

Learning Disability Ministerial Advisory Group



Notes from our 4th meeting on 4 December 2019



People who came to the meeting

- **Sophie Hinksman** – Co-chair
- **Humie Webbe** – Co-chair
- **Louise Barry** - All Wales Adult Service Heads
- **Adrian Burke** – Community Housing Cymru
- **Rebecca Cicero** - Social Care Wales
- **Wayne Crocker** – Mencap Cymru
- **Lynne Evans** – All Wales People First
- **Christine Griffiths** - Welsh Therapies Advisory Committee
- **Julian Hallett** – Down’s Syndrome Association
- **Edwin Jones** – Challenging Behaviour Community of Practice
- **Rachel Jones** – Improvement Cymru
- **Emma Mulinder** – All Wales Adult Service Heads
- **Ruth Northway** – University of South Glamorgan
- **Jason O’Brien** - All Wales Heads of Children’s Services
- **Hazel Powell** – Swansea Bay UHB
- **Joe Powell** – All Wales People First

- **Zoe Richards** – Learning Disability Wales
- **Hayley Tarrant** – Welsh Nursing and Midwifery Committee
- **Lance Watkins** - Royal College of Psychiatrists
- **Michelle Williams** – All Wales People First
- **Pauline Young** - All Wales Forum of Parents & Carers

Others:

- **Tracey Drew** – supporting Sophie
- **Delyth Lloyd-Williams** - supporting Michelle
- **Dawn Price** – supporting Lynne
- **Emma Curtis** – Children’s Commissioners office
- **Edward Oloidi** – Edward came with Ruth Northway
- **Sam Dredge & Sinead Brophy** – National Centre for Population Health Data Science. They came to talk about **Mortality rates and people with a learning disability**

Officials:

- **Liz Davies** - Mental Health and Learning Disability
- **Andrew Stevenson** – Learning Disability Improving Lives Team
- **Natalie Hughes-Owen** – Learning Disability Improving Lives
- **Alyson Collins** – Social Services and Integration



People who could not come

- Dermot McChrystal
- Michelle Martin
- Oliver Townsend
- Jane Rodgers
- Sharon Williams
- Sue Beacock
- Karen Eveleigh

1. Welcome and introduction



Sophie welcomed everyone. Lots of new people were at the meeting. So we introduced ourselves again.



We spoke about who could not make the meeting. Karen could not come because her mum was unwell. Andrew covered for her.



It was Chris Griffiths' last meeting. Her place will now be taken by Jo Griffin. Sophie thanked Chris for all her work.



Sophie read out the rules for our meetings. And asked everyone to listen to and respect each other.

2. Our new co-chair



Sophie introduced our new co-chair – Humie Webbe. Humie told us about herself.



We are pleased that Humie is our new co-chair. We are looking forward to working with her.

3. What happened at the last meeting

Restrictive practices



Oliver has written a paper about **Positive Behaviour Support** and **Adverse Childhood Experiences**.



We need to do a bit more work on this. Karen and Andrew will talk to Oliver.



Action

Karen, Edwin and **Oliver** to think about Oliver's paper when finished. **Natalie** will talk to **Oliver** and organise a sub-group meeting.



Social care stories

Rebecca and Emma Mulinder have collected good news stories. Please send them more if you have them.



Action

Send **Rebecca** good news stories.

Health actions



Karen would like some help from us on the work to deliver the health actions. Especially the actions about:

- specialised services
- education and training
- **reasonable adjustments**
- making primary care stronger
- getting more people to have Annual Health Checks



We will keep up to date with all the work on this. And have our say on what is happening.



Zoe will write a letter about the annual health checks to send to the Minister. **Natalie** will send this out to us all first.



Cwm Taf and barriers to health

RCT people First will let us know what they learn. They will send us their report.



Action

Alyson to send the report out to all of **us (Sent 12 December 2019)**.



Self-advocacy

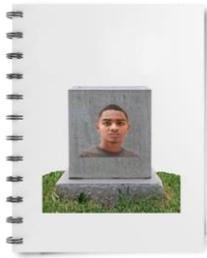
All Wales People First have sent out a consultation to their members about [self-advocacy](#). When this is finished they will meet with Welsh Government to talk about it.



Action

Joe will tell us about the consultation and meeting with **Welsh Government**.

4. Presentation about mortality rates and people with a learning disability



Mortality rate means the number of people with a learning disability that die.



Sam Dredge and Sinead Brophy came to talk to us about this.



Sinead said they had looked into the difference annual health checks can make.

They found out that:



- People who have had an annual health check live around 6 years longer



- Health checks make the biggest difference to people with autism and people with epilepsy.



- Health checks make the biggest difference when people start going from a young age.



