

Cross-Party Group Annual Report.

4/12/15

Cross Party Group on Autism

Chair: Mark Isherwood AM

Secretariat: Meleri Thomas, National Autistic Society Cymru

1. Group membership and office holders.

Mark Isherwood AM, Aled Roberts AM, Jeff Cuthbert AM and Rhodri Glyn Thomas AM

2. Previous Group Meetings.

Meeting 1.

Meeting date: 10 June 2015

Attendees: Attached

Summary of issues discussed: Minutes copied below

Meeting 2.

Meeting date: 11 September 2015

Attendees: Attached

Summary of issues discussed: Minutes copied below

Meeting 3.

Meeting date: 18 November 2015

Attendees: Attached

Summary of issues discussed: Minutes copied below

3. Professional lobbyists, voluntary organisations and charities with whom the Group has met during the preceding year.

Creasmile North Wales: The Old School, Towyn Road, Towyn, Conwy, LL22 9ER

Your Space: Black Park, Halton, Wrexham LL14 5BB

Gwynedd & Anglesey Autism and Aspergers Support Group: Ffordd Crwys, Bangor, LL57 2NT

Autism Wishes: Westfield Court, Wrexham, Clwyd, LL13 8JA

Disability Sport Wales: Sport Wales National Centre, Sophia Gardens, Cardiff, CF11 9SW

Annual Financial Statement.

4/12/15

Cross Party Group on Autism

Chair: Mark Isherwood AM

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Group's Expenses. [met by NAS Cymru]	Cardiff to Wrexham travel [Red Spotted Hanky] 1/9/15	£64.00
	Wrexham Accommodation [Premier Inn] 4/8/15	£198.00
Costs of all goods.	No goods purchased.	£0.00
Benefits received by the group or individual Members from outside bodies.	No benefits received.	£0.00
Any secretariat or other support.	No financial support received.	£0.00
Services provided to the Group such as hospitality.		
All refreshments paid for by NAS Cymru.		
Date	Description and name of provider	Cost
10/6/15	Charlton House	£65.64
18/11/15	Charlton House	£49.92
Total cost		£377.56

Minutes / Cofnodion
Cross Party Autism Group / Grwp Trawsbleidiol Awtistiaeth
Mehefin 10 June 2015
National Assembly for Wales / Cynulliad Cenedlaethol

1 WELCOME / CROESO

CPAG Officer and Acting Chair, Jeff Cuthbert AM, welcomed everyone to the second meeting of 2015.

The meeting was attended by the following AMs: Aled Roberts; and William Powell. Representatives from the offices of Suzy Davies and Mark Isherwood were also in attendance.

2 MINUTES OF THE LAST MEETING AND MATTERS ARISING/ COFNODION A MATERION YN CODI

There were no matters arising and the minutes were agreed to be an accurate account of the previous meeting

3 UPADTE ON THE WELSH GOVERNMENT'S INTERIM DELIVERY PLAN ON AUTISM / DIWEDDARIAD AR GYNLLUN GWEITHREDU INTERIM Y LLYWODRAETH AR AWTISTIAETH

Meleri Thomas, NAS Cymru's External Affairs Manager, updated the group on the progress of Welsh Government's ongoing 'refresh' of its Autism Strategy. Meleri informed the group the work is still underway within Government to assess the impact new legislation will have on the Autism Strategy and so have published instead an interim delivery plan for 2015-16 detailing immediate actions for the year ahead. The Interim Delivery plan can be found here: http://www.asdinfo.wales.co.uk/resource/150518_ASD-interim-delivery-plan-2015-16.pdf

3.1 Queries were raised as to the details involved in a number of the Actions listed in the Interim Delivery Plan. Michael Williams questioned the reference to 'Dormant Accounts Money' that is proposed to pay for an autism employability programme. Jeff Cuthbert informed the group that this money is distributed by Welsh Government from money left in dormant bank and building society accounts.

3.2 David Malins questioned the effectiveness of the Community Monitoring Project as referenced in the Interim Delivery Plan. The action is to continue with the Project as it is.

