

	Learning Disability Ministerial Advisory Group Minutes of the 4th meeting 4 December 2019	
Attendees - Members 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 Wales 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	Apologies - Members Dermot McChrystal Michelle Martin Oliver Townsend Jane Rodgers Sharon Williams Apologies – Officials Sue Beacock Karen Eveleigh	

<p>Others</p> <p>Tracey Drew - supporting Sophie Delyth Lloyd-Williams - supporting Michelle Dawn Price - supporting Lynne</p> <p>Emma Curtis – Children’s Commissioners office Edward Oloidi – attending with Ruth Northway</p> <p>Sam Dredge & Sinead Brophy – National Centre for Population Health Data Science : attending for item 4 on the agenda</p> <p>Officials</p> <p>Liz Davies : Medical Officer , Mental Health and Learning Disability Andrew Stephenson : HSS – LD Improving Lives Team Natalie Hughes-Owen : HSS – LD Improving Lives Team Alyson Collins : HSS – Social Services and Integration</p>	
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1.	Welcome, apologies, introductions	
	<p>1.1 Sophie welcomed everyone to the meeting. As there were a number of new people at the meeting Sophie invited everyone to introduce themselves and who they were representing. The apologies were noted. Karen was unable to attend the meeting as her mother was unwell and Andrew advised that he would be covering her agenda items. Chris Griffiths said that this was her last meeting and that the place on the group would be taken by Jo Griffin. Sophie thanked Chris, on behalf of members, for her valuable contribution to the work of the group.</p> <p>1.2 Sophie read out the ground rules for the LDMAG meetings and reminded members of the need to listen to others and respect their views.</p>	

2.	Introduction of the new co-chair	
	<p>2.1 Sophie introduced Humie Webbe the new co-chair of group. Humie spoke about her background and experience and how she would work with members and take things forward on their behalf.</p> <p>2.2 Members said they were pleased that Humie had accepted the position of co-chair and that they were looking forward to working with her.</p>	
3.	Minutes of the previous meeting and actions outstanding	Responsibility
	<p>The minutes of the previous meeting were considered along with the action log.</p> <p>3.1 Restrictive practices – Andrew said that Oliver had prepared a paper on Positive Behaviour Support and how it can prevent Adverse Childhood Experiences. Some additional work on the paper had been requested and Karen and Andrew would be discussing this with Oliver early in the new year.</p> <p>3.2 Social Care stories – Rebecca and Emma Mulinder said they had collected some good news stories and that others would be welcome.</p> <p>3.3 Health Actions – Karen welcomes contributions from members on the development work to deliver the health actions in the programme. All of the actions are being taken forward in collaboration with a range of stakeholders and many LDMAG members are also members of working groups and national groups. In particular, LDMAG members need to contribute to the actions relating to adult and children specialised services, the education and training framework, reasonable adjustments and strengthening the primary care response, including the Annual Health Check. In addition to input during the development stage, draft final products will be circulated/presented to the LDMAG for input and comment. General updates on progress to deliver the health actions will as usual be incorporated in the bi-annual progress report for all actions in the programme.</p> <p>3.5 Cwm Taf and barriers to health – Lynne said that RCT People First were happy to share their findings</p>	

	<p>with the group and would send their report to Welsh Government for circulation to members.</p> <p>3.6 Self-advocacy – Joe said that All Wales People First had sent out a consultation paper on self-advocacy to its members for return by late January. A meeting with the Welsh Government would then be arranged to discuss further.</p>	
Actions	<ul style="list-style-type: none"> ➤ Restrictive practices – to work with Oliver and others to finalise the paper and for this to be considered by the LDMAG sub-group when finalised. ➤ Social Care stories – to send Rebecca good news stories. ➤ Health Actions – To draft a letter for the LDMAG to send to the Minister on delay in progress on Annual Health Checks – to send to Natalie first to circulate to the group. (Carried over from September meeting). ➤ Cwm Taf and barriers to health – to circulate the RCT findings to members. ➤ Self- advocacy – to report back on the outcome of the consultation and the meeting with Welsh Government. 	<p>Natalie to discuss with Oliver and arrange sub-group meeting.</p> <p>Members</p> <p>Edwin, Emma, Joe, Oliver and Zoe. Zoe to prepare the draft letter.</p> <p>Lynne to send to Alyson to circulate to the group (circulated 13/12).</p> <p>Joe</p>
4.	Presentation : Mortality rates and people with a learning disability	
	<p>Sophie welcomed Sam Dredge and Sinead Brophy to the meeting to talk about their research on annual health checks.</p> <p>Sinead said they had been asked to look into the difference that having an annual health check made to</p>	

