



abcd cymru

Empowering Black and Minority Ethnic
Disabled Children and Young People



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aims

- To provide support and advocacy for children and young people (0 - 25 years) with disabilities and chronic illnesses from Black and Minority Ethnic (BME) communities and the families of such children and young people.
- To work with service providers and policy makers to raise awareness and be more responsive to the needs of such children, young people and their families.

what we do

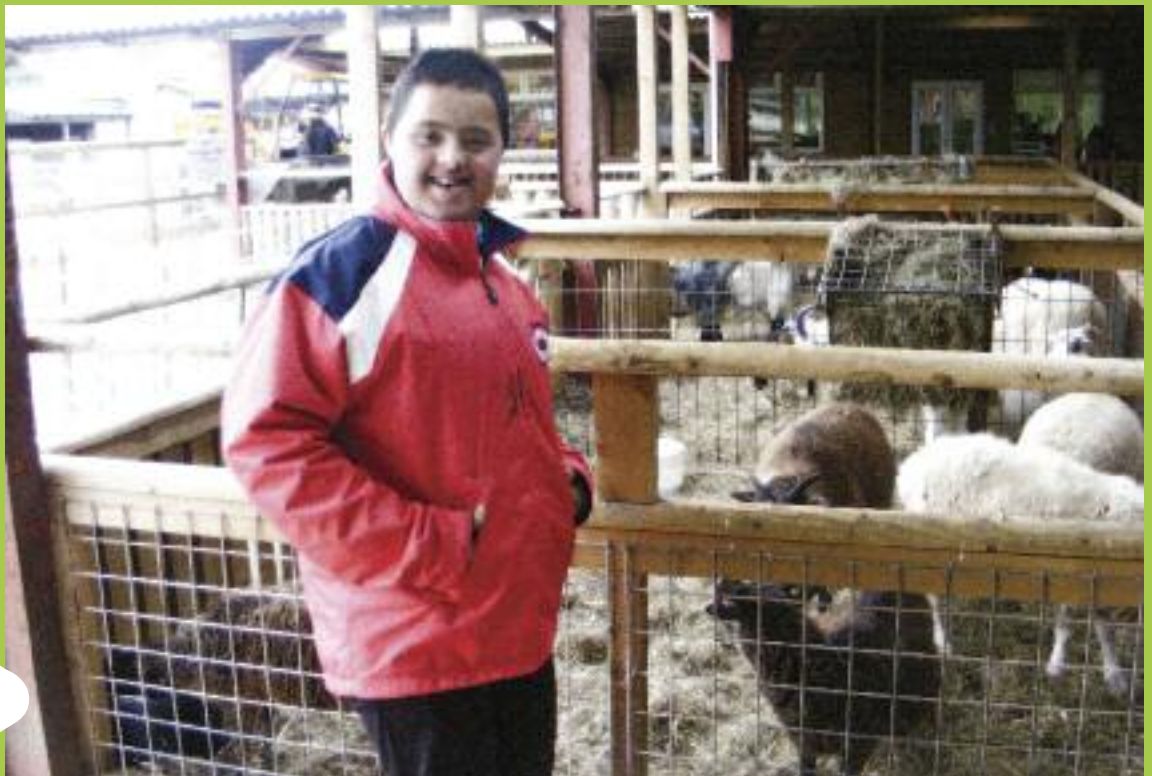


Direct work with children, young people and their parent carers:

- Undertake **direct casework** with them on an individual basis on any social care, health, education and related issues.
- Provide **information** on services relevant to them in appropriate languages and formats.
- Arrange and **facilitate referrals** to agencies, social services, play/leisure providers, housing, employment, training, carers' groups and others.
- Provide supported and culturally appropriate group **play and leisure activities**.
- Initiate, develop, maintain and facilitate **parent support** groups and provide opportunities for mutual support.
- Provide a **specialist service for young people**, assisting access to training and employment opportunities.

At a strategic and policy level:

- **Represent BME disabled communities**, locally and nationally, via forums and working groups.
- **Provide demographic information** for policy makers on ethnicity, language and disability conditions.
- **Conduct focus groups** and provide relevant case study to respond to local and national consultation processes that affect the lives of the community we serve.
- Undertake **research** which can be used to the benefit of our families.
- Work with mainstream disability organisations and professionals in the public sector in relation to: Health, Education, Social Services, Training & Employment and Play/Leisure.
- Provide relevant **training** and training resources.
- Provide **consultancy and advice**.



