Storysharing in Somerset Final Report



Storysharing project 2008-2011

FINAL EVALUATION REPORT Somerset Learning Disability Partnership Board Jane Harwood Project Leader



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years

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OPENSTORYTELLERS Storysharing project FINAL EVALUATION



2008-2011

'Creating a narrative culture of storysharing across Somerset.'

....It's a terrific success, it leads on to other services, we want to see it succeed and grow' - T. B., January 2010.

'Innovative'; 'Moving'; 'Uplifting'; 'Really really useful!' – delegate feedback from the Storysharing conference, May 2011.

1. Background to the project

Storysharing was already established as a worthwhile and effective activity at the outset of this work. Previous funding from the Esmee Fairbairn Foundation had enabled the Unlimited Company (now Openstorytellers) to pilot the work in locations across Mendip.

This storysharers' project sought to extend the reach of this intervention across the county and, in effect, create 'a narrative culture of storysharing in Somerset.'

The agreement sought to build a partnership between Openstorytellers and LD services within the Somerset Community Directorate.

The project set out to reach nine locations across the county. Embedding staff training in each of these locations would enable sustainability. A team of peer mentors with moderate learning disabilities were recruited and trained to co-deliver the work.

The project was delivered and managed mostly by Jane Harwood, on behalf of Openstorytellers. Dr Nicola Grove, director of Openstorytellers, oversaw the running of the project, and led one course.

Somerset LD services team member, Carol Pearce, was seconded to the project, and trained as a tutor. Carol led a course in West Somerset.

Contacts with the steering group (representing Somerset), team leaders and nominated team members were of paramount importance.

For the tutor / project manager, concerns about issues of personal capacity (health, and logistics of delivery across a large area - fortunately, never really a problem, except for a few bad weather postponements) were countered by

a privileged overview, across three years, of how storysharing can work across the county.

This project was an opportunity to reach many lives and communicate effectively with people who have profound and multiple learning disabilities in ways which, when given the correct support from within the service, could effectively make change.

This final evaluation report seeks to summarise the impact of the work for people with learning disabilities and their families, reflect on difficulties encountered, consider what changes could have been made, and make suggestions for sustainability.

2. Creating a community of storysharers: team members, tenants, service users – ownership.

Providing opportunities for service users with high support needs to recall and share significant personal experiences and develop friendships with others.

The nine courses were a foundation for creating a 'narrative culture of storysharing', but being discrete, more work was needed. The project manager felt that the establishment of a community of

storysharers should be the lynch pin of the work.

Regular team meetings, newsletters, extra and additional training, informative visits to team meetings, and a full-scale conference were provided to bolster this community.

At the team meetings, service users were provided with regular, bi-annual social opportunities, enabling them to share their stories with a wider circle of friends:

"...the big groups, when everyone gets together, encourages houses to meet up and allows service users to have worthwhile trips out and allow them to see people who they know but may not often meet." P. B., DTL, Greengates.

This storysharing network also facilitated interaction between team members (whether or not they were trained in storysharing) to exchange news and ideas, and create links. Project workers could assess impact and progress, and gather ideas for improvement.

Storysharing can be used a catalyst for bringing people together – Orchard Bungalow (Taunton) had two parties and a picnic, inviting people from Camden Road (Bridgwater); the Eldermere (Shepton Mallet) group regularly meets with people from Delmore Road (Frome) and Old Wells Road (Shepton Mallet).

'The socialisation that results is superb.' T. B. (Network manager, steering group member).

3. Storysharing in action

'assisting people with a severe learning disability to communicate through the process of telling stories and participating in the story using whatever communication is appropriate'

'What impressed me about the story sharing was that it was not discriminatory regards disability; on the contrary, at Orchard Bungalow it was very much allencompassing irrespective of disability and communication barriers. An example of this at Orchard Bungalow was supporting an individual who had acquired acute dementia - this didn't exclude him from participating in sessions; with a little support from staff and making changes to the story sharing format he was able to take part with great success.' (S. L., TL, Orchard Bungalow, steering group member)

Openstorytellers' mission statement is 'for people with learning and communication difficulties to be heard, understood, included and valued'.

3.a -Impact on the lives of individuals.

(For more information on this subject, please refer to the annual reports.)

