



OUR SOCIAL NETWORKS: EVALUATION FINAL REPORT

The importance of
friendships and
relationships for people
with a learning disability

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Executive Summary

This is the final evaluation report of [Mencap Cymru's Our Social Networks \(OSN\)](#) project. OSN was funded by the National Lottery Heritage Fund (HLF) to improve inclusivity in the heritage sector and use the technique of oral histories to improve the awareness, attitudes and services around friendships and relationships for people with learning disabilities, and to improve inclusivity in the heritage sector.

From 2017 to 2021, OSN worked to:

- capture and preserve the heritage of people with a learning disability, a voice often absent from heritage and society more generally;
- improve understanding of, and support for, friendships and relationships for people with learning disabilities, by collecting and sharing their oral histories around this theme;
- enhance inclusion and access in the heritage sector;
- provide employment and create models of support for adults with learning disabilities.

Oral histories around friendships and relationships for people with disabilities

OSN collected 40 oral histories around friendships and relationships from 59 people, most of whom were adults with learning disabilities. This exceeded the original target. More were planned for 2020, but could not proceed because of Covid -19. However, 10 additional recordings were undertaken, focusing on the impact of the pandemic on people with learning disabilities. All the oral histories were transcribed by OSN and, where consent was provided, OSN arranged for these to be made available at the National Repository in St Fagan's National Museum of History, in Cardiff. The project hoped that the oral histories would improve attitudes towards, and services for, people with learning disabilities. From these narratives, OSN created and toured exhibitions across Wales, conducted a thematic analysis, produced three short films and presented these and the emerging themes to a range of audiences across Wales. The first film highlighted six people with a learning disability retelling their oral histories to camera. The team also commissioned animators to create two short films: one highlights the scope and benefits of collecting personal narratives from people with learning disabilities; the other provides tips on making museums more accessible.

The significance of friendships and relationships and challenges faced

The oral histories highlighted the importance of friendships and relationships for people with learning disabilities, how these boost people's sense of self-identity, promote well-being, provide substantial benefits, such as mutual support and acceptance, and help people feel part of the wider society. However, these first-hand accounts also shed light on the substantial day-to-day challenges people faced in simply meeting people; having a social life; being allowed to spend time with friends or loved ones; the pervasiveness of bullying when young; continued social exclusion as adults; the low expectations of others in this area; and the level of control exercised by service providers, support staff and families over people's friendships and relationships.

Such barriers were often coupled with a general blind-spot and others' fears around intimacy, sex and sexuality and presumptions made around lack of capacity, all aggravated by an individual's lack of education, agency and autonomy. The OSN project framed the issues raised in these oral histories in the context of human rights, health and well-being. OSN argued that if agencies, professionals and families do not actively support people with learning disabilities to have friendships and relationships, then they are actually preventing them exercising their human rights, which also has a profound negative impact on their health and well-being.

Sharing the oral histories

Over the three years, the project shared the oral histories in innovative ways to a range of audiences in different towns across Wales. Six pop-up exhibitions were organised, mostly in non-conventional sites, such as leisure centres, cafes and vacant high street shops. In the third year, OSN designed scattered exhibitions in two towns. These enabled the public to listen to the stories through an app designed for mobile phones and tablets, or at listening posts scattered around the towns. Further exhibitions scheduled for 2020 had to be shelved because of Covid-19.

OSN responded to the disruption created by the pandemic by negotiating to take over other agencies' social media platforms for a week to share some oral histories and project findings, and engage new audiences from the respective agencies' social media followers. These social media 'take-overs' were agreed with Cardiff Story, Wrexham and Abergavenny museums and some social care agencies. While the museum work went ahead, the furloughing of OSN managers in early 2021, in response to Covid-19, delayed the social media take-overs of the social care organisations until May 2021. Of the three participating museums, Cardiff Story did the most posting and this attracted a relatively high rate of engagement.

Exhibitions were accompanied by five, fun, story-telling events: 'Disastrous Dates' and 'Smutslam', and a music and cabaret evening with Drag Syndrome. Although light-hearted, these focused on the themes of friendships and relationships and brought together audiences of disabled and non-disabled people as well as professionals. Over the three years, but especially in 2020 and 2021, OSN shared the key messages from the oral histories in 32 seminars, workshops, film sessions, presentations and meetings with service providers, policy makers, politicians, people with learning disabilities and carers. Dissemination plans for the final year were substantially changed because of Covid-19, and converted to online formats. These worked well and helped reach a diverse audience.

Impact of the oral histories, films and presentations

Overall, the reception to the oral histories and the presentations based on them was overwhelmingly positive. Audiences reported that the narratives provided new, poignant and sometimes distressing insights around lives and issues they generally knew nothing about. Many said that the exhibitions, films or presentations helped them appreciate the multiple, and layered, barriers faced by people with learning disabilities in simply pursuing a social life, friendships or relationships. Professionals and service providers who provided feedback found the points raised, especially around the significance of friendships and relationships and the challenges faced, eye-opening and moving. Policy makers and service providers said that although they were already somewhat aware, the OSN work helped them realise how commonly friendships and relationships were ignored and did not get the priority or support they deserved. This work exposed the need for much better staff training, support and guidance as well as improvements in service design and prioritisation. Professionals felt that the personal narrative form offered great opportunity to help understand service users and their needs and priorities. It is too early to know how any of this might translate into improved services, attitudes or outcomes for people with learning disabilities, but OSN has provided stark evidence on the need for change as well as detailed recommendations.

Improving access at museums

Another major arm of this project was to improve inclusive practice in five regional museums. Four adults with learning disabilities worked as 'Ambassadors' in partnership with the heritage staff in these museums. They networked with local disability groups to evaluate access and suggest improvements. Unfortunately, this work was interrupted by Covid -19, just when it was beginning to bear fruit. Nonetheless by then, it had succeeded in gaining some focus on inclusion and access in its

broadest sense, e.g. to include sensory, cognitive and wider physical needs, and see beyond wheelchair access. OSN produced a film for the heritage sector providing guidance around inclusion. The project's model demonstrated the value of working collaboratively with disabled people and how adjustments in attitudes and small or cheap changes can make a significant impact.

This arm of the project also provided substantial insight around employment matters. The Ambassadors and Project Officer had a wide range of abilities and needs, little or no previous employment experience and varied links with local disability groups. They required much more guidance and support than originally anticipated, particularly in understanding the role, planning work, personal confidence and using computers. The limited hours allocated for them, their support staff and the museums was found to severely curtail what could be achieved and did not match the inherent expectations. The Supporter role emerged as critical. Supporters' assessments, responsiveness and assistance helped the Ambassadors develop personal and work-related skills, alongside the project work. As well as achieving outcomes with the museums, the Ambassadors enjoyed working on OSN. They and others reported many positive employment-related and personal outcomes, including improved skills, confidence, communication and independence. Worthwhile learning points also emerged for OSN, especially around planning employment projects for people with learning disabilities and collaborative projects with the heritage sector.

Adapting to the Covid -19 pandemic

The project gained momentum and built on experience and expertise gained each year. Unfortunately, Covid-19 struck just when much of the groundwork was bearing fruit, for example widening the reach of oral histories, disseminating findings, influencing policy and practice, inviting disability groups to visit and embedding work at the museums. The pandemic and social distancing restrictions forced a complete redesign of all the plans made for the third year and many aspects had to be cancelled. It put paid to the work done to gather more oral histories, just as this was beginning to snowball; the Ambassadors' work to improve inclusivity at museums; and the scheduled exhibitions, events, meetings and other activities to disseminate the findings. The pandemic forced OSN to end the Ambassador and Supporters roles earlier than planned. In early 2021 the two remaining staff were furloughed, and the project paused for three months. However, OSN and NLHF responded in a typical agile manner. Timescales were extended, the project collected 10 narratives around Covid -19's impact on people with learning disabilities, and the exhibitions and seminars were converted to online and social media formats.

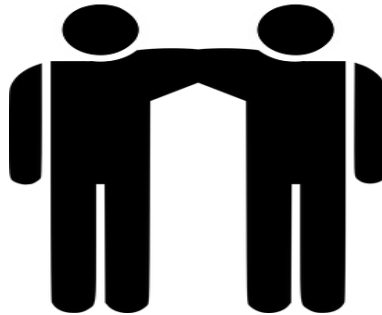
Overall, OSN proved an innovative and necessary intervention and created a thought-provoking bridge between the heritage and social care worlds. The project responded creatively to the many unexpected challenges emerging, not least the global pandemic. OSN's oral history work highlighted the enormous potential and benefits of personal narrative, and the extent of the barriers faced by people with learning disabilities. Through airing the voices of a group who are generally excluded from society, and an issue which is often brushed under the carpet, OSN demonstrated the need for much more support to help people with learning disabilities have meaningful social and emotional connections and to ensure their human rights are upheld. OSN illustrated that expectations and standards in this field need to be raised and that this will require significant improvements in the education, support and training provided to relevant staff, service providers, service commissioners, as well as to disabled people. Disability access and inclusivity in the heritage sector was similarly found to be less advanced than hoped, despite decades old legislation. On the positive side, this project demonstrated the enormous scope to use a narrative, oral history, approach to explore personal perspectives and find ways to address individuals' needs.

At a glance, OSN



collected 40 oral
histories from 59
people

mostly about
friendships &
relationships



and 10 about C-19

used Social media
to share narratives



shared the
narratives and key
issues in 8
exhibitions



made 3 films,



employed 4 adults with
learning disabilities to
work with 5 museums to
improve inclusion



and
74 volunteers who helped
deliver OSN

and at 32
seminars &
meetings across
Wales



ran 4 'Disastrous
Dates' & many
other social events



Introduction and background

[Our Social Networks \(OSN\)](#) was a [Mencap Cymru](#) project, funded by the National Lottery Heritage Fund (NLHF) to improve awareness, attitudes and services around friendships and relationships for people with learning disabilities, and also to capture and preserve their heritage. OSN aimed to further some of Mencap's top priorities, namely:

- improve people's lives, by supporting friendships and relationships;
- counter discrimination and stigma; and
- encourage positive public and professional attitudes around friendships and relationships.

In particular the OSN project aimed to

- capture and preserve the heritage of people with a learning disability, a voice often absent from heritage and society more generally;
- improve understanding of, and support for, friendships and relationships for people with learning disabilities, by collecting and sharing their oral histories around this theme;
- enhance inclusion and access in the heritage sector;
- provide employment and create models of support for people with learning disabilities.

OSN started in 2017 and was due to end in 2020. However, to respond to the disruption brought about by the Covid-19 pandemic, the project continued into 2021.

OSN worked across Wales and had three main work strands:

- **Oral histories around the meaning and significance of friendships and relationships**

OSN used an oral history format to explore friendships and relationships for people with learning disabilities and their need for a social life, close personal bonds and relationships. These narratives were turned into exhibition displays, films and presentations and shown across Wales, usually in untypical venues, such as cafes and shopping centres. In their different formats, these narratives explained the extensive barriers faced by people with learning disabilities achieving this basic human right. They were shared with diverse audience, including service providers, professionals, policy makers, carers, families and the public. Through linked events and activities, OSN aimed to improve attitudes and services for people with learning disabilities, and demonstrate the scope and value of using a personal narrative approach in social care.

- **Improving inclusion in the heritage sector**

The second strand worked on enhancing inclusion and access at five regional museums: Bangor Storiol, Abergavenny, Monmouth, Cardiff Story and Wrexham. This work was mainly pursued by the Ambassadors who networked with and involved local disability groups and were assisted by their support staff.

- **Enhance inclusion, employment and skills of people with learning disabilities**

OSN employed four adults who had learning disabilities to collaborate with and improve inclusivity at the five regional museums and provide learning for the wider sector. Three employees worked four hours a week. Each had a Supporter who did the same hours. The fourth person was employed as a Project Officer. As well as completing the same role as an Ambassador, they had additional responsibilities around outreach, engagement and public events.

The Independent evaluation

The formative, process and outcome evaluation aimed to assist Mencap Cymru meet its aims, shed light on key issues emerging and provide helpful insights for future projects. In the first two years, the evaluations mainly examined project processes and intermediate outcomes. These found that good progress was made in collating oral histories and sharing these in pop-up exhibitions, and that the narratives were proving enlightening to audiences. However, some aspects of the project were found to be more challenging than originally anticipated, and OSN addressed many of the emerging recommendations around internal communication, staffing and the Ambassador role. This final report focuses on outcomes and learning points for future work.

The key evaluation questions were:

- To what extent have priority aims and outcomes been achieved?
- How effective has OSN been in improving understanding and attitudes?
- How have people with learning disabilities experienced their involvement in this project?
- What have been the key challenges and enablers and learning emerging?
- What recommendations we made for implementing similar projects in the future?

