information effectively both within and across services in order to provide a 'joined up' approach to service delivery.

Many examples of collaborative working were found and need to be acknowledged as the way forward. In Rhondda Cynon Taff, VI and Hearing Impairment Service in education meet with Sensory Services and Disabled Children's Team once a term to discuss any issues, needs and progress children they support. This ensures that all services are aware of the children in the area and referrals can be discussed. This is particularly important around transition. Similarly, in Conwy, the QTVI meets with Social Worker on an annual basis to discuss the needs of VI Children.

Periodic regional meetings organised by the Children's Low Vision Advocate on a more regional basis is one opportunity to share information and liaise with other agencies.

Often better communication between services relies on the determination of one or two individuals, usually set against a heavy caseload, to forge a pathway of communication. This research has found examples of individuals in all sectors who have worked hard and over long periods of time to build relationships and referral pathways. One Sensory Service Manager in Social Services who is proactive in building a stronger relationship with education pointed out:

*'if we are not involved now then we'll be picking up the pieces later on'*

An example of good collaborative practice is highlighted in Pembrokeshire where, as soon as a baby or child becomes known to the education service, QTVI contacts ROVI and arranges an initial joint visit.

Also in Ceredigion, when a young person is leaving education, the Mobility Specialist undertakes a hand-over to the ROVI or Mobility Officer in Social Services.

Worryingly, in three authorities where ROVIs work with both children and adults, education professionals did not know the names of the ROVIs in their areas and conversely, ROVIs were not aware of who provides mobility training in education. Clearly, there is a need for relationship building to benefit the child or young person. The Welsh Government is advocating 'to move away from education services being perceived as in the lead, to one of full partnership between education, health and social services.'<sup>19</sup>

Good communication with young people themselves and with parents is fundamental. One parent found it difficult to get information about what support her son was given around mobility training. She asked for copy of Environmental assessment from the Mobility Officer more than once but it has not been received.

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<sup>19</sup> <http://wales.gov.uk/consultations/education/senframeworkconsultation/?lang=en>

It is hoped that the introduction of IDPs will ensure the child/young person at the centre of the process and their views and parents views will be listened to and acted upon.

### 3. Transition to Adulthood:

This report did not specifically look at transition but it emerged as one area of work with children and young people with VI where gaps in service provision were highlighted by VI professionals and where there is the greatest need for partnership working. Development of self esteem, confidence and independence is of prime importance, leading towards autonomy. Parents need specific information and guidance as to opportunities which would be beneficial to their child, for example, opportunities to travel home from school on the bus or going shopping with friends. Developing independence and social skills at this age is crucial and co-ordinated involvement of a ROVI is needed to ensure specific needs relating to visual impairment are identified. If not possible, links should be made at as early a stage as possible with adult rehabilitation services.

Parents commented that they worry about their child finishing school and reiterated that planning and communication is crucial to ensure that the process runs smoothly. At present if a statement of SEN is in place, a transition plan should be drawn up in school in accordance with statutory guidance. The Welsh Government is currently piloting schemes in Wales to develop transition key working for disabled teenagers with complex needs.

Good practice needs to be applauded such as the work being carried out by the RNIB Transitions Officer's peer support scheme and the Young People's Buddy Service run by Cardiff Vale and Valleys. In Caerphilly, ROVIs providing a service to adults only work with young people of 16+ if a VI need has been identified at the transitions meeting.

#### 4. Registration Process:

Under Section 29 of the National Assistance Act 1948 local authorities are required to compile and maintain a classified register of 'persons who are blind...'<sup>20</sup>. Local authorities also have a duty under the Children Act 1989 to keep a register of disabled children in their area, usually known as the Child Disability Index. For children and young people the process of becoming registered as Sight Impaired or Severely Sight Impaired with a local authority varies greatly. 5 of 22 authorities do not offer any assessment of VI needs following receipt of the CVI, Map 3. Parents' experiences reflect this as one parent explained that she had not heard about registration until a parent at an Actionnaires Group mentioned it. The parent repeatedly contacted social services until a registration card was sent out which was 6 years after the CVI was completed. An assessment by social services has never been offered.