Each individual beneficiary of the storysharing project underwent a baseline referral, and was consequently assessed by the tutor against consistent criteria for evidence of change.

Staff provided written feedback at the end of each session, and were interviewed at the end of each course, and during follow-up visits, to assess longitudinal impact.

A sample of the many observed examples of the impact of storysharing:

- Storysharing was 'a very good way for J. to talk about new experiences.'
- T. showed concern for others, and had an idea: 'can I take L. on the train, to Paignton zoo?' Team members noted this idea for next year's holiday.
- 'M. really surprised me' said one team member. '...amazing .. sitting in, interacting playing his drum. He's enjoying it: he looks happy.'
- G. became 'chatty. Comfortable comfortable enough to say 'no".
- "I can't remember other occasions when service users have willingly sat together – so unusual. It's really exciting! I wouldn't have believed it! It surprised me.' – N., team member.
- J.: '. People with profound learning disabilities don't know how to have a conversation but this gives everyone a right to do this makes friendships between everyone.'
- 'it gave D. an air of her own importance. It's a good example of confidence being built by an activity.'

The storysharing project trained, and was co-delivered by, four peer mentors with learning disabilities, who developed friendships with tenants and staff. Each peer mentor was paid for the time they spent delivering sessions and attending training.

This was the one area where the project did not meet original targets, which were to recruit and train 6 - 8 peer mentors. Regarded as a pilot idea within the project, the use of paid peer mentors was well received by houses and tenants. Consistency, a degree of independence and reliability were recognised as key qualities for peer mentors. Having finally recruited an established team of two efficient, trained mentors it was considered better to continue to build their skills rather than bring in new recruits. They have both now moved on to training in arts administration.

Peer mentors say 'it broadens your horizons, and outlook'; that 'the experience helps you deal with daily life issues'.

Being a peer mentor makes you 'adult in your expectations - supporting staff to run sessions - taking things seriously – having more control.'

3.b. - the broader impact of storysharing

'I have regular feedback and teams seem to be really excited about the progress, so my only comment would be it's wonderful work, helps us as a service enormously in supporting service users in having their say about a number of issues and it further encourages interaction and having fun together.' T. B.

The project has proved storysharing can have impact on the daily life of service users with profound disabilities, beyond the remit of dedicated sessions.

Tenants are using storysharing to speak about issues they are facing. ' Storysharing has built individual's confidence and self esteem. It goes a great way in ending social isolation within the home. Communication skills have improved, and turn taking whilst in conversation, showing respect to others.

'Orchard Bungalow is a Supported Living home and owned by a Housing Association; Story Sharing now involves talking about housing related issues that effect them as being 'Tenants'. (S. L).

Tenants at Orchard Bungalow now have mini-macs (communication buttons) in their rooms, where they can record complaints that are then shared at tenants' meetings.

There were reports of improved communication for service users: 'Staff at Eldermere have noticed that recently, two service users have been using verbal communication more and more and appear to have a wider vocabulary. Their families have also commented on this. As you are aware we have been putting in a lot of communication tools for people who live at Eldermere, however, I am sure that the story sharing sessions have really supported this.' (S. S.)

Improved skills for team members:

A.: 'it's made a difference to my work – communication – it's bonded my relationships with the individuals. Story sharing has enabled this – I'm too busy otherwise. It's built a trust element. I have seen things I wouldn't have

seen about service users otherwise. It gives each person importance – puts a spotlight on them – it's made our interactions more valuable. Often, people who are the loudest get the most attention. So, it's about allowing time. It's made me more aware of everybody's abilities. And it's made me more keen to build on those abilities.'

N.: 'I learned to understand K. better – all the service users here, actually.'

Storysharing also has an impact of relationships with families. Story cafes gave families an opportunity to come and be involved in storysharing. With this understanding, they could then appreciate the need for story gathering.

'T's family has been brilliant with his life stories. It has been a great chance to learn about his past, and Sandhill. It prompts you to find out more about people. Life story work is fascinating.' – team member, Sunnyside. 'Precious moments which should be treasured' – Bridget, P's sister. At Cliffe View, B.'s brother came to the story café. He said: 'you've started something really good.' Team members noted: 'It's a really lovely way to have families involved.'