This evaluation report is based on primary data collected directly by the evaluator, combined with secondary analysis of data provided by the OSN, for example monitoring and feedback from exhibitions and events, surveys, thematic analysis of the oral histories and other data. Full details are given in the Appendix. In each of the three years, the Evaluator generally conducted in-depth, qualitative interviews or focus groups with those directly involved in project delivery:

- the OSN Programme Manager and Project Manager ($n=2$)
- the Ambassadors and Project Ambassador ($n=4$);
- the Ambassador Supporters ($n=7$);
- the Project Officers ($n=2$) and one Project Officer's Supporter
- OSN volunteers ($n=12$)

In the first and final years, the evaluator also interviewed heritage staff in the partner museums ($n=6$) and Mencap Cymru's Head of Strategic programmes. In the second year she interviewed the Head of Operations and in the third year she interviewed two policy personnel to help assess where this work fitted within the wider policy field; and senior representatives from two agencies which provide services for people with learning disabilities in Wales. In the third year, the Programme and Project Managers were furloughed just before the scheduled interviews. This meant they had to answer the interview questions in writing.

The Evaluator and project staff developed tools for this evaluation and OSN's own data collection in partnership. In the first two years, most of the evaluation interviews and focus groups were conducted in person. In the third year, all were conducted by telephone or by online video conferencing, because of Covid-19. All were recorded, and then analysed using the 'Framework' system. Framework provides a rigorous and systematic way to organise, condense and summarise data from different sources. It is flexible and responsive and enables thematic analysis plus answering the evaluation questions and comparison across different groups and individuals. It can also accommodate unanticipated emerging themes. (Braun and Clarke, 2013; Ritchie et al. 2014¹).

¹ Braun, V. and Clarke, V. (2013) *Successful Qualitative Research: a practical guide for beginners*. London: SAGE.

Chapter 1. Oral histories on friendships and relationships

OSN gathered 40 oral histories from 59 people around the topic of friendships and relationships for people with learning disabilities and, in the third year, an additional 10 oral histories around the impact of Covid-19. The overall aims of this area of work were to:

- collect narratives from people whose lives and voices normally go unheard and unrecorded;
- explore the significance and contexts of friendships and relationship for people with learning disabilities, because these topics are rarely discussed, little understood and often taboo;
- share these stories with policy makers, service providers and the public, to increase awareness and understanding about the lived experiences, views and needs of people with learning disabilities, and to inform and improve policy and practice in this area.
- demonstrate the scope and usefulness of personal narratives in this sector.

The oral histories gathered highlighted important issues around human rights, attitudes and gaps in understanding, training and support. This chapter covers the process of collecting the oral histories and the main themes emerging. The next chapter looks at how OSN shared these narratives with a wider audience through exhibitions, seminars, presentations and social media and the reception they received from the public, professionals, service providers and politicians.

The oral history work and dissemination met the following HLF outputs and outcomes

- Heritage will be identified and recorded (Hear My Story)
- People will have had an enjoyable experience
- People will have volunteered time
- More people and a wider range of people will have engaged with heritage (Save My Story / Change the Story)
- Heritage will be better interpreted and explained (Share My Story)
- Heritage will be better managed (Save My Story)

Gathering and recording oral histories

The oral histories were mostly conversations between a couple, or two friends, following outline topics drafted by OSN, but some were given by individuals. Over the project's lifetime OSN recorded 40 conversations about friendships and relationships from 59 people, 50 of whom had a learning disability. The other nine people were parents, friends and professionals. The momentum to collect personal narratives grew over the three years, as the project developed its expertise and reach to groups and agencies across Wales, and as more people with learning disabilities, carers and professionals heard about the project and wanted to take part. However, this work was severely curtailed by the Covid-19 pandemic. Invitations to visit more groups of people with learning disabilities and supported living settings and undertake more oral histories over 2020 had

Ritchie, J., Lewis, J., McNaughton Nicholls, C. and Ormston, R. (2014) Qualitative Research Practice: a Guide for Social Science Students and Researchers. 2nd edition. London: SAGE.

to be shelved. However, 10 people who had previously provided narratives agreed to talk about the impact of Covid -19 on their lives.

Detailed and iterative consent process

The project took great care to follow best practice in gaining valid consent to undertake, record and archive the oral histories, based largely on experience gained from Mencap Cymru's previous Hidden Now Heard project, as well as training and advice given by St Fagan's. Securing informed consent and getting to the stage of making a recording took considerable time and effort, extensive travelling across Wales, working with layers of gatekeepers and gaining their understanding and trust, before meeting participants to explain what was involved accessibly, both verbally and in writing.

OSN encountered and highlighted some ethical dilemmas in gathering and sharing oral histories. Sometimes the project's assessment of the person's capacity to consent to participate differed from those of relevant gatekeepers, who felt very concerned, cautious and reluctant to agree to the individual's participation. The project's copyright consent process had been very carefully developed, but nonetheless over time tensions emerged. The oral history contributors were given a number of options in the consent form. For example, they could consent or not to have their story reproduced in print, or audio, or online and any combination of these. However, in practice OSN came to realise that some combinations seriously undermined the scope of the project. For instance, if someone agreed to have their oral history included in a written publication, but not to be available online, this affected OSN's scope to publish the whole report online, although this is increasingly the main platform and expected medium to communicate findings.

If someone consented, the OSN staff arranged another visit to record a conversation. They returned again after that to share the recording with the contributor, check if they wanted to embargo any sections and to seek their consent for the recording and transcript to be used by the project (for example in exhibitions) and/or stored in St Fagan's, and to agree copyright. OSN boosted the sound quality of the audio recording, but retained an untouched copy for the archive. Then OSN staff or volunteers transcribed the recordings. There was some attrition between initial interest and getting a final usable transcript or recording. Of the 90 people who were originally interested in providing oral histories, 62 did. In 40 cases full consent and copyright agreement was provided for recordings to be shared by OSN in its exhibitions and archived in St Fagan's. OSN staff noted that some people who decided to not proceed, or withdrew their consent for their recordings to be used, were worried about how others would react to what they said.

Who provided oral histories

The people with learning disabilities who provided oral histories tended to be slightly older, live independently and be in relationships. Of those who provided age information, nearly six in ten were aged 25-40; one in three were over 40; and roughly one in ten were under 25. In comparison to national trends, a relatively high proportion, one-quarter, lived independently without support; one quarter lived with their parents; another quarter lived in supported housing; and some attended a residential college². In their original plan, OSN had envisioned getting oral histories from two distinct age groups to compare their lived experiences: 18-25 year olds, and those aged 45 and over. In

² Available data indicates that across the country, 38% of PWLD live with family or friends, 22% in residential care, 16% in supported living and 15% have their own independent tenancies - https://www.mencap.org.uk/sites/default/files/2016-08/2012.108-Housing-report_V7.pdf

practice, the challenges in working with two layers of gatekeepers for those aged 18-25 (e.g. educational staff and parents/carers) made it easier to recruit people aged 25-40. In 2020, OSN staff had started recruiting more people who lived in supported accommodation, to rebalance the sample and make it more representative. But these plans had to be shelved because of Covid-19.

Roughly one quarter (11) of the 40 narratives were provided by couples, reflecting a substantially higher proportion of coupledness than the general rates among people with learning disabilities, which is estimated to stand between 3% and 6%³. Three further narratives were provided by people who were in a relationship, but who participated alone. Eight conversations were between two friends; 11 recordings were provided by individuals. Families and professionals gave seven.

OSN staff speculated that this profile, especially the number of participants who lived independently, may reflect some greater ease in recruiting people who had fewer gatekeepers to negotiate with and who in turn were less likely to have their mental capacity to consent to participate questioned.

Feedback from those who shared their stories

OSN gathered feedback from those who gave narratives. Most said that although they had felt nervous before, they enjoyed taking part and were motivated by a desire for others to hear about, and understand their lives. Many hoped the recordings might shift attitudes. Everyone reported that the process had been explained fully and that fully understood the oral histories' scope and purpose.

"I was a little apprehensive at first but once I met [OSN staff] and we discussed everything, I felt at ease"

[Oral history contributor]

"Having the opportunity to tell my story allowed people to hear and understand what it was like for me to build and maintain a social life, but also how I kept social links ... when moving home"

[Oral history contributor]

OSN staff remarked on an unanticipated outcome related to the process of sharing their stories. This often prompted people to reflect on their situation and their social needs, explore their feelings about their relationships with others, and appreciate how much of their lives were shaped by staff or family. Sometimes the project gave people the 'space and context' to think or talk about matters for the first time and was observed to have a 'profound effect on their understanding of themselves'.

"The most difficult things for me were when someone recognised for the first time a barrier, but was still powerless to change anything"

[OSN oral history interviewer]

"..one individual [said] that no-one had ever asked them the questions we were asking – about being in love, having a crush etc, suggesting reflection on these topics isn't often done."

[OSN oral history interviewer]

³https://www.lancaster.ac.uk/staff/emersone/FASSWeb/Emerson_08_PWLDinEngland.pdf

Other artefacts collated

The project collected a number of personal photographs and artefacts from participants, to store in the People's Collection Wales. These were displayed in the exhibitions, to augment the narratives, and included 44 historical photographs, and 146 present-day images. OSN was disappointed that this work had to be suspended in early 2020, because of Covid-19, and that they had not secured any images from local authority-run services, or community groups. But feedback suggested that organisations were anxious about the potential risk of breaching data protection by sharing such photographs.



The key themes raised by the oral histories

OSN analysed 25 of the oral histories in depth to extract the [key themes](#). These oral histories provided rich insights into the lives and feelings of people with learning disabilities, which would otherwise have remained hidden. Reflecting the overall sample, the thematic analysis was based on narratives from people across all of Wales. As roughly one-third of the narrators lived independently (35%) and another one-third lived with their families (32%), it is possible that both groups had more autonomy than people living in other situations. Ten conversations were between two romantic partners, six between two friends and nine with individuals. Their stories encompassed views on friendships and relationships and the enablers and challenges experienced. However, as the sample might be skewed towards those who are more independent and who had friendships and/ or relationships, the challenges they raised may just be the tip of the iceberg. The main themes identified were framed around power, autonomy and human rights:

- **The importance of friendships and relationships for people with learning disabilities.**
Friendships and relationships were found to be critical to personal identity, pride and self-worth. Friends and partners were said to provide validation, acceptance, mutual care and respect, and meet a human need for connection, all often otherwise absent. Being accepted as a member of society had been a life-long ambition and challenge, but most still felt like outsiders and that they were not accepted, despite a lifetime of trying to fit in. This undermined their sense of identity. One person had not received a birthday or Christmas card or present from the age of five until they met their partner. OSN staff emphasised how important friendships and relationships were to people's mental and physical health and that work on health inequalities needed to prioritise people's emotional and social well-being.
- **Relationships provided companionship, mutual benefit and support and social kudos**
As well as finding love, mutual support and companionship, being in a relationship or getting married, carried additional significance. OSN staff conjectured that this might reflect the high social significance of these institutions and desires for belonging and societal acceptance.
- **Limited scope to meet other people**
Many narrators reported that their main contact was with their immediate family and care staff. Profound loneliness and ostracisation were evident. Opportunities to meet people were limited and

declined dramatically after leaving school or college. For many narrators, socialising was restricted to structured, timetabled, groups, such as attending day centres or scheduled learning disability group meetings. This was even the case for couples in a relationship who wanted to meet. As well as indicating a lack of practical and other support to enable social interaction, this also reflected fears among both people with learning disabilities and their carers about going out and about, especially in the evening or night-time. Scope to be spontaneous was distinctly lacking. For example, any socialising had to fit shift patterns. Someone who received support from care workers described how their relationship was conditional on compliance with the service's routine.

"they're alright about it, but they did say as long as ... the relationship don't interfere with the support ... it don't matter"

[Oral history contributor]

- **Extensive and pervasive exclusion**

Many said they only started to feel accepted and safe when they joined a learning disability group, including those who had attended mainstream education. OSN commented that the extensive bullying and effective social exclusion experienced by people with learning disabilities, at school and elsewhere, challenged current philosophies and policies around integration.

"Oh, horrendous for me. Horrendous to make friends. I didn't have any friends at school. I was the one that no-one wanted to be friends with ... why I don't know. But nobody ever, ever... I was bullied horrendously to the point that I actually missed a lot for school"

[Oral history contributor]

- **Narrow perceptions of sex and sexuality**

Misconceptions, fears and confusion were evident in relation to sex and sexuality. There were indications that couples were often, and were expected to be, platonic. At most, many held hands or kissed. Lengthy engagements were common. One couple in their forties recounted how they had been instructed to keep their bedroom door open, when together. Of the narrators who spoke about sex, few had had a sexual relationship. Many were under the misconception that sex always resulted in conception, alongside an unspoken understanding that pregnancy was to be avoided at all costs. It was clear from oral histories that many had been given a very restricted and fearful picture of sex. Intimacy or enjoyment were definitely not on the agenda. Being lesbian, gay, or transgender (LBGTQ+) further epitomized contradictions: the right to identify as gay was said to be accepted by services: as long as individuals did not want to meet other gay people or start a relationship. For OSN this all pointed to inadequate education, guidance or support for people with disabilities, families and support staff.