- Health checks help to find health conditions. Including serious health conditions.



Health checks are really important. That is why Sinead said it is very worrying that only 3 out of 10 people get a health check. And only 1 out of 10 people get them every year.



We talked about things that might stop people getting a health check, like:

- The words used by GPs
- Not knowing someone has a learning disability
- Lack of easy read information about annual health checks
- The support available for health checks
- People may have bad experiences of annual health checks.



Zoe told us that Learning Disability Wales with Improvement Cymru are writing an information pack about annual health checks. This will be sent to all GPs in Wales.



Actions

Sam will give us their report on mortality rates and people with a learning disability. **Natalie** will contact Sam to check when the report will be ready.



If you have any questions about this send them to **Alyson**. Alyson will pass them on to Sam and Sinead.

5.Reducing restrictive practices



Edwin had planned a presentation on this. But we ran out of time. So he told us about the reducing **restrictive practices** frameworks' 4 headings:



1. Human rights
2. **Positive Behaviour Support**
3. Reducing the use of **restrictive practises**
4. How to use **restrictive practices** properly



Edwin said the framework is excellent. And said it was important for us all to take part in the consultation. You must do this by 7 January 2020.



We agreed that we should support the framework. And that we should send a response as a group to support it.



Actions

Edwin will write a response for us. He will send it to **Sophie** and **Humie** for them to check over. Please send **Edwin** your comments on this by week starting **30 December**.

6. Research and Development update



Ruth reminded us about the work being done to find research on learning disabilities.



They found 62 studies. Most were about health and social care. Karen has the report on this work.



Actions

Alyson will send us the report on this work with the minutes from our meeting.



Alyson will organise another meeting for the **research and development sub-group**.

7. Learning Disability Improving Lives Programme



Andrew explained what work had been done on the 28 actions:



Action 1. Oliver wrote a paper about [Positive Behaviour Support](#) and [Adverse Childhood Experiences](#)



Action 2. The report called: 'Research on the number of children in Wales placed into care from parents with a learning disability and the reasons behind their removal' will be ready on 17 December.



At first Wayne was unhappy that we were not involved. Because he thought we had organised this research.



But the research was actually organised by the **Looked After Children Ministerial Advisory Group.**



The First Minister will start work on this by talking to parents with a learning disability. Karen has spoken to **Learning Disability Wales** and **All Wales People First** about this. Karen will update us on this in March.



Action

Alyson will send us all a copy of the report called: 'Research on the number of children in Wales placed into care from parents with a learning disability and the reasons behind their removal'. (This was done on 17 December).



Action 3b. The childcare offer. The childcare offer is now available all over Wales. But in the 1st year not many people used it. There have already been more people using it this year though.



Actions 5,6,7 and 9. Integrated Care Fund and Housing. People working in housing are very pleased with how this is going.



Action 8. People working in housing have said doing research on homelessness is hard. There is not much information. There will be a meeting to talk about what to do next. Wayne asked about which homelessness organisations were involved.



Action

Andrew will ask staff working in housing which homelessness organisations they are working with.



Action 13. Improvement Cymru is looking at different ways of doing annual health checks. Karen is going to meet with Improvement Cymru to talk about this.

Wayne said we should be involved. Improvement Cymru have said they will make sure us and other groups are fully involved.



Action 14. Andrew said NHS staff who work with people **must** have learning disability training.



Action 17. This action has been given green status even though the Additional Learning Needs (ALN) Bill has been set back by over a year. This is because the work done on this action will finish at the same time as work on the Improving Lives Programme. Andrew will check up on this.



Action 20. Employment and skills. Zoe asked why the Engage to Change project had not been mentioned. Zoe is very happy to tell us all about the project at 1 of our meetings. Andrew will ask Welsh Government staff about this on 10 December.



Action

Zoe will send **Andrew** information about **Engage to Change**. We will think about putting this on the agenda at a future meeting.



Action 22. We are not happy that work has not been done on this action so far. This is the only action with red status.

Andrew has written to the main people involved and work will start soon. Pauline said **All Wales People First** and **All Wales Forum of Parents and Carers** would be happy to be involved again.



Action 24. Work was slow on this action at first. But now a good amount has been done.

There will be a consultation and a new **Wales Transport Strategy** in 2020. People working in Transport have said they will come and tell us about this work.



Action

We would like to hear about the **Public Transport Policy** and people with a learning disability. **Alyson** will organise this.

8. Important things to know about



There has been a check on placements for adults with a learning disability in England and Wales.



The report on this will be finished and sent out by 10 February 2020.



Action

Alyson will send the report out to us when it is ready.



In a written statement on 6 November 2019 the **Deputy Minister** said that all NHS staff that deal with people **must** have learning disability training.