Parents not directly involved in the project began to hear of its impact – the conference enabled others to understand the work. 'I am not surprised there is high demand for the work you are doing - it sounds so interesting. And there is such a need to enable people like J. to have new ways to express themselves.' – C. de H. (Parent)

4. Delivering an effective project: learning gained

Provide training and increase awareness of staff, volunteers, advocates and carers to adapt to the skills of a person with learning disabilities to create space that will allow them to contribute.

4.a.- Communication between service providers and service purchasers

The storysharing project was a large piece of work that sought to give coordinated, consistent, good quality, equal access to the activity for service users and staff across the county.

A considerable amount of co-ordination, planning and problem solving went in to the delivery and smooth running of the project.

The initial letter of agreement stated that the service purchasers would provide:

- Access to centres and homes where service users with profound disabilities are present.
- Awareness of the project at each level of management of the service.
- Commitment to support the delivery of the project
- Recognition of the significance of narrative culture at the level of policy and target setting in the service.

The steering group was the pivot for this relationship, providing the project manager with a platform for reportage, advice, problem solving and guides to protocol.

As stated in the contract, four reports to the steering group were written each year.'the quarterly review will focus on day-to-day issues of the Delivery of the Service. The Service Providers will be expected to provide a report for each review covering Expected Outcomes/Targets of the Service as set out above.' It often proved difficult to convene the group because of the vast amount of other commitments the group members had to deal with: by the end of the project this group had become virtual and communication was mostly one sided, with reports being sent by email.

Hosting the Storysharing project has required a certain amount of trust on the part of the Community Directorate – the project team have needed to conduct baseline referrals, in depth observations of service users, one-to-one interviews with staff and team leaders: also a need access to peoples' homes and information about their lives.

Openstorytellers always respect the individuals' right to privacy – in addition, the storysharing project contract required compliance with legislation on personal information.

Running an embedded project, as an outside agency, has inherent issues - delivery inevitably touches on issues of confidentiality, and requests for information can run into closed systems.

Openstorytellers would like to acknowledge the warm welcome they have been afforded across the county when entering peoples' homes, and the amount of time and support they have been granted by team members and team leaders in interviews, communications, and meetings.

4.b. - Peer mentors

The target for trained peer mentors was initially 6-8. Thirteen potential mentors attended the recruitment day – three were recruited, and one came into the project following a later referral.

The project finally accommodated four peer mentors: one based in Taunton, one in Yeovil, one In Wells and one in Street.

It was seen as more important to deliver this strand effectively than compromise to include more people. Particular skills were needed, plus independence, good health, and the ability to be reliable. Training was peer based and quite intensive.

Peer mentors one and two found the work challenging in several ways: peer mentors three and four enjoyed the work and were keen to continue. They have both now moved forward into further related training, with the prospect of fully paid employment.

Supporting peer mentors with learning disabilities requires an understanding of, and access to, the networks that surround them. Links have to be made

with social workers, work preparation managers, housing associations, key workers, families, and transport services. It was not to be assumed that each individual in this network would know about the storysharing project, or understand the need for information exchange.

- Peer mentors reported they felt that sometimes
 - There can be problems with GES / training / placements

• *Felt nervous about independent visits – transport; finding places* Issues sometimes arose about consistency, commitment, and availability.

Transport arrangements were hard to manage and often peer mentors could feel let down.

Protocols for booking transport changed at short notice in July 2010, when social workers were no longer required to manage bookings. This information was not passed on to the project manager, until transport failed to arrive.

The project manager would always provide transport herself whenever possible, rather than rely on outside agencies. This added to the workload but allowed for reliability – and also (coincidentally) saved money.

Missing or misdirected invoices for transport costs caused problems for the project accountant.

Miscommunications have also resulted in confusion over pay and benefit entitlements.

As an outcome of this project, Openstorytellers worked closely with Work Preparation Services to draw up template contracts for the paid employment of service users.

4.c.- Partnerships: SLT, STC, I.I.

Partnership working was anticipated between Openstorytellers, the Speech and Language Therapy service, and Somerset Total Communication. It was agreed that these partnerships would 'develop an inclusive communication environment (ICE) within the bounds of Somerset County Council policy and practice'.

During years one and two of the project, Openstorytellers' tutors delivered independently commissioned communication training to staff across the county.

The key contact for SLT, Tracy Rose, left the service in year two of the project: from this point on there was no nominated replacement to represent SLT services on the steering group.

