

Welcome

Growing Older with Learning Disabilities (GOLD)
**Supporting people with profound and multiple
learning disabilities.**

We'll be starting shortly! Why not introduce yourselves in the chat?



Agenda

Item	Speaker	Time
Introduction from our chair	Lindsey Allen, Bild Learning Disability and Autism Manager	5 minutes
Presentation	Sarah Swindells, Health & Wellbeing Lead, Dimensions UK Annie Fergusson, Associate Family Consultant, Dimensions Jordan Smith, Advocacy Lead, Dimensions UK	45 minutes
Q&A	All invited to participate	10 minutes

Growing Older with Learning Disabilities

- Supporting people to live long, happy and healthy lives.
- Webinars, conferences and workforce development
- National Steering Group is made up of professionals, experts with experience, service providers and experts in the field



Find out more about GOLD

<https://www.bild.org.uk/growing-older-with-learning-disabilities-gold/>

About GOLD

We are exploring the opportunities and challenges of an ageing population of people with learning disabilities. Visit our web page to find out more.

Future events

GOLD conference

30th September 2022



BILD's Growing Older with Learning Disabilities (GOLD) network is delighted to announce early bird booking is now open for the 2022 Ageing Well with Learning Disabilities Conference.

Held in Birmingham's Crown Plaza Hotel on 30 September, with attendees also having the option to attend online, the conference will feature a range of fantastic keynotes from professionals working in the field and people with lived experience, exploring best practice in supporting people as they age.

To find out more and register, please go to: bit.ly/GOLDconf22register

Find out more about Bild

www.bild.org.uk



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Join us!

Become a Bild member to access resources, webinar recordings and discounts on workforce development programmes, conferences and events

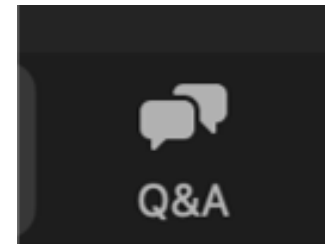
www.bild.org.uk/membership

Housekeeping guidance

- This webinar will be recorded and an edited version will be shared with **Bild members**. To find out more about Bild membership, go to **<https://www.bild.org.uk/membership/>**
- Any discussion via the chat function will not be included in the recording
- Please do not take pictures or record parts of the webinar yourself
- Please be mindful this is a public forum if you decide to contribute to the session, whether that's in the Q&A at the end, or in the chat
- This is a kind and supportive space

Zoom guidance

- Please use the Q&A function to ask questions to the panel
- Please use the chat box to introduce yourself and discuss topics with the other participants





