

# PMLD LINK

sharing ideas and information

Access

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## Recipe for a Hanging Out Café

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The Hanging Out Café is a get together and celebration of people who primarily use body, gaze, reach, sound, and movement communication. It has been inspired by the Hanging Out Program, principles of reverse inclusion, and the need for accessible environments for people with profound and multiple learning disabilities (PMLD).

### Ingredients

- A large room where people can move around easily, booked for 3 hours (30 minute set up and pack up, with 120 minutes for the café)
- Some basic catering stuff – nothing too flash
- Some chairs
- Some handy resources that people can take away like the HOP booklet or copies of PMLD Link
- Up to 15 people with PMLD and their support workers
- Up to 15 people who are used to interacting with people with PMLD
- Up to 10 people who haven't had much experience being with people with PMLD (e.g., experienced peoples' partners, students)
- Many, many hours to advertise, explain, beg, beg again, convince people that "yes the person you

support sounds perfect to come along," and patience to deal with the many gatekeepers between the event and individuals with PMLD.

### Method

1. Get people to register for the event, including request for consent for photos.
2. On the day, set up the room. A table for some foods, a drinks area. Groups of 3 chairs spattered around the room (remembering that prolonged quality engagement has reduced likelihood if people are standing as opposed to sitting next to someone). A room with a quiet end and more active end can be useful.
3. Allow your 12-year-old son to plonk himself in a corner with his computer, knowing that even if he doesn't engage directly, just being there helps him

to be part of the disability community. Take up his suggestion that maybe he can bring some friends along next time to help out.

4. Expect people to arrive at different times. Welcome them. Be mindful of encouragements you might need to give to support workers to allow people to move about the room freely (to discourage hovering or well-meaning controlling behaviours that might be ingrained in their workplace culture).
5. Engage with people as they come in, or encourage other partners to engage.
6. Keep an eye out for anyone who might not be being engaged with.
7. Offer to make cuppas or show people where food is BUT it is critical that people know that the main ingredient of the experience is Hanging Out, not the food and drink. You do not want people coming in, eating, drinking, thinking they are done, and leaving – missing the best meal of the day of - engagement with another person.
8. Try to take photos.
9. Support experienced and inexperienced people to be able to engage – they might need ideas, highlighting of the focus of the individual with PMLD, ideas for sharing that focus, permission to play, or share silence. They might want to ask questions without feeling judged.
10. Be ready to support support workers, who may not have seen the level of engagement with the person that they support. They may have been in cultures missing good quality interaction.
11. Let people float in and out.
12. Go with the flow.
13. After pack up, send out photos of individuals to their contact person, so the celebration and modelling of great interaction continues on after the event.

### Comments

**R**esist the urge to overengineer. Before each Hanging Out Café you might be thinking of all the switch



equipment, toys, lights, vibrating things, and stuff that you can bring along. Perhaps bring along what you need to address your own sensory needs (my diffuser goes everywhere). Pulling out communication apps for picture sharing or YouTubing AC/DC is permitted. But resist the urge to complicate. Bring things back to basics – attending to the person in front of you. Don't get lost behind bells and whistles.

Be aware you may have a desire to orchestrate every item on the list, but this is not possible, so delegating photographing, trusting others to do things, and allowing yourself to share moments with people is needed.

Thanking those who attended the 2nd Annual Hanging Out Café. The Hanging Out Café has been an event run with AGOSCI Australia in celebration of International AAC Awareness Month in October. It is part run to highlight that body, sound, gaze, reach, and movement communicators need as much celebration as people using formal communication devices and communication books.

### Contact details

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### References

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Available from: <https://sheridanforster.com.au/wp-content/uploads/2014/08/hop-a5.pdf>

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**PMLD LINK** was established to make a difference to the lives of children and adults with profound and multiple learning disabilities (PMLD). People with PMLD have profound intellectual and multiple disabilities, very severe communication difficulties, often extreme physical and/or sensory disabilities, and complex health needs. Their needs are frequently overlooked by more general support organisations for people with learning disabilities. PMLD LINK maintains a clear focus on this small and often hard to reach group.

Since 2007 PMLD LINK has been a registered 'not for profit' charity and its affairs are managed by volunteer trustees who have in-depth knowledge and are relatives of people with PMLD and/or are academics and professionals with relevant backgrounds in health, education or social care services, and other community and voluntary services.

Revenue from subscriptions to PMLD LINK and all grants and donations are used to maintain the production and dissemination of the journal, the development of the PMLD LINK website and the management of social media platforms for networking and information sharing.

**Currently the trustees are:**

**Rob Ashdown (Treasurer):** Former teacher of pupils with severe and profound and multiple learning difficulties and special school Headteacher.

**Annie Fergusson (Chair):** Family carer for her brother with profound and multiple learning disabilities, retired professional and academic in the learning disability/special education field and a member of several national advisory groups and of the Families Team at Dimensions, a social care provider. Annie was one of the team who developed the PMLD Standards.

**Michael Fullerton:** Director of Health & Wellbeing with Achieve Together and leads a health team focused on the quality of life of people with profound and multiple learning disabilities. Michael was one of the team who developed the PMLD Standards.

**Martin Goodwin:** Head of department and teacher of pupils with PMLD and specialist in approaches to improve interaction, communication and participation of people with severe and profound learning disabilities

**Becky Loney:** (Vice-Chair) Independent advocate and has supported people with profound and multiple learning disabilities for over 30 years.

**Wendy Newby:** (Secretary) Headteacher at The Shrubberies School, Stonehouse, Gloucestershire, for students with Severe and Profound and Multiple Learning Difficulties .

**Maureen Phillip:** Creative Director for the Scottish charity PAMIS (promoting a more inclusive society) and works in partnership with people with profound and multiple learning disabilities to support communities to recognise that people with profound and multiple learning disabilities are the best educators, as they teach us what it is to be human.

PMLD LINK would not function without its wider team of marvellous volunteers who have an interest in and a commitment to improving awareness, services and opportunities for people with PMLD. Our volunteers maintain PMLD LINK's activities and influence and this work benefits so many people, enabling them in turn to support many more people with PMLD, in various ways.

Each of the wide-ranging tasks are shared between two or more individuals who share practical information and give support as required through meetings online or occasionally in face-to-face meetings. Volunteers fulfil various roles. Most obviously, they edit issues of the journal – commissioning and editing articles, researching for and developing news items, reviews of resources and books, and providing details about courses, events and other relevant opportunities. The team of editors changes on a rotational basis for each journal issue.

There is other important, behind-the-scenes work that volunteers do besides:

- Ensuring that the PMLD LINK website is up to date and adding new resources and new electronic copies of the journal and other material as they are produced.
- Maintaining an active social media presence to keep people informed about news, events, opportunities and resources.
- Receiving and responding promptly to e-mails and other communications to PMLD LINK.
- Ensuring that printed copies of the journal are mailed to subscribers and others.
- Contributing to a reference group that identifies current and relevant topics which provides direction for PMLD LINK's developments and the content of journal issues

If you are interested in supporting PMLD LINK in any way, please contact any of the trustees listed on the Charity Commission website or e-mail [info@pmldlink.org.uk](mailto:info@pmldlink.org.uk).

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Visit [www.pmlmlink.org.uk](http://www.pmlmlink.org.uk)

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