How do we create and sustain 'ethical organisations' to support people with PMLD (including schools, care providers, social services and health services)?

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The recent, and shocking, Panorama expose, https://www.bbc.co.uk/iplayer/episode/m00059qb/panorama-undercover-hospital-abuse-scandal showed unethical treatment of people who rely on our support to lead safe, and fulfilling lives. Undoubtedly, government backed investigations and reports will need to be initiated, re-visited and reviewed to provide clear policies and procedures to prevent this from happening in the future. However, in light of this programme, I have been thinking about ethics, and have some thoughts on practical ways we can work towards creating and sustaining ethical organisations for people with PMLD.

I find that the more I think about what we consider to be 'morally good or correct' (*ethical - Oxford dictionary)* for people with PMLD, the more diverse and complex this question becomes. Most of us are, thankfully, opposed to what is clearly unethical, however, we are all individually governed by our personal values, ethics, and codes of conduct. Some of these are subjective, but all are effected by social influences and conditioning, assumptions, our culture, upbringing, past experiences, our genetic predisposition, and our 'in the moment' energy levels and mood. Balancing the expectations of society, an efficient and effective organisation, and the individual needs of the person with PMLD, is complex. Add to this the limited resources available for people with PMLD (funding, consistent staff, time etc…) and the question becomes even more multifaceted.

It is, of course, ethical for people with PMLD to be supported to lead a fulfilling, productive and social life, to be heard, understood and responded to, treated with dignity and respect, and to be safe. Recruiting the right person for the supportive role is, obviously, an ideal starting point. Posing well thought out questions should give an employer a 'feel' for someone's suitability. Detailed, ethical policies and procedures are also obvious requirements, as are robust induction and training packages. In addition, and in my experience, staff who are educated about the physical, sensory and communicative differences

of the people they support are usually more empathic and sensitive to their diverse needs. Intensive Interaction training is one way in which employees can gain an insight into the people they support, and foster positive relationships with them.

Intensive Interaction channels our empathic instincts, and is based on the way all people learn to engage, connect, communicate and become social beings. From the day we are born, our parents and/or caregivers instinctively 'tune-in' to us, spending relaxed, undemanding, time observing our expressions so that they can understand our personality, idiosyncrasies and needs. They encourage our communication and sociability by mirroring our expressions, and echoing our vocalisations, instinctively embellishing them in a conversational way to enhance our skills. This in-turn builds upon fundamental communication skills that develop before language such as, attention and concentration, shared engagement and turn-taking, understanding expression, gestures, body language, eye contact, vocalisation, and leaning to have fun and play. Many people with PMLD and/or autism may have found it difficult to understand the self-affirming attention given to them at the early stages of development. They also, very probably, were unable to fully access and learn our typical communication techniques. Intensive Interaction encourages staff to re-explore these initial stages of social exploration and communication with people with PMLD and autism. Engaging in a recognisable and meaningful ways (ie. 'tuning-in', copying, echoing, sharing interests) opens up the possibilities of connection, understanding and development in communication skills and sociability. This is turn, should also lead to enhanced feelings of self-worth and empowerment for the people we are supporting.

Sustaining an ethical organisation can, I feel, often be more of a challenge. Despite good intentions, staff turn around, heavy workloads, necessary administration tasks, fatigue etc. can impact on best practice. The basic needs of the person being supported (as shown in Maslow's hierarchy of needs below) understandably take priority, and staff may naturally revert to their habitual and personal ethics and codes of conduct, as opposed to those stipulated by the company. This can then impact on the emotional, communicational and social well-being of the people being supported. Ironically, this can then cause 'basic needs' tasks to become more challenging and time costly for staff and the person being support.
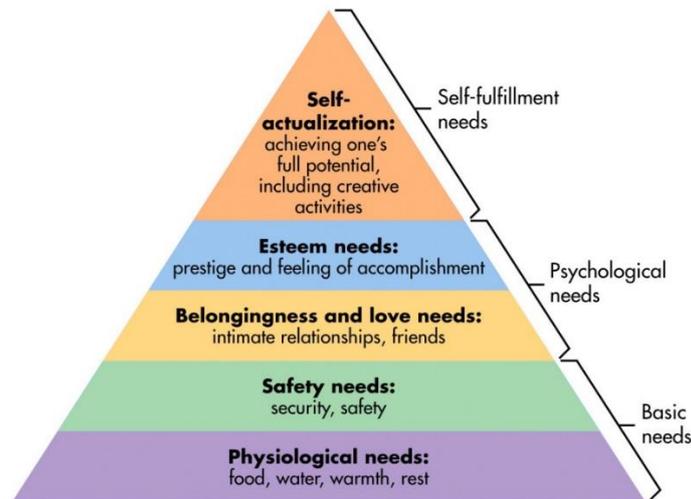
Comparable to the people that we care for, employees need to feel supported and listened to. Also, policies, procedures, and training outcomes need to be re-visited and revised regularly to become firmly established. Structured supervisions, 'in the moment' conversations, appraisal systems, staff meeting, and training re-fresher courses are invaluable. In addition, 'day to day', ongoing expectation of ethical standards need to be embedded.