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<sup>20</sup> [www.legislation.gov.uk/ukpga/Geo6/11-12/29](http://www.legislation.gov.uk/ukpga/Geo6/11-12/29)

Map 3.



Another parent echoed this experience as her daughter's CVI indicated eligibility to be registered Sight Impaired and subsequently Severely Sight Impaired a few years later. A letter from social services has been received each time but no offer of an assessment from them despite the fact that her daughter has complex medical needs.

Parents also felt strongly that support was needed at the time of diagnosis.



*'I didn't know where to turn...the opportunity to speak to another parent who understood at the time would have been invaluable'*

Another parent suggested setting up a Point of Contact specifically for parents at hospital eye clinics.

A lack of registration process results in lack of information about services and entitlements which has far-reaching implications for children and young people and their families on a long-term basis. One report from Cardiff Vale and Valleys told of a 20 year old student who did not know he was entitled to a bus pass even though he had been registered sight impaired from the age of 12.

In 3 authorities where habilitation for children in social services is not available, on receipt of a CVI for a child ROVIs in Adult Social Services contact the families/carers offering registration either by telephone or in person and providing valuable information on entitlements and specialist VI services. In these 3 authorities ROVIs are directly employed by social services and receive CVIs directly for both adults and children.

#### 5. Access to Children's Disability Services:

The Eligibility Criteria for assessment in Children's Disability Service varies greatly between Authorities. The criteria try to ensure that services are directed at those with the greatest need and who are at the highest risk. Some VI professionals reported that eligibility criteria in their area are strict with some Disabled Children's Teams offering an assessment if a child has a profound VI and/or has additional needs. Many VI professionals in Adult Social Care expressed concern that children with VI may not be offered an assessment by Social Services as well as not having access to Specialist VI Services.

One ROVI new to an authority found that when CVIs were received by the Disabled Children's Team they were filed in the Health Section of child's file without any other action.

## 6. Opportunities for social groups:

VI children in mainstream school lack the opportunity to meet other VI children. There may be many activities available for disabled children and young people but this research has shown a lack of regular VI specific groups across Wales. In the areas where groups are provided by the Third Sector, professionals and parents have noticed vast improvements in self-esteem and confidence. Actionnaires groups and RNIB Family Days offer the option for siblings to get involved; they provide a valuable opportunity parents and siblings to discover the capabilities of their visually impaired family member. One parent spoke of trying to attend the Actionnaires group as much as possible as she feels it provides opportunities to try different activities which would be too expensive to access otherwise. It is in a safe environment with instructors who have experience or who are supported with training to meet the needs of VI. VI-specific activities provide opportunities for VI children to meet and interact with VI peers but also an opportunity for parents to meet other parents of VI children. So much support, advice and information is gained by sharing experiences and information, and parents value and benefit from this.

One parent explained the importance of the only VI social group accessible to her daughter. Her daughter was involved in the week-long UCAN workshop for the first time last year but it was cancelled this year as there were only four children able to come. The parent describes her daughter as being 'devastated' as there are no other accessible social groups in the area they live.

In one authority, education professionals commented on the marked difference they observed when some of the visually impaired students joined the VI football club. Youngsters had the opportunity to attend a tournament in RNC Hereford (by Soccer Sight), met with potential role models in disability sport as well as gaining an understanding what RNC Hereford has to offer.

## 7. Young People's Views:

Five visually impaired 16-18 year olds attending Neath Port Talbot College were interviewed as part of the project. They had all received support from their LEAs before attending college. 4 out of 5 of them had positive experiences of specialist support whilst in school.

3 out of 5 young people cited problems with mobility as one of the three issues affecting them as visually impaired young people.

*'Getting around on my own is a problem. I can't go anywhere I don't know'*

This is also reflected in the Action for Blind People Transitions Report 2011 regarding Services for blind and partially sighted young adults<sup>21</sup> where young adults of 14-25 years old surveyed stated that problems with mobility/independent travel/transport was the top issue affecting them (51% of respondents). Lack of social life/friends came a close second.