"While we know that relationships and sexual education is not good enough, but the oral histories also raised an issue around why that continues to be the case – and does not get corrected by professionals and families"

[OSN staff]

- **The central role of families and professionals in enabling friendship and relationships**

The narratives illustrated how families and support staff played a key role in enabling friendships or relationships. Or not. As well as examples of relationships being actively prevented, what emerged in

the narratives was that relationships required proactive assistance, not just neutral acceptance. Organisational culture, systems and attitudes were found to often operate as barriers to best practice, albeit unconsciously. Many couples described how others decided if and when they met, and whether they lived together.

“...hopefully we’ll come out as being married in the end...Living together, hopefully, one day”

[Oral history contributor]

“One interview in particular was quite difficult. Basically, the relationship was just stopped by the various parents. Many were quite funny and light-hearted, but this was really, really, sad... That one did strike a chord ... I thought “if that was me and my parents had done that in my relationship. I would never forgive them. I would never, ever, forgive them”

[OSN volunteer who helped transcribe interviews]

OSN argued that not actively supporting people to have friendships and relationships was effectively blocking them.

“It isn’t enough for us to say in principle that we support people with a learning disability to have relationships: we have to be part of facilitating this ... relationships are not able to thrive unless our support structures are there facilitating and supporting those. To put it bluntly, if we’re not being proactive, we’re actually being obstructive”

[OSN staff]

Positive examples were also shared, for example of families and staff enabling people to spend time together and get to know each other more. While resources were found to affect feasibility, often relatively minor changes made a difference, for example pushing two single beds together in lieu of a double bed, or changing shift patterns to enable support to be provided so that someone could go out in the evening. In one case, a staff member advocated with management for a couple who lived in a care home to be allowed some time alone in the evening (up to 11.30pm). Examples were given of staff accompanying young people to late night music gigs and a parent described nudging their son’s relationship along:

“...we’d drop [him] off ... so that they had their own space and then leave them and that went on for about a year... So, then I took him and let him choose a ring and then ... it was up to them two...”

[Parent]

Families’ and services’ hesitancy was felt to derive from multiple factors: the lack of priority given to friendships and relationships; a tendency to infantilise the person; taboo and distaste, not least around sex; and fears around safeguarding and harm. In this a disconnect was noted between principles and practice. While professionals and carers endorsed people’s rights to have meaningful relationships, in practice fears and desires to protect them often trumped those rights being a reality. For their part, people with learning disabilities were reluctant to upset or go against families or staff, and also were reliant on them for other life basics, such as shelter and food.

- **Framing friendships and relationships as a core human right**

Amidst the anxieties around risk and protection, friendships and relationships were often observed to be considered optional extras. The scope for families or services to dictate peoples’ friendships

and relationships, regardless of their competence, reflected their lack of power and autonomy. It was common for additional thresholds to be tacitly applied around someone's capacity to consent. In other words, contrary to law and guidance, incapacity was often the starting presumption, not capacity. OSN concluded that staff and parents needed more training, guidance and other input to overcome fears and equip them to provide the necessary support and advice to help individuals exercise agency and make decisions.

Additional findings from the Covid-19 interviews

Over 2020, OSN conducted ten additional interviews, with twelve previous participants, to explore how the pandemic had impacted on people with learning disabilities. It was already known that people with learning disabilities suffered disproportionately during the pandemic in many ways. For example, rates of serious illness and death were much higher than for the general population⁴. In addition, social restrictions, closure of day centres and social groups, lockdowns and other measures impacted them severely, especially not being able to see family or friends. The OSN interview process helped people reflect on their need for social contact and, in one case, the interviewer enabled a couple, who have been together for 8 years, to see each other for the first time in nearly a year.

OSN staff identified a number of key themes from these narratives. These included the importance of digital technology to help stay in touch with social groups, friends and family, and mixed experiences of being able to maintain contact with groups. Some people had no contact at all, whilst others described joining new groups and building new friendships online. Those who lived with their partners described the support and companionship this provided during a difficult time, but those who lived apart talked about the additional stress caused by the separation and inability to spend time together, because of the social distancing and travel restrictions. Many valued the support they received from their family during lockdown. However, on the other hand their family's increased involvement in their decisions sometimes triggered concerns about the limitations this posed to their autonomy and independence. And while some expressed a desire to change their living situation, they found this hard to do as it risked upsetting their family.

⁴ <https://www.mencap.org.uk/press-release/eight-10-deaths-people-learning-disability-are-covid-related-inequality-soars>

Chapter 2. How OSN shared the oral histories

Ultimately the narratives will be housed in, and made available through, the national repository in [St Fagan's National Museum of History](#); and the films and thematic analysis will be available through Mencap Cymru's [website](#). Clips will also be available on the People Collection Wales' [website](#). In the meantime, OSN used the three years of this project to share the recordings, the thematic analysis and other findings from the oral history work with the general public, groups of people with learning disabilities and their families, service providers, professionals and politicians.

This dissemination work aimed to promote understanding around the importance of friendships and relationships for people with learning disabilities, highlight the usefulness of personal narrative and improve services. In the first two years, the oral histories were mainly shared through exhibitions around Wales. OSN developed the key messages into films, presentations, seminars and meetings and also ran some fun, social, activities. Covid-19 put paid to many of the plans made for 2020. But the project diversified, extended into 2021 to make up for lost time and designed social media take-overs, video conferencing and other methods to share the messages in ways compatible with the restrictions imposed by the pandemic.

This Chapter looks at these activities in order and examines their reception and feedback provided.

- A. Week-long pop-up exhibitions across Wales in the first two years
- B. Scattered exhibitions across Wales in Year Three
- C. Social and promotional events to accompany the exhibitions
- D. Social media take-overs in Year Three
- E. Presentations, films, webinars and other influencing events in Year Three

The dissemination of the oral histories addressed the following HLF outputs and outcomes

- Heritage will be better interpreted and explained (Share My Story)
- People will have learnt about heritage (Change The story)
- People will have changed their attitudes or behaviour (Change the Story)
- People will have had an enjoyable experience
- More people and a wider range of people will have engaged with heritage

A. Pop-up Exhibitions across Wales 2018-20

Over the first two years, OSN staff and volunteers designed pop-up exhibitions for Bangor, Wrexham, Cardiff, Abergavenny and Treorchy. Exhibitions centred on sharing the oral histories, mostly with the general public and ran for approximately a week in each location. To broaden the reach and attract those who tend to not visit exhibitions in museums or art centres, the exhibitions were usually displayed in non-traditional venues, such as community centres, cafes, a leisure centre and disused high-street shops.

The exhibitions provided the public and others with the opportunity to listen to recordings of, and read excerpts from, the personal narratives and look at photographs and the personal artefacts

displayed. This aimed to counter misconceptions and promote understanding. OSN was responsible for all the publicity and each year built on experience and feedback to improve the exhibitions. Table 1 below gives the locations and recorded attendance rates. Social events were organised for each of the exhibition towns to augment the messages and promote the exhibitions (see C. below)

Table 1: Location and timing of pop-up exhibitions and recorded visitor numbers

Timing	Location	Venue	Dates	Attendance numbers
Year 1	Bangor	Pontio Arts Centre	June 2018	85
	Wrexham	Plas Madoc Leisure Centre	July 2018	81
	Treorchy	High Street Social Cafe	September 2018	192
	Abergavenny	Abergavenny Community Centre	October 2018	42
Year 2	Bangor	Deiniol Shopping Centre	April 2019	172
	Cardiff	Chapter Arts Centre	June 2019	194
Total recorded number of visitors recorded				766



To make the exhibitions engaging, the OSN team designed several innovative features, such as listening to recordings in phones and teapots, and designing interactive games, including a giant ‘sex and ladders’ game. This illustrated common challenges people faced (snakes) such as limited opportunities to meet people, access and transport, and the enablers to relationships (ladders). In most venues, OSN staff and volunteers were present to answer questions or discuss the project with visitors and to collect their views and feedback.

Factors which affected public engagement

Although the feedback and other data collected indicated that the exhibitions had gone well and had achieved many of OSN aims, project staff and museum interviewees reflected in hindsight that the original plans and targets had been over-ambitious: not least covering the whole of Wales, producing and publicising many of the exhibitions remotely, using venues which do not usually host exhibitions, to introduce novel and thought-provoking topics in a fresh way, and challenge deep-seated ways of thinking.

The precise timing and the type and location of each venue were found to influence the form and extent of engagement. In the Treorchy café, customers were observed to engage very well, largely because they were already comfortable in that venue and they had the time to listen to the oral histories. Similarly, the exhibition in Chapter Arts Centre attracted reasonable numbers and visitors spent a long time listening to the oral histories, reading display boards and



discussing the issues with OSN staff. This positive engagement was attributed to the fact that people who go to art centres probably expect to interact with exhibitions. In Cardiff, Treorchy, Bangor and Abergavenny the OSN team of staff and volunteers were also able to exploit their local presence and networks to promote the pop-ups and events.



In contrast, exhibitions which relied on attracting the public as they passed, including the Bangor high street shop front and the leisure centre, fared less well. Heritage sector interviewees commented that using non-traditional settings for exhibitions makes it more difficult to attract visitors than using a known site and requires a very appealing, experiential, offer, as well as extensive publicity and engagement activities. OSN staff reflected that to work well, the exhibitions needed a lot more time to enable the project to build relationships with staff in each venue and also to network with local groups and communities. The promotional activities supported engagement and attendance at the exhibitions, as well as the ideas behind them, but also relied on local contacts and networks for publicity.

"[In hindsight] I think we should have remained with museums for the exhibitions. We tried to be too clever and innovative but didn't have the local knowledge or reach to pull those things off. In Cardiff and Treorchy, where the exhibitions went really well, we had that local knowledge"

[OSN Staff]

One community partner who hosted an exhibition felt that it would have helped more if project staff had attended a meeting to explain the issues behind the project to staff. That would have informed their understanding and appreciation more, rather than leaving them to view the exhibition alone.

"... got good stuff, challenge is getting more people to hear it"

[Community partner in exhibition venue]

Public reactions to and feedback on the oral histories and pop-up exhibitions

Written, verbal and survey feedback was invited from people attending the exhibitions, community partners who helped host them and the volunteers who helped transcribe some interviews. Visitors were very positive about the exhibition themes and the content. They reported gaining a new appreciation of the benefits of oral histories and of the importance of friendships and relationships for people with learning disabilities. The response rate to feedback surveys was variable and highest where staff were present to encourage this.



Analysis of the survey feedback on the pop-ups found that:

- 80% of respondents reported an increased understanding about the lives of people with learning disabilities, and the importance of friendships and relationships for them;
- 80% of staff and 60% of public said they saw the value of oral histories; and

- 60% of the public said they got a broader understanding of heritage and that this included people's personal stories, not just buildings.

Exhibition visitors praised the project's aims, the exhibition content and how the information was presented. The reported finding the narratives thought-provoking, inspiring and well presented, for example using telephones and jewellery boxes, as well as traditional headphones to listen to the personal stories.

"Many of the facts ... were new to me. I knew very little previously about people with Learning Disabilities"

[Written feedback from exhibition visitor]

"The concept was really good, how you approached it using the everyday and ... sitting in the chair with headphones ... quite [an] intimate experience. Having the volunteers around to talk to you afterwards was a big help too"

[Written feedback from exhibition visitor]

In addition, OSN staff recorded their own observations on how visitors interacted with the exhibits and their conversations with visitors. Whilst most were favourable, some negative comments were also made. For instance, the exhibition in the shop window, which used a double bed, often occupied by a couple with learning disabilities (mimicking John Lennon and Yoko Ono) attracted some tutting. One person expressed concerns about people with learning disabilities having children, reflecting a perception of people with learning disabilities only being a 'burden' on society.

OSN volunteers, were generally shocked and amazed at what they learned, for example when transcribing the oral histories.

"I'd never considered it before... It was a big eye-opener for me. What really struck me was they had ... things they wanted to do in their lives, but they were not in control. Even though they were the same age as me sometimes, it was their parents who decided, even if they were allowed to go for a walk in the park, have a relationship, get married."

