Cross-Party Group Annual Report.

21/03/2018

Cross Party Group on Autism

1. Group membership and office holders.

Mark Isherwood AM (Chair)

Hefin David AM, Jayne Bryant AM, Dai Lloyd AM (Officers) Mike Hedges AM, David Rees AM (Members)

Meleri Thomas, National Autistic Society Cymru (Secretariat)

Other members: National Autistic Society Cymru Branches

2. Previous Group Meetings since the last AGM.

Meeting 1.Meeting date: 14/06/17

Attendees and Summary of issues discussed: Please see minutes attached

Meeting 2. Meeting date: 08/09/17

Attendees and Summary of issues discussed: Please see minutes attached

Meeting 3. Meeting date: 06/12/17

Attendees and Summary of issues discussed: Please see minutes attached

Meeting 4. Meeting date: 14/03/18

Attendees and Summary of issues discussed: Please see minutes attached

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

[Include name of lobbyist/organisation/charities as follows. e.g.]

Autistic Women's Empowerment Project theaweprojectwales@gmail.com

Keith Ingram, Cardiff and the Vale Integrated Autism Service, Avon House, 19 Stanwell Road, Penarth, CF64 2EZ

Mat Mathias, Electoral Reform Society Cymru Baltic House, Mount Stuart Square, Cardiff, CF10 5FH

Claire Morgan, Carers Wales, Ynys Bridge Court, CF15 9SS

Jo Salmon, Welsh Autism Ball

Annual Financial Statement.

21/03/18

Cross Party Group on Autism

Chair: Mark Isherwood AM

Secretariat: Meleri Thomas National Autistic Society Cymru

[met by NAS Cymru]	Talybont, Bangor (08/09/17):	
	Venue Hire: Neuadd Reichel,	
	Bangor University	£201.00
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 G		
All refreshments paid for by	NAS Cymru.	
All refreshments paid for by Date	Description and name of provider	Cost
	Description and name of	Cost £75.18
Date	Description and name of provider	
Date 14/06/17	Description and name of provider	£75.18

Minutes / Cofnodion Cross Party Autism Group / Grwp Trawsbleidiol Awtistiaeth Mehefin 14 June 2017 Cynulliad Cenedlaethol Cymru / National Assembly for Wales

1 WELCOME / CROESO

CPAG Chair Mark Isherwood AM, welcomed everyone to the meeting, which was attended by Dai Lloyd AM, as well as support staff from the offices of Mike Hedges, Alun Davies and Paul Davies.

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

The minutes were agreed to be an accurate account of the previous meeting, with the addition of one correction on ensuring the support needs of autistic people working within the emergency services are met.

3 UPDATE FROM THE MINISTER FOR LIFELONG LEARNING AND THE WELSH LANGUAGE

Alun Davies AM, the Minister for Lifelong Learning and the Welsh Language gave an overview on the reform to the special education needs system, adding that he is expecting the new legislation to be given Royal Assent by Christmas and on the statute books next year. He took questions on a range of issues, including funding for specialist provision, the Education Tribunal, School Transport, the Individual Development Plans, Training for Professionals and the Welsh Language. In response to concerns, the Minister outlined a number of ways in which these could be addressed, including amendments to the proposed legislation around Welsh Language provision as well as template and timeframes for IDPs. He also spoke about extra financial resource to support implementation of the Bill and ongoing work exploring how the Educational Tribunal could be strengthened to ensure decisions are delivered.

4 EMMA CARVER, YSGOL Y DERI

Emma Carver, assistant head at Ysgol y Deri, described how they had used specific autism money from the Vale of Glamorgan to develop a new resource for local schools, to help them better understand autism. She explained how it had started off as a paper copy and had developed into something a lot more interactive that could be downloaded. Demand for the resource was increasing with interest from all corners of the world. On the issue of making the resources available in Welsh, Emma said that it was something that they hoped to explore further with Welsh Government.

5 ANY OTHER BUSINESS / UNRHYW FATER ARALL

Jeff Morris raised the issue of autistic people wrongly being detained because of a lack of understanding of autism and resulting in autistic people wrongly having a criminal history. Members agreed that it was an issue and that the Crown Prosecution Service be invited to a future meeting of the group.

The Chair reminded the group that the National Assembly would be discussing a Private Members Bill on introducing autism legislation in Wales later the same day and invited members to listen to the debate in the Senedd's viewing gallery.

6 ACTIONS / CAMAU GWEITHREDU

The group will write to the Minister for Lifelong Learning and the Welsh Language to gain clarity over funding for specialist provision. We will also write to him separately on a number of the issues raised during the meeting regarding the ALN Bill.