4 DISABILITY SPORT WALES / CHWARAEON ANABLEDD CYMRU

Dan Bufton, the Disability Sports Officer for Merthyr Tydfil discussed the ongoing projects in the area and collaboration with the Merthyr NAS Branch. He said that in the past, there were very few opportunities for people with ASC but collaboration with the branch has opened up new possibilities for individuals with autism. The projects currently undertaken include Rock Climbing, Physical Literacy, Scheduling/PECs as well as wider autism awareness amongst staff at sport and leisure facilities in the county.

4.1 Jill Grange, Branch officer for NAS Cymru's Bridgend and District Branch spoke about the positive impact working with Disability Sport Wales in her area has had. The branch are now able to offer Judo, Golf, Swimming and Athletics to its members.

4.2 Ann Fowler asked if there was an age limit for the individuals DSW could support. Dan Bufton said that there was no limitations based on age.

4.3 Alwyn Rowlands, who runs Gwynedd and Anglesey Autism and Asperger support group also agreed that the funding for DSW programmes is making a difference throughout Wales.

4.4 Alis Hawkings, NAS Cymru Family Support Worker queries that, with a global trend of many people with autism, especially younger people, not identifying themselves as

'disabled', whether or not this could be a barrier to them choosing to access these great services.

4.5 Theresa James, the ASD Lead for Monmouthshire CC said that the work going on in her area was particularly promising, with every leisure and sport facility undergoing basic awareness training.

4.6 Dan Bufton shared the story a young man with autism who is a DSW Young Ambassador and sits on the steering group. The impact that the sport programmes has had has been transformational for him.

4.7 Ruth Jones, Branch Officer for NAS Cymru's Merthyr Tydfil Branch said that while these programmes were making a big difference, particularly to those with Aspergers, individuals with Classic autism are not catered for in the same way. Ruth spoke about how difficult it was to get important Occupational Therapy, essential for her own son.

5 ARRIVA TRAINS WALES: AUTISM AND TRANSPORT / TRENAU ARRIVA CYMRU: AWTISTIAETH A THRAFNIDIAETH.

Arriva Trains Wales representatives Michael Vaughan and Ben Davies outlined the company's policies for ensuring accessibility for all. They spoke about a commitment to reduce social exclusion through a positive policy of improved access to services for customers with disabilities. They said they will work closely with rail industry colleagues to achieve this where they are responsible for the provision or ownership of facilities. They ended by promoting the Orange Wallet scheme, aimed at providing staff with an indication that an individual may have additional travel needs. Michael and Ben stressed that they were there to listen to problems and solutions and opened the debate to the floor.

5.1 Mat Mathias from NAS Cymru said that while anything that can help support people to travel independently, such as the Orange Wallet Scheme, could be welcomed, the nature of the training provided to staff to support people with disabilities was the crucial issue. Ben said that this is something ongoing, with refresher training for staff every 16 weeks.

5.2 Louise Rixon made the point that she is unable to use the train as a method of transport with her son as the toilet and changing facilities aren't compatible with their needs. Where there are changing facilities, they are only for very small children. Arriva Trains Wales said they are committed to making all stations and trains accessible moving forward and that as new services are developed, they will account for the changing needs of their customers.

5.3 Janet Williams spoke about a bad experience that her son had when dealing with staff at Swansea Train Station. She suggested the autism awareness and understanding isn't where it should be and present.

5.4 Colin Foster, from NAS Cymru Merthyr Tydfil Branch said that ASC Passports are being developed and asked if they were compatible with the Orange Wallet. Similarly, Alka Ahuja mentioned a mobile app that provides a pen-pic of an individual and their needs. It was suggested that anything that helps communicate the additional needs of an individual would be useful to staff.

6 CATH DYER

Cath Dyer wanted to update the group on her daughter Claire's progress since the removal of her Section. Claire has been thriving at home under her new support arrangements and sang at the Autism Hero Award Nominations and will do so again at the Award Ceremony. Cath said that she is enjoying being home, surrounded by friends and family and is glad to be supported by people who understand autism.

