Easy Read

Learning Disability Ministerial Advisory Group

Notes from our second meeting on 4 June 2019

People who came to the meeting

- Sophie Hinksman – Co-chair
- Adrian Burke – Community Housing Cymru
- 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
- Dermot McChrystal – Association of Directors of Education
- Michelle Martin – Care Forum Wales
- Ruth Northway – University of South Glamorgan
- Joe Powell – All Wales People First
- Zoe Richards – Learning Disability Wales
- Jane Rodgers – All Wales Heads of Children's Services

- Hayley Tarrant – Welsh Nursing and Midwifery Committee
- Oliver Townsend – Cymorth Cymru
- Michelle Williams – All Wales People First
- Sharon Williams – Public Health Wales
- Pauline Young – All Wales Forum of Parents & Carers

Others:

- Tracey Drew – supporting Sophie
- Celia Lewis – supporting Michelle
- Dawn Price – supporting Lynne
- Louise Barry – attending for Suzanne Clifton
- Emma Curtis – Children's Commissioners office
- Julie Heal – attending with Jane Rodgers
- Emma McDonald – attending for Emma Mulinder
- Professor Meena Upadhyahya – Cardiff University
- Edward Oloidi – attending with Ruth Northway
- Wendy Parry – attending with Jane Rodgers

Officials:

- Hazel Powell – Office of the Chief Nursing
- Karen Eveleigh – Learning Disability Improving Lives
- Natalie Hughes-Owens – Learning Disability Improving Lives
- Alyson Collins – Social Services and Integration

People who came to talk about things on the programme:

- Dan Jones – Housing Directorate
- Jon Williams – Health Directorate

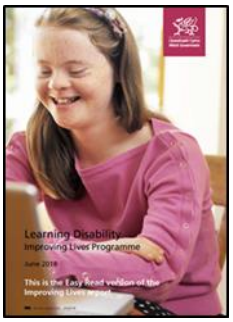
People who could not come

- Raghu Baburaj
- Rebecca Cicero
- Suzanne Clifton
- Emma Mulinder
- Jason O'Brien

1. Welcome and introduction

Karen said she would help Sophie to lead the meeting. Professor Meena Upadhyaya might help in the future.

Sophie welcomed everyone. She asked people to say their names and who they worked for.



Karen said Claire Hough has moved job. Claire helped make the Improving Lives Programme happen. We thanked Claire for all her hard work.

Karen said Natalie Hughes-Owen had joined the Improving Lives team. They will hire someone to take over Claire's job.

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

She also spoke about the **Learning Disability Programme Group's** rules. She asked if we would like to use these rules too.

Action

Alyson will send you the **Learning Disability Programme Group's** rules and ask what you think.

2. What happened at the last meeting

Lots of members want time in our meetings to talk about things that are not on the agenda. So if something important happens we can talk about it.

For example the Panorama TV programme about hospital abuse. We will call this part of the meeting **Any Other Business**.

Members would also like to know about events. They would like to get this information in a newsletter or an e-mail.

Action

We agreed to talk about the Panorama programme at the end of the meeting.

3. Improving Lives Programme

Before the meeting you were sent a report about the **Improving Lives programme**. This was the second report about the programme.

Karen spoke about the main things in the report including:

Making health fair for everyone

Health boards are getting more money to make their learning disability teams better. And to make their **hospital liaison nurses** better.

Adverse Childhood Experiences Hub

Adverse Childhood Experiences means bad things that happen when you are young. For example, if your parents take drugs or if you are abused. We usually call them **ACEs** for short.

The **ACE Hub** had a meeting with the **Improving Lives** team. They talked about how the **ACE Hub** can help with **Improving Lives** work.

We talked about the **Believe in Every Child** event that happened in March.

And about how people who work in schools should learn how to deal with problems without using **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.

Karen said that the **Task and Finish group** on restrictive practices had planned a meeting for July 15th.

Actions

You can tell your ideas for lowering restrictive practices to Dermot McChrystal. He will share ideas with the **Association of Directors of Education**.

Karen will add talking about what **Improving Lives** says about health to the agenda for our next meeting.

Dan Jones told us about the **Integrated Care Fund Capital Programme**. This programme gives money to:

- social services projects
- health projects
- housing projects.

Dan said more people now know how important good housing is for people's health and well-being.

The programme is giving away £105 million over the next 3 years. Most of this money will go to:

- people with a learning disability
- carers
- older people
- children who need extra support.

Regional Partnership Boards will apply for this money. They can use information from their **population assessments** to help them decide how to use the money.

We talked about:

- how this money is being spent
- new housing for people with learning disabilities
- and who is in charge of making sure the projects are running properly.