Supporting people with profound and multiple learning disabilities

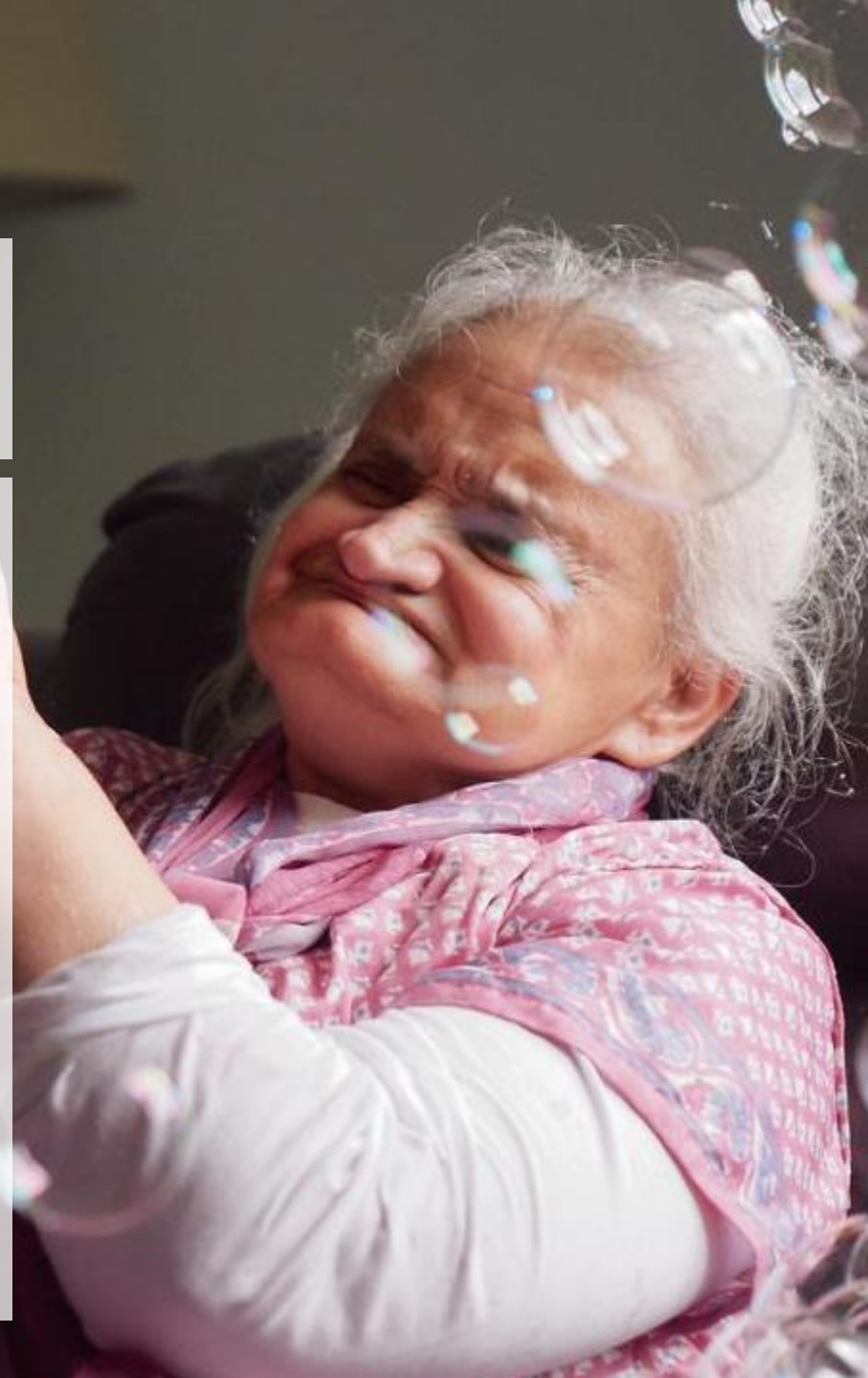
Welcome to the 'Supporting people with profound and multiple learning disabilities' webinar.

Sarah Swindells, Health and wellbeing lead, Dimensions

Annie Fergusson, volunteer with PMLD Link and part of the Dimensions Families team

Jordon Smith, Advocacy Lead, Dimensions

You can follow [@DimensionsUK](https://www.instagram.com/DimensionsUK) on social media.





About us

Sarah Swindells

Health & Wellbeing Lead



Annie Fergusson

Families Team & PMLD LINK



Jordan Smith

Advocacy Lead



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This isn't about us...



Proving life can get better



Aims of our webinar

- To achieve **better lives** for people with profound and multiple learning disabilities.
- Today we will discuss:
 - ‘Who’ we are talking about
 - Why it is important to have a focus on this group.
 - What the core and essential service standards are and how to use them to support people
- Sharing stories



What is a Profound and multiple learning disability?

People are
much more than labels.
Let's focus on how unique
people are, their strengths,
talents and interests.



People with profound and multiple learning disabilities

Marginalised and isolated

Low expectations and assumptions held

Greater health inequalities

Excluded on many levels

Experience greater barriers

Need responsive, high-quality services and opportunities



Who do we mean?

More than one disability:
The most significant of which is a severe/profound intellectual disability

Great difficulty communicating (but can communicate)

Often have other disabling conditions such as:

- Physical disabilities
- Sensory impairments
- Sensory processing difficulties
- Complex health needs

May use their behaviour to show unmet needs

Mental health difficulties



Beyond the labels

A holistic view is essential

Complex nature of needs

Compound impact

High support needs

When we get things right

“Profound” ... our responsibility

Challenge to think differently



What causes a **Profound and Multiple Learning Disability**?

- For many there is **no** single known cause
- Where causes are **known**, they can be varied:
 - › Ante-, peri- or post- natal
 - › Genetic disorders
 - › Brain damage as a result of infection
 - › Other acquired brain injuries
- Medical advances likely contribute to the growing numbers of children and adults with **Profound and Multiple Learning Disability**.