6.1 Jeff Cuthbert was glad to see Claire's progress and said there was much to be learned for this case.

7 ISSUES RAISED / MATERION A GODWYD

7.1 Keith Ingram spoke briefly about some work with Job Centres that is being undertaken and wanted to raise awareness of new resources available online. They can be found here: http://www.asdinfo.wales.co.uk/home.php?page_id=8722

7.2 A Cardiff resident wanted to raise a local issue. In the last review she had attended, her son's psychiatrist had told her that they were under direction not to see children with autism, who had no co-morbid condition. This would mean no diagnostic pathway for autism.

7.3 David Malins asked for more detail on Welsh Government's recent announcement of funding for CAMHS. He would like to know exactly how it will be spent and if it is funding that was previously allocated elsewhere. David also commented that post diagnosis services for adults are not available and cited his own situation as an example of someone with a diagnosis who can't access the support needed.

4. ACTIONS / PWYNTIAU GWEITHREDU

CPAG will write to the Minister for Health and Social Services to get more detail on the recent announcement on more funding for diagnostic services in CAMHS.

5. ANY OTHER BUSINESS

Date and location of the next CPAG meeting: 11th September 2015 / Glyndwr University, Wrexham. Next Cardiff meeting 18 November 2015 at the National Assembly for Wales.

Minutes / Cofnodion
Cross Party Autism Group / Grwp Trawsbleidiol Awtistiaeth
Medi 11 September 2015
Prifysgol Glyndŵr University

1 WELCOME / CROESO

CPAG Chair Mark Isherwood AM, welcomed everyone to the 2015 North Wales meeting. The meeting was also attended by CPAG Officer Aled Roberts AM. Mark passed on apologies from other AMs unable to attend and welcomed the Assembly's translation team. Mark also updated the group on the ongoing work in the National Assembly, including January's Private Members debate on an Autism Act. Mark welcomed the various organisations who were presenting to the group today.

2 MINUTES OF THE LAST MEETING AND MATTERS ARISING/ COFNODION A MATERION YN CODI

There were no matters arising and the minutes were agreed to be an accurate account of the previous meeting.

3 AUTISM WISHES.

Autism Wishes' Mandy Neal and Jo Perera summarised the work of the charity and played a video that highlights their success to date. There was a question from the group relating to the age ranges for the play scheme Autism Wishes provide. The group is primarily aimed at younger people but all are welcome.

4 ANGIE ATHERTON

Angie spoke about her personal experiences and played a video detailing her and her son's story. Angie shared how, after identifying gaps in services, she set up her own support service helping people with autism and their families. She also wanted to highlight the work of the Autism Flintshire Group. A group member who had received support from Angie said that the help received has been invaluable.

5 "YOURSPACE" WALES

Tamara Hall spoke of the work that "Your Space" do to support people with autism in North Wales, including their various social and activity clubs

6 CREATASMILE

Sharon Bateman spoke about how Creatasmile was founded and the work it does across the region. Sharon also mentioned a new funding grant from the Postcode Lottery and how this will allow them to expand their work.

7 NATIONAL AUTISTIC SOCIETY WREXHAM BRANCH

Kerry Roberts and Kelly McLeod-Andrews spoke about the work the branch has done in the last year, including the fundraising success of the Healthy High Street Scheme and their election hustings events. There was a question raised about the university support that the NAS provide in North Wales. Meleri Thomas of NAS Cymru agreed to discuss the provision available after the presentation.

8 JO TAYLOR OF FLINTSHIRE COUNTY COUNCIL

Jo, along with her colleague Trevor Brand discussed the approach taken by the Authority in supporting people with autism. They shared recent case studies of how individuals have been supported. Jo also discussed how positive outcomes have been achieved through the community monitoring support service, and that although funding for this is due to end, the

North Wales region hopes to pilot a new service to follow on from this work. Jo also made the Group aware of the ASD Info Wales website and the employment resources available. There were queries from the group asking for clarity on the support available. Jo said that there is no generic service but tailored support to help achieve specified outcomes. The Wirral Autism Society Chief Executive clarified the relationship they have with Flintshire Local Authority. Another group member said that after referral to Jo, her son has made great progress.

