

Telling Stories Together

Prepublication version

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Introduction

If you have severe or profound or multiple disabilities, you are highly dependent on others to make your needs and interests known. There is increasing recognition of the power of peer support and co-production, particularly for self advocates (Duffy, 2022). However, most examples seem to involve people who have sufficient language skills (in whatever modality) to manage discussion, self identification, and reminiscence. Although people with high support needs sometimes take part, the main support strategies seem to involve either yes/no questions (eg. *Do you remember when we went to Birmingham?*) , or more informatively, presentation (eg. films or digital stories see Critten & Kurcikova, 2016). Is it possible for people with complex and severe communication challenges to take part more actively? In a funded project employing peer advocates, Storysharing® was used successfully to create enjoyable and meaningful group reminiscence, across residential homes in Somerset (Harwood, 2011).

Storysharing® is an intervention developed twenty years ago through observing how often staff told stories ABOUT people they cared for, and sometimes TO them (especially in schools where multi-sensory storytelling is common practice) but rarely, if ever, WITH them. When people recognise their own experiences in these anecdotes, we learn from each other, and build connective networks (Grove, 2014). The approach involves finding good stories that we can tell together, using all the resources available to an individual, + objects, photographs , video clips and simple communication aids. We tell directly to responsive listeners, who join in by actively reacting.

The project: Storysharing® partners with One Trust and Generate

Two charities in South London expressed interest in a project to explore how people who communicate nonverbally and have complex needs, could link up with people who are verbal communicators to tell stories together. One Trust (<https://onetrust.co.uk>) runs personalised day services for people with learning disabilities in South London, and specialises in providing meaningful services and quality care to those with complex needs. Generate (<https://generate-uk.org>) supports young people with learning disabilities and autism to lead fulfilling lives and form social connections. Both charities were enthusiastic about the opportunities to interact, to learn more about communication techniques and to find ways of collaborating.

The team

Two staff members (Luke and Josefina) and two members (Gary and Michael) volunteered to take part from One Trust. From Generate, one staff member (Chiloshe/Chiz) supported two young people (Kai and Rio). Nicola facilitated the group.

Consent to take part in sessions and in writing this article was negotiated with each person individually, using accessible forms. All participants were capable of providing informed consent.

We have been meeting online each week for an hour since March 2022. The meetings are recorded and the films used to evaluate sessions and plan for the next.

Organisation of the sessions

Before the project started, the Storysharing Partners were each provided with a Big Mack communication aid. This established a level of equality between them. Early sessions focused on ways of communicating. We quickly established a structure. Sessions begin by Michael checking that everyone is happy to be recorded, holding up an image of a record button. Next, each partner poses a question, pre-recorded on their Big Macks. These started as very simple "What did you do this week?" , but soon developed into stimuli for stories .. "What was the best thing that happened this week and what was the worst thing?" "If you were an animal, what animal would you be?"

The main starting point of the project was to make memory boxes into which people could deposit a few items that meant something to them. We introduced ourselves by sharing likes and dislikes, and some of these went into the boxes, which the two Generate advocates made enthusiastically for themselves, and One Trust staff made with Michael and Gary. There was a lot of imagination and thought put into these, but as important as the items were, it was the stories behind them that we wanted to uncover. For example, football was a shared passion for Michael and Kai, who both support Chelsea, but a definite thumbs down for Rio, who revealed that she had been hit in the face by a mis-kicked football when she was 8, and had lost a tooth.

At the end we recapped what we had done and made plans for the following week, with the support staff giving up a great deal of time and imagination to prepare, collect resources, make boxes, and remind the advocates of what we were doing (around three hours a week).

Process: news into story

News often amounts to an exchange of facts, but often a story emerges spontaneously. This was the case with Gary's news about having a new haircut, an important event for him, as one of the key aspects of his identity is that he likes to look smart. Another support worker said that his hair had been "un-combable"! Recording this one word on the Big Mack meant that Gary could provide the punchline to his own story, which he did at the right moment and then repeated, with everyone laughing in encouragement. Kai also used his Big Mack to put in a question "What style would you like?" To which Gary spontaneously replied "uncombable!" Gary also touched his hair as the story was being told.

Retrieving this kind of spontaneity is challenging, but a necessary skill if people are to become accomplished co-tellers. We discussed, planned and rehearsed small stories to give as much opportunity as possible for everyone to take part.

Moving into advocacy

In peer or group advocacy, people with a shared interest come together to support each other, in campaigning, protesting, making views heard in a particular forum,

or socialising in a space where they set the agenda and feel valued (Anderson & Bigby, 2017). In all these situations, the relationship between the advocates and those they represent need to be based on deep knowledge of, and trust in, each other. Sharing stories each week, finding out how we can contribute to and co-tell our experiences, enables relationships to be built very naturally, and provides the foundations for tackling difficult issues.

One such is the issue of loneliness, which was one we all felt strongly about, and has indeed been shown to be pervasive for people with learning disabilities, being exacerbated during the pandemic (Gilmore & Cuskelly, 2014; Tilley et. al., 2020). Loneliness had come up early on, for both Kai and Gary who identified this as something they hated. Kai had a story for his memory box about how isolated he had felt during the pandemic, and this is our next theme. Rio, who is a drama student, has improvised "loneliness" for us by wrapping herself in a duvet and looking sad. We are also exploring stories of independence and choice.

Evaluation

Nearly three months into the project, everyone is enthusiastic. Meeting online has been a challenge, but has enabled everyone to take part regularly. The benefits for the peer advocates are really noticeable. Kai and Rio have shown great commitment in their attendance, have found nothing too difficult. Rio said "I really enjoyed sharing experiences with Gary and Michael, which then helped us all to tell stories together. I learnt that Gary and Michael have many interests that they were able to communicate and share with us. For a project like this to work you need a BigMack, you need openness and creativity". Kai said "I have learned that Gary or Michael love coffee. When I met Gary and Michael I would have never thought they would like coffee. For this project to work you need trust and friendship."

Chiz made the point that although Kai's remark about coffee may appear insignificant, it is actually a very important observation. When we recognise the preferences, experiences and aspirations that we share with others, barriers start to crumble.

For One Trust, Luke and Josefina reported that Gary and Michael have been really enthusiastic about coming each week, they look forward to it (both

raised arms and smiled as we discussed this). “The networking and learning how to use a switch has been particularly valuable, We have been really surprised by how successful the storytelling together has been. It’s been such fun and we really want to do more here”. It’s important to realise that though the process looks very simple and intuitive (and is!), it involves a great deal of careful observation, an open willing attitude, commitment to equality, and dedicated imaginative preparation.

Moving forward

It has been so obvious through the project that, with the right support, people with very high support needs really can share actively in the telling of stories - both their own and those of others. They teach us how to pause, how to value small things (like enjoying coffee!). We are continuing to meet, now with a focus on how we can reach out to others to share what we have learned.

If you are interested in learning more about the project, or training as a Storysharing partner, please email info@storysharing.org.uk

Training resources for Storysharing® including free introductory courses, can be found at <https://storysharing.thinkific.com>

References

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