Chief Executive's

report

The past year has been very exciting with new staff joining the organisation, bringing with them their unique skill sets, as well as tremendous enthusiasm, energy and ideas.

This has led to a great deal of innovative ways of working with families, and ensuring we provide the services that are most needed by them. ABCD Cymru's capacity to work with these families has gained further depth, allowing us the opportunity to engage with them in a variety of ways, to consult closely with them to ascertain their needs, and to tailor our services accordingly.

Reflecting back on my nine years with the organisation, it has been great to look at the many ways ABCD Cymru has moved forward: from a local project to an all-Wales Charity and Company Limited by Guarantee; our work has developed from only supporting families of Black and Minority Ethnic disabled children up to the age of 16 to working with children and young people up to the age of 25; moving on from mostly supporting families on a one-to-one basis to working with them in group settings, and on a strategic and policy level on issues including Health, Education and Social Services.

We continue to work closely with our families, and are pleased to have representatives on our Board of Trustees, on the Parent Play Steering Group, as part of our staff Team, and as volunteers within the organisation. Their input is invaluable.

There are many people whom we wish to thank. Firstly, the Trustees, for their support, and dedication to the work of the organisation, and who have shown tremendous interest in the issues faced by the families and looked at ways to ensure they receive a quality service. I would also like to take this opportunity to thank all the staff for their commitment and dedication, which goes beyond the call of duty.

Lastly, we would like to thank our funders, and the agencies who work in partnership with us, enabling us to improve our capacity to deliver an all-Wales remit. In particular we would like to thank Mencap Cymru, SNAP Cymru, and Race Equality First, for sharing their knowledge, skills and other resources, to ensure we can deliver the projects needed by our families.

Mrs Wahida Shah Kent

“I'd like to thank ABCD Cymru for everything you've done for me. Without it, I really don't think I'd be where I am now. You helped me when I was going through a terrible time, and now I think things couldn't be any better”



Chair's Introduction

welcome

I am delighted to present this report on behalf of ABCD Cymru's Trustees.

Over the past year, ABCD Cymru's committed and dedicated staff have achieved great success in meeting its aims.

The reports included here demonstrate how their highly professional work provides significant benefit to an extremely vulnerable group, both directly, by personal contact and support, and indirectly, by representing them at a strategic level and building awareness and expertise. ABCD Cymru's holistic approach ensures that the whole family have gained from their relationship with the charity.

Despite significant challenges of the current economic climate, ABCD Cymru has remained focussed on its objectives and continues to take the organisation forward.

Since inception, ABCD Cymru's main work has been primarily concentrated in the Cardiff area. However, this small team provides a significant level of support across Wales and has now expanded its direct operations to include the Newport area.

ABCD Cymru has also continued to build on its close relationships at strategic level, through consultation and participation, in order to support the formulation of strategies that are sensitive and appropriate to their families' needs. ABCD Cymru's new website will be further developed to help in the dissemination of relevant information, report on activities and research, and encourage feedback and suggestions.

Additionally, ABCD Cymru has been successful in building the capacity of the Board of Trustees to include enhanced user participation and experience, and expertise in financial and strategic management. This will support the Board members in continuing to pay due regard to their duties under the Charities Act 2006.

The Board would like to take this opportunity to record their sincere thanks to the Chief Executive and her team for their diligent and valuable work. We are continually impressed with their dedication and commitment and their ability to make a difference and to do so in an economic and efficient manner.

Finally, we thank our funders who make ABCD Cymru's work possible and demonstrate their commitment to a very isolated and vulnerable group in society - primarily the Welsh Assembly Government, Cardiff County Council, Lloyd's TSB Foundation for England and Wales and BBC Children in Need. In the current economic climate, it is more than ever vital that we demonstrate that ABCD Cymru's activities provide measurable added value. I am confident that this Report will help us achieve further progress through another successful year.

Dinah Clements OBE

Development Worker

- Social Care, Health and Education

report

The Development Worker in this post has specialist training, including working with children and young people, dealing with disabilities, equality and diversity and in social services provision and works with children on ABCD Cymru's register aged between 0 and 16.

The work involves liaising with the parent carers, assessing the disabled child's needs and the needs of the family as a whole. Many parent carers are still trying to come to terms with their child's disability or the child has just been diagnosed with an illness or disability not known to them. A holistic approach is taken and a practical and achievable solution is discussed with the family and any other agencies involved. Advice and information is given in their choice of language. ABCD Cymru is fortunate to have bi-lingual workers who are happy to utilise this skill, or where appropriate, we will use a professional interpreting service.