9 GWYNEDD AND ANGLESEY AUTISM AND ASPERGERS SUPPORT GROUP

Alwyn Rowlands spoke about the range of work his organisation does including working with students in Bangor Uni to provide the Sbectrwm club. Alwyn also noted the significance of the CPAG meeting in North Wales, one of the few that travel outside of Cardiff and paid tribute to the AMs who have supported it. Alwyn suggested that the momentum that was brought by the Welsh Government's autism strategy is slowing, citing the example of the loss of David Oliver to the area. Alwyn finished by saying that there are not sufficient services to complement a rise in diagnosis rates, especially for those who don't have a co-occurring mental health condition or learning disability. He reinforced the importance of those support groups and organisations who had presented to the CPAG today.

10. ANY OTHER BUSINESS

Elin Walker Jones asked how the group could help support Mark Isherwood and NAS Cymru's call for an Autism Act. Mark said that all parties are currently drafting their manifestos and the group should use the opportunity to make their views clear to their own AMs. He mentioned that those who supported his call for an Act in his Private Members debate are on record [<http://www.assembly.wales/en/bus-home/pages/rop.aspx?meetingid=3102&assembly=4&c=Record%20of%20Proceedings&startDt=18/01/2015&endDt=24/01/2015&keyword=autism>].

Meleri Thomas of NAS Cymru reminded the group of a free concert to be held at St. Asaph Cathedral for parents and carers of people with autism. The concert will feature pianist Norika Ogowa; and starts at 1030 on 29 September.

A member of the group shared details of another organisation offering speech and language therapy groups.

Date and location of the next CPAG meeting: 18 November 2015 at the National Assembly for Wales from 12:15pm-13:15pm.

Minutes / Cofnodion
Cross Party Autism Group / Grwp Trawsbleidiol Awtistiaeth
Tachwedd 18 November 2015
Cynulliad Cenedlaethol Cymru / National Assembly for Wales

1 WELCOME / CROESO

CPAG Chair Mark Isherwood AM, welcomed everyone to the final meeting of 2015. The meeting was also attended by William Powell AM and a representative from the office of Simon Thomas AM.

2 MINUTES OF THE LAST MEETING AND MATTERS ARISING / COFNODION A MATERION YN CODI

There were no matters arising and the minutes were agreed to be an accurate account of the previous meeting.

3 RESEARCH INTO THE EXPERIENCES OF PARENTS OF BLACK AND MINORITY ETHNIC PUPILS WITH AUTISM

Dr Sheladevi Nair shared her research paper with the Group. The paper examined the experiences and perceptions of parents of Black and Minority Ethnic (BME) pupils with autism and the support they and their children received in mainstream and special schools in an urban city area within a Local Authority in south Wales. The paper also explored the perceptions of stakeholders in education and relevant support organisations who provide support for these pupils and their parents.

Dr Nair's research concluded that:

- The local community must recognise that BME parents of children with autism cannot depend on their own BME communities for support, and disability within BME community is often considered a stigma
- The BME community regard themselves as diverse and not homogenous, with parents referring to themselves as being Chinese, Pakistani or African and not BME as a whole
- There is the perceived need for culturally appropriate educational services. Service provision in education are generally similar for all pupils without differentiating for the different cultural needs of BME pupils
- There is a sense of apportioning blame and shifting responsibility between parents and stakeholders

4 EDUCATION AND CARE

Colin Howarth from Orbis Group outlined the different provision that they offer children young people and adults with autism. They offer safe and supportive environments in which to learn, gain life and work skills, build confidence and self-esteem, and help individuals to have as good and as independent a life as possible.

Colin also outlined Orbis' new services at Port Talbot and explained the concept of 'The Orb' – a new day service in Porth, which offers a range of learning environments and activities that can be provided in conjunction with schooling or as an alternative to a formal college placement on leaving school.

5 SCHOOL TRANSPORT

Lisa Rapado from the NAS Cymru Ystradgynlais Branch highlighted a number of issues with school transport and discrepancies in provision across Local Authorities in Wales.

ACTION: CPAG to write to the Minister for Transport seeking clarification on the School Transport Guidelines

10. ANY OTHER BUSINESS

Date and location of the next CPAG meeting: 24 February 2015 at the National Assembly for Wales from 12:15pm-13:15pm.