	<p>people with learning difficulties or a learning disability.</p> <p>Their key findings were that:</p> <ul style="list-style-type: none">○ People who had a health check lived on average, 6 years longer;○ The health check made the most difference to people with autism and people with epilepsy.○ Health checks made the most difference if they were first done when young.○ Health checks improve detection of serious and less serious conditions. <p>Sinead added that given the difference an annual health check can have it is of great concern that only 3 in 10 people who are eligible for a health check have one and that only 1 in ten eligible people have one every year.</p> <p>A discussion followed about possible barriers to people going for a health check such as: the coding used by GP's; people not being identified as having a learning disability; the lack of easy read information on the annual health check; the support available for the health check; and in terms of subsequent health checks the patients experience at the previous health check.</p> <p>Zoe said that Learning Disability Wales working with Improvement Cymru were developing an information pack on the annual health check which would be circulated to all GP's in Wales.</p> <p>Sam and Sinead said that they would be happy to answer any questions members may have on their research.</p>	
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Actions	<ul style="list-style-type: none"> ➤ When available Sam will provide the full publication of '<i>Mortality in adults with learning disabilities with and without a health check: a cohort study</i>' for circulation to the group. ➤ To send any questions on the research to Alyson to send on to Sam and Sinead. 	<p>Natalie to contact Sam to confirm when this report will be available.</p> <p>Members</p>
5.	Reducing restrictive practices consultation	
	<p>Edwin had prepared a presentation for this item but there was insufficient time available to copy the paper and present (presentation circulated 13/12).</p> <p>Edwin spoke about the framework's 4 headings: Human rights Positive Behaviour Support Reducing the use of restrictive practises How to use restrictive practices appropriately.</p> <p>Edwin commended the framework to members and the importance of members responding to the consultation on behalf of the organisations they represent and collectively as members of the LDMAG.</p> <p>Edwin stressed that any responses needed to be received by the closing date of 7 January 2020. Members agreed the framework should be supported and that a positive response should issue from the LDMAG and as appropriate organisations represented on the group.</p>	
Actions	<ul style="list-style-type: none"> ➤ Edwin offered to draft a response from the LDMAG and send it to Sophie and Humie for their consideration. ➤ Edwin invited members to send their comments/the responses from their organisations to him by the week commencing 28 December for him to incorporate in the draft reply. 	<p>Edwin</p> <p>Members</p>
6.	Research and development update	
	6.1 Ruth reminded members of the mapping exercise	

	<p>underway to identify what research has been undertaken on learning disabilities in recent years. 62 studies had been identified, some large, others small most looking at health and social care. The report was now with Karen for consideration.</p>	
Actions	<ul style="list-style-type: none"> ➤ To circulate the report to members when agreed. Update – Karen confirmed this can be circulated now and that it would be issued to members with the draft minutes. ➤ To arrange a further meeting of the research and development sub-group in the New Year. 	<p>Alyson</p> <p>Alyson</p>
7.	The Learning Disability Improving Lives Programme - update.	
	<p>7.1 Andrew spoke to this item and said that out of the 28 actions (which includes 4 with two parts): 18 have green status; 9 have amber status; and 1 has red status. He commented on a number of individual actions as follows:</p> <p><u>Action 1</u>: Oliver has prepared a paper on Positive Behavioural Support in relation to Adverse Childhood Experiences (ACE's) which will be discussed with ACE colleagues once finalised. This delay had resulted in progress on this action dropping from green to amber.</p> <p><u>Action 2</u> – The research report 'Research on the number of children in Wales placed into care from parents with a learning disability and the reasons behind their removal' is to be published on 17th December. Wayne expressed concern that given the involvement of the LDMAG in commissioning this research, this report did not come to the group for consideration prior to it being finalised and published.</p> <p><u>Update - The report was commissioned by the Looked after children MAG and not the LDMAG. The First Minister will be discussing the next steps in relation to this report with key stakeholders. The starting point will be discussions with parents with a learning disability. Karen has discussed with</u></p>	

Learning Disability Wales and All Wales People First in relation to this meeting and will provide a verbal update at the March MAG.

Action 3b: Childcare Offer. This has now been rolled out across all areas of Wales and an evaluation of year 1 of the programme has been undertaken. Take-up in year 1 was poor with only 35% of available funding being drawn down, improved take-up in current year with this figure already exceeded.

Actions 5,6,7,9: Integrated Care Fund and Housing. Housing colleagues are very pleased with progress in the last year following the last Wales Audit Office report.

Action 8: Housing colleagues have advised that undertaking meaningful research on homelessness is proving a challenging area as information was proving difficult to find. Improving Lives Programme officials will be meeting with Housing colleagues to discuss how this action could be taken forward. Wayne asked if advice could be provided on which homelessness organisations they were talking to as this could help with any research.

