

WHY HISTORY?

Social History of Learning Disability Conference 2016



Why the stories of people with profound and multiple learning disabilities have value.



Life story work with Andrew and Geoff (2012)



Vulnerable to abuse



People with profound and multiple learning disability (PMLD):

- Have extremely delayed intellectual and social functioning
- May have limited ability to engage verbally, but respond to cues within their environment (e.g. familiar voice, touch and gestures)
- Often require those who are familiar with them to interpret their communication intent
- Frequently have an associated medical condition, which may include neurological problems, and physical or sensory impairments

Bellamy et al, 2010

Making Memory Sites: Extending opportunities for people with profound and multiple learning disabilities to participate in life story work





HOW?



- March 2015 – April 2016
- 3-6 hours every week with each with Marian, Amelie and Jack and their circles of support

Phase 1

- Personal Collections of their 'life history materials'
- Participant Observation of their 'every day' activities
- Interviews with people in their 'circles of support'

Phase 2

- Participatory life story work
- Construction of 'Memory Sites' and other life story artifacts

Why?

- For the individuals themselves?



- For those who support them?



- For wider historical use?



"Yes I think that actually this whole project has been fantastic for Amelie. I feel that even though I've been working with her for ten years, where you get so used to a way of working, I just feel that it's opened up different doors for her. It's made me think differently. Rather than working in the same way all the time I can see that there are certain ways that Amelie can communicate and relive her past which is really important to her and she seems to respond really well to."

Follow up interview: Amelie's Team leader April 2016

A daughter, an aunty, a schoolgirl, a brownie?



Heroes of the 'here and now'?



Being part of the 'conversation'



"And Jack was really proud. You could hear people saying 'is that Jack? Is that Jack in those photos?' [] His friends were saying 'I didn't know he could stand up. What's he doing there?' And he was taking this all in and it was one of those lovely moments in Jack's life when everyone was talking about him, all positive things. And he was thinking 'They're looking at my pictures'".

Interview: Jack's Keyworker September 2015

"A lot of time it was about having evidence of her presence, of her reality, of her being in the world, because so much of what normal living in our culture said was that someone like Marian didn't count and therefore didn't really exist and would only exist if she could co-operate in presenting herself in acceptable ways, all of which were pretty much beyond her. And so we became- us and her teachers and all the people who are involved in her world and with lots of other PMLD individuals- we became her archivists to try and maintain a level of evidence for her."

Follow up interview: Marian's Mother April 2016

Making sense.

Re-presenting.

Making accessible.



"It brings her to life, doesn't it? The good thing about it is someone coming in and rather seeing a young lady who's in a wheel chair- Amelie is not able to verbalise her life, her experiences and everything else- but from doing this she can. It makes her more of a person. It makes people see her differently I think and maybe be a little more compassionate with her."

Follow up interview: Amelie's Team Leader April 2016

Personal stories and historical value?

- Stories about the personalisation agenda
- Stories about the development of communication tools
- Stories about education
- Stories about digital technologies
- Stories about changing attitudes



Stories have the capacity to connect



“For Marian and others like her with PMLD, they are also people who have lives exactly as ours are. It’s just that for some reason we have the human ability to paint that out and to make hoops through which they have to jump, which they are incapable of jumping through, in order to preserve our blindness to them”

Follow up interview with Marian’s mother, April 2016

“And when I interrogate myself about how I feel about Marian in our lives and in the world, I always think that she is one of those people who has come into our world to, to make sure that we have to face the absolute worst of ourselves in order to remember how hard and how important it is to build the best of us. It goes a long, long way beyond making sure her pad is changed and that she’s fed and kept healthy. It goes so far beyond that. Those things often stand in for the value of a person- the right for this, the right for that- but actually the real right is the right to be acknowledged as ‘us’.”

Follow up interview with Marian’s mother, April 2016



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