[OSN volunteer who helped transcribe interviews]

B. Scattered Exhibitions in Year Three

In the final year, 'scattered' exhibitions were designed for Wrexham, Abergavenny, Bangor and Cardiff. These aimed to enable OSN to reach more people, by inviting them to listen to people's stories at listening posts, which were dispersed across the town. Viewers could scan the QSR code, given at each site, to download a mobile phone app and listen to some oral histories. However only two scattered exhibitions were able to proceed in full before Covid-19 struck: one in Wrexham, which ran from September to November 2019; and one in Abergavenny, from December 2019 to January 2020. The exhibition scheduled for March and April 2020 in Bangor only ran for two weeks. Initial feedback from social media suggested a much higher level of engagement than previous exhibitions. The Cardiff exhibition (May to July 2020) had to be cancelled. The map below indicates the spread of the listening posts in Wrexham.

Although records show that the exhibition's mobile app was downloaded 52 times, the dispersed nature of the exhibition made it impossible to assess the type or amount of engagement in Wrexham and Abergavenny.

Anecdotal feedback gathered by OSN indicated the app was often too large to download and would have benefitted from geolocation features. OSN staff reflected that designing a scattered exhibition was possibly too adventurous, especially combined with the novelty of the topic.



C. Social events to promote the key messages and inclusion

Over the course of the project, OSN collaborated with other agencies to put on a number of events around the country, to coincide with the exhibition in that area. As well as promoting the exhibitions and oral histories, these aimed to influence attitudes by bringing disabled and non-disabled people together and providing a forum to talk about relationships, friendships and sex, in a fun, relaxed and equal way. The events included:

- Disastrous dates
- SmutSlam
- Drag Syndrome

Table 2: Location, audience and attendance at OSN social events

Year	Month	Event	Location	Venue	Attendance
2018	September	Disastrous Dates	Treorchy	High Street Social	14
2019	June	Disastrous Dates	Cardiff	Chapter Arts Centre	25
	June	Smutslam	Cardiff	Story Museum	125
	June	Drag Syndrome	Cardiff	Tramshed	250
	October	Disastrous dates	Wrexham	Waterstones	16
2020	January	Disastrous Dates	Abergavenny	Melville Theatre Cafe	12
	March	Disastrous Dates	Bangor	Pontio Arts Centre	Cancelled C-19

Table 2 shows the locations. These events attracted the general public, people with learning disabilities, carers and professionals. Feedback given indicates that each proved very enjoyable. They

also provided a vehicle for OSN to promote integration and reach the general public and audiences, many previously unaware of the lives of disabled people. In turn OSN brought a new demographic to these agencies and introduced them to the lives of people with learning disabilities, with whom they had little or no previous contact. Many events scheduled for 2020 had to be cancelled because of Covid-19. The following is a brief description of each. More detail was provided in the OSN second Year evaluation.

Disastrous Dates

Disastrous Dates uses a story-telling format for people to share awkward, calamitous and silly moments about dating, with the chance of winning a prize. In this project it also brought the subject of dating for people with learning disabilities to new audiences. In Cardiff, a local performer helped engage the art centre audience and using a café in Treorchy attracted *'more ordinary folk'*. People with and without learning disabilities contributed their personal mishaps. Participants provided written and verbal feedback and said they enjoyed the stories and appreciated the fact that not all the stories were of romantic, or heterosexual, relationships. Those with a learning disability commented that they had not known beforehand what to expect and had worried how their story would be received and if they would fit in, but reported that their anecdotes had gone down well. The Abergavenny café provided a warm, welcoming and cosy atmosphere and the small group *'sat around, drank tea, ate cake and shared a story'*. Despite initial nerves this was enjoyed by all.

*"the audience went hysterical and for that moment I forgot
about my lack of confidence I had in acting and public speaking"*

[Contributor with a learning disability]

"everyone has a tale to tell be it good or bad, funny or sad"

[Audience member]

*"It is difficult to bring new people to events without someone local, on the ground to
help draw people in. Also, there are challenges around people with a learning disability
attending events in the evening"*

[OSN Staff]

Smutslam

[Smutslam](#) is an open-mic, storytelling event, about sex and relationships. OSN collaborated with a Welsh company, [Big Loop Theatre](#), and SmutSlam's creator, Cameryn Moore, to host an event in Cardiff, during the 2019 Learning Disability Week. Feedback was collected from volunteers, venue staff and the audience and through the evaluation interviews.

The audience and organisers appreciated being exposed to a new group of people and issues and SmutSlam said they would apply the learning gained to future events to make them more inclusive. Despite feeling anxious, the people with learning disabilities who shared their stories enjoyed doing so. Their stories went down very well, and the commonality observed among disabled and non-disabled people proved somewhat levelling. It helped illustrate that everyone, disabled or not, was likely to feel awkward talking about relationships and sex and often lacked appropriate language to do so. The event helped dispel many myths and helped non-disabled people in the audience become more aware of the importance of relationships for people with learning disabilities. The narrators with learning disabilities recommended improving the education available around relationships and

sex and how to talk about these topics and felt this would help boost people's confidence and ultimately protect them. OSN staff and volunteers described the event as provocative, an 'eye-opener' and enjoyable, and that it was augmented by the creation of a 'safe', 'open' and 'respectful' environment.

Drag syndrome

OSN, in collaboration with the wider Mencap Cymru, organised a music and cabaret evening in Cardiff during Learning Disability Week in 2019. This show-cased [Drag Syndrome](#), a London based group of performers who have Down's Syndrome and use their act to challenge gender and disability stereotypes. The audience included 70 people with learning disabilities, their families and carers and 180 people who did not identify as disabled. The event attracted very positive coverage on ITV Wales and on Twitter. People praised the high standard of entertainment and its 'inclusivity', allowing disabled and non-disabled people to have fun and dance together. People with learning disabilities commented on how much they had enjoyed having a night out where they felt safe and comfortable.

'went to this last night and it was really electric. @Drag syndrome were class. But really it was all the learning-disabled and non-disabled people having an absolute blast together that struck me - you very rarely see it, but that's how it should be'

[Comment on Twitter]

OSN staff observed that local events, such as disastrous dates went best when they were convened and organised with local agencies and based on their knowledge and networks to help publicise and attract new people. But often despite promises made, many of the learning disabled people who had said they would attend, failed to show. This accidentally brought to light another barrier faced in socialising and pursuing friendships and relationships: evening events were generally inaccessible, because few had support in the evening or night-time to enable them to go out, and/ or felt it was unsafe to go out alone, due to the risk of being attacked.

D. Social media takeovers

As well as exploiting social media to publicise and report on its activities, OSN responded in a virtual way to the forced cancellation of the physical exhibitions scheduled for 2020, because of Covid-19. Project staff designed a series of 'social media take-overs' to promote the project and relay key messages about friendships and relationships for people with learning disabilities and reach new audiences amongst these agencies' followers. The Project negotiated social media take-overs with Cardiff Story, Wrexham and Abergavenny museums and some social care organisations.

OSN supplied each museum with enough posts to distribute a new message twice a day, for seven days. The takeover of Cardiff Story Museums Twitter feed, for a week in November 2020 (9th-15th), was the most successful. This saw 20 original tweets being broadcast. In total, these attracted 223 engagements. The museum reported that this was higher than their average rate of engagements per tweet for that month. The tweet which drew the highest engagement (47) was one describing the likelihood of being bullied at school:



The museum staff felt that the OSN Tweets compared very favourably with the engagement rate of tweets marking Armistice day, which proved very popular.



However, the other two museums only issued between two and five posts each in their allocated weeks. These attracted limited engagement. This was partly attributed to different expectations and working with personnel new to OSN. This social work also work had to be suspended in January 2021 because of Covid-19 and the furloughing of the OSN Programme and project Managers. The three-month project suspension delayed this work. However, by May 2021 the project had agreed to run social media take-overs with a range for agencies, including Mencap Cymru, Mirus, the Supported Loving Network, Drive Ltd, HiJinx Theatre Cardiff, and Gig Buddies. Some others were in the pipeline.

E. Presentations, seminars and films to improve understanding and policy

In the third year, as planned, OSN shifted their main focus to informing and influencing policy makers and service providers, by sharing the oral histories and the main themes emerging with them. Public dissemination, including to groups of learning disabled people, continued alongside. This work highlighted the importance of friendships and relationships for people with learning disabilities and the benefits of using personal narrative to improve services and practice. OSN presented the main themes from the oral histories to politicians and policy staff, and to service providers and professionals in the learning disability sector.

To augment the dissemination, OSN made two short films to explain the processes used and findings, and to share the voices of people with learning disabilities directly with influential professionals and the public. One film featured a couple, two friends and two individuals describing the importance of friendships and relationships to them. The second film promoted the value of using a narrative approach as a way to get to know somebody and help them explain who they are. In addition, OSN made a presentation summarising the main themes emerging from the oral

histories, which included excerpts of recordings. The links to these films and the presentation are given below.

Fig. 2: OSN short films and links

<ul style="list-style-type: none"> • OSN made a film with six people with learning disabilities who contributed oral histories. In it they talk about the importance of friendships and relationships to them. https://www.youtube.com/watch?v=Ogl9xc119kww • People with learning disabilities talk about the role and importance of personal narrative: https://www.youtube.com/watch?v=di_C9WEIVfc&feature=emb_rel_pause • Link to summary of the oral history main themes, used in webinar and other presentations: https://www.youtube.com/watch?v=X8EKziI9BeY&feature=emb_logo

OSN also screened the short films to the public, usually as part of a discrete film session and alongside another, feature-length film, on a related topic. These included *'Peanut Butter Falcon'*, a general release film about how a young man with Downs Syndrome chooses his friends and friendships; and *'Friends of Mine'*, a story about friendships and relationships among a group of young people with learning disabilities.

Disruption caused by Covid-19

Because of the long-term restrictions imposed over 2020 and 2021, OSN had to redraft the original plans and cancel or re-arrange, or totally re-design planned events. For example, many events and meetings were converted to online video conferencing. Despite this flexibility, some of the dissemination work to improve policy and practice had to be rescheduled and was not completed by the time of this evaluation. Overall, the pandemic caused considerable disruption and delays, despite additional planning and compensatory efforts to move the work online.

Table 3 below shows the range of seminars, meetings and presentations undertaken and the numbers who attended.

Table 3: OSN dissemination and influencing events

Timing		Location and/or group	Audience- participants	Numbers attended
2019	Oct	Glyndwr University Wrexham	Public	40
		Cunliffe Day Centre (Wrexham): OSN film & <i>'Friends of Mine'</i> film	People with learning disabilities (PWLD), staff & students	26
		Learning Disability Wales Conference (South Wales)	PWLD & professionals	32
		Learning Disability Wales Conference (North Wales)	PWLD & professionals	17
		Mirus, Ceredigion: OSN film	PWLD & staff	12
		Mirus, Ceredigion: discussion group	Service managers	6
	Dec	The Melville Centre, Abergavenny	LD Professionals, PWLD, local councillor	4

2020	Jan	Llansadwrn Comm Cinema, Carmarthenshire - OSN film & <i>Peanut Butter Falcon</i> film	Public	33
		Telemachus (young people's arm of Hijinx)	Young people with LD	12
	May	Drive Advisory Group meeting	PWLD, chief executive, professionals	18
		Jiwsu Seminar (North Wales)	Professionals	15
	August	Relationships & Dating meeting (North Wales Together)	PWLD, parents, professionals	12
	Oct	Mencap Data Community of Practice group	Mencap staff	14
		Social Care Wales LD meeting	Social Care Wales staff	8
	Nov	Mencap Cymru Parent Carers Working Group	Parents	6
		Mencap Friendships & Relationships working group	Mencap staff	11
		Mencap Inclusive Communities Directorate	Mencap staff	10
		The Cartrefi relationships & sexuality group for PWLD	Staff & PWLD	7
		LGBT group	Professionals	4
		Drive Patch meeting - Cynon North	Service managers	6
		OSN Webinar – 'A Life More Ordinary'	Professions & PWLD	50
		Learning Disability Wales conference	Professionals & PWLD	34
	Dec	People First - Monmouthshire	PWLD	7
		Drive Patch meeting - Merthyr/ Aberdare	service managers	5
		All Wales People First - West	PWLD	3
		Ludlow Street Healthcare	Health professionals	1
		Mencap	MeTime Staff	6
		Bangor University	Student nurses	11
		Darwen College Wrexham	Staff & students	12
		Royal Mencap Society	CEO	1
2021	Mar	Royal Mencap Society Board of Trustees	Staff	20
		Institute of Welsh Affairs: Rethinking Wales seminar	Policy /professionals	25
	Apr	Welsh Government Steering Group on Isolation	Politicians & policy advisers	28

Reactions to the films

The OSN short films were well received. Thirty-three people attended the film screening in the community cinema in Llansadwrn, which the local organisers commented was a high turnout for that venue. The films went down well in other areas too and proved very thought-provoking:

"33... is a really good crowd for our screenings"

[Sinema Sadrwm organiser]

"It was a great turn out, a great response to the short and to your introduction,

and it fitted really well with the main feature”

[Wrexham film organiser]

“After watching the film, one individual with a learning disability disclosed to his Support Worker that he had no friends. The support worker felt that the individual recognised that they had lots of people around them but that they didn’t have any proper friends”

[OSN staff]

Webinar November 2020

The largest event was the Webinar held in November 2020, called ‘A Life More Ordinary’. This attracted over 50 people, including policy makers, health academics, people with learning disabilities, staff from statutory and voluntary sector services and supported living providers. While originally organised to get around Covid-19 restraints, the online format may have attracted a wider range of participants, from further afield and proved more accessible than if it had been a physical conference. After [the presentation](#) based on the thematic analysis, break-out groups discussed the issues highlighted. The webinar was very well received.