Action 13: Improvement Cymru are looking at alternative models for the delivery of annual health checks. Karen would be meeting with Improvement Cymru in the new year to discuss progress. Wayne suggested that the LD MAG should be fully involved in the development of these proposals so their expertise could be utilised.

Update – Karen has confirmed that Improvement Cymru have committed to ensuring that members and stakeholder organisations are fully engaged in the development of these proposals.

Action 14: Andrew confirmed that the education and training framework being developed would include mandatory LD training for NHS staff in public facing roles. (See para 8.2 below for full details of the discussion on this issue)

Action 17: Emma Curtis queried why this

	<p>recommendation had been given green status given there was a delay of over a year with the ALN Bill. Lead officials had acknowledged this but still felt that action would be substantially complete within the life of the Improving Lives programme. Andrew to follow this up in discussions with policy leads.</p> <p><u>Action 20:</u> Employment and Skills. Zoe queried why there was no mention of the Engage to Change project and said that she would be very happy to provide information on this project (what has worked/what hasn't) and present the findings at a future LDMAG meeting. Andrew agreed to discuss this with Welsh Government Employability colleagues during a planned meeting on 10 December.</p> <p><u>Action 22:</u> Disappointing that no progress had been made on this action to date with this being the only red action within the report. Andrew had now written to main bodies and work will start shortly with regulators to strengthen the voice of people with a learning disability and families and carers in inspections and reviews. Pauline reminded members that All Wales People First and All Wales Forum of Parents & Carers had been involved in previous inspections and would be happy to be involved again.</p> <p><u>Action 24:</u> After a slow start good progress was starting to be made in this area with a comprehensive Wales Transport Strategy set to be launched in the New Year. This would include a comprehensive consultation exercise involving a wide range of stakeholders. Transport colleagues have advised that they would be happy to do a presentation to the group.</p>	
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Actions	<ul style="list-style-type: none"> ➤ <u>Action 2</u> – The research report ‘Research on the number of children in Wales placed into care from parents with a learning disability and the reasons behind their removal’ to be circulated to the group (link circulated 17/12). ➤ <u>Action 8</u> – to ask housing colleagues which homelessness organisations they are in contact with to help take forward this recommendation. ➤ <u>Action 20</u> – Zoe agreed to send information to Andrew on the Engage to Change project. Consideration to be given to a presentation on the Engage to Change Project at a future LD MAG meeting. ➤ <u>Action 24</u> – Members said they would welcome a presentation on Public Transport Policy and people with a learning disability. 	<p style="text-align: center;">Alyson</p> <p style="text-align: center;">Andrew</p> <p style="text-align: center;">Zoe Secretariat</p> <p style="text-align: center;">Secretariat</p>
8.	Topical issues to note	

8.1 Review of placements of adults with a learning disability in England and Wales – Andrew advised that a draft report had been received but there were some final parts to be completed. It has not yet been considered by officials so it was not ready to be shared at this stage. The report will be published on 10 February 2020 with a Written Statement by the Minister.

8.2 Outcome of the Plenary debate on the provision of mandatory training on learning disabilities for hospital staff – Andrew advised that in a Plenary Statement on 6 November the Deputy Minister had announced mandatory learning disability training for healthcare staff in public facing roles across Wales. This would be incorporated into the equality and diversity training within the Education and Training Framework currently being developed by the University of South Wales on behalf of Welsh Government and Improvement Cymru.

A discussion followed on the progress of the education and training framework and whether this would be ready for roll-out in line with the timetable of spring 2020 announced by the Deputy Minister. It was acknowledged that this timetable would be challenging but Ministers were very keen to ensure it is achieved.

Queries were also raised over the format and type of training as well as who would be involved in delivering this training. It was confirmed that this level of detail would be developed as part of the process but it was anticipated that several different methods would be involved (face-to-face, online, etc) with LD groups being involved in the development of the training.

Wayne suggested that LDMAG should be fully involved in the development of these proposals. This was supported by other members.

Update – Karen has confirmed that the University of South Wales have committed to fully engaging with stakeholder organisations and expert groups in the development of the proposals. Timing may not allow the LDMAG or a LDMAG sub-group to fully engage with the plans at the development stage but individual members and their organisations would be fully involved as their expertise will be essential to the delivery of an appropriate outcome. It is anticipated that the LDMAG (or a LDMAG sub-group) will have the opportunity to comment on the proposals prior to their publication and roll-out.

