

# Cross-Party Group Annual Report.

**28/06/2019**

## 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, Mandy Jones 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: 20/06/18

Attendees and Summary of issues discussed: Please see minutes attached

Meeting 2. Meeting date: 14/09/18

Attendees and Summary of issues discussed: Please see minutes attached

Meeting 3. Meeting date: 05/12/18

Attendees and Summary of issues discussed: Please see minutes attached

Meeting 4. Meeting date: 20/03/19

Attendees and Summary of issues discussed: Please see minutes attached

Meeting 5. Meeting date : 26/12/2019

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.]

Lisa Morgan / Gareth Tarrant - The Autism Directory

Joe Allen - Cymru TUC Wales

Andrew Misell - Alcohol Change UK Cymru

Hazel Lim - Chinese Autism Support Group

# Annual Financial Statement.

**28/06/19**

## Cross Party Group on Autism

**Chair: Mark Isherwood AM**

**Secretariat: Meleri Thomas National Autistic Society Cymru**

<b>Group's Expenses.</b> [met by NAS Cymru]		
20/06/18	Refreshments: Charlton House	£44.46
14/09/2018	Venue Hire/refreshments: Glyndwr University	£333.60
5/12/2018	Refreshments: Charlton House	£46.80
20/03/2019	Refreshments: Charlton House	£50.40
26/06/2019	Refreshments: Charlton House	£50.40
<b>Costs of all goods.</b>	No goods purchased.	£0.00
<b>Benefits received by the group or individual Members from outside bodies.</b>	No benefits received.	£0.00
<b>Any secretariat or other support.</b>	No financial support received.	£0.00
<b>Services provided to the Group such as hospitality.</b>		

<b>Date</b>	<b>Description and name of provider</b>	<b>Cost</b>
<b>Total cost</b>		<b>£525.66</b>

**Minutes / Cofnodion**  
**Cross Party Autism Group / Grŵp Trawsbleidiol Awtistiaeth**  
**June 20 Mehefin 2018**  
**National Assembly for Wales / Cynulliad Cenedlaethol Cymru**

**1 WELCOME / CROESO**

Group Chair, Mark Isherwood AM, welcomed everyone to the meeting, which was also attended by Bethan Sayed AM, Hefin David AM, Mike Hedges AM, Lee Waters AM and David Rees 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 UPDATE FROM THE CABINET SECRETARY FOR HEALTH AND SOCIAL SERVICES / DIWEDDARIAD GAN YSGRIFENNYDD Y CABINET DROS IECHYD A GWASANAETHAU CYMDEITHASOL.**

The Cabinet Secretary outlined the progress the Welsh Government has made in implementing its refreshed ASD Strategic Action Plan, which was published in 2016. Whilst recognising that there will be families who don't currently feel supported, he said that we have come some way since the first strategy was published in 2008.

The Cabinet Secretary provided an update on the development of the Integrated Autism Service, the Learning with Autism Programme, assessment waiting time targets and the Additional Learning Needs Act. Whilst not persuaded by calls for specific autism legislation, the Welsh Government will issue a Code of Practice to reinforce existing rights and entitlements of autistic people in Wales.

The Cabinet Secretary addressed a range of questions from members, including those in relation to:

- accessible transport and the number of companions required to ensure travel safety, especially within the rail network;
- a lack of communication and inconsistency in terms of the professionals attending key meetings;
- access to further education post 16 and flexibility of choice;
- the Welsh Independent Living Grant and inconsistencies in its distribution by LAs in Wales;
- better understanding of autism by professionals within the criminal justice system; and
- an innovative proposal for an alert device for use by members of the emergency services attending an incident involving autistic people (and, potentially, any other condition also), which would be produced by a social enterprise employing people with special educational needs.

The Cabinet Secretary asked the group to provide him and his officials with these concerns in writing so he could seek to address them, along with colleagues across Government, and monitor progress. The group agreed to write to his officials following the meeting to raise the issues discussed.

The All Wales Forum and Shared Lives Cymru also raised work being undertaken to better support those with autism or a learning disability who develop further health conditions, such as dementia, as they get older. The Cabinet Secretary suggested those involved with this project liaise with the relevant officials across government as it develops.

**4 ANY OTHER BUSINESS / UNRHYW FATER ARALL**

There was no further business raised.

**5 ACTIONS / CAMAU GWEITHREDU**

The group will write to the Cabinet Secretary's officials outlining the issues raised during the meeting.

