

Involve me



Today

- About **Involve Me** and people with PMLD
- What are we doing at the moment?
- Communication, choice, decision-making and consultation
- How can we change things?

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People with PMLD

About profound and multiple learning disabilities

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- have more than one disability
- have a profound learning disability
- have great difficulty communicating
- need a lot of support with most things in their daily lives
- often have additional sensory or physical disabilities, complex health needs or mental health difficulties
- may have behaviour we find difficult to work with.

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The Involve Me project



People with PMLD will have better lives if we support them to share their experiences in ways that involve them in decision-making.

Make sure staff, carers and organisations and policy-makers get the skills, knowledge and understanding to effectively involve people with PMLD.

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**Why is this
project important?**

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Communication



- Most people with PMLD don't use any formal communication, like words or symbols.
- Because of this they cannot 'speak up' for their needs like other people with a learning disability can.
- People need to use creative approaches to communicate with people with PMLD and help them share their preferences and what is important to them.

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This means



More people with a learning disability are speaking up and being heard than ever before – for example in self-advocacy groups, on partnership boards and in groups involved in decision-making.

But people with PMLD are still being missed out because people don't have the skills to involve them.

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Why do people with PMLD get left out?



- People don't understand their needs properly.
- They can have **complex health and communication needs.**
- **They need specialised support** as well as the support other people with a learning disability need.
- People don't think about their needs when they plan services.

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This means



People with PMLD are not being meaningfully involved in decisions that affect their lives.

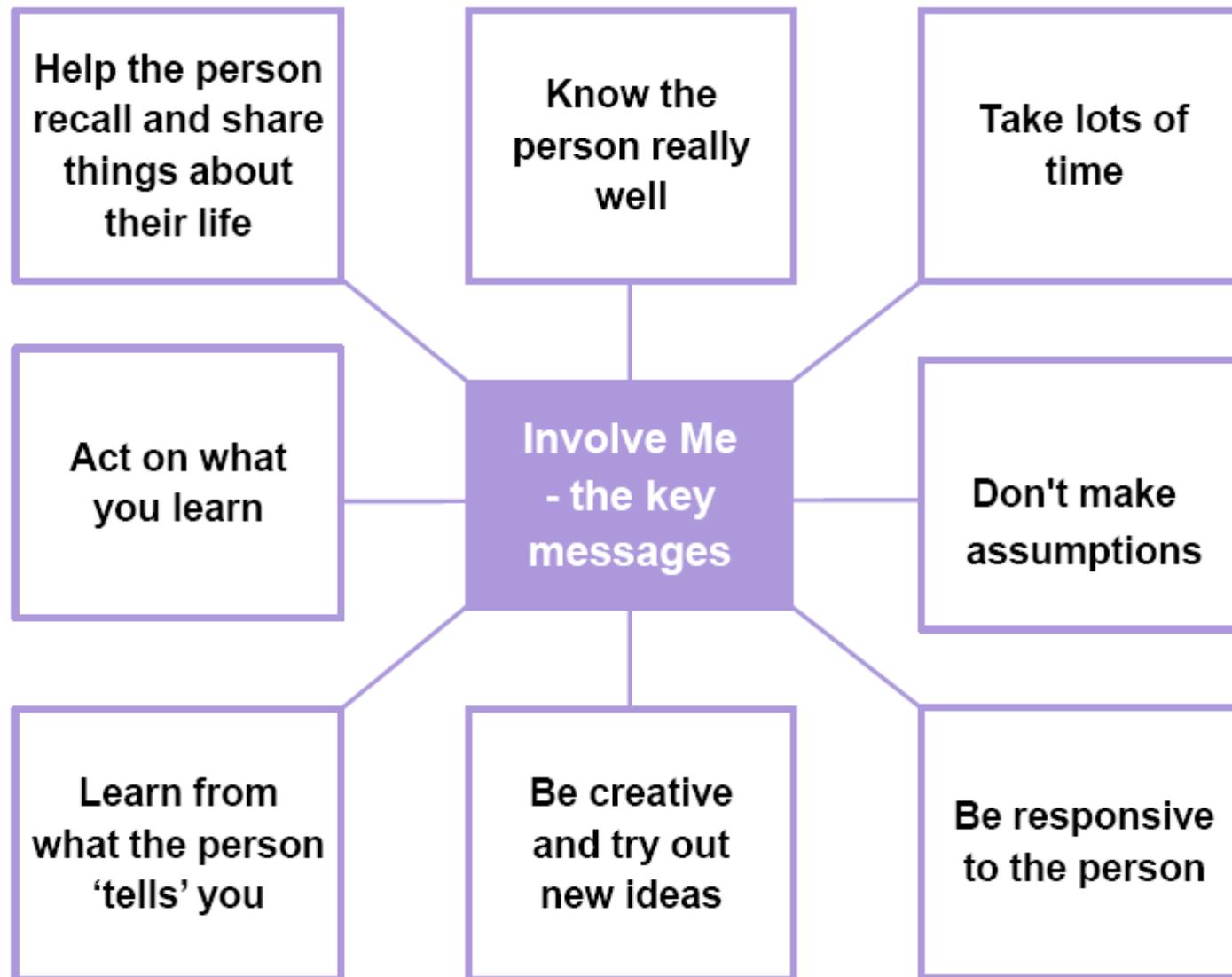
People are not finding out what is important to them and speaking up for their needs enough.

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Involving people with PMLD

- We need to find out what people prefer.
- What we know about people can tell us what their preferences are.
- We need to try out new experiences.
- We need to revisit old or long-standing experiences.
- We need to be clear about what we want to find out.

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Summary



If we support people with PMLD to influence decisions that affect their lives...

... if decision-makers and service-planners listen and respond to what is important to people with PMLD

... this should lead to better lives for people with PMLD.

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Thank you!

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