The project could not have been delivered without the support of Somerset Total Communication. Constant use was made of resources (DVDs, symbols) in compiling resources for story packs, newsletters, and accessible information for service users. STC developed dedicated story-based symbols in consultancy with Openstorytellers. Originally it was thought that STC based story kits would be useful for storysharers. As the project developed it became apparent that a general use of resources was more efficient – communication aids, taking photo albums, STC based templates (including some developed by houses in response to the activity). Each house that received a course was left with a comprehensive resource pack. Storysharing packs, including story-gathering templates, were distributed beyond this network, across the county. STC also supported Robin Meader (Openstorytellers) in the acquisition of graphic facilitation skills. Robin uses these skills to create storysharing resources and was artist in residence at the storysharing conference.

Openstorytellers also agreed to encompass the values and working ethos of Intensive Interaction within the project.

Team members often remarked on the similarity between Storysharing and Intensive Interaction, seeing the two as complementary skills.

Overlaps between the two disciplines include, most significantly, responding to and joining in with the behaviour of the service user; repetition; building content and flow by allowing the service user to lead and direct – learning to share attention with another person.

Storysharing extends this by including others in the relationship – building community through communication.

5. Delivering an effective project: issues encountered

As the project rolled out it became apparent there were certain issues that were going to recur across the county.

Staff capacity for successful support of the courses was the most common barrier to the successful hand-over of the work from tutor and peer mentor to staff.

Illness, annual leave, and short staffing levels all worked against creating dedicated, trained, storysharing leaders.

'A very valuable course - we are finding it difficult to sit down with tenants and give them the time they need and deserve due to staff shortages and heavy workloads.... We would like you to visit more regularly to ensure the group continues...' Team leader.

On occasions this situation could engender poor communication. Internal confusions resulted in wasted time – visits not expected, key dates not written down in diaries and daybooks, people not available for meetings scheduled, tenants out on other activities, stories not gathered, forms not returned, referrals not completed. This could be confusing and upsetting for peer mentors, especially when they were visiting houses independently.

This problem noticeably escalated as the changes and cuts associated with internal re-structuring began to take effect. On the final follow up visits, it was often the case that staff had been re-deployed or were simply not available: those taking their places had no experience or understanding of storysharing - all barriers against the aim of creating a narrative culture of storysharing.

'I am hoping that this project can ... continue as I think it has made a positive impact on people's lives.... I fear that the project may not survive as it could get pushed aside due to the large amount of other pressures on the houses.' Team leader.

6. Making storysharing a success

'Enabling people with severe and profound learning disabilities to be empowered to have quality experiences that they can recall and share to build friendships and relationships within the learning disabled community of Somerset.'

If applied correctly, storysharing is an intervention that can empower people to have quality experiences – by re-enforcing the moment, by sharing with others, by using appropriate tools, and by repetition.

Through hearing about the lives of others, we get to know them better: by sharing stories of our community, we appreciate our place in that community.

The storysharing project brought together groups of people who live together, and in many cases, friends from other locations, on a regular basis. Staff feedback identified this as 'quality' time:

- "Because communication is part of what we do 90% of our job it's got to be positive. Nothing worse than people sitting in silence staring at the wall.' (Rhydderch House)
- 'The fact that we're all sitting together as a group that's really important – people say there's not much going on but there's all sorts of communication going on. The interaction between the tenants is nice.' (Cliffe View)
- 'It was nice to have time with the guys intensive communication.' (Vesuvio)
- 'I can't remember other occasions when service users have willingly sat together – so unusual. It's really exciting! I wouldn't have believed it! It surprised me.' (Eldermere)

Team meetings extended this, opening doors to storysharers old and new. The community grew as the project went on and the boundaries expanded. Favourite, key stories (The bus stuck in the mud, Meeting Prince Charles, etc.) were shared with large groups, remembered and taken away. Peoples' ability for recall was evidenced.

'The big groups, when everyone gets together, encourages houses to meet up and allows service users to have worthwhile trips out and allow them to see people who they know but may not often meet.'

Storysharing was taken up as an effective tool for tenants' meetings. 'Story Sharing now involves talking about housing related issues that effect them as being 'Tenants' - Stephan Law.

Team members reported that '*Communication skills have improved*' as had '*Turn taking whilst in conversation*' and '*showing respect to others*'.