The next meeting of the Cross Party Autism Group is to be held in North Wales in September. The next meeting in Cardiff will be 5 December 2018 at the Pierhead building

**Minutes / Cofnodion**  
**Cross Party Autism Group / Grŵp Trawsbleidiol Awtistiaeth**  
**September 14 Medi 2018**  
**Glyndŵr University / Prifysgol Glyndŵr**

**1 WELCOME / CROESO**

Group Chair, Mark Isherwood AM, welcomed everyone to the meeting. Apologies were noted from Mike Hedges AM and David Rees AM, Sharon Bateman from Creatasmile and Cllr Elin Walker Jones.

**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 UPDATE ON THE DEVELOPMENT OF THE NORTH WALES INTEGRATED AUTISM SERVICE / DIWEDDARIAD AR DDATBLYGIAD GWASANAETH INTEGREDIG AWTISTIAETH GOGLEDD CYMRU**

Mel Hough and Sioned Thomas provided details of how the North Wales Integrated Autism Service (IAS) was developed and information about ongoing recruitment and priorities. It was discussed that the IAS was not replacing existing services and that a key area of work will be ensuring that existing services are upskilled to help them recognise and support the needs of autistic people.

Questions were asked by attendees seeking a detailed understanding of what the role of the service would be in terms of providing direct support to individuals. Attendees were informed that following a referral, support could be provided in the form of information and advice and, in some instances, direct support. Attendees also emphasised that failure by those providing public services for autistic people to first give careful consideration to the communication environment and the autistic person's communication needs can cause confusion for the autistic person and escalate their anxiety.

**4 'A VISION OF EXERCISE', ANDREW EDWARDS, AUTHOR / AWDUR**

Andrew provided an overview of his personal experiences, as an autistic person, detailing the positive impact of exercise on his mental health and in reducing stress. Andrew noted that his exercise routine had brought structure and discipline. Andrew also suggested that there was little helpful information available about maintaining a healthy diet and eating but was grateful to find a fantastic support in his new personal trainer, Geraint Llyr Roberts. Andrews's experiences inform his newest book, 'A Vision of Exercise'.

**5 DEPARTMENT FOR WORK AND PENSIONS COMMUNITY PARTNER UPDATE / DIWEDDARIAD PARTNER CYMUNEDOL YR ADRAN GWAITH A PHENSIYNAU**

Sandra Morgan led a presentation on the work that the Department for Work and Pensions are currently undertaking through their Community Partners. Sandra works across 19 Job Centres providing advice and training to job coaches, enabling them to better support

autistic people into work. Feedback from attendees included suggestions that work is needed around the physical environment of Job Centres to ensure they are autism-friendly. The current structures of community partners in Wales are funded for 2018/19. The group agreed to write to the Minister responsible for this scheme in the UK Government recognising the positive work of Community Partners in supporting autistic people into work and calling for these roles to be extended beyond 2018/19.

## **6 A PERSONAL STORY OF AUTISM AND GETTING OLDER / STORI BERSONOL AM AWTISTIAETH AC HENEIDDIO, GWEN WILLIAMS**

Gwen Williams discussed the experiences of her cousin, who is aged 73 and autistic. After being in a hospital for 45 years, Gwen's cousin is now living in the community. Gwen spoke about a number of challenges that her cousin has faced in accessing the right support. Gwen successfully applied to be a legal deputy, allowing her to advocate for her cousin and make a positive impact on her quality of life.

## **7 NATIONAL ASSEMBLY FOR WALES OUTREACH TEAM / AUTISM BILL**

### **TÎM ALLGYMORTH CYNULLIAD CENEDLAETHOL CYMRU / BIL AWTISTIAETH**

The Outreach Team spoke about the work they do to inform people across Wales about the work of the National Assembly. The Assembly's Health, Social Care and Sport Committee are currently working on scrutiny of the proposed Autism (Wales) Bill and wanted to make attendees aware of the opportunity to have their say. The team will present the views that they gather throughout the consultation period to the Committee to support their scrutiny.

## **8 ANY OTHER BUSINESS / UNRHYW FATER ARALL**

Angie Atherton provided information about the North Wales Autism Conference which will be held on 19 October at Glyndŵr University.

## **9 ACTIONS / CAMAU GWEITHREDU**

The group will write to the relevant UK Government Minister, recognising the positive work of Department for Work and Pensions community partners in supporting autistic people into work and to call for these roles will to be extended beyond 2018/19.

The next meeting of the Cross Party Autism Group will be in Cardiff, on 5 December 2018, at the Pierhead building.