The group will write to the Crown Prosecution Service inviting them to a future meeting to discuss issues raised by the group.

The next CPAG meeting will be in Bangor University on the 8 September 2017 from 10:30am. Further details will be available closer to the day.

The next meeting at the National Assembly for Wales is scheduled for 6 December 2017 from 12:15pm-1:15pm with the exact location yet to be confirmed.

Minutes / Cofnodion Cross Party Autism Group / Grwp Trawsbleidiol Awtistiaeth Medi 8 September 2017 Prifysgol Bangor University

1 WELCOME / CROESO

CPAG Chair Mark Isherwood AM, welcomed everyone to the meeting and notified the group of apologies received from Hefin David AM, Mike Hedges AM, Jeremy Miles AM, Neil McEvoy AM, Simon Thomas AM, Llyr Gruffydd AM, Bethan Jenkins AM and Paul Davies AM.

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

The minutes were agreed to be an accurate account of the previous meeting.

3 WILLOW HOLLOWAY: UPDATE ON WORK OF AUTISTIC WOMEN'S EMPOWERMENT PROJECT & AUTISTIC UK CYMRU.

Willow updated the group on the continued development of the peer to peer and self-advocacy network, the Autistic Women's Empowerment Project as well as her role in expanding the role of Autistic UK Cymru to be a strong voice for autistic people in Wales. Willow spoke about the opportunity the current consultation on a proposed Autism Bill offers autistic people to ensure that their voices are heard. Willow also promoted the upcoming North Wales Autism Conference, on 29th September as well as an event to mark International Women's Day on the 8th March 2018, looking at the unique challenges faced by autistic women.

4 DELYTH LLOYD WILLIAMS: 'SAVE OUR INDEPENDENT LIVING FUND'

Delyth informed the group about changes to the Independent Living Fund (ILF) in Wales. After initially being administered by the UK Government until 2015, responsibility for the fund was transferred to the Welsh Government, who replaced the ILF with the Welsh Independent Living Grant (WILG), with existing recipients receiving their payments from the Local Authority. The Welsh Government has since decided that full responsibility and funding will be transferred to Local Authorities from 2018-19. The WILG will continue in its current format in 2017-18. During this time local authorities will meet with recipients to agree a package of support to meet their needs.

Delyth was inspired by campaigner Nathan Davies whose 'Save Our Independent Living Fund' campaign seeks to maintain the current arrangement, where the fund is ring-fenced. It is feared that that councils could use the funds to make up for financial shortfalls in other areas.

The National Assembly will be discussing this issue in October and Delyth urged the group to take part in the campaign by signing the petition.

Mark Isherwood noted that this is an issue being looked at by the Cross Party Group on Disability and suggested liaising with the members of that group. Mark also noted the wider context of the Independent Living Fund across the UK, suggesting that the disability sector in Wales was more in favour of the co-production models operating in Scotland and Northern Ireland and ring-fencing the funding. Further comments from the group included clarification

that the fund has been closed to new claimants for two years and that many younger people are disadvantaged as a result of this.

5 THE NATIONAL AUTISTIC SOCIETY CYMRU'S AUTISM HOUR

Samuel Stone from The National Autistic Society Cymru informed the group about the charity's Autism Hour, a campaign aimed at engaging local shops and businesses and encouraging them to be more accessible to autistic people. Sam said that The Autism Hour will take place on the 2nd October at 10am with shops encouraged to take part any time that week. It's hoped that once businesses realise how such small steps can make a big difference, they will look at adopting some of these changes permanently. The group discussed how this would be beneficial not only for autistic people but for the shops themselves. Members also raised concerns about the accessibility of other places, such as hospitals.

6 DISCUSSION ON THE AUTISM BILL CONSULTATION

Mark Isherwood updated the group on the progress of the proposed Autism Bill, introduced by Paul Davies AM, and informed the group that a public consultation on what should be included in the Bill began on August 30th. Meleri Thomas of The National Autistic Society Cymru presented an overview of the key themes that the consultation addresses, including diagnosis, service provision, training and costs, and encouraged people to participate in the consultation. The group raised a number of further ideas that it was felt the Bill should cover, including access to health care, lifelong learning and Welsh language provision. The consultation closes on 20th November.

8 ANY OTHER BUSINESS

The group were informed about a yoga-based autism group that is looking to start in the area.

7 ACTIONS / CAMAU GWEITHREDU

The group will liaise with the Cross Party Group on Disability to find out more about their work on changes to the Independent Living Fund.

The next meeting of the Cross Party Autism Group will be at the National Assembly for Wales on 6 December 2017 from 12:15pm-1:15pm with the exact location yet to be confirmed.