Feedback on the OSN webinar and other influencing work

Overall, the feedback from policy professionals and service providers, including supported living providers, was extremely positive. The format and content of the oral histories was praised and described as ‘*insightful*’. Many managers and frontline professionals stated that the themes resonated with their own observations and welcomed the impetus, evidence and encouragement to prioritise and advance these issues through policy and practice. They reported that they had already shared the thematic analysis and the videos with others and planned to cascade these resources more in the future. The video version of the presentation and the accompanying films facilitated sharing and kickstarting discussions, and their format was praised for their accessibility and clarity. OSN’s positioning of friendships and relationships as a human rights issue was new to most. But also welcomed. Service and policy personnel were hopeful that this platform would prove effective in shifting perspectives in both the short and long-term.

“The feedback was good. People recognised the problem, and although the issues are not new to professionals, we provided a space and context to discuss them ... They spoke positively about being able to hear things in someone’s own voice – it’s different to hearing a second or third-hand story about a problem”

[OSN Staff]

Oral history themes resonated

Discussions and feedback at the webinar showed that the films and presentations proved forceful and enlightening, and the themes resonated, especially for people with learning disabilities. Participants said that they learnt a lot from the presentations and discussions, and appreciated the opportunity to discuss matters in a forum where people with learning disabilities were on an equal footing with professionals.

“The format, which included videos as well as interactive breakout sessions, really helped to make [it] interesting”

[Professional survey respondent -post event]

“..the fact that the group were so diverse, including people with learning disabilities, brought the subject to life”

[Professional survey respondent -post event]

“...it's so frustrating for us all. I just wish people would understand how we are all feeling. It so depressing sometimes”

[Survey respondent with a learning disability - post event]

In one service, the team managers and other staff echoed, expanded on and contextualised many of the themes. All recognised the lack of opportunity for people with learning disabilities to meet new people. Many noted how common it was for people with learning disabilities to have no friendships apart from with staff members. One support worker recounted how one person they worked with had never experienced any physical contact, other than from professional care staff. Everyone endorsed the recommendation to prioritise social engagement, friendships, and improve awareness and practical training across the board. It was said that this would also allay fears and keep the issue on the agenda.

“Tons of new ideas and angles, as well as being personal and emotional”

[Survey respondent - post event]

The evaluator undertook six in-depth qualitative interviews with policy personnel and senior representatives from two large providers of services for people with learning disabilities. Although each worked in different contexts, all these interviewees reported that the oral histories chimed with their own observations and experience, but that they had nonetheless found the presentations ‘*mind-blowing*’. All said they had undergone a ‘*fundamental shift in approach*’ and mindset. They pointed to tendencies among services and staff which perpetuated the situation, namely to: infantilise people with learning disabilities; view basic needs to mean only food and shelter and ignore social, emotional and sexual needs; brush these issues under the carpet; presume all people with learning disabilities lack capacity to consent; and to prioritise risk avoidance over rights, and protecting people over enabling them to develop necessary skills. This approach was said to be even more pronounced for people with poor verbal communication. At the same time, interviewees recognised that staff’s protectionism derived from deep-seated fears and concerns around safety. Unfortunately, these issues usually went unchallenged and sat in the context of poor training and little progress to re-balance the equilibrium between enabling and safety.

OSN helped to prioritise issues, previously ignored

Across the board, what emerged from the evaluation interviews was that these issues were already somewhat known within the learning disability sector, but what proved different, ‘*powerful*’ and more effective was the OSN approach and format. Getting first-hand accounts from people with learning disabilities was said to be far more persuasive than second-hand information from carers,

or written reports. Framing issues in the context of power and rights encouraged professionals to think about individual agency, and minimise some perceived hurdles.

“Stories are really valuable...powerful... important, because professionals can forget the human being, can get caught up in the legal, statutory stuff, and get into the structure of that legislation. Might lose sight of the impact on the person at the end of it... the video of two people living in a residential care home is really helpful in reminding us of impact on the human being and their civil and human rights”

[Policy interviewee]

“people talking about where it’s gone wrong. For example, the guy who wasn’t allowed to move because his parents said ‘no’ – that’s not a first-hand account many would ever hear”

[OSN Staff]

Interviewees reported that even where the need to progress work around friendships and relationships had already been identified as necessary, it was still in its infancy and inconsistent. It was said to need a combination of agency-wide and national initiatives to improve quality and to become embedded in policy and practice across all relevant agencies, services and commissioners. Policy personnel and service providers felt that the benefit of the OSN work was that it showed that enjoyment and happiness, reducing loneliness and improving personal development, should be included as desirable outcomes for service delivery. One provider was so inspired by the presentation, they had shared the OSN materials and raised these matters with area and senior managers, planned to use them further and commissioned staff training on this topic.

“It would need friendship and relationship and sexuality training to be e mandatory for staff and sit within a friendship and relationship framework – but spending the necessary time on this is currently a luxury and staff don't have time”

[OSN Staff]

Need for improved professional guidance, training and processes

The presentations were said to have *“made the case very well”* and prompted *“some good and honest discussion about some of the challenges faced”*. Some professionals and service providers had started to identify where necessary changes could be instigated in their work. However, they and policy personnel felt somewhat hampered by the current policies, which they described as unclear and often conflicting. All stressed the need for better information and guidance. For instance, services and staff were often unsure how best to support people around sex, sexuality and relationships, while ensuring safeguarding. Matching individuals’ needs and enabling them to take personal risks presented tensions around safety and vulnerability, especially if their risk awareness was low. On a practical level, organisational systems, such as rotas created challenges, and last but not least, individual staff could hold values and beliefs which were at odds with best practice, for instance, but not limited to, sexuality. This had implications for staff recruitment and training.

People with learning disabilities who attended OSN events emphasised how they were *‘constantly waiting for other people’s support to do things’*, e.g. to be able to socialise, and that staff or carers could either be helpful or obstructive. They said they would like opportunities to meet a wider range

and number of people including those outside disability groups, and to have social lives in the evening and weekends *'life doesn't end at 9pm'*. Virtual cafes and speed-dating events were suggested.

Heated discussions took place in one seminar, among people with learning disabilities and health and social care professionals. Whilst everyone agreed with the oral histories' themes, challenges emerged in how to link policy to practice in a meaningful way. Once again, professionals pointed to a tension between allowing individuals to take risks through relationships, and safety concerns and additional fears about who would be blamed if anything went wrong.

It was noted that these matters were typically approached agency by agency, rather than as a sector-wide or nationally. Moreover, despite the desirability of collaboration, the internal competitive market inherently undermined the sharing and development of best practice.

People need different degrees of support to articulate their needs and desires

OSN showed the potential to use the personal narrative process to enable someone to explain their feelings and priorities, and move beyond the more typical focus on a few basic care needs. However, it was also acknowledged that it can be conceptually difficult for people (disabled and non-disabled) to articulate desires if these lie outside their previous lived experience and if they have little exposure to other ways of living. Asking someone about the future can be very abstract if they lack the necessary life experience, self-awareness, concepts or language skills to conceive of, or express, ideas. In addition, some people might tend to guess the 'right answer', and/or try to fit in with their carers' preferences, and/or simply say what they have always said. More-so if there are power dynamics at play. In other words, individuals may need more or less education, advice and support around friendships and relationships. Any such input needs to be individually modulated, and within a couple each individual will need their own type and level of support.

Feedback from families

Reactions from parents and families were reported to be more variable and some engagement activities planned did not transpire. While those who attended the exhibitions gave very positive feedback its key messages and welcomed and endorsed the initiative, the response to the OSN films and presentations were less enthusiastic. One person said that they did not recognise the issues raised. OSN staff accepted that some parents and carers might presume that they were being directly challenged, although this was not the project's intention. OSN was keen to stress that they did not feel parents were to blame for the current situation, but wondered how much this reaction along with dealing with the Covid-19 pandemic might explain the low take-up of offers to run presentations and workshops with parent groups.

"what we're talking is a power imbalance and people with best of intentions having control over sons and daughters, and those sons and daughters having no power to change that. That's difficult for anyone"

[OSN Staff]

Chapter 3. The scope of narrative story-telling in social care

Interviewees felt that the narrative approach and the oral histories generated in this project demonstrated the rich value and potential in enabling people with a learning disability to explain what matters to them in their own way.

“Much more persuasive.. came to life... just more real”

[Service provider]

*“... story-telling seems to really resonate and excite service providers –
a real sense of recognition when we share the animation”*

[OSN Staff]

Using narrative, and ideally recording these as audio or video, was seen to provide two-way benefits: narrators had a more accessible opportunity to describe their issues, wants, needs and priorities; and the process helped them develop a better sense of their personal identity. Many interviewees and people who attended OSN dissemination events were struck by what was said by a young man in the OSN film:

“people have always asked me what I want, not who I am”

[Narrator in OSN film]

At the same time, the story-telling approach offered service providers and commissioners greater scope to get to know people, find out and prioritise what was important to them, and build on that in assessments, rather than limit these to pre-defined areas. It was said that current assessments often focussed on the process, for example completing a support plan, rather than the individual. Personal narratives were said to offer a better instrument to understand peoples' needs, as it connected the professionals and narrator on an emotional level and were more likely to trigger empathy, than written explanations or reports.

Provides insights otherwise unavailable

The narrative form was seen to provide an opportunity for people to explain what they understood, and in turn for this to be corrected if necessary. Many insights came to light through gathering the OSN oral histories, which are likely to have remained hidden otherwise. Many illustrated just how little input people with learning disabilities receive around relationships. As a result, many believed fallacies, typically around pregnancy, e.g. that kissing made you pregnant. Interviewees believed that these misconceptions were allowed to persist because people had not been invited to talk about sex and relationships and explain their perceptions before.

The combination of hearing people speak in their own voice, giving their own emphasis and sharing their emotions, were said to make the words more powerful than for example if the same information had been written down. Interviewees believed that a major potential benefit of personal narrative was that it offered a way to help people with very limited communication skills to 'speak', and in turn emphasised the importance of identifying methods to overcome any barriers in communicating. At the same time, OSN staff advised that using a narrative format requires skills and training and fine-tuning to match individual needs and circumstances. Some service providers asked

Mencap Cymru for more assistance to help staff develop skills and, at the time of writing, Mencap Cymru had decided to create a new Story-Telling Development role.

Important process as well as tool

OSN staff identified the potential risk of limiting stories to case studies or evaluation tools, rather than prioritising the process in itself. However, it may be difficult for services to persuade funders and commissioners of the value of personal narratives: as there may be no outcomes to show and any improvements for a person may be totally subjective and difficult to evidence. For example, someone may be happier, and their needs better met, but there may be no outward, measurable, signifiers, for example in their behaviour (especially if they were previously very easy-going and compliant), and they may lack the insight and communication skills to describe any changes. This exemplified a significant problem with meeting funders' evidence requirements. This work highlighted the gap between funders' and commissioners' desires to see countable metrics around outputs and outcomes, and the slow, minute and nearly imperceptible impact from the storytelling process. In OSN's case, many of the issues which emerged, both directly and indirectly, had not been anticipated (e.g. having scope to voice a desire for, and the value attributed to, friendship and companionship). By nature, surveys and other measuring tools are not good at capturing unanticipated outcomes, or matching the complexity of people's lives, especially the hitherto unknown lives of a group of people, mostly hidden from mainstream society. OSN staff felt that the learning disability sector, including funders and commissioners, needs to acknowledge the limitations of existing approaches to 'evidence' and support the development of more useful and pragmatic methods to explore what practice and services work best.

The project's work has had an impact on the rest of Mencap (RMS) too. At the time of writing, Mencap Cymru was investing in a new storytelling role and had started collaborating with the University of South Wales to fund a Master's dissertation, exploring the link between storytelling and identity. The invitation to OSN to present their findings to the RMS Board of Trustee was described as significant and to indicate a broader commitment to embed storytelling across the charity.