**Minutes / Cofnodion**  
**Cross Party Autism Group / Grŵp Trawsbleidiol Awtistiaeth**  
**December 5 Rhagfyr 2018**  
**National Assembly for Wales / Cynulliad Cenedlaethol Cymru**

## **1 WELCOME / CROESO**

Group Chair, Mark Isherwood AM, welcomed everyone to the meeting, which was also attended by David Rees AM and staff representing Mike Hedges 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. Chair, Mark Isherwood AM, provided a brief update on the Autism (Wales) Bill, on which a number of Assembly Committees will report by 7th December. Mark added that there will be a debate

in the Senedd on January 16th 2019 on whether the Bill should carry on to the next stage of scrutiny and called on people who want the Bill to go forward to contact their own five AMs and urge them to vote for this, explaining why it is important to their constituents.

Mark also informed the group that the Welsh Government has launched a consultation on a new Code of Practice on the Delivery of Autism Services which closes on March 1<sup>st</sup> 2019.

### **3 THIRD-SECTOR SPECIALISED AUTISM PROVISION THROUGH AUTISM SPECTRUM CONNECTIONS CYMRU / DARPARIAETH AWTISTIAETH ARBENNIGOL Y TRYDYDD SECTOR GAN AUTISM SPECTRUM CONNECTIONS CYMRU.**

Aled Thomas discussed the provision of services for autistic adults at the One Stop Shop in Cardiff. This service has provided support with benefits, employment as well a range of other specialised services for autistic people. Aled raised concerns that, due to a lack of funding, services are being reduced at the One Stop Shop. He also suggested that despite the development of the local integrated autism services, which provides some much needed support, the loss of services provided by the One Stop Shop could be detrimental to those such as himself who have significantly benefited from them. Aled discussed his ongoing campaign to help maintain the One Stop Shop provision, including submitting a petition to the National Assembly Petitions Committee. It was agreed to write to Autism Spectrum Connection Cymru, who run this service, for an update on the issues raised.

### **4 UPDATE FROM THE AUTISM DIRECTORY / DIWEDDARIAD GAN THE AUTISM DIRECTORY**

Gareth Tarrant and Lisa Morgan discussed the work currently undertaken by the Autism Directory, which includes a helpline service, employment and benefits advice and support, and training. These services are self-funded. They employ a team which is made up of 60% autistic staff, and these staff take a strategic lead in planning and informing the charity's work.

### **5 THREATS & BARRIERS TO THE AUTISTIC COMMUNITY / Y RHWYSTRAU A'R BYGYTHIADAU SY'N WYNEBU'R GYMDEITHAS AWTISTIAETH**

Sara Jane Harvey (Agony Autie) is an autistic vlogger and advocate. Her platforms reached 8 million people last month and she uses these channels to discuss her experiences as well as a wide range of issues, particularly those that have a significant impact on the lives of autistic people. Discussing the particular issue of threats and barriers to the autistic community, Sara spoke from her own experiences of co-occurring conditions, stigma and applying for PIP. Sara said that many autistic people are written off because of perceptions around their behaviour and the instinct of others to teach compliance rather than to understand what is being communicated. Sara believes that a revolution in attitudes is needed to ensure that autistic experiences are better understood.

### **6 ANY OTHER BUSINESS / UNRHYW FATER ARALL**



Correspondence from Sarah Newton MP, Minister of State for Disabled People, Health and Work, confirmed that Community Partner roles within the Department for Work and Pensions, providing employment and benefit related support to autistic people, will cease in April 2019. The group had initially written to the UK Government to support the continuation of these roles and following a further update from Rhian Lloyd-Protheroe on the positive outcomes these roles continue to have, it was agreed that the group would write again to the Minister to outline our disappointment at this decision and request a meeting to discuss this issue further.

An attendee raised a particular concern around her daughter struggling to access education since moving to Cardiff and a further issue was raised around the loss of motability vehicles in the Caerphilly area, particularly disadvantaging those who are accessing provision which requires them to travel to a particular service. It was suggested that these concerns be initially raised with local Councillors and Assembly Members to try to find solutions in the first instance. A further question was asked about the impact the Brexit may have on third sector funding and if sufficient work had been undertaken to plan for different outcomes. Mark Isherwood AM noted significant work undertaken UK wide but, in particular, the work done by the Assembly's External Affairs and Legislation Committee.

### **7 ACTIONS / CAMAU GWEITHREDU**

Write to ASC Cymru to ask for information on their current capacity to provide much-valued support through the One Stop Shop service.