We addressed nearly 500 issues in the last year, such as:

- Accessing social work services.
- Benefits entitlement and advice.
- Special Educational Needs.
- Funding.
- Housing/disability adaptations.
- Further education and work placements.
- Advocacy, focussed on the child/young person.

We provided advice:

- In person, at home visits, appointments, or in our office.
- Over the phone.
- At drop in sessions.
- Via emails and on our website.
- At Information Sharing Sessions.

One of our main concerns is how unaware the families may be of the help that is available to them, their entitlements and how to access the appropriate facilities and services. This can contribute to social exclusion, isolation and disempowerment.

We mainly signpost to appropriate agencies and where necessary make supported referrals. We also attend multi-disciplinary team meetings, accompanying health and social workers and service providers from other statutory or voluntary organisations to visit families. This empowers the families to make informed choices and decisions.

Information and advice is also provided to other professionals as many are not aware of how to engage with BME families and do not understand the cultural/religious barriers that the families may be facing.

Nazia Akram



“ Even though we parents don't speak the same languages, we still manage to support each other ”

report

Play and Events Co-ordinator

The Play and Events Co-ordinator is funded by BBC Children in Need to help families access existing play and leisure opportunities and also to organise special events in the school holidays.

Play is essential for the well-being of all children and young people, and especially so for those that are disabled. The families we work with are very isolated and often socially excluded. Through attending our free play sessions, trips and events they are able to socialise with other families of disabled children and find mutual support.

We run events for the whole family so that they can experience an enjoyable day together in a safe and secure environment. This boosts their self-esteem and confidence.

Where possible we work in partnership with other agencies with similar aims to enhance our provision for our service users. In the past we have worked with: Cardiff Play Services, The Touch Trust, Cardiff Music Services, and Barnardo's.

Previous trips organised by ABCD Cymru have included Cadbury World, Longleat, Oakwood, Touch Trust, Brecon Mountain Railway to see Father Christmas, Bristol Zoo, bowling and St. Fagans National History Museum.

We facilitate a Parents' Play Steering Group, which meets regularly to gather information about the families' needs and to plan events accordingly. This forum is also used to generate ideas for fundraising to pay for such events. Identifying and acquiring funds to support future events is also a part of the role of the Play and Events Co-ordinator.

The types of events we organise include swimming, bowling, arts and crafts, cinema, woodwork, free play, and trips. The Play and Events Co-ordinator compiles a Summer Events Programme which is full of varied activities suited to our children and young people.

Our aim is to continue to increase the opportunities for play available to disabled children and young people and thus provide benefit for the whole family.

Shau-Wai Sim



“ It was really fun and enjoyable. I liked it so much ”



“It was nice to get careers advice in an informal setting and talk about my child’s education and the choices open to them, thank you ABCD”

Development Worker - Working with Young People (aged 14-25) with Learning Disabilities

report

The post is funded by the Welsh Assembly Government. The aims are to secure advocacy for young people with learning disabilities and to increase their choices in relation to education, employment, training, and leisure opportunities. Also we improve their self-esteem and confidence by informing them of the options available to them, and empowering them to make choices in a supportive environment.

We have undertaken research with the young people, via an accessible questionnaire, to ascertain their existing level of engagement in relevant activities and their access to services, as well as asking what sorts of further opportunities they would like.

After analysing the data, we identified gaps in their knowledge of opportunities available to them, and approached relevant agencies to attend Information Sharing Sessions. These allowed young people and their parent carers to have the opportunity to meet those who offer these services, and the chance to ask further questions. We also organised a tour of the Cardiff City Football Stadium and a tour of the new Cardiff Central Library.

Guest speakers have included: Pedal Power, Fairbridge De Cymru, Career Wales, Venture Out, the Duke of Edinburgh's Award Scheme and Coleg Glan Hafren. We received encouraging feedback from the families and service providers and will hold more such sessions in the future.

One-to-one casework is undertaken with the young people, exploring ways of empowering them to access services such as benefits, work experience, education, training, employment, housing and leisure opportunities.

Work is ongoing with Vision 21 to offer young people free taster sessions in pottery, gardening, woodwork and cooking skills.

David Singh



“It's great to get the chance to go out as a family, and just have fun!”