Actions

- **Alyson** will send us links to the **population assessments** so we can read them.

- **Alyson** will also ask people from the **Integrated Care Fund Capital Programme** to come to our meeting in September.

  We will ask them to give a presentation. And we will have the chance to talk about any issues.

4. Transition services

The Welsh Government wrote a paper about their policies to help young people transition to adult services. This paper was sent to us before the meeting.

Transition means changing from being a child to an adult. It means changing from children's social services to adult social services.

Jon Williams talked about a new piece of work to help young people transition to adult health services.

This work should make sure that children and young people get the right health services at the right time.

The first meeting for this will be on June 17.

Jon said they would stop using the word **transition**. Because it is often used to talk about people changing their gender. It could be confusing. Instead, they would use the word **handover**.

Most members were not happy with the word **handover**. Because it sounds like the young person's choices are being handed over to professionals.

They thought that people understood that transition meant the journey from childhood to adulthood.

Jane Rodgers, Julie Heal and Wendy Parry spoke about how transition happens in Monmouthshire. They talked about what worked well and what did not.

They said that transition was a hard and scary time for families. Some families were afraid of things like:

- Losing support

- Having to start new relationships with new support workers

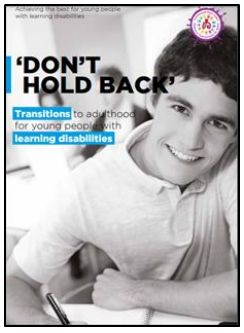
- Realising that their child is becoming an adult. And that the law is different for adults.

- Realising that the way of deciding who gets **Continuing Health Care** is very different for children and adults.

Members said that transition could be better if different services put their money together.

They said that services would need to work together to make this happen. And that they would need a clear plan.

Members also thought that people who get **Continuing Health Care** should get **direct payments**.



Emma Curtis said members should look at the recommendations in the **'Don't Hold Back'** report. This was a report about transition. It was written by the **Children's Commissioner for Wales**.

	Actions • **Alyson** will send us the terms of reference for the **Project Board**.
	• **Alyson** will send us a link to the consultations on **Continuing Health Care**.
	• Karen will bring up the issue of **Continuing Health Care** and **direct payment** with officials.
	• **Alyson** will send us Gwent's new way of working for transition.
	• Jon Williams will tell the **Project Board** about our views on the term **handover**.

5. Research work

Before the meeting, we sent you a presentation about learning disability research in Wales. The main researcher for this work is Edward Oloidi.

He spoke about how he did the research. And gave examples of the questions he asked.

We learned about how **the Learning Disability and Autism Network** helped with the research before.

We wondered if the group could start again. Or if we could keep all the research in 1 place.

Karen said that the Research group would look at the results of Edward Oloidi's research.

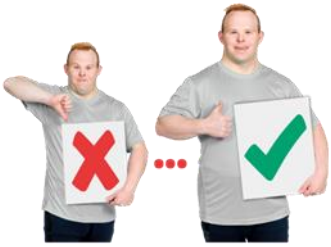
Karen said she would meet the:

- **Wales Office of Research and Development for Health and Social Care.**
- **Knowledge and Analytical Services**.

Llywodraeth Cymru
Welsh Government

These are parts of Welsh Government that do research.

Professor Upadhyaya said more work needs to be done to find out what causes learning disabilities. She said we need to know this to meet people's needs better.



Karen said that the **Learning Disability Improving Lives programme** was started because services need to be better for people with Learning Disabilities.

Action

- We will tell Edward about any learning disability research we know about.

6. Independent enquiry into Child Sexual Abuse

Sanjay Vedi was supposed to speak about abuse. But he could not come to the meeting. He will come a meeting another time.

Action

- **Alyson** will plan for the group to talk about child sexual abuse at another meeting.

7. Any Other Business

We were very worried about the **Panorama Programme: Undercover Hospital Abuse Scandal**. This programme was about abuse at Whorlton Hall hospital.

We wanted to know how we can be sure this kind of abuse was not happening in Wales. Or to Welsh people in hospitals outside Wales.

Hazel Powell said that there is a piece of work being done. It will look at care placements outside Wales and see if they meet people's needs.

Joe Powell said there are lots of types of abuse. Sometimes it is physical and sometimes it is people's attitudes. He said we need to change our culture to make sure we treat people with learning disabilities with respect.

Action

- We will write a statement in reply to the Panorama programme.

8. Future meetings

Tuesday 10 September 2019
11am to 3pm

Wednesday 4 December 2019
9.45am to 3pm

The December meeting will at 9.45am. This is because the Deputy Minister will come to the meeting.

9. Next meeting

Tuesday 10 September 2019