

Storysharing® for Inclusion

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We all need to have friends, to feel part of a community, and to have a voice in making decisions that affect our lives. This can be a real challenge for people with PMLDs and their families (Hughes, et. al., 2011; Reinders, 2008). Clement and Bigby (2009) found that staff and families often had different ideas of what inclusion meant, and that some staff felt that the people in their care were just too different to be included in society.

A major barrier is of course the perception of communication difficulties of people with profound and complex needs, and how these impact on everyday participation with friends and in civic life. Communication skills are critical, whether for a topical discussion, networking, first time encounters, or the sharing of news with people who matter in your life. In each situation, it is the skill of narrative, storytelling, that connects individuals (Fivush *et al.*, 2011) and makes sense of experience (Lambrou, 2014). The stories capture significant, 'reportable' events that hold meaning and interest for both the teller and the listener (Labov & Waletzky, 1997). We also know that telling your story is one of the best ways of changing minds and reducing prejudice. This is because when you hear a story – as distinct from a set of

facts - the empathetic, feeling part of your brain kicks in and influences you in subtle ways¹.

In 2002, Grove (2007) was working in a day centre for people with PMLDs. She noticed that staff continually recounted tiny stories about what they had been doing during the day - funny, surprising, or even anxiety provoking. As soon as two staff members were together, storytelling was inevitable. The stories were told ABOUT the people who attended the centre. But they were never told BY them, or WITH them. You might say this is obvious - people with PMLDs don't talk, so how can they tell stories? Well it turns out that they absolutely can - as long as you adopt the appropriate perspective, and the appropriate tools. Over the last 15 years, the charity Openstorytellers has been developing and refining an approach that enables everyone to take part in the telling of stories, called Storysharing® (Grove, 2014). The emphasis is placed on social participation and emotional engagement, rather than developing well-formed narrative structure. Outcomes have included an improved balance in the contributions of supporter and individual, a greater focus on the high point of the story rather than the factual events, and increased expression of feelings through the use of expressions, gestures, vocal sounds (Bunning *et al.* 2017). From the start, community participation and inclusion has been a real focus of what we do.

Storysharing for friendship

We noticed early on in our work that when people exchanged stories of personal experience, the barriers between them fell away. A lady who had lived in a village all her life recalled the floods of her childhood, and one of our members had experienced the same event. Together they reminisced excitedly. The same thing happens when people with PMLDs share their stories - Linda shows a rose and opens her mouth while a staff member uses coconut shells for horse hooves - and we all feel shock at how her favourite flower was eaten. We laugh about it with her, and what was at first rather an upsetting event becomes one to tell and retell with friends. Horses also featured in a story told to his peers by a severely autistic boy: who had experienced a frightening event. The teacher was unsure if he would want

¹ <https://aeon.co/essays/once-upon-a-time-how-stories-change-hearts-and-brains>

to tell this story, yet he persisted. His teacher notes *'this was a really good way of dealing with an emotion that T. wasn't sure about - and we weren't either...'* When he subsequently came to class with a story about getting back on the horse, his pride and pleasure were shared by everyone, further validating his resilience in the face of challenge.

Storysharing and Decision making

Children learn to participate in society first by being included in family discussions which often arise out of personal experiences, and they take those skills into the classroom. For youngsters with special needs, two critical places for decision making are annual reviews and school councils. Storysharing enables students to be included in decision-making processes concerning their lives by bringing significant stories to their annual reviews. Co-narrated anecdotes about real things that have meaning for the young person can be powerful and pertinent; very different from a list of points being read from a sheet of paper on their behalf.

When we began in one school, a senior manager commented *'...at the moment, the students' voice is only a very very small fraction of the annual reviews. We have to listen to the parents, get through the paperwork, and problem solve....and hear what the class teacher has to say.'* We saw that often attending a review may be deemed too stressful for the young person. Providing appropriate support isn't just about making information accessible; it's about supporting genuine, valid contributions from the student.

In a PMLD class at Exeter House School in Salisbury, we worked with a class teacher and two non verbal pupils who prepared stories together for their annual reviews. Their teacher said *'I've got to know the children and it's helped me understand them and know them as people ...For our students, these stories are age appropriate and its personal. It gives them a voice - a lot of them don't have expressive communication to say things important to him.'*

S's story, about a new bath installed downstairs in her parents' house, was significant not only because she loved the fragrant Jacuzzi bubbles, but because as she was leaving school it meant her parents could continue to care for her at home.

Storysharing encourages repetition, which helps to build confidence, memory, and recall. We use all the young persons' communication toolkit to support their contributions. Familiarity with the story invites increased participation through interaction.

At Threeways School in Bath, P brought a story to his annual review. His teacher says : - *'He loved it and I felt he really grasped that to make it more funny for the audience he needed to emphasise that 'mummy tried to do it anyway and got vey wet! '... it was a positive experience all round, P shared his story with real animation and pride. It was great to see, and his mum and dad were really enjoying seeing his confidence. P really felt like an equal member of the team.'*

Here we also developed work with the school council. Grove and Chalmers (2014) describe how a boy with PMLD, supported by a Deaf peer, told his story of how the noise of chairs being stacked led to spasms, with a knock on effect on his health and comfort. This powerful contribution led to a rethink by youngsters who were at first unwilling to take responsibility for changing their habitual rush to leave the dining hall.

Civic inclusion

Storysharing has been used by Openstorytellers to promote active citizenship and civic participation. One example is the nationwide campaign against withdrawal of mobility allowance for people with disabilities in residential homes in 2011. Our company ran a public meeting specifically for people with PMLDs to tell their MP stories of how they used this money and what it meant to them, using karaoke, art and drama. We were not telling the stories FOR these individuals - they were up front, showing props, photographs and use of voice output communication aids. The MP, then in coalition, voted against the measure. Other projects we have run include sensory town planning; general election hustings, and an active citizens programme (Grove et. al., 2014)

In conclusion, we know that sharing personal experience stories is one of the most effective ways of forming and sustaining relationships, breaking down barriers and combating prejudice, and enabling marginalized voices to be heard in ways that can

be revolutionary. The techniques we use to support active narration by people with PMLDs are simple and cheap (though we won't deny that a Big Mac really does help!). Conversational practices that put people in passive roles (for example, rhetorical questions "You went to the circus, didn't you?") can be very entrenched, and take time and training to shift, but when that shift comes, the benefits are remarkable and longlasting.

For more information about Storysharing® training and practice, visit www.openstorytellers.org.uk. The latest film showing Storysharing in action can be viewed at <https://www.youtube.com/watch?v=B8V5iBeGGJs>

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