Participation and Engagement Officer

report

This post, which commenced in November 2009, is funded by the Lloyd's TSB Foundation for England and Wales. The role involves **working with families to enable them to have the confidence to make their voices heard in processes which affect their lives.** Through offering them support in engaging in consultation events and other activities, we aim to empower them to play a more active role in society. We also contribute to policy formulation on both a local and Wales-wide level.

The task is both rewarding and challenging due to the extent of the obstacles the families face in participating. Language barriers and difficulty accessing interpreters are issues we came across repeatedly, as well as problems relating to physical access and low income.

Nevertheless, despite all this, many families were able to get involved in the various consultation events we have organised. In January we were asked by the Welsh Assembly Government to run a **focus group** to gather feedback about paediatric audiology services. In March the Welsh Assembly Government requested that we **conduct surveys with our families** about their experiences of NHS equipment services for disabled children.

In addition, they **commissioned us to write case studies about the specific difficulties BME families face** with this. We have also worked closely with the Vale of Glamorgan Council on their Disability Equality Scheme and we produced consultation responses in partnership with Mencap Cymru.

To date we have **responded to 12 consultations.** This ensures that the families we support are fully represented in the policies that affect their lives. We have been in contact with over 250 individuals and families, as well as relevant organisations, to raise awareness of the barriers to accessing services that face the distinct and often vulnerable group that we work with.

The community we work with is often referred to as 'invisible' or 'hard-to-reach', and we ensure that they are neither by removing some of the barriers to their participation.

We look forward to conducting more focus groups and undertaking further consultations with our families over the coming months to ensure that their interests are always at the forefront of what we do.

Bethan James

Supporting 4 Young People with Learning Disabilities

case study 1

Mrs Akbar is a carer for four young people with severe learning disabilities aged between 15-21. Her English is limited and she lacks the confidence to request an interpreter, resulting in their problems becoming exacerbated. She is a lone parent.

Issues before being referred to ABCD Cymru.

- Lack of information and support regarding Special Educational Needs.
- Advice needed regarding benefits entitlement.
- Correct information regarding the Independent Living Fund (ILF) and its procedures, as payments were suspended.
- Advice and information needed regarding further education for one of her sons.
- Advice and information needed regarding appropriate disability adaptations.
- Isolation - unable to go out all together as a family.

Support from ABCD Cymru

- ABCD Cymru advocated for the family to have a statement for her one son to be revised, resulting in extra support for speech and language therapy. This saved Mrs Akbar going to a tribunal as the issues were resolved.
- Facilitated supported referral to Mencap Cymru regarding entitlement in benefits for herself and her children.

- ILF reinstated.
- Referred family to Occupational Therapist regarding disability adaptations and facilitated the process.
- Family have attended trips together with ABCD Cymru.
- Referred mother to culturally appropriate carer's groups.

Outcomes and achievements

- Mother now coping much better.
- Family have the opportunity to go out together as a unit.
- A satisfactory Statement was provided which was then taken on board by the school.
- Mother is more confident in asking for help before reaching crisis point.
- Mother able to advocate for self (as carer) and for the young people.



“What a fun day we had, when is the next trip planned?”

case study 2

Helping a Young Wheelchair User Regain His Freedom

A young person from the Newport area was referred to us by a mainstream learning disability organisation. He has a learning disability, visual impairment, multiple sclerosis and is a wheelchair user. He was in a respite centre in Liverpool when ABCD Cymru got in touch with him. He told us he was very unhappy and he missed his family. He wanted to be somewhere nearer to his home and to access some training. However, his family are very busy with their own lives and he was often left alone at home. He felt very lonely and isolated.

Issues before being referred to ABCD Cymru

- Wanted respite closer to home.
- Was lonely and isolated.
- Wanted help accessing transport.
- Had received no support from social services or contact for approximately six months.

ABCD Cymru intervention resulted in the following

- He was allocated a new social worker.
- His care package was reviewed and updated to include the following:
 - Four hours respite twice a week with a personal assistant.
 - Help to manage his money better
 - Hydrotherapy sessions, once a week with transport.
 - Re-assessment for a power assisted wheelchair.
 - Re-assessment for environmental controls on his wheelchair, so he can access light switches and the television and can open and close the front door via the remote. Thus greater independence.
- He has a disabled persons plus carer's free bus pass.
- He has access to the INFO shop in Newport, which have now put Supernova on their systems to help with his visual impairment and where he is hoping to do The Duke of Edinburgh's Award Scheme.