In the RNIB Cymru survey 2012 'What does independence mean to me?'<sup>22</sup> children and young people in Wales were also asked to give three issues which affected them as young people with VI.

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<sup>21</sup> [www.actionforblindpeople.org.uk/assets/Uploads/Miscellaneous/Action-transitions-report-Final-19Aug11.doc](http://www.actionforblindpeople.org.uk/assets/Uploads/Miscellaneous/Action-transitions-report-Final-19Aug11.doc)

<sup>22</sup> [www.wvsreporting.org/resources.php](http://www.wvsreporting.org/resources.php)

Lack of social groups where visually impaired young people can meet others with the same disability was second highest, being highlighted by 9 out of 27 young people aged 12-17 years old. The top issue was 'not seeing like my friends do/difficulties accessing print' (10 of 27 responses).

Only one student interviewed for this study mentioned 'lack of opportunities to socialise' as one of the three issues affecting her.

The RNIB Cymru survey also demonstrates the importance to young people of being able to decide what they want to do and be able to follow this through independently. The ability to travel independently and being able to care and look after themselves were the main ways in which young people viewed being independent. 70% agreed strongly with the statement 'I am generally an independent person' whereas 11% replied they were not independent at all.

Although not asked directly about Information Communication Technology (ICT), what emerged from the five interviews is the importance of ICT especially when it comes to keeping in contact with friends. Although opportunities to meet up other VI young people may be limited, social networking sites such as Facebook and face-to-face communication such as Skype and Face Time (iPhone) plays a crucial part in keeping in contact with friends from other areas made on RNIB and Action for Blind People trips, as well as UCAN workshops. In some authorities specialist ICT equipment is provided for school use only. The impact of ICT on the lives of young people is not to be underestimated and needs to be taken into account when decisions regarding ICT needs are being made.

## 8. What parents said about services

### **At time of diagnosis:**

‘Information at the hospital would have been really helpful’.

‘The fear of not knowing what to expect was the worst. It was only by talking to another parent that I realised what support was available.’

‘A point of contact at hospital to link with other parents is needed.’

‘I didn’t know where to turn.’

‘There weren’t any leaflets. There should be some information available at the hospital.’

### **Mobility/habilitation:**

‘I didn’t know that there were specialists in social services who provide mobility’.

‘Mobility is not available out of school time.’

### **Registration:**

‘He was registered in 2005 but it took 6 years to get a Registration Card. We didn’t have a visit from social services’

‘I had a letter from Social Services each time she was registered but a visit was never offered.’

Paraphrased: CVI was filled out in 2005 for partial sight and there wasn't any follow-up from social services. Mum heard about registration from a parent at Actionnaires Group and had to ring social services more than once until a registration card was sent. This was 6 years after CVI was completed.

Paraphrased: Daughter (with complex medical needs) was registered partially sighted and subsequently registered blind. She has had a letter from social services each time regarding registration but no offer of a visit from them.

### **Social Groups:**

'He loves it. It provides opportunities to do activities that I would never be able to provide and I thought he was too young to do. We would never be able to afford the activities as a family.' (Talking about the Actionnaires Group).

'We found out about VI football from another parent.'

Paraphrased: UCAN come to the area once a year. Daughter did it for the first time last year but it was cancelled this year as there were only four children able to come. Her daughter is 'devastated'. There are no other social groups that she can attend in the area.

### **Third Sector:**

'I got a warm reception at NW Society [North Wales Society for the Blind].'

'Local society is providing emotional support'.

'We didn't contact RNIB as I thought they only support blind people' (child has nystagmus).

## **Education:**

'We did not get any feedback from VI teacher but we are now starting to get copies of assessments.'

Paraphrased: It took three years for the school to get a nappy bin.

Paraphrased: Video magnifier (CCTV) arrived at school but there was not a table to put it on, was a full year before the ROVI had to get involved and take a table to school and set it up.