Time will tell if plans materialise into concrete improvements in services and experiences. It was too early at the time of writing (Spring 2021) to ascertain what effect this work has had, as much of what was reported to this evaluation were aspirations at the time; and many of the desired outcomes are inherently small, incremental and difficult to measure. Moreover, the lives of, and services for, people with learning disabilities were drastically affected by the Covid-19 pandemic in many different ways, including socially and emotionally. It would be worthwhile to revisit these aims and desired outcomes regularly to assess advances in policy and practice.

Links to OSN films on the importance and scope of personal narrative	
https://www.youtube.com/watch?v=di_C9WEIVfc&t=9s	https://www.youtube.com/watch?v=w0WIM0Z1eII&t=12s

Chapter 4. Improving access at museums

The OSN project endeavoured to enhance inclusion in the Welsh heritage sector in two main ways:

- Four Project Ambassadors worked with five regional museums to improve access.
- 26 of the OSN oral histories have full copyright permission to be held in the national repository at St Fagan's.

This work formed part of OSN's aims to enhance the management, community enjoyment of and participation in heritage, and help people learn more about heritage, as part of the project's Change the Story and Save My Story themes.

This work fed into the following HLF outputs and outcomes:

- Heritage will be better managed (Save My Story)
- People will have learnt about heritage (Change The story)
- People will have changed their attitudes or behaviour (Change the Story)
- Your local area / community will be a better place to live, work or visit (Change the Story)

This chapter explores the work of the OSN Ambassadors to improve disability access at Cardiff Story, Bangor Storiell, Wrexham, Abergavenny and Monmouth Museums.

A key objective was to broaden the conceptualisation and implementation of inclusion and disability access, beyond the confines of wheelchair accessibility, to encompass wider physical, sensory and cognitive disabilities. Most of the museums reported that they attracted mostly older people and some families with young children, but few visitors with learning disabilities and the Cardiff Story Museum specifically wanted to know why they attracted so few families with young children. In each museum, the Ambassador and their Supporter liaised closely with one member of staff, usually a manager as well as working with other staff.

Inviting disability groups to visit and assess museum access and inclusivity

For each museum, the Ambassadors networked with local groups of disabled people and local special schools to audit access and recommend improvements. Often these were once-off, but some groups made repeat visits to review progress and in one museum a series of interactive workshops were run with a group of disabled young people. One Ambassador facilitated visits by individual families with disabled children, giving them a bespoke tour, while also getting their views. Visits were two-way: Ambassadors explained the museum and its artefacts to the visitors to make it interesting and accessible, while also gathering their experiences of and opinions on access. Ironically perhaps, some group visits were impeded by the lift (essential to access and often the only access feature) breaking down.

"...the Ambassador role brought connections to groups which we would not have had connection with. Brought much greater insight into the needs of people"

[Museum Interviewee]

Ambassadors, Supporters and museum staff reported that this approach, especially getting disabled people's direct input, gave them valuable insights into and ideas around access, which otherwise would not have been shared. It was also noted that most of those who visited the museums on these occasions had never visited any museum before and would not have without the project's invite and facilitation.

"Some voices can get lost .. and often the ones that get lost are the most important ... It is often the quieter ones, the more reserved ones that need encouragement to speak up .. but when they have the courage to speak up and say 'this needs to change' others go 'oh that's interesting'"
[Supporter]

"We know we have hurdles .. we had long conversations with families about what worked and what didn't and what came back was heart breaking. One mother talked about being terrified that her child would damage something. I had to tell her 'that's not your problem that's our problem'. That was ... not this specific museum, their perception of museums overall"
[Museum interviewee]

Outputs and outcomes

The people who the Ambassadors helped visit the museums fed back that they had enjoyed their visits. Many planned to return another time, even if they had experienced access problems, such as lifts not working. Some access improvements were made in museums as a result of the Ambassadors' input, but it is too early to tell how much any changes in attitudes have become embedded, especially as museums were closed for so much of 2020 and 2021. Some generic resources were created for these five and other museums to use:

- Together the Ambassadors developed a basic PowerPoint presentation, which each customised for their museum and shared with local disability groups. These aimed to familiarise people who might not otherwise visit the museum, highlight the interesting aspects and artefacts held there and inform people about access points.
- A disability awareness training session was run with staff at Cardiff Story Museum. Others planned for Wrexham and Abergavenny could not take place due to Covid-19.
- The Ambassadors and Programme Managers created access guidelines for museums, and made these into a video (<https://www.youtube.com/watch?v=TJsl8QuDY4w&>).
- In two cases, short films were made showing how to access that museum from the train station. In Wrexham, specific access guides were created for people with Autistic Spectrum Disorder, to help them prepare for a visit, e.g. alerting them to the signage used, and when the café might be busiest and noisiest (i.e. to be avoided), and how to find the toilets.
- Two Ambassadors started developing visual story boards to help explain how to get to their museum and what to expect there. The Museums welcomed these and, although a new concept, immediately saw their scope and usefulness. Unfortunately, Covid-19 prevented the Ambassadors' from completing these.

"Although we had had other information, e.g. where to park, we had not considered this before ... Much more visual and so makes the museum accessible"
[Museum Interviewee]




OSN Top Tips to improve museum access

Guidance in English: https://drive.google.com/file/d/1Lvz_2pZtU2XhXCsof_iBjy0k7mfhwzbS/view

Guidance in Welsh <https://drive.google.com/file/d/1DOuAfFgFWQGXBCYPfutEVn7J6UjIAa/view>

The chart below details the other key activities, outputs and outcomes per museum.

Table 4: Activities, outputs and outcomes for each museum

Museum	Activities and achievements	Outputs and outcomes
Abergavenny Castel Museum 	<p>The Ambassador developed a close working relationship with the Learning Manager of Abergavenny and Monmouth Museums.</p> <p>They arranged many visits by a local group of PWLD, to look at access and subsequently review the changes made.</p>	<p>Based on the recommendations made by the first group, the Ambassador applied for and secured a grant to implement some access improvements. This grant funded a ramp to help avoid the steps into the building; a tablet to provide visitors with a video link to exhibits in inaccessible rooms on another floor; more handling objects; and 'talking tiles' to allow people to access audio descriptions of the exhibits if they could not read the written information.</p>
Monmouth (Nelson) Museum 	<p>Five visits and activities were organised with a local special school.</p> <p>A series of interactive workshops were prepared for and attended by the pupils over late 2019 and early 2020. These were mainly in Years 7, 9 and 10.</p>	<p>The pupils and staff enjoyed these and gave positive feedback. They prepared a quiz and other activities based on the museum, to be part of a local summer funday. The young people took photos and wrote the captions to provide a visual story of the museum. This had not been considered before.</p> <p>Another engagement activity, showcasing how to make the museum's contents more interesting and accessible for disabled people, was co-produced with pupils and planned for Summer 2020. This had to be cancelled because of Covid-19.</p>
Cardiff Story Museum 	<p>The Ambassador developed a strong working relationship with the museum staff. They provided general help and advice to staff, e.g. access points about specific exhibits. The Ambassador invited and hosted four groups of PWLD, including one special school, to visit the museum, and gave groups and individual families guided tours. The Ambassador worked</p>	<p>The museum acted on recommendations to improve the experience of exhibits, enhance explanations and include some sensory items. The Ambassador and groups visits helped them appreciate more about the access limitations within the building and how these variously impacted. The Ambassador made a short film showing how to access the</p>

	<p>with a group of families with children of various ages, to discuss the access barriers for disabled children and their carers. Two further adult groups and an autism awareness training for staff were planned for Spring 2020. But these had to be cancelled because of Covid-19.</p> <p>In the second and third years the Ambassador and OSN staff delivered disability awareness training to 14 members of staff and the museum hosted six OSN volunteer events and a social media takeover.</p>	<p>museum from Cardiff Train Station, and a visual story book, using photographs of various aspects of the museum, to help people prepare for a visit.</p> <p>The Ambassador routinely reported access issues to the Museum, such as the lift not working, or a ramp being dirty and unwelcoming.</p>
<p>Storiol Museum, Bangor</p> 	<p>The Ambassador spent a lot of time at the museum, helped staff in general ways and provided practical tips on access.</p> <p>Two group visits planned for early 2020 were cancelled because of Covid -19</p>	<p>The Ambassador made a short film showing how to access the museum from Bangor train station. Sadly the film was held on a USB stick, which was lost during the change in support workers.</p>
<p>Wrexham Museum</p> 	<p>The Ambassador arranged and hosted visits by four groups of people with learning disabilities. In two groups people with profound communication issues helped highlight specific access needs. In October 2019 the Ambassador and the North Wales Project Officer planned to deliver Learning Disability awareness training to museum staff, but due to a confusion over dates no staff turned up. Several further visits by disability groups and schools planned for Spring 2020 had to be cancelled because of Covid-19.</p>	<p>Many ideas were shared and developed around improving signage, information, interpretation and lighting at the museum, and to consider the needs of and accommodate people with sensory and learning difficulties.</p> <p>A presentation and a quiz created by the Ambassador helped disabled visitors interact more with the museum exhibits. The Ambassador contributed towards Autism Awareness training led by Autism in Museums. This was well received.</p>

More generally, the Ambassadors' input put disability access on the agenda and kept it there for a few years and also helped these museums engage with local disability groups. This provided staff, who were already keen to promote access, greater leverage as well as more detailed insight to pursue improvements. They particularly welcomed the scope to explore idea and issues with the Ambassadors. Often, to be effective, these required granular detail. Their discussions helped address fears of pursuing the wrong solution and at the same time widened their conceptual framework and understanding of the social model of disability.

“This was a problem-solving process – an awareness that if you make things right for a group of people, you will probably makes things right for an awful lot of people ...”

[Museum Interviewee]

Feedback on the learning disability awareness training delivered by the OSN Ambassadors and staff was very positive. Attendees reported an increased understanding of learning disability.

“I enjoyed the activities and discussions. It was really good to explore the language we use and the way people communicate”

[Written feedback from Museum training attendee]

Key enablers reported

- Ambassadors developed a close collaboration with museum managers and other staff. Many were passionate about promoting access and inclusion, provided invaluable support and ensured that other staff collaborated with them.
- Where liaison was with lead personnel with a museum or school, their commitment, oversight and authority helped drive change and encouraged other staff's engagement and assistance.
- By the project's third year, the Ambassadors had a good grasp of their role, access challenges and potential solutions and how to engage with and attract disability groups. By then they had also developed good relationships with their respective museum, were receiving the support they needed and had developed more skills and confidence to work effectively.
- The Ambassador working with Monmouthshire Museum was able to demonstrate mutual benefits to the local school, as the activities they had planned for the pupils at the Museum also supported their Welsh Baccalaureate coursework and exam.
- The Ambassadors' openness and frankness about disability matters was appreciated and enabled staff to ask questions they would have otherwise found too embarrassing.

“The Ambassador brought openness and we could ask the elephant in the room questions... nothing judgemental, nothing around ‘you should know this already: why are you asking this?’ You need frankness... ask questions: it's a confidence builder”

[Museum Interviewee]

Key challenges and learning points reported

The heritage work proved more challenging than had been anticipated. This was attributed to: insufficient resources; a low starting point in museums' physical access and understanding of access; engaging disability groups; the split between this work and rest of OSN; and the impact of Covid-19.

- **Project and museum resources were too limited**

The Ambassadors, Supporters' and museum staff had few hours to devote to this work, and once it got underway it was realised that this work required substantially more input than had been anticipated (12 hours per month). These factors were aggravated by the Ambassadors' inexperience, the turnover of Project Officers and Supporters, varied investment and prioritisation by museums, the project's geographical spread and conflicting project demands on OSN Programme Managers. Original plans to involve volunteers in the heritage work proved unrealistic. There was no budget for practical outlays, although even relatively minor items, such as tactile displays, talking tiles, or an iPad require funding. Another factor was the differing capacities of regional museums to engage,

which also changed over time. Interviewees recommended that future projects included substantially more match-funding to allow museums to cover adequate staff time.

- **Efforts to improve access had to start from a much lower point than anticipated**

Most of the museum buildings had not been designed with access in mind and any existing features were generally based on a very restricted concept of disability and access: typically, a lift for wheelchair users. Generally, methods to help people with other physical, sensory or intellectual disabilities access heritage were missing. In two museums, the Ambassadors' work had to start from scratch, to develop assessment tools and methods to gauge and improve access, rather than building on existing resources, which was an original project assumption. Ironically perhaps, the lift broke down on the day of groups visited, making the toilet unreachable for many, and arguably accentuating an approach to disability access as a remote, side-issue. In one museum the lift could not be fixed quickly as that part of the building was managed by another organisation.

Many of the Ambassadors' own appreciation of disability and access was quite limited in the beginning and often confined to their own direct experience. Similarly, museum staff had a narrow understanding of disability access and although supportive, some did not comprehend this work, or were noted to be '*stuck in their ways*' [OSN Ambassador]. This limited insight was felt to account for the lack of upkeep and maintenance of some of the minor changes introduced, such as labels explaining exhibits, tactile objects and remote links to displays which were otherwise inaccessible.