'Until last week, I didn't even know K could make a sound!' - staff, Mendip.

Louisa Whait, Mencap National Manager (PMLD National Support Unit) noticed this when she gave a keynote speech at the Storysharers' conference. Afterwards, she wrote to say:

'Thank you for inviting me to speak at your event last week. The day was fantastic. I have been to a number of events which aspire to meaningfully involve people with learning disabilities but often fall short with professional's taking over and having conversations which eliminate the involvement of people with learning disabilities and their families.

The day was truly inspirational as to how to hold an event where everyone present - families, people with learning disabilities and professional's were learning and sharing on an equal basis.

It was true testament to the power of Storysharing that people had developed in confidence enough to actively participate in my presentation bringing a much more interesting and surprising dynamicwithout prior planning!'

7. Storysharing in Somerset - the future

Outcomes and action plan for ensuring work continues from the learning gained.

The entire project can be seen as a toolkit for sustainable storysharing in Somerset.

Every part of the work delivered was about imparting skills towards creating the 'narrative culture' of storysharing.

Training adults with moderate learning disabilities as peer mentors capable of independent visits enabled gentle hand-overs from tutor-led to staff-led sessions.

Each course began with staff induction, supported staff in experiential learning, and ended with face-to-face interviews. Everyone involved was offered free access to regular meetings and extra training. Add-ons included top up days, one-off visits to extra locations, and talks at team meetings.

End of project research demonstrated that three locations were storysharing regularly, three regularly but infrequently, one occasionally, and only one – the resource centre – not at all, due to changes in team leadership and redeployment of staff.

Of those that had adopted the activity, all were using it in ways that had adapted to the needs and profile of the tenants and staff – in other words, it had a life of it's own – beyond the project.

7.a.Conclusions - what ensures effective storysharing?

Barriers to effective storysharing were identified by one team leader:

- What is key for successful Story Sharing is sufficient Story material; this may require planning before hand. Some staff find it difficult to think on their feet
- Those leading story sharing have to be gregarious and put aside any inhibitions and to be motivated.
- Commitment on behalf of the team to ensure SS happens
- Keeping those participating engaged, therefore keeping SS interesting.

This was backed up by the findings of the project manager.

7.b.Recommendations – for future sustainability

S. S. (TL, Eldermere, also steering group member) emphasised that 'sustainability should be tenant based - not least because staff move on. Members of existing groups could go out and act as ambassadors for additional groups. This creates opportunities to meet new people and avoids stagnation.'

As an outcome of this project, Openstorytellers will run a course for self advocates to test out the possibility of establishing a small group of people with severe/profound disabilities who could be paid to participate in storysharing training courses for professionals.

Openstorytellers recommend:

1. Staff involvement and understanding

Storysharing is most successful when the *whole* staff team (members and leaders) are behind it, and understand the need for (and the definition of) personal stories.

2. Regular sessions

Changing rotas mean that the nominated staff pool needs to large enough to ensure consistent delivery – this enables the activity to become regular, familiar and entrenched.

In all cases where storysharing has become a regular activity, the team leader has ensured it is included as a regular activity in rotas.

3. Effective story gathering

The *gathering* of stories needs the whole staff team behind it. Any person, at any time, may witness a reportable story unfolding: that person should know how to enforce the event, and record it for others to share it. (Story templates

were provided, and many different gathering methods developed by participating teams – boxes, books, wall charts etc.)

4. Choosing the right team

Those responsible for leading sessions should be energetic, committed and enthusiastic. It's not really a job for someone who is shy! Creative minds can find many applications for storysharing. 'The group has been out to the park and to the beach for a couple of sessions in the summer and went out together for a Christmas meal. All of which have been very successful' – Eldermere.

In some locations dedicated leaders are brought in on purchased hours. For this to work well the responsibility for story gathering needs to lie with the whole staff team.

7.c.The future – implementing Storysharing as part of ICE

Following the conference, an end-of-project meeting was held between David Dick and the Openstorytellers management team. It was agreed that the aim of the next phase of the project is to ensure sustainability and growth through:

1. Embedding the approach within existing service framework, through the inclusive communication environment. This would involve setting up coordinators who could then deliver training and oversight. Future action on this lies with the Community Directorate.

2. Providing time limited support from Openstorytellers to keep the momentum up through a series of visits to the lead homes.