Actions	<ul style="list-style-type: none"> ➤ To send members the report on the 'Review of placements of adults with a learning disability in England and Wales' when published. 	Alyson
9.	Terms of reference and meeting protocols for the group and making the meetings more accessible.	
<p>9.1 Andrew said that as the group had been operating for a year it was a good time to review its Terms of Reference and meeting protocols.</p> <p><u>Terms of reference:</u></p> <p>Proposed changes to the Terms of Reference had been circulated to members prior to the meeting. The updates were mainly referring to changes to Ministerial titles and recognition that the group had joint co-chairs.</p> <ul style="list-style-type: none"> ○ During earlier items concerns were raised that the LDMAG was not being consulted prior to publication of significant policy announcements which it was felt was a missed opportunity and an oversight given their expertise. ○ There was a discussion about the role of the group and what exactly 'providing strategic leadership' meant (3.1). Although some members thought this was an accurate reflection of their role others did not. ○ Members thought there should be greater use of the expertise within the group by setting up sub-groups to directly take forward specific pieces of work. ○ Humie said that the LDMAG needed to be more visible. ○ Zoe queried how it was decided what was to go on future agendas. Andrew said that some items were agreed at the previous meeting and others were agreed by Karen and the co-chairs to reflect emerging priorities. Members were though welcome to suggest agenda items and this was covered in the meeting protocols. <p><u>Meeting protocols and accessibility:</u></p> <p>Andrew explained that meeting protocols were being developed to try to make sure that meetings and papers were as accessible as possible for members and the public. The protocols in the paper provided were suggestions only and additions and comments were being sought on</p>		

	<p>what else could be done to help make things easier.</p> <p>Joe said that he had met with the Learning Disability Improving Lives Team to discuss the accessibility of meetings and it had been recommended that:</p> <ul style="list-style-type: none"> ○ when possible all papers to be produced in easy read including the agenda; action log and minutes. ○ To issue guidance to presenters on tailoring their presentations to suit the audience. ○ To make the meetings more accessible, different seating arrangements could be adopted to suit the needs of the group such as a cabaret style or a combination of cabaret and board room. ○ Papers to be provided in line with agreed timetables. <p>The group agreed to adopt the updated Terms of Reference and Meeting protocols. The latter would be monitored for effectiveness and adapted as appropriate. These would be reviewed again formally in December 2020.</p>	
Actions	<ul style="list-style-type: none"> ➤ To produce easy read agendas, action logs and minutes as well as key governance docs such as Terms of Reference/Meeting Protocols ➤ To develop guidance on presentations to the Group. To help with this Zoe offered to share the guidance Learning Disability Wales has developed. ➤ For cabaret style to be adopted for the March 2020 meeting ➤ Should members wish to suggest an agenda item then they need to contact Karen at least one month before the meeting. ➤ A LD MAG webpage has recently been added to the Welsh Government site and needs to be further developed to become more public facing https://gov.wales/learning-disability-ministerial-advisory-group Meeting minutes and agendas to be published to highlight the work of the group. 	<p>Secretariat</p> <p>Secretariat Zoe</p> <p>Secretariat</p> <p>Members</p> <p>Secretariat</p>

10	Review the membership of the LD MAG	
	<p>10.1 – This is a standing item with a formal review of the group after 12 months being agreed at the December 2018 meeting.</p> <p>10.2 - Members were broadly happy with current membership of the group and considered it had the necessary people around the table to take the Learning Disability Improving Lives Programme forward. It was recognised that it does have the option of co-opting people onto the group or sub-groups should other areas of expertise be needed.</p>	
Actions	<ul style="list-style-type: none"> ➤ To review membership in December 2020 	Secretariat

11.	Any other business	
	<p>11.1 Commissioning Supported Living – Edwin spoke about the commissioning guide ‘Support for Living’ produced by the National Commissioning Board with support from the WLGA, Cymorth Cymru and Learning Disability Wales. Although published in March 2019 there is little evidence that this document has had any impact. Oliver, Cymorth Cymru working with Learning Disability Wales has produced a paper detailing how the commissioning guidance could be promoted and implemented across Wales with a benchmarking exercise being undertaken to establish a ‘baseline’ level of engagement with the guide and for two pilots to be undertaken where the guide is being used to assess and review commissioning and practice. Funding will be needed to take this forward. Members supported the proposed benchmarking exercise and pilot projects.</p>	
Actions	<ul style="list-style-type: none"> ➤ To circulate Oliver’s paper with the minutes ➤ To contact Edwin, Oliver and Zoe to establish when they would be ready to discuss their benchmarking exercise and explain that it would fall to Housing and Social Care Policy to lead on and be the funding source, ➤ To send Oliver’s paper to Housing and Social Care policy leads to discuss how to move forward with this paper. 	<p>Alyson</p> <p>Andrew</p> <p>Andrew</p>

	<p>Revised dates for meetings in 2020 :</p> <p>25th March (The Deputy Minister will be attending this meeting)</p> <p>11th June</p> <p>11th September</p> <p>8th December</p>	
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