- **Attracting local groups of disabled people proved much more difficult than anticipated**

Contrary to expectations, most of the Ambassadors had limited personal links to local disability groups. As a result, they had to cold-call groups and schools to spark interest in this project. Many of the special schools and groups they contacted were keen, but could not fit the necessary trips into their existing timetables and plans. Ironically, some scheduled visits had to be aborted because museum lifts were not working on the appointed day.

- **The access work was too distant from OSN's work on the friendships and relationships**

Conceptually and physically, the heritage access work and the oral history work were two distinct project strands. The link between them was difficult for the Ambassadors to explain and museum staff to comprehend: '*It always felt like a project with two halves*'. Often Ambassadors did not know what was happening in the friendship and relationship work. In practice, as the oral history work proved very demanding throughout, constantly evolving and required extensive input, this had the unintentional effect of making the Ambassadors' role feel like a parallel, but less important, workstream. In the third year, the friendship and relationship arm started to liaise more closely and co-hosted events and did a social media takeover with Museums, which helped bridge the gap, but as with other work was interrupted by Covid-19.

The impact of Covid 19

From March 2020, the Covid -19 pandemic seriously affected this work and, most unfortunately, just as the Ambassadors had got into their stride and had lined up many group visits and other activities. It meant that many plans had to be left uncompleted, as Museums closed, relevant museum staff were furloughed, completing this work remotely in any meaningful way was not feasible and the project funding came to an end.

Chapter 5. Employing people with learning disabilities

Chapter 4 looked at the work of the Ambassadors to improve museum access. This chapter examines the processes around and learning achieved from employing the four people with learning disabilities. Three were employed as project 'Ambassadors' and one combined the Ambassador role with a more senior 'Project Officer' position. However, for simplicity, all are referred to here as 'Ambassadors'. These posts were designed to be mutually beneficial: to help people with learning disabilities gain employment skills, experience and knowledge; while using their personal experience of learning disability and their local networks to inform the museum disability access work and OSN project development. This Chapter examines the roles and respective outcomes and the most significant learning points and recommendations emerging.

This work fed into the following HLF outputs and outcomes:

- Your organisation will be more resilient (Change the Story)
- Heritage will be better managed (Save My Story)
- People will have learnt about heritage (Change The story)
- Your local area / community will be a better place to live, work or visit (Change the Story)
- People will have changed their attitudes or behaviour (Change the Story)

Outcomes for those employed

While Mencap Cymru and the museums gained from this aspect OSN (see Chapter 4), the Ambassadors also reported enjoying the experience and getting a lot from their work. All appreciated being given the chance to display their skills and abilities, as well as learning and developing. Everyone felt that the ambassadors had gained valuable employment related skills, personal confidence and abilities and a greater understanding of disability and access.

"I loved every minute: it was awesome"

[OSN Ambassador]

• **Employment related skills**

Two of the Ambassadors had previously worked in the private sector and two had no previous work experience. Overall, the group started out with varying insights and limited appreciation of the working world and computer literacy. Most needed considerable support to use computers. One had never owned or used a mobile phone and two had never used email before. Just as Mencap Cymru learned a great deal about employing people with learning disabilities, the Ambassadors gained valuable work experience and developed employment related skills, including learning how to:

- meet the expectations of employment contracts and employers;
- plan their own work time and activities, within tight parameters;
- plan activities for others, such as schools, disability groups and museum visitors;
- relate to, communicate and collaborate with a range of people, including museum staff, managers, schools and people with a range of disabilities, backgrounds and needs;

- use computers, mobile phones and different software, often for the first time, such as email, Word, Excel, PowerPoint, Audacity, Microsoft Teams and video conferencing; and
- plan and deliver presentations to a range of professional and public audiences.

The role helped demonstrate the Ambassadors' abilities and, in some cases, their readiness for a more open employment market. At least three of the Ambassadors were keen to look for more paid work and volunteering opportunities as a result of their Mencap role.

"I found it really inspiring. Showed the usefulness and potential of work like this... We should have a lot more: so much more useful and important than say pottery ... learned about the real employment of people with learning disabilities ... a brilliant experience. More of it should be done ..When it works it's beautiful"

[Supporter]

- **Personal growth and increased confidence**

The Ambassadors' self-confidence grew as they developed more appreciation of their own strengths and abilities. They received a lot of positive feedback for their work from OSN colleagues, museums and partner agencies.

'It has helped me improve my confidence in myself and speaking out'

[OSN Ambassador]

The Ambassadors' independence developed, albeit to different degrees, in line with meeting the expectations and responsibilities of the role, such as communicating with officials and engaging with, and representing the project to, museums, schools and local disability groups. Incidental aspects also helped boost independence skills and personal confidence, such as travelling around Wales, sometimes alone, and having access to, and learning to use, their own computer and phone. The Ambassadors enjoyed having a role and broadening their own horizons and ambitions. Positive feedback from the museums and project staff helped them feel more confident and independent outside of work too, for example in their local groups and within their families. They also reported feeling, and were observed to be, more relaxed talking to strangers and new groups of people and reported that their families, friends and acquaintances began to see them in a new light, appreciate their abilities and respect them more. Some Ambassadors gained a wider social network and source of personal support, as previously many had quite a limited circle of friends and social activities, which chimes with OSN's work on friendships and relationships.

Working on the project helped some of the Ambassadors develop more insight into their own needs and appreciate that they might require support at times and accept that there was no shame in needing, or asking for, support.

"The barriers faced fuel you.. and then you see it happening as well as in the oral histories or when you talk to people about relationships"

[Supporter]

- **Increased knowledge and understanding of disability and access**

The Ambassadors developed a deeper and broader appreciation of the two main project topics: disability access; and friendships and relationships for people with learning disabilities. They enjoyed providing a conduit and voice for other disabled people.

An initial presumption when employing the Ambassadors was that they would share their own insights from their lived experience of learning disability and use these to improve museum access. This expectation was found to be largely misplaced. Most of the Ambassadors arrived with little appreciation of the wider disability world, let alone the range of potential access barriers. However their understanding grew, mainly through direct input from other project staff and Supporters; from learning about the [social model of disability](#); and from engaging with groups and individuals with different disabilities and needs. With time, exposure and discussion, they developed an appreciation of how access is determined by the design of the public realm, and structural, attitudinal and societal constructs, rather than by someone's diagnosis. By the end of their time on this project most of the Ambassadors had grasped the requirements of their role, were reaching out to and engaging disability groups and providing good results. However, this was interrupted abruptly by Covid -19.

"[This work] emphasised that doing the bare minimum, e.g. to meet the needs of disability legislation alone, is unlikely to be enough and the range of improvements necessary will need championing and commitment"

[Museum interviewee]

Key enablers in relation to the Ambassador work

- There was huge enthusiasm and drive to make this work as effective as possible.
- In particular the Ambassadors and other project staff gave their utmost to make this aspect of OSN succeed.
- The Ambassadors brought more insights, skills and talent over and above those originally anticipated and each grew into their role and developed competencies over time.
- Ambassadors brought contacts and trust with local disability groups, which Mencap Cymru and museums would have struggled to establish otherwise.
- Mencap Cymru showed responsiveness, flexibility and ability to learn, especially in response to the early feedback and the first two years' process and formative evaluations. These helped the project acknowledge some of the inherent design problems within the Ambassador role and address some of these.
- For example, from the second year, the Ambassadors and Supporters from across Wales met more regularly in person and online. This helped overcome the geographical distances and enhanced Ambassadors' sense of belonging in a team and their grasp of the overall project, and provided some mutual learning opportunities. The joint meetings also generated very useful project ideas and a unified presentation template for museums.
- The Supporters all brought considerable experience, expertise and flexibility which was reflected in their skills to assess and meet the diverse needs of the people they supported.
- The findings show that including individual one-to-one support from the outset was well conceived, and helped capture valuable learning around the support needs and other considerations when employing people with learning disabilities.
- The Ambassadors' enthusiasm and hard work was noted.

"The ambassador was brilliant, absolutely fabulous... Great working relationship... would go the extra mile ...couldn't have asked for anyone better to work with"

[Museum interviewee]

Key challenges and learning points emerging

This part of the project highlighted some additional considerations when employing people with learning disabilities in general as well as issues specific to this project. Some took considerable time to resolve, and at times detracted from work to promote museum access. The main issues identified were:

- **Anticipating Ambassadors' needs and strengths**

At the start each Ambassador completed a Mencap assessment form to explain their strengths and needs. But these did not capture a full picture of the type or amount of support required, possibly due to the Ambassadors' lack of employment experience. Supporters' subsequent assessments and other staff observations noted that needs were substantially greater than originally understood. The Project Managers then had to re-plan how to meet higher levels of need, while matching individual personalities and contexts. This demonstrated the value of individualised assessments.

- **Meeting support needs**

There was a high level of turnover among Supporters, which was mainly attributed to the limited hours and pay. This resulted in gaps in the support provided, and Project Officers and Managers having to step in, although it was difficult for the Project Managers, based at the Cardiff, to support Ambassadors in North Wales. Over the length of the project, two Ambassadors had three Supporters, and one had two. This amount of change proved discombobulating for Ambassadors and substantially impacted their work, as some could not work at all without support.

- **Ambassadors' limited experience and understanding of employment**

Some of the Ambassadors had little understanding of employment expectations, such as carrying out an agreed task within a timeframe, or routinely checking for, or responding to, emails. Most grew up with low employment expectations, two had no prior experience of using computers and one was anxious using phones. Developing these insights and skills proved a steep learning curve and took considerable time and support, but were essential starting points before project work could begin.

- **Expectations around the role**

Numerous assumptions underpinned the Ambassadors' work with museums. In hindsight most informants felt that the design and remit were over-ambitious, too vague and did not suit people with learning disabilities, who had little or no previous work experience. These included the expectations to: work on a separate arm of the project alone, remotely from the Mencap Cymru offices and with minimum input from, or contact with, other project staff; be self-starting and able to design new workstreams and innovative activities for diverse groups from scratch; develop new contacts and networks and motivate them to get involved in the project; understand disability 'access' in its widest sense; have excellent project planning and time management skills, to plan a 3-year work schedule involving other agencies; and negotiate and represent the project and promote access with diverse heritage staff, including senior people and those with no interest in and/or misconceptions about, this topic. The geographical spread of the project and its fixed and limited budget restricted joint meetings, support, networking and scope to respond to some challenges when they became apparent.

- **Inadequate contracted hours**

The three hours a week allowed for the Ambassadors and Supporters proved totally unrealistic to carry out the core tasks of community engagement and developing museum access, as well as

administration, attend national project meetings and training, or maintain contact with the rest of the project. In hindsight it was felt that this role required at least a half-time input or more. One Ambassador who had accumulated overtime was instructed to stop all work in early 2020. But doing so would have meant finishing prematurely with nothing to show for all their hard-won and effective community engagement work with the museum and local schools. The Supporter role also required additional hours for planning and preparation, besides their face-to-face time with the Ambassador.

- **Expected links with local disability groups**

Ambassadors were employed on the presumption that they had lots of contacts with local learning disability groups and could enhance Mencap Cymru's engagement with groups across Wales. In practice, only one person met those expectations. The other Ambassadors had a connection with just one local group and did not know other agencies or groups in the area.

- **Royal Mencap Society processes and IT systems**

The central Mencap processes and IT systems were reported to be often unsuitable and too rigid. They took considerable time away from project work and extenuated Ambassadors' existing support needs. Some of the training expectations were described as disproportionate for this role. Although expected to work remotely in community and museum settings, remote access to the internet and Mencap email system remained unreliable throughout the three years of this project. In many instances the issues were relatively minor, such as getting an internet connection, providing password reminders, or being given a phone or a tinted computer screen. Mencap's approach to meetings, IT and management were all based on a model of staff being office-based and did not cater for remote working, let alone the needs of people who required substantial support with IT. These issues undermined Ambassador's confidence and scope to their job.

- **Abrupt ending, due to Covid-19**

This work was forced to end abruptly during the third year because of the pandemic. Covid-19 and the associated lock-down, social and physical distancing and other restrictions proved very difficult for the Ambassadors and Supporters. It took some time to ascertain which if any project staff would be furloughed and then it became clear in Spring 2020 that this would not be permitted under the funding terms of the project. However, lockdowns the closure of museums, schools and groups, social distancing rules, inability to work with their supporters and the nature of the role made it impossible for the Ambassadors to continue. All their presentations, community events and activities and group visits to Museums had to be cancelled. Unfortunately, this came just when the Ambassadors had gotten into their stride and their work was beginning to bear fruit.