**Introducing the Profound
and Multiple Learning
Disability Core & Essential
Standards**



Raising the bar ... work in progress



Organisation

1. Leadership
2. Quality
3. Staff Development (skills & confidence)
4. Physical Environment
5. Communication
6. Health & Wellbeing
7. Social, Community & Family Life

Individual

1. Communication
2. Health & Wellbeing
3. Meaningful/Quality Relationships
4. Social & Community Life
5. Meaningful Time
6. Transitions, *Loss and Change*

*Source: Doukas et al (2017) <https://www.pmlmlink.org.uk/resources/#pmlid-standards>



Relationship between the two sets of standards

Individual (what and why)

1. Communication
2. Health & Wellbeing
3. Meaningful/Quality Relationships
4. Social & Community Life
5. Meaningful Time
6. Transitions, *Loss and Change*

Organisation (how)

1. Leadership
2. Quality
3. Staff Development (skills & confidence)
4. Physical Environment
5. Communication
6. Health & Wellbeing
7. Social, Community & Family Life

*Source: Doukas et al (2017) <https://www.pmlidlink.org.uk/resources/#pmlid-standards>



What makes you happy?





Living a great life (examples)

Eating good nutritious food

Social life

Hobbies and interests

Drinking plenty of water

Fish and chip Fridays

Having a job

My garden

My pets

Sleeping well

Going out to the shops/cinema

Having my health needs met



Real people, real lives



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Standard 1: Communication

3 essentials for effective communication:

- What
- Who
- How

Total communication approach

- Own communication respected
- Environment and approaches
- Roles and status of communication partners

Sharing information to ensure consistency

Introducing Brian



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Standard 2: Health and wellbeing

Proactive - levels of risk/ holistic vulnerability

Physical and emotional wellbeing

Baselines - what is usual?

Annual Health Checks + Health Action Plans

Key roles –external support

Introducing Alice



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Standard 3: Relationships

Connection and belonging

Priorities: who and what

Circles or continuum of support

Be creative

Enable empowerment

Learning to *just be* – **HOP principles** (Forster, 2008)

Introducing Mei Li



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Standard 4: Social & community life

Thriving not just surviving

Belonging

Visible and active

Participation – strengths

Contributions are unique

Authentic citizenship



Introducing Steven

Steven and his support worker, Hannah, noticed there wasn't an accessible swing local to them.



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Standard 5: Meaningful time

Focus on the person's interests and preferences

Access – match to the activity

Engagement is situation- specific

Opportunities - specialist and mainstream

Personalise

Balance of opposites

Introducing Rob



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Standard 6: Transitions, *loss and change*

Planning and predictability

Handling unexpected change

Life events and daily living

The importance of acknowledgement

Holistic approach



Simple guiding principles to consider

People are our most responsive asset

Routines and repetition

Consistency and predictability

Key-working where possible

Opportunities to support and promote early learning in all areas

Bring the 'world' to the person



Develop your inner detective!

How to get to know the person really well

- It takes time!
- Families and supporters are experts
- Families and professionals should work together

Look in detail (video is fantastic)

- How do they respond?
- Discuss and agree
- Barriers and adjustments
- What works? Why?



Using the **PARTY** prompt

Contextual factors include:

P - people, place, positioning, preferences

A - activity, arousal state or attention, adaptations

R - responses

T - time

Y - anything about YOU!

 **And finally, in practice....**



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Useful resources

- PMLD Standards: <https://www.pmlmlink.org.uk/resources/#pml-d-standards>
- PMLD LINK: free Guest access to online journal archive <https://www.pmlmlink.org.uk>
social media @PMLDLink
- Mansell (2010); Raising our Sights report + *how to* guides and videos from <https://www.pmlmlink.org.uk/resources/>
- How to meet the needs of people with profound and multiple learning disabilities (PMLD) in hospital: A guide for healthcare professionals, families and support staff <https://www.pmlmlink.org.uk/wp-content/uploads/2020/02/Treat-Me-Well-Guide.pdf>
- Forster, Sheridan(2008) HOP: Hanging Out Program: Interaction for people at risk of isolation. <https://sheridanforster.com.au/wp-content/uploads/2014/08/hop-a5.pdf>

- Pamis: services and resources <https://pamis.org.uk/>
- Dimensions: <https://dimensions-uk.org/what-we-do/profound-multiple-learning-disability-autism/>
- NAC: Promoting emotional wellbeing <https://www.nacwellbeing.org/>



Thank you!

- Any questions?
- If you'd like to contact us you can: enquiries@dimensions-uk.org



Thank you for joining us!

bild

If you require any further information about our speakers today, please contact hello@bild.org.uk

Future webinars

To find out more and register, please go to: www.bild.org.uk/webinars

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