3. Involving volunteers, training them in the approach so that they could run groups.

4. Training a small group of peer storysharing leaders. These would be people with severe and profound disabilities who have shown a real aptitude for and enjoyment of storysharing. They would be involved in training the volunteers (by taking part in and demonstrating, storysharing) and would be paid for their input. Openstorytellers have funding for this aspect of the training. Two storysharing peer mentors will take a lead role in the training.

7.d.Summary of aims:

- Storysharing co-ordinators identified and trained

- Hubs for storysharing set up in the four regions

- A network of volunteers would be trained in storysharing, starting with those attached to houses

- Storysharing training is delivered in house (as with intensive interaction)

- A small group of peer leaders would be confident in working as participants in training contexts.

Openstorytellers envisage they would need to be involved long term in monitoring the quality of the training, which would be CPD accredited.

8. Conclusions drawn from the project

'I have seen this make a difference with peoples lives...... It is a scheme that can be run in the houses themselves and encourages the service users to communicate with each other, to communicate with staff and to help with memory. Also, the service users can become very much integrated with the storysharing group, coming out of their shell somewhat when they feel comfortable with those around them and the fact that they can see that they are contributing and getting their point across.' P.B., deputy team leader.

Starting from the consideration that *everyone* has a story, and a need to share that story; that listening is an active skill; and that people with a range of profound disabilities may need support to engage in this process – has this been an effective piece of work?

An 'effective project' could be considered as one where the intervention is felt to be 'owned' by those who participate, and the legacy is sustained use of the intervention beyond the remit of the project.

Openstorytellers believe that the evidence gathered over the course of three years storysharing in Somerset shows that in the majority of instances service users have engaged and met personal targets as a result of being involved in courses.

There have been no instances of people choosing to opt out of courses, and many un-nominated service users and staff have been included through meetings, gatherings and the conference.

The target for staff involvement has exceeded targets.

In eight out of nine instances the activity is on going – including groups who are now three years past the original intervention.

Most significantly, the activity has continued to grow and change to suit the needs and skills of those delivering it. Creative ownership of the activity has enabled it to become a vehicle for core values - interaction, choice, friendship, and tenants' issues.

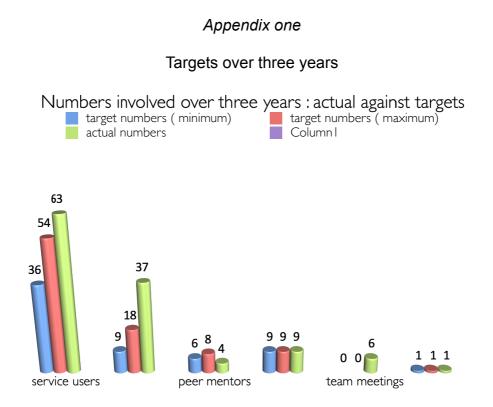
This could be regarded as a 'narrative culture of storysharing in Somerset.'

There is a lively call for more access to the activity, and requests for regular support.

Openstorytellers believe it is essential to provide some support systems to enable storysharing to continue to grow across the county.

Most crucially, this support needs to be organised and steered effectively, with appropriate training systems in place, to ensure that the original ethos and integrity of storysharing holds true.

Jane Harwood For Openstorytellers August 2011



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	Melissa Smith (British Institute of Learning Disabilities)
Peer mentors:	
	Jane Hughes James Souchet Clemma Fleat Katie Branch
Steering group:	
	Terry Binding Pam Woodburn Tracy Rose Stephan Law Sharon Scott
Participating houses / centres:	

Orchard Bungalow, Taunton Eldermere, Shepton Mallet Rhydderch House, Crewkerne St James' Resource Centre, Yeovil 1, Dodd Avenue, Wells Cliffe View, Cheddar Vesuvio, Westonzoyland Sunnyside, Williton 80, Camden Rd (Rowan), Bridgwater

Associated houses / centres

Old Wells Rd, Shepton Mallet Charlton Rd, Shepton Mallet Mawbry House, Chard

Whilom, Chard Greengates, North Petherton Lowermead, Dulverton Pepperall Rd Community Group, West Huntspill

Openstorytellers would like to acknowledge the input of families who supported the project by sharing stories from their personal histories, and who came to story cafes and meetings.

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