Minutes / Cofnodion
Cross Party Autism Group / Grŵp Trawsbleidiol Awtistiaeth
Rhagfyr 6 December 2017
Cynulliad Cenedlaethol Cymru / National Assembly for Wales

1 WELCOME / CROESO

CPAG Chair Mark Isherwood AM, welcomed everyone to the meeting, which was also attended by Dai Lloyd AM and Paul Davies AM.

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

The minutes were agreed to be an accurate account of the previous meeting, with one member seeking an update on the actions in relation to the work of the Cross Party Group on Disability on the Independent Living Fund.

3 UPDATE ON THE DEVELOPMENT OF THE AUTISM [WALES] BILL / DIWEDDARIAD AR DDATBLYGIAD Y BIL AWTISTIAETH [CYMRU]

Paul Davies AM thanked the group for their support during the recent consultation on the Autism [Wales] Bill, which received 90 responses. Paul will, over the coming months, develop a draft Bill for further consultation. He has until 13th July to introduce a Bill to the National Assembly for Wales. Paul said he has been engaging with Welsh Government to see if significant progress is being made as a result of their own reforms, and he hopes to meet soon with the new Cabinet Secretary, Vaughan Gething soon. The group asked Paul to consider data collection, diagnosis, access to services and professionals' training in the development of the Bill. It was also suggested that further online consultation could be effective.

4 'MISSING VOICES' PROJECT REPORT / ADRODDIAD PROSIECT 'LLEISIAU COLL' Mat Mathias, from the Electoral Reform Society Cymru, updated the group on its current project, 'Missing Voices', in which they hope to identify barriers that people face to engaging in politics, democracy and elections. The main themes emerging from the survey and focus groups were confusion, frustration and hope. Many people who took part in the consultation had ideas for how to improve engagement and to make politics more accessible. The report will be launched on 11th December.

5 PROGRESS UPDATE ON CARDIFF AND VALE OF GLAMORGAN INTEGRATED AUTISM SERVICE/ DIWEDDARIAD AR WASANAETH AWTISTIAETH INTEGREDIG CAERDYDD A'R FRO

Keith Ingram, service manager for the Integrated Autism Service in Cardiff and the Vale, gave an overview of what the service is able to offer and its future development plans. Keith said the service aims to enhance existing services rather than replace them. He also said that the service is working with existing services, such as mental health, to ensure autism expertise is provided when needed. Questions were asked around how people can access the service, for example, if they didn't have a diagnosis or if they had a co-occurring condition. Keith added that the nature of the service was prescribed in detail by Welsh Government, and although there was some local flexibility, the reporting procedures would be the same in every service across Wales, to avoid a 'postcode lottery'. It was noted that representation from the WLGA to provide an update on the services across Wales would be welcome.

6 ANY OTHER BUSINESS / UNRHYW FATER ARALL

Mark Isherwood AM noted that Vaughan Gething, the Cabinet Secretary for Health and Social Services has taken responsibility for autism policy. It was proposed and agreed to invite him to a future meeting to provide a progress update on implementation of the Welsh Government Strategic Action Plan and hear the views and concerns of the group.

7 ACTIONS / CAMAU GWEITHREDU

To write to the Cabinet Secretary for Health and Social Services, inviting him to a future meeting of the Cross Party Autism Group to provide a progress update on the Welsh Government Strategic Action Plan.

To write to the WLGA, inviting them to attend a future meeting of the Cross Party Autism Group to provide an update on the development of the integrated autism service across Wales.

Minutes / Cofnodion Cross Party Autism Group / Grŵp Trawsbleidiol Awtistiaeth Mawrth 14 March 2018 Cynulliad Cenedlaethol Cymru / National Assembly for Wales

1 WELCOME / CROESO

Group Chair, Mark Isherwood AM, welcomed everyone to the meeting, which was also attended by Dai Lloyd AM, Hefin David AM, Paul Davies AM, Lee Waters AM, Mandy Jones AM, David Rees AM and David Rowlands AM. Staff representing Mike Hedges AM also attended.

2 ANNUAL GENERAL MEETING / CYFARFOD CYFFREDINOL BLYNYDDOL

Mark Isherwood AM was re-elected Chair of the Cross Party Autism Group. Meleri Thomas, on behalf of the National Autistic Society Cymru, was re-elected to provide the Grop's secretariat. Hefin David AM, Dai Lloyd AM and Jayne Bryant AM remain Group Officers with Mike Hedges AM, David Rees AM and Mandy Jones AM all confirming their membership.

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

The minutes were agreed to be an accurate account of the previous meeting. Mark Isherwood AM raised the recent publication of a report on the progress of the Welsh Government's Autism Strategy and the Integrated Autism Service. It was agreed that the report would be circulated.