'There is a waiting list of a year to see the IT Specialist'.

## **Recommendations**

1. Every VI child and young person in Wales should have access to a full habilitation service. In the current model of service provision, habilitation service needs to be improved as follows:
  - i. An increase in mobility services in education to ensure that every VI child and young person should have an assessment of their mobility needs. The mobility service should address mobility needs at school, in the child's home and in their local community.
  - ii. The creation of a Rehabilitation / Habilitation Officer post for children and young people on a regional level to provide a service in the authorities where there is no service provision (10 authorities in Wales). The post, possibly joint-funded between education and social care, needs to be based in Children's Services to increase awareness of the specialist needs of VI children and young people and to promote joint-working across services.

The needs of young people of transition age 14-25 are greatest as current provision varies greatly from one authority to another.

2. Creation of a Transitions Officer for VI post based in North Wales to provide a similar level of support for children and young people as that provided in South Wales. The current RNIB Transitions Service is undergoing expansion with the potential recruitment of a part-time Transitions Officer for South Wales and an equivalent in North Wales.
3. Creation of regular VI-specific social groups for children and young people in each region. The data on VI children supported by Local Education Authority (LEA) in Table 4 provides a geographical spread of children and young people with VI.

Measures which can be taken within current resources:

1. Highlight the findings regarding registration with Eye Clinic Liaison Officers (ECLOs). Equip ECLOs with information on entitlements of registration for children and young people and information on statutory and third sector services available in each authority. For example, the eye clinic in Singleton Hospital in Swansea sends CVIs to Swansea, Neath Port Talbot, Powys and Carmarthenshire. Service provision for children varies significantly for each of these authorities and the ECLO has a crucial role to play with providing information, particularly in authorities where a habilitation service is not provided for children and young people.
2. Working together to improve communication and partnerships, especially between education and social services leading to multi-agency working with young VI people ultimately achieving their potential for an independent life.



3. Where habilitation services currently exist for VI children and young people, VI specialists in education and social care need to meet regularly to discuss the needs and plan service intervention to provide continuity and improve outcomes for VI children and young people.
4. Where habilitation services for VI children and young people don't currently exist, improvement of the transition to adulthood process is required by prioritising the needs of visually impaired young people by Adult VI services. Identify one ROVI to take the lead on transition working whilst ensuring that protected time is allocated to ensure that other aspects of their job do not take priority over their role with young people.
5. Links need to be made at an early stage between VI services in education and Rehabilitation services in Adult Social Care to ensure the young person is aware of services available to them. Referrals should be made as appropriate.
6. Capitalise on resources already in place. For example, the Independent Living Skills Co-ordinator in Gwent Visual Impairment Services has developed a series of 'I Can Do It' leaflets, step-by-step guides for children, parents and Teaching Assistants to show them how to complete tasks such as using a microwave or tying laces.

## **Appendix 1 - Abbreviations used**

ALN	Additional Learning Needs
CVI	Certificate of Visual Impairment - the certification form for patients which specifies eligibility for registration as sight impaired (partial sight) or severely sight impaired (blind).
CYP	children and young people
ECLO	Eye Clinic Liaison Officer
ICT	Information Communication Technology
IDP	Individual Development Plan
ILS	Independent Living Skills
LEA	Local Education Authority
LSA	Learning Support Assistant
MSI	Multi Sensory Impairment
PD	Physically Disabled
QTVI	Qualified Teacher of the Visually Impaired
ROVI	Rehabilitation Officer Visual Impairment
SEN	Statement of Educational Needs
SENCo	SEN Co-ordinator
SI	Sensory Impairment
TA	Teaching Assistant
VI	Vision/Visual Impairment, visually impaired