I work for 'Us in a Bus', an organisation that supports people with PMLD, complex needs and/or autism. We visit people in their homes or in a community space and, using creative, client lead and Intensive Interaction based methods, provide opportunities for people to express themselves and build relationships with others. We also offer training and consultancy, and coaching and mentoring. We have an 'Ethics & Conduct' policy, the purpose of which is to engage with others in a way that embodies and reflects the principles of dignity and respect. Our four core conditions (simplified for the purpose of this article) are:-

- **Congruence** – Between what is expected of the people we visit and what we expect of ourselves. Much is expected of them, including being observed, reviewed, reported about, encouraged to stretch their comfort zones. We should not expect less from ourselves.

- **Acceptance –** Unconditional positive regard**.** We can separate our judgement of the ***behaviour*** from our value of the ***person***. Acceptance is fostered by working relationships based on mutual support, active encouragement, trust and respect.

- **Realness -** Being real and genuine in all our interactions. It is then easier for others to recognise us, relate to us and be themselves. In this way, we can be truly equal with our service users and each other.

- **Empathy -** Aiming to try to understand the person from their point of view. Hasty decisions do no one any favours.

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The policy goes on to describe expected conduct from Us in a Bus Staff

- **Communication** – To keep all channels of connection and communication open.

- **Confidentiality** – We have a duty of confidentiality to the people with whom we work and each other. Causes for concern should be reported through the right channels.

- **Awareness and sensitivity** - With our service users. We should not make assumptions. When it is necessary to have specific information about a person, we get this from that person, from our observations and in co-operation with their support staff.

- **Working relationships** – We work towards creating working relationships based on mutual support, active encouragement, trust and respect.

- **Reputation -** We are all responsible for the good reputation of Us in a Bus.

The principles of our Code of Ethics are emblazoned on the wall of our office, and are referred to regularly! The four core conditions apply to our working relationships as well as those with the people that we visit. We also have a robust 'feedback' system whereby we are required to give both positive and, if necessary, negative feedback to each other. These discussions are not always easy, but are an unconditional part of our contract and, with practice and repetition, foster better practice and open, trusting relationships between colleagues.

So, as mentioned, creating and sustaining 'ethical organisations' to support people with PMLD is complex. However, I feel that, giving employees and the people they support continuous opportunities to learn, to revise their learning, to be heard, understood and supported, will result in improved relationships and more ethical organisations.

ETHICAL EMPLOYERS
CREATE Recruitment   Induction   Policies and Procedures Training (Inc. Intensive Interaction)
SUSTAIN Supervision   Appraisals   Code of Ethics   Ongoing Training Staff Meetings   Feedback   Discussions   Support
BENEFITS Ethical Practice   Better Relationships Happier, More Empowered, More Fulfilled Staff and People with PMLD

If you want to read more about how Us in a Bus evolved its ethical stance (chapter written by Janet Gurney, UIAB Director of Training) and about how other organisation strive to embed good practice, we recommend:

Delivering Intensive Interaction Across Settings: Practice, Community and Leadership by and Graham Firth, Edited by Mark Barber, GRAHAM FIRTH, et al. | 8 Mar 2019

Available from Amazon in paperback or kindle format.

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Us in a Bus

website: usinabus.org.uk