4 UPDATE ON THE DRAFT AUTISM [WALES] BILL / DIWEDDARIAD AR Y BIL AWTISTIAETH [CYMRU] DRAFFT

Paul thanked the group for the opportunity to update the group on his draft Autism Bill, which is currently out for consultation. The consultation ends on the 17th April 2018 and Paul urged all attendees to take part. Following the consultation, Paul will review the responses before finalising the draft Bill, which needs to be introduced by July 13th 2018. Paul also informed the group that in January he had met with Vaughan Gething AM, Cabinet Secretary for Health and Social Services, to discuss the Bill along with Welsh Government proposals to improve autism services in Wales. Paul is awaiting a further meeting with the Cabinet Secretary.

5 CARERS RIGHTS IN WALES / HAWLIAU GOFALWYR YNG NGHYMRU

Claire Morgan, director of Carers Wales, informed the group about their work across Wales promoting the rights of unpaid carers. Claire outlined the rights of carers under the Social Services and Well-Being Act, including their statutory right to a carer's assessment. Claire went on to provide a number of statistics illustrating the contribution of carers throughout Wales. Carers Wales are working on their 'Track the Act' campaign which aims to ensure that the Social Services and Well-Being Act is being implemented as intended, as well as their annual 'State of Caring' report. Claire also welcomed the recent Welsh Government announcement of a Ministerial Advisory Group on carers which she hopes will lead to a specific carers strategy and action plan.

Garry Loynes then gave a personal account of caring for his two autistic sons. Garry spoke about how 'life became a series of meetings and appointments' which put a huge strain on family life. In the case of Garry's sons, he said the system really began to fail after their school years, with a continuous fight to access support to help them gain employment or to live as independently as possible. Garry expressed his worries about who would fight for his sons when he was no longer able to. The support and understanding from other parents and carers has been invaluable and led Garry to set up a support group, Support Additional Needs Neath and District. Garry also recognised he was fortunate to have an advocate who has been a huge help in accessing support. Responding to comments from members Garry suggested that the challenges facing carers in recent years have got harder and not easier.

6 AART 2018 - AUTISM ART EXHIBITION

Raj Chand and Michael Charles informed the group about the upcoming event which aims to give autistic artists the opportunity to display their work at an exhibition to be held at the National Assembly for Wales. Raj spoke about how being an artist and designer who received an autism diagnosis in his 30s had inspired efforts to promote the skills and talents of autistic people instead of the 'limitations' and 'difficulties'. Raj said that these limitations are not inherent in autism and only reflect challenges and barriers imposed by others. The exhibition, running from the 9th-13th April, hopes to encourage people to think about the insight of the artists and how this influences their work. AART 2018 is being organised in association with the annual Welsh Autism Ball

7 TIM RHYS- QUIET HANDS

Playwright Tim Rhys informed the group about his latest play, Quiet Hands, following on from the success of his previous production, Touch Blue, Touch Yellow. Quiet Hands focuses on the issue of 'mate crime' where vulnerable people, including those with autism, are befriended by people seeking to take advantage of them. Tim said that this is an under-reported crime and he wanted to bring attention to the issue. Tim will be putting on a special production of Quiet Hands at the National Assembly later in the year. It was agreed that the group would be provided with further information as it becomes available.

8 ANY OTHER BUSINESS / UNRHYW FATER ARALL

It was noted that, following correspondence from the group, the Cabinet Secretary for Health and Social Services, Vaughan Gething AM, will be attending the next meeting. It was agreed that, ahead of this, the group will write to the Cabinet Secretary to raise some of the issues highlighted by the recent evaluation of the Welsh Government's Integrated Autism Service and Autistic Spectrum Disorder Strategic Action Plan. In particular, the letter should address its findings regarding co-production given the concern expressed by a parent/carer who spoke at the meeting that unless co-production and early intervention is prioritised, higher costs of more acute interventions will result.

Ryland Doyle, representing Mike Hedges AM as well as being a Swansea County Councillor, referred to the contribution of Garry Loynes and suggested that both he and Mike would be happy to support constituents facing similar challenges in the Swansea area.

9 ACTIONS / CAMAU GWEITHREDU

To circulate the recently published evaluation of the Welsh Government's Autism Strategy and the Integrated Autism Service.

To write to the Cabinet Secretary for Health and Social Services, raising some of the issues contained in the report ahead of his contribution to the Cross Party Autism Group in June. To circulate details of the Quiet Hands showing as they become available.

The next meeting of the Cross Party Autism Group is to be held on 20 June 2018 at the Pierhead building