He now regularly travels everywhere by bus and often comes to our offices in Cardiff to tell us about the places that he visits and "how he enjoys his new found freedom." His family have also said "over the last six months his quality of life has become very much better".

“ We appreciate the fact that ABCD work with all family members and we can all do things together ”





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“I'm so glad I attended this session, my son now enjoys riding on the specially adapted bicycles”

Supporting Families Who are Affected by Autistic Spectrum Disorders

case study 3

A family from Ghana was referred to ABCD Cymru by a Special Needs Health Visitor. They had a child aged three who had recently been diagnosed as being on the Autistic Spectrum. The parent carers were asylum seekers and unaware of the systems or procedures regarding access to Social Care, Health and Education issues.

Issues arising:

- Lack of knowledge regarding benefits entitlement.
- Advice and information regarding how to manage and support a child with Autism.
- Advice regarding immigration issues.
- Social isolation – due to lack of local area knowledge and the availability of activities for the child and family.
- Lack of information and support regarding Special Educational Needs (SEN) for the child.
- Information requested by parent carer regarding volunteering opportunities within the local community.

ABCD Cymru input:

- Supported referral made to Snap Cymru regarding SEN.
- Information provided to family regarding Autism.
- Opportunities provided for family to meet other families in similar situations.
- Facilitated referral to a registered agency regarding immigration issues.
- Family invited to ABCD Cymru trips and events.
- Put parent carer in touch with relevant organisations regarding volunteering opportunities.

Outcomes and achievements:

- Able to make an informed decision on which school is suitable for their child.
- Family attend trips with ABCD Cymru and go to places they previously did not have the confidence to attend.
- More confident in approaching service providers.
- Family feel supported and not isolated and welcome the opportunity to befriend others in a similar situation for mutual support.
- Receiving advice and information regarding immigration issues.
- Specialist advice provided by benefits' specialist.

Information Sharing Sessions

ABCD Cymru organise Information Sharing Sessions bi-monthly.

These two-hour sessions aim to give our families and other organisations the opportunity to come together and meet informally. Here the guest organisation can explain what services they provide and how they are able to help and support families. This also gives them an opportunity to engage directly with the service providers and to ask any questions or to discuss any issues.

Similar Information Sharing Sessions are also arranged for our young people. The speakers for the young people's Information Sharing Sessions were identified via consultation to ascertain their existing level of engagement in

relevant activities, their access to services required and asking what further opportunities they would like to have access to. Once the data was analysed the appropriate organisations were invited to attend ABCD Cymru Information Sharing Sessions.

These Information Sharing Sessions came about as a result of our families asking for this information and also expressing their need to meet individuals in similar circumstances for mutual support, advice and befriending.

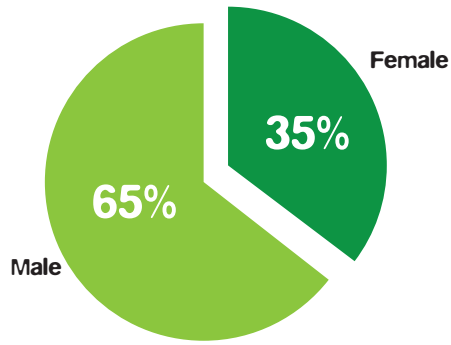
Information Sharing Sessions

Date	Organisation	Feedback from attendees
July 2009	Women Connect 1st, Women's Workshop	'Very interesting, I want to do more'
October 2009	Cardiff County Council Play Services and BAWSO	'This is very good, I will come again'
November 2009	Cardiff and Vale Coalition for Disabled People and Cardiff Advocacy (Tros Gynal)	'Keep up the good work'
December 2009	Carers Centre (Upna centre) and SNAP Cymru	'Its good to know this information'
February 2010	Cerebra and Community Legal Service	'This is an excellent way to share information and network'
March 2010	Mencap Cymru Surgery	'I wish I knew this before I would not have cancelled my claim'
March 2010	Pedal Power, Venture Out and Duke of Edinburgh Award Scheme	'Great we have a referral'
April 2010	Family Information Service, Islamic Social Services and NDCS (National Deaf Children Society)	'This will help me'
April 2010	Coleg Glan Hafren, Career Wales and Fairbridge Cymru	'This lady knows so much'
June 2010	Advocacy Matters, Riverside Advice and Menfa	'The relaxed environment means I feel more comfortable asking questions'
June 2010	SNAP Cymru Surgery	'I wish I knew this 10 yrs ago'