Write to Sarah Newton MP to express disappointment at the decision to cease the Community Partner roles and request a meeting to discuss issue further.

The next meeting of the Cross Party Autism Group is to be held in Cardiff in March 2019.

**Minutes / Cofnodion  
Cross Party Autism Group / Grŵp Trawsbleidiol Awtistiaeth  
Mawrth 20 March 2019  
National Assembly for Wales / Cynulliad Cenedlaethol Cymru**

### **1 WELCOME / CROESO**

Group Chair, Mark Isherwood AM, welcomed everyone to the meeting, which was also attended by Group Officer Hefin David AM and staff representing Mike Hedges AM and Lee Waters 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. Chair, Mark Isherwood AM, provided a brief update on the Autism (Wales) Bill, which was rejected by the National Assembly in January 2019, and subsequent commitments made by the Welsh Government to improve autism services in Wales.

Mark also informed the group that the Welsh Government are currently consulting on the draft Additional Learning Needs Code for Wales, which closes on 22<sup>nd</sup> March 2019.

Hefin David AM declared a personal interest.

### **3 NATIONAL AUTISM TEAM UPDATE AND FUTURE PLANNING / DIWEDDARIAD TŪM CENEDLAETHOL AWTISTIAETH A CHYNLLUNIO I'R DYFODOL**

Sara Harvey, National Strategic Lead of the National Autism Team, and Wendy Thomas, National Professional Lead, provided an update on their four areas of work:

- Autism Awareness and Understanding,
- Resources,
- Training; and
- Development of the IAS.

They informed the group that the Welsh Local Government Association had recently completed the Autism Team's employer accreditation scheme. They are planning to launch a parent and carer film and host a national conference during World Autism Awareness Week. They hope to also launch an emergency services scheme and a work-based learning programme. The Autism Team's future plans include a participation and engagement strategy, supporting development of the Code of Practice on the Delivery of Autism Services and update and roll out key resources in a strategic way.

Questions around the availability of post-diagnostic resources were raised by Hefin David AM and other attendees. Wendy Thomas committed to feed this back to responsible teams. Attendees also urged that autistic people were included in the development of services and support as some concerns were raised that in some instances, the service and support provided by the IAS were not clearly identified or accessible. The Autism Team agreed and said that this will form part of their participation and engagement strategy. It was also suggested that the National Autism Team should develop further training for Job Centres to better support autistic people, especially following confirmation that the roles of DWP Community Support Partners will not continue.

### **4 ACCESSIBILITY UPDATE FROM TRANSPORT FOR WALES RAIL / DIWEDDARIAD HYGIRCHEDD GAN DRAFNIDIAETH CYMRU**

Barry Lloyd and Sarah Rennie, from Transport for Wales Rail discussed their ongoing development of plans which aim to make the railway accessible to everyone, seven days a week. Barry and Sarah outlined the work that their accessibility panel are doing, such as station visits and developing training. They also announced that the accessibility panel will have a budget to make improvements as issues arise, so that they can be dealt with quickly. Other initiatives that Transport for Wales Rail are developing include the Orange Wallet Scheme, mystery shopping and familiarisation trips.

Questions were raised in relation to the regulatory body to which TfW Rail are accountable. The Office of Rail and Road set policy in this area. Improving punctuality was suggested as key to improving the experience of autistic people on trains, and public transport more widely. Barry Lloyd said that wider planned improvements to the network will make services more efficient and reliable. It was also asked if TfW Rail contractors, such as revenue protection inspectors, would be subject to the same training as those directly employed. It was confirmed that this would be the case.

## **5 ANY OTHER BUSINESS / UNRHYW FATER ARALL**

Lisa Morgan, from The Autism Directory informed the group of their upcoming conference, focussing on employment and helping organisations to understand how to become disability-confident employers.

Ian Cutler wanted to share information with the group about the support and campaign group, Autism Injustice, which seeks to ensure criminal justice and care professionals are aware of and follow existing guidelines and policy relating to autistic people in a way that properly safeguards them. It was agreed that details of this group would be circulated with these minutes. As community safety is devolved, it was suggested that Mark Isherwood AM may consider raising questions on this issue with the responsible Welsh Government Minister.

Mark Isherwood AM informed attendees of the Going Gold for Autistic Acceptance event, organised by Autistic UK and the Autistic Women's Empowerment Project, which is taking place in the National Assembly for Wales on April 2<sup>nd</sup>.