## Appendix 2 – Statistics

**Table 1 – Full-time equivalent figures for Mobility Specialists and QTVIs in Education**

<b>Authority</b>	<b>Number (fte) of Mobility Specialists</b>	<b>Number (fte) of QTVIs</b>
Anglesey	-	1.75
Blaenau Gwent	0.2	1.40
Bridgend	0.5*	1.80
Caerphilly	0.2	1.40
Cardiff	1.0	5.00
Carmarthenshire	0.5	2.00
Ceredigion	0.5	1.75
Conwy	1.0	2.50
Denbighshire	0.6	1.80
Flintshire	0.2	1.00
Gwynedd	-	1.75
Merthyr Tydfil	0.1*	1.00
Monmouthshire	0.2	1.40
NPT	1.0	1.80
Newport	0.2	1.40
Pembrokeshire	-	1.20
Powys	-	3.00
RCT	1.0	2.50
Swansea	1.0	2.80
Torfaen	0.2	1.40
Vale of Glamorgan	0.4	2.00
Wrexham	1.0	1.00
<b>Total</b>	<b>9.8</b>	<b>41.65</b>

\*Estimated figure which is variable

Note: GVIS is a regional service covering 5 authorities, Blaenau Gwent, Monmouthshire, Torfaen, Caerphilly and Newport.: 7 QTVIs (represented as 1.4 fte in each authority) and 1 Mobility Specialist (represented as 0.2 fte in each authority). They also employ 1 Mobility Assistant (not represented).

Services in Anglesey and Gwynedd are run by a joint SEN Committee with a total of 3 QTVIs (represented as 1.75 fte in each authority).

**Table 2: FTEs for ROVIs either working directly in Social Services or contracted to Social Services from outside agency (nb: figures in brackets indicate the number of individual ROVIs employed)**

Authority	Total Number (fte) of ROVIs	Number (fte) of ROVIs working with Adults Only	Number (fte) of ROVIs working with Adults and Children	Number (fte) of ROVIs working with Children Only
Anglesey	1.1 (2)	-	1.1	-
Blaenau Gwent	0.4 (1)	0.4	-	-
Bridgend	2.5 (3)	-	2.5	-
Caerphilly	1.5 (2)	1.5	-	-
Cardiff	1.5 (2)	1.5	-	-
Carmarthenshire	2.0 (2)	2.0	-	-
Ceredigion	0.8 (1)	0.8*	-	-
Conwy	1.0 (1)	-	1.0	-
Denbighshire	2.2 (3)	2.0	-	0.2
Flintshire	1.6 (2)	-	1.6	-
Gwynedd	1.9 (3)	1.0	0.6	0.3
Merthyr Tydfil	1.0 (1)	-	1.0	-
Monmouthshire	2.3 (3)	2.3	-	-
NPT	1.0 (1)	-	1.0	-
Newport	1.0 (2)	1.0	-	-
Pembrokeshire	2.0 (2)	1.0	1.0	-
Powys	2.4 (3)	-	2.4	-
RCT	4.0 (4)	-	4.0	-
Swansea	1.5 (2)	1.5	-	-
Torfaen	1.0 (1)	1.0	-	-
Vale of Glam	1.0 (1)	1.0	-	-
Wrexham	2.2 (3)	2.0	-	0.2
<b>Total</b>	<b>35.9 (45)</b>	<b>20.0</b>	<b>16.2</b>	<b>0.7</b>