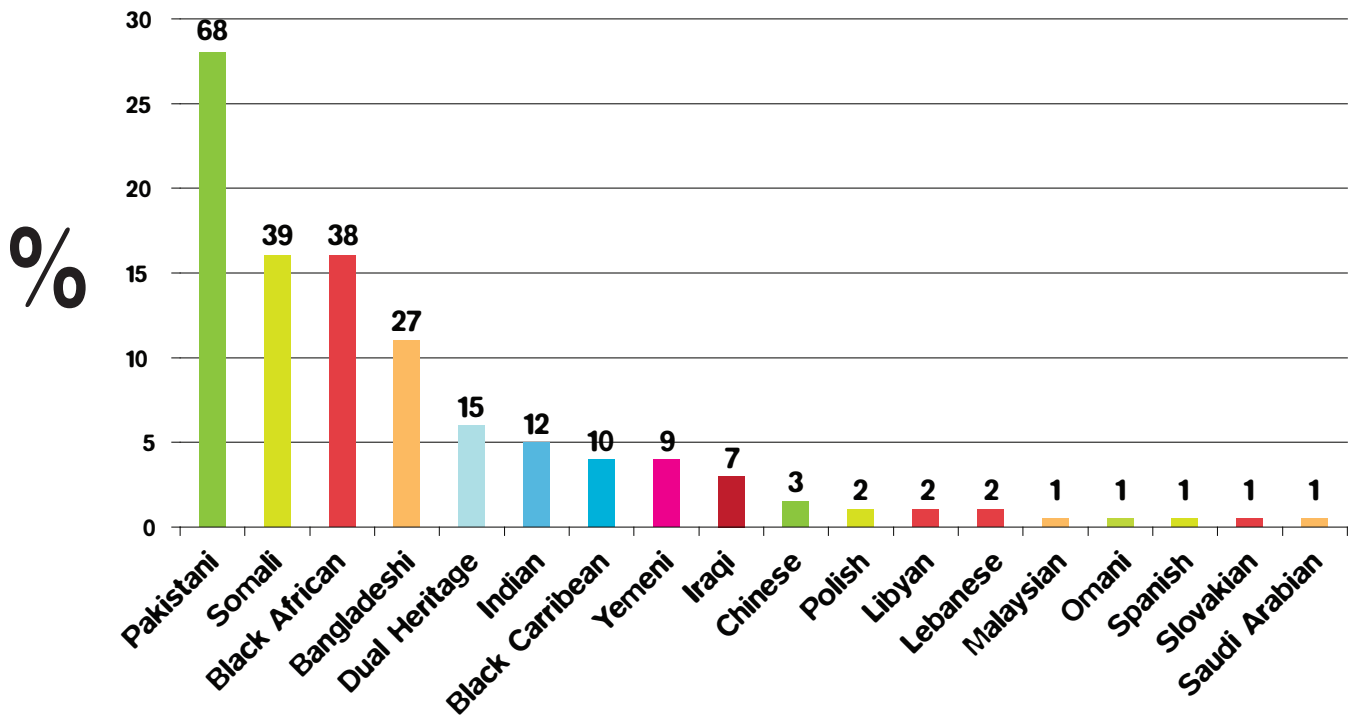
General feedback from these sessions was that the families liked the atmosphere as it was very relaxed. They were not afraid to speak or ask questions as they were not intimidated. The guest speaker enjoyed having a direct conversation with families and listening to their issues. Some believe they would not have had the opportunity before these sessions to meet directly with families.