## **6 ACTIONS / CAMAU GWEITHREDU**

To share details of the Autism Injustice campaign with the Cross Party Autism Group mailing list.

The next meeting of the Cross Party Autism Group is to be held in Cardiff in 26 June 2019.

**Minutes / Cofnodion**  
**Cross Party Autism Group / Grŵp Trawsbleidiol Awtistiaeth**  
**Mehefin 26 June 2019**  
**National Assembly for Wales / Cynulliad Cenedlaethol Cymru**

## **1 WELCOME / CROESO**

Group Chair, Mark Isherwood AM, welcomed everyone to the last meeting of the current Assembly term, which was also attended by Group Officer Hefin David AM. Apologies were received from Llyr Gruffydd AM, Helen Mary Jones AM and Adam Price 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 AUTISM AWARENESS IN THE WORKPLACE / YMWYBYDDIAETH O AWTISTIAETH YN Y GWEITHLE**

Joe Allen discussed the Wales Trades Union Congress' 'Autism Awareness in the Workplace' guide to attendees. The guide, which was requested by trades union (TU) reps, has three main aims: to educate TU reps to help them better support autistic colleagues; to provide general information on some of the relevant legal aspects of employment; and to provide practical guidance to employers so they can better support autistic staff.

The guide includes examples of where a good understanding of autism from employers and colleagues have had positive outcomes for autistic employees. It also explores the impact that a lack of understanding can have on the employment prospects of carers.

The Wales TUC aim to promote this document further and provide training to TU reps. Sara Harvey of the National Autism Team offered to host the guide on the ASDinfoWales website. Joe welcomes comments or suggestions on how the guide could be improved, with one attendee seeking assurances that the guide was inclusive of wider neurodevelopmental conditions.

#### **4 ALCOHOL USE AND AUTISM / DEFNYDD O ALCOHOL AC AWTISTIAETH**

Andrew Misell, of Alcohol Change UK Cymru, and Mark Brosnan, of Bath University discussed their ongoing work exploring the links between alcohol use and autism, with a particular focus on ensuring that services supporting dependent drinkers are autism-friendly. Some studies have suggested that autistic people are at a higher risk of alcohol harm. Research also indicates that autistic people have negative experiences of accessing support in this area due to a lack of awareness and understanding of autism. Andrew and Mark summarised that reasonable adaptations to how support is provided to autistic people can lead to much better outcomes. Their aim is to now focus on working with alcohol support services to share their knowledge and provide training.

This programme of work will be discussed in more detail at the upcoming Alcohol Change UK Cymru conference in Wrexham in September.

Some attendees discussed personal experiences and suggested that this issue may be exacerbated if autistic adults have not received a diagnosis. Mark Isherwood AM raised the Drink Wise Age Well campaign. While this campaign is focussed primarily at tackling increasing alcohol consumption by older people, some possible causes for this rise, such as social isolation and anxiety, may also relate to autistic people.

#### **5 AUTISM AND THE CHINESE MINORITY / AWTISTIAETH A'R LLEIAFRIF TSIEINIAIDD**

Hazel Lim, of the Chinese Autism Support Group, began by sharing her personal experiences as a parent of an autistic child seeking help from the Chinese community. Hazel told of the stigma attached to autism within the Chinese community, and shared an account of being told to leave the room after asking a Chinese group if any of their children were autistic.

Hazel suggested that culture is particularly difficult to change and that, some instances, negative value is ingrained even within language itself – autism can be interpreted to literally translate as 'self-closed disease'. This makes the perceived taboo difficult to overcome.

Hazel had secured funding to produce a fully bilingual Chinese-English autism guide. She hopes to increase awareness of this issue and improve understanding of autism in the Chinese community.

#### **6 ANY OTHER BUSINESS / UNRHYW FATER ARALL**

Mark Isherwood AM informed the group of open Welsh Government consultations on NHS continuing healthcare guidance and continuing care for Children or Young People. The annual review of the Welsh Government's autism strategy is also expected in June.

Sara Harvey informed the group that the National Autism Team will also be publishing a report this week and asked for it to be circulated.

An attendee raised concerns over the guidance exam boards provide to exam invigilators in relation to providing support to autistic pupils. Sara Harvey said that the National Autism Team will look into this and take it forward.

Denise Inger of Snap Cymru raised the issue of how changes to the additional learning needs system could impact upon early recognition and diagnosis of autism.

The next meeting of the Cross Party Autism Group is in Prestatyn on 18<sup>th</sup> October 2019.