\*In addition, a full-time mobility officer works with adults only

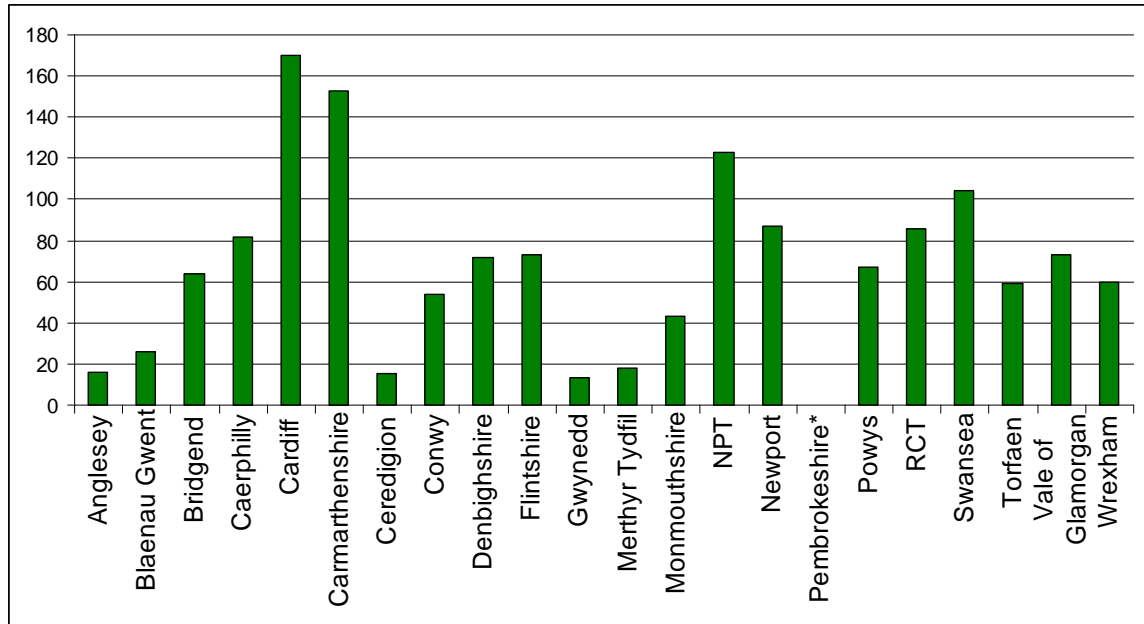
**Table 3: Number of Specialist Social Workers in each Authority**

<b>Authority</b>	<b>Number of Social Workers VI working with Adults Only</b>	<b>Number of Social Workers VI in Adult Services working with Adults and Children</b>	<b>Number of Social Workers in Children's Services with specific responsibility for VI</b>
Anglesey	-	-	-
Blaenau Gwent	-	-	-
Bridgend	-	1	-
Caerphilly	-	-	-
Cardiff	2	-	-
Carmarthenshire	-	-	-
Ceredigion	-	-	-
Conwy	-	0.7	-
Denbighshire	-	-	-
Flintshire	-	-	-
Gwynedd	-	-	-
Merthyr Tydfil	-	-	-
Monmouthshire	-	-	-
NPT	-	1	-
Newport	-	-	1
Pembrokeshire	-	-	-
Powys	-	-	-
RCT	-	-	-
Swansea	1	-	-
Torfaen	-	-	-
Vale of Glamorgan	-	-	1
Wrexham	1	-	-
<b>Total</b>	<b>4.0</b>	<b>2.7</b>	<b>2</b>

**Table 4: Number of VI Children and Young People (0-19) supported by LEA in 2011/12**

<b>Authority</b>	<b>Statements</b>	<b>School Action Plus</b>	<b>Pre-School</b>	<b>Other</b>	<b>Total Number of VI Children supported by LEA</b>
Anglesey	12	3	1		16
Blaenau Gwent	6	17	3		26
Bridgend	20	34	10		64
Caerphilly	35	45	2		82
Cardiff	118	32	20		170
Carmarthenshire	90	52	11		153
Ceredigion	10	5	0		15
Conwy	25	24	5		54
Denbighshire	26	41	5		72
Flintshire	34	22	4	13	73
Gwynedd	9	2	2		13
Merthyr Tydfil	5	13	0		18
Monmouthshire	21	18	4		43
NPT	55	61	7		123
Newport	24	59	4		87
Pembrokeshire	39	Unavailable	Unavailable		
Powys	36	26	5		67
RCT	16	59	11		86
Swansea	51	45	8		104
Torfaen	15	42	2		59
Vale of Glamorgan	50	20	3		73
Wrexham	30	7	6	17	60
<b>Total</b>	<b>727</b>	<b>627</b>	<b>113</b>	<b>30</b>	<b>1497</b>

# Children and Young People (0-19) supported by LEA



\* No figure supplied for Pembrokeshire