The training will be written into the **equality and diversity training** from the new **Education and Training Framework**.



The **Education and Training Framework** is being written by the **University of South Wales**.



The **Education and Training Framework** should start to be used from **spring 2020**. There is a lot of work to do on it and this will be hard. But Ministers are very keen to make sure it happens.



We wondered what the training would be like. And also who would be involved in writing the training.



Wayne said we should be fully involved in this. We all agreed.



Update: The **University of South Wales** will make sure learning disability groups will have a say. We may not be able to be involved because of timing but we should all get the chance to have a say through our organisations.



We hope that we or our sub-group will be able to comment on the training before they are finished.

9. Rules for our meetings



Our group has been meeting for a year now. So Andrew said this was a good time to check over our rules.

Terms of reference



You were sent ideas for changes to our [terms of reference](#) before the meeting. The changes were mainly about people's job titles.



- At the beginning we were worried that people were not coming to us for advice on important things.



- We talked about the role our group. And what exactly **providing strategic leadership** means. Some people thought that this explained what we do well. But others did not agree.



- We thought there should be sub-groups to help work on certain things.



- Humie said that we need to make sure we are noticed more.



- Zoe asked how our agendas were planned. Andrew said we agree on some agenda items in meetings. Other agenda items were organised by Karen and our co-chairs. But all members are able to suggest things for the agenda.



Rules and accessibility

Andrew said that rules were being written to help us make sure all our meetings and information were accessible. These are just suggestions. We are still looking into what we could do to make things easier. We were asked about our ideas for this.



Joe said he had a meeting with the **Learning Disability Improving Lives team** to talk about how to make our meetings **accessible**. They suggested that:



- When possible all written information should be in easy read. Including the agenda, action log and minutes.



- We should give guidance to people who come to speak at our meetings about **accessibility**.



- We should think about the way we arrange the tables and chairs to make sure they are **accessible**.



- Written information should be given out on the dates they are timetabled to.



We agreed on the new [terms of reference](#) and rules. We will keep checking on the rules to make sure they are working. We will look at everything again in December 2020.



Actions

Write easy read agendas, actions logs and minutes. Also other documents like our terms of reference and rules.



Write guidelines for speakers. To help with this **Zoe** offered to share the guidelines **that Learning Disability Wales** have written.



Change the way we organise our chairs and tables to cabaret style.



If you want to suggest an item for the agenda please tell **Karen** at least 1 month before the meeting.



There is a new LDMAG page on the Welsh Government website:
<https://gov.wales/learning-disability-ministerial-advisory-group>. It needs more work. We need to put minutes and agendas on this page.

10. Checking our membership



We will check the membership of this group every 12 months in December.



Members are mostly happy that we have the right people in the group to work on the **Learning Disability Improving Lives Programme**. We can also bring in different people as and when we need.

6. Any Other Business



Edwin told us about the guide called **Support for Living**. It was written by the **National Commissioning Board** with help from the **WLGA**, **Cymorth Cymru** and **Learning Disability Wales**.



This guide helps people who are responsible for supporting people with a learning disability get the best support.



But it is not being used much. Oliver from **Cymorth Cymru** and **Learning Disability Wales** has written a plan about how the guide could be promoted and used. They will need money to do this. We supported the idea.



Actions

Alyson will send us the plan written by Oliver.



Andrew will talk with **Edwin**, **Oliver** and **Zoe** to find out when they would be ready to talk about their plan.



Andrew will send Oliver's plan to policy staff in Housing and Social Care. He will talk to them about how to make this plan happen.

7. Future meetings



The next meeting will be on **Wednesday 25 March 2020**.

The Deputy Minister is coming to this meeting.



In 2020 the meetings will be on:

- Tuesday 9 June
- Tuesday 8 September
- Tuesday 8 December



All the meetings in 2020 will be at the Welsh Government Offices, Cathays Park, Cardiff.

The meetings will start at 11am until 3pm.

Hard words

Accessibility

Accessibility means making sure somewhere or something is easy for disabled people to use.

Adverse childhood experiences

Adverse Childhood Experiences means bad things that happen when you are young. For example, if your parents take drugs or if you are abused.

Mortality rate

Mortality rate means the number of people with a learning disability that die.

Positive behaviour support

Positive Behavioural Support is about understanding why a person behaves in a challenging way. And trying to sort out the problem.

Reasonable adjustments

Reasonable adjustments are changes that places and services can make to make sure everyone is able to use them. For example putting ramps in buildings for wheelchair users. Or giving information in easy read.

Restrictive practices

Restrictive practices are when people try to control your behaviour by stopping you from doing things. It can be things like holding you down. Or putting you in a room alone.

Self-advocacy

Self-advocacy is when you are supported to speak up for yourself.