Facts and Figures

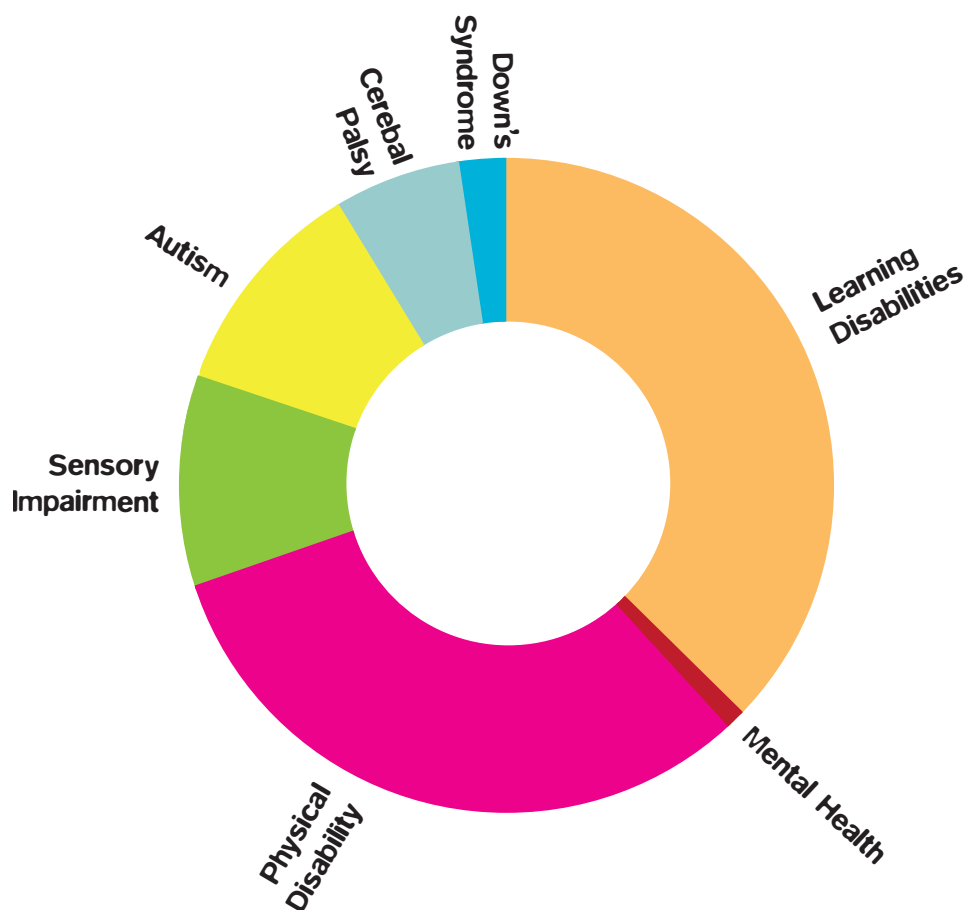
Sexes










Ethnicity



Primary Health Issue



	Actual Numbers	Percentage		Actual Numbers	Percentage
 Learning Disabilities	89	37.5%	 Autism	26	11%
 Mental Health	2	1%	 Cerebral Palsy	15	6%
 Physical Disability	75	31%	 Down's Syndrome	6	2.5%
 Sensory Impairment	25	10.5%			

Record of Consultation Responses

Title	Organisation
Fulfilled Lives, Supportive Communities: Commissioning Framework and Guidance	Welsh Assembly Government
Draft Disability Equality Scheme	Vale of Glamorgan Council
Complex, Specialist & Children's Community Equipment Service Project	NHS Wales
Quality Standards in Paediatric Audiology	NHS Wales
Paying for Care in Wales (Green Paper)	Welsh Assembly Government
The proposed Carers Strategies (Wales) Measure	National Assembly for Wales
Wheelchair and Equipment Design Project	NHS National Innovation Centre/ Whizzkidz
Cardiff and Vale University Health Board Scheme for Equality and Human Rights	NHS Wales
Child Poverty Definition (Wales) Regulations	Welsh Assembly Government
Reform of Adult Social Care Law	The Law Commission
Child Poverty Strategy for Wales	Welsh Assembly Government
Disability-related Harassment Inquiry (ongoing)	Equality and Human Rights Commission

parent carer testimonial

Our son was diagnosed as profoundly deaf when he was a few weeks old almost 13 years ago.

We didn't know anybody who was deaf or had ever met a deaf person. At a time when information was not as easily available as it is now via the internet, we were desperate to find out as much as we could about deafness.

A thoughtful friend introduced us to ABCD Cymru, who were very efficient in directing us to an appropriate organisation who could support us and give us the appropriate information regarding our son's hearing impairment.

ABCD Cymru have been a supportive organisation listening to the concerns of parents and trying their best to help in any way they could. Whether it was just to listen or give information.

We as a family have enjoyed the wonderful trips that ABCD Cymru have organised; they have given us the invaluable opportunity to socialise with other families from same and different backgrounds and disabilities. Thus being able to share experiences and give each other support.

We are very grateful to ABCD Cymru and would hope that this organisation has enough funding to carry on supporting families and continue this invaluable work.

All the best

Mr and Mrs K

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