Ambassadors and Supporters were extremely frustrated that their three years had ended in this way and without being able to complete their work. Ambassadors' emotional and psychological support needs increased due to this abrupt cessation and the Covid-19 pandemic itself. As well as isolation, anxiety and frustration, many experienced serious illness and deaths among those close to them. But the Supporters could not meet them in person and for some, telephone or online meetings were either unfeasible or less effective than meeting face-to-face. To add to this, there was some confusion over the precise dates when the contracts would end, and the redundancy process had to be done remotely. The Ambassadors were very sad that the project was ending. They had enjoyed it and were not fully prepared for the premature ending. Unfortunately, social distancing and lock down rules removed the chance to provide a gentler ending process.

Chapter 6: Achieving National Lottery Heritage Fund outcomes

This chapter explores how well OSN met the intended outcomes agreed with the National Lottery Heritage Fund (NHLF). The anticipated outcomes and main themes (in brackets) were:

- a) Heritage will be better interpreted and explained (Share My Story)
- b) Heritage will be identified and recorded (Hear My Story)
- c) Heritage will be better managed (Save My Story)
- d) Staff and volunteers will have developed skills
- e) People will have learnt about heritage (Change The story)
- f) People will have changed their attitudes or behaviour (Change the Story)
- g) People will have had an enjoyable experience
- h) The local area and community will be a better place to live, work, or visit (Change the Story)
- i) A larger and wider range of people will engage with heritage (Save My Story & Change the Story)

By the time of this evaluation, there was limited evidence available in relation to many of these intended outcomes. This was not surprising as, although many interviewees reported changes, such as a greater appreciation of the importance, benefits and challenges of friendships and relationships and described intentions to improve services for people with learning disabilities, it will take time before evidence of such plans would translate into better service design, and longer still into improved outcomes for service users. In addition to those more 'normal' considerations, Covid -19 interrupted all this work and affected people with learning disabilities very severely, in terms of high levels of illness and deaths, interrupted service delivery and even further restrictions on their socialising and support.

Outcomes for Heritage

a) Heritage will be better interpreted and explained (Share My Story)

One of the main aims of the exhibitions was to challenge people's perceptions of what constitutes 'heritage', through the oral histories.

The role of the oral histories in improving interpretation and explanation

- In the long-term, the OSN oral histories will be stored at, and available from, St Fagan's Museum, making them accessible to the public and others for years to come.
- This goes some way to fill a gap in the heritage sector. These narratives share the voices of people who are seldom heard, and explain and chronicle the social exclusion and even victimisation they experience in modern day Britain.
- The OSN exhibitions, presentations, seminars, film evenings and other events provided a vehicle to interpret an aspect of life mostly hidden from view and share life stories with professionals, politicians, volunteers and the wider public.
- The methods used by OSN helped this heritage reach far beyond the walls of a museum. Indeed, the project's innovative exhibitions and locations helped bring heritage to people who do not normally visit museums.
- Interpreting the points raised by narrators within human rights, health and well-being agendas helped explain people's lives and needs to new audiences.

- At the same time, it proved a subtle, but powerful, way to raise awareness, and gave agencies and professionals working in this field some fresh perspectives and appreciation of the importance of this issue.

“People are not perceived as adults. They may be vulnerable, but they are still adults – should be able to make their own decisions”

[OSN volunteer who helped on exhibitions]

An additional, unanticipated, outcome was the Ambassador’s work in improving interpretation

- As outlined above, the OSN Ambassadors worked hard and collaborated closely with the five regional museums to improve access to and the interpretation of heritage.
- They introduced many simple solutions to improve the interpretation and explanation of museum displays and artefacts for people who have sensory, or intellectual or physical difficulties, for example by introducing simple digital features, touch tiles and sensory bags.
- For many people with learning disabilities and their carers the Ambassadors encouraged them to visit a museum for the first time and also interpreted the museum to them.
- For the museums, the Ambassadors’ input and these visits helped highlight many basic access challenges, beyond the build environment. They exemplified a more inclusive approach to ‘access’ and assisting people to interact with, and get more from, museums.
- The Ambassadors’ work also helped museum staff and OSN realise how much work there is still to do to improve comprehension and practical aspects of inclusion.
- Staff interviewed felt it armed them with arguments and evidence to take this work forward.
- The guidance for museums and staff is a vehicle to continue to improve inclusion.
- The guides to help find and get around the museums may encourage more disabled visitors.
- Before Covid-19 interrupted their work, the Ambassadors introduced many local disability groups and special schools to museums and vice versa. There were hopeful signs that these relationships would continue.

b) Heritage will be identified and recorded (Hear My Story)

OSN recorded 40 oral histories about friendships and relationships from 59 people: 50 of whom had a learning disability. The original target had been 60 people with a learning disability. However, over time the project recognised the need to engage with families and others as well, and so also interviewed nine friends, parents, and professionals. The project gathered a further 10 narratives from 12 people with learning disabilities about their experiences of the Covid-19 pandemic. Most of these oral histories have full relevant consent and copyright agreements to be stored at, and made available by, St Fagan’s. Although OSN exceeded their original numerical target, it proved more difficult than anticipated to get the demographic range expected. For instance, few young people, or people living in supported accommodation participated. However, OSN built on the momentum and trust gained and had looked set to address this and rebalance the sample in early 2020, but the Covid-19 pandemic made this impossible.

The oral history work showed the following outcomes:

- Sharing their stories provided a voice and platform for a group of disabled people who are less often heard around a topic that is usually brushed under the carpet;

- People who provided their life stories found the experience enjoyable. It helped many appreciate as well as voice the barriers they faced in their day-to-day lives.
- The recordings and the exhibitions and presentations based on them helped illuminate an issue and change the views of a number of professionals, service commissioners, policy makers and politicians. For example:
 - ✓ It introduced and demonstrated the benefits of a narrative approach, e.g. within assessments and service delivery;
 - ✓ OSN's framework helped assimilate and respond to the themes emerging;
 - ✓ Service providers, policy makers, other professionals, volunteers and the general public realised the importance of friendships and relationships for people with learning disabilities and the need for more support in this area.

c) Heritage will be better managed

Many of the outcomes listed above also address this requirement. For example, improving museums' inclusivity helps a wider range of society to access museums and artefacts, and can help ensure the voices of disabled people are captured within heritage collections. Another notable outcome is that the senior museum staff interviewed felt that OSN's work had helped raise the profile of inclusion, improve their connection with local disability and family groups, and illustrated that inclusivity is as much or more a way of thinking and not just about bricks and mortar. They reported that this provided them with a useful framework to approach relevant topics with staff and management and progress this work in the future.

"...it's made people far more likely to say 'stop, think, does it work? Can everybody access this?' It put [access] on the agenda and kept it on the agenda. Managers were influenced: that's where the difference has been. The management now get it more...Widened it beyond wheelchair access. We kept getting feedback from groups that people want to touch, handle, interact..."

[Museum Interviewee]

OSN was hopeful that their top tips guidance will help the heritage sector continue to design better ways to open up the sector and collections to sections of society, who hitherto have found museums inaccessible, irrelevant or out of the question.

For numerous reasons, in practice OSN was unable to meet its target numbers of current and historical images to archive. Volunteer photographers were engaged to provide the current-day images. However, it was sometimes hard to synchronise their schedules with those contributing oral histories; it took considerable additional time to seek specific consent to use photographs; and last but not least, many participants were anxious about confidentiality and anonymity, which would have been even harder to protect if images were used.

In relation to the historical images, it proved difficult to get originals. Often contributors were nervous about losing photographs, or only had poor quality copies. It emerged that the largest collections were held by groups, clubs, local authority services and care providers, who were anxious about data protection. Covid -19 limited the team's time to address these issues in the final year.

Outcomes for People

d) **People will have developed skills**

This aim covered the four OSN Ambassadors and 60 volunteers. The Evaluator conducted focus groups and individual interviews with Ambassadors and Volunteers and also used written feedback and views gathered from volunteers by project staff in focus groups.

As stated earlier, the four Ambassadors arrived with limited relevant employment experience and varied expectations, low skill levels and little self-confidence. Through their OSN employment, they developed a range of personal and employment related skills, grew in confidence and developed more connections and networks locally. These may help them in their personal lives and in finding future work. One Ambassador was able to secure a new job before the end of their role, and soon after had two part-time jobs. Some of this might be attributable to their employment on OSN.

OSN's experience of engaging volunteers was mixed and highlighted a number of important considerations around expectations to engage and support volunteers. Originally, the project aimed to recruit, train and maintain 60 volunteers to assist with different arms of the project over its lifetime. In all 74 were engaged, exceeding this target. But in practice, most volunteers were involved for short periods, typically a month, to help prepare for and manage the exhibition in their area. The original plan to develop volunteer 'heritage hubs' and support long-term volunteer involvement, was based on the intention to host exhibitions and events in the same towns and cities (Wrexham, Bangor, Abergavenny and Cardiff) each year. In practice, it was not possible to develop these hubs because of the long periods which required little or no volunteer activity in an area, as the exhibitions and associated events moved around the country and more locations were added. It would have created a disproportionate and unsustainable drain on OSN's limited resources to create work for volunteers, support them and maintain momentum in the times when the project was focussed elsewhere. As a result, volunteers mostly had to be recruited and trained from scratch in each area, each time, and for each activity. During that time work was intense, but short-term. This did not suit many prospective volunteers. In addition, much of the work required precise skills, and usually the capacity to work alone without supervision, e.g. designing exhibitions or publicity materials, heritage skills, or transcribing interviews. Few people offering their time for free had the necessary skills, and the expectation to work alone did not always appeal. Moreover, there was no designated volunteer coordinator and supporting the volunteers fell to already over-stretched project staff. Last but not least, many volunteered for OSN on the presumption that they would be working directly with and assisting people with learning disabilities, which was not the case.

Despite all this, OSN managed to find 74 volunteers who found the roles appealing. Most assisted with designing, setting up and curating exhibitions; some helped with publicity; a few transcribed a small number of oral histories; and two photographers, captured people, activities and events, but mainly over the first two years because of Covid-19. Volunteers felt that they had gained knowledge and skills as well as having new experiences. Most of the new learning acquired was around people with learning disabilities rather than heritage skills. The main change they reported was a greater appreciation of the importance of friendships and relationships for people with learning disabilities and a deeper insight into people's lives and the challenges they face.

"It was a big eye-opener for me ... That struck me, that disconnect - they have the same feelings, the things they want to accomplish in their lives, but don't have the tools or agency, and have restrictions placed on them by other members of their family"

[OSN volunteer who helped transcribe interviews]

e) People will have learnt about heritage (Change The story)

This was achieved in different ways:

- OSN's oral history work highlighted the hidden heritage within the lives and perspectives of people with learning disabilities and brought this to the public, through innovative exhibition methods, community engagement activities, film and other activities. The findings indicate that many of the public and professional audiences would not have engaged with heritage otherwise and certainly would not have learnt so much about the lives of people with learning disabilities.
- This evaluation found that OSN increased the appreciation of the potential of using personal narrative among service providers and professionals as much as in heritage and. As well as deepening understanding around normally invisible lives, the stories showed the scope to bridge the divide between reality and concepts of heritage and service delivery.
- The Ambassadors' work helped many groups of people with a range of disabilities, including learning disabilities, schools and families engage with heritage for the first time. As well as introducing the museum to people who normally do not visit them, for these families' this initiative helped overcome their perception that their children were not wanted in these places. This work provided valuable learning points around involving local disability groups and the breadth of the divide with the heritage sector.
- OSN's work with museums and art establishments and the guidance they produced illustrated the significant mutual benefits when disabled people and the heritage sector collaborate, and how simple methods can help interpret heritage and improve access for large groups of people, enabling them and hopefully others to engage more with heritage.
- On reflection, the mobile app proved too ambitious an initiative without adequate specialist support and prior piloting and testing of its appropriateness, functionality and acceptability to the public. In hindsight OSN staff felt that the nature of the oral histories did not lend itself to site-specific geo-location technology and the size of the app possibly deterred people from installing it on their phones. Moreover, this type of technology is in constant flux and between conception and roll-out, views on the appeal and usefulness of QR codes and apps for heritage projects had changed.

f) People will have changed their attitudes or behaviour (Change the Story)

It is too early to tell and outside the scope of this evaluation to collect relevant data to assess if or how much OSN had impacted on anyone's behaviour. However, in terms of attitudes, the evaluation found that the exhibitions, presentations, seminars and films based on the oral history work were very well received. They were seen as powerful tools in shedding light on a whole population, area of life, experiences, opinions and feelings which were largely unknown to professionals and the public. To that extent they may have contributed to seem shift in attitudes. Even those who had some awareness of the importance of friendships and relationships for people with learning disabilities said they were informed, moved and shocked by the stories, especially the lack of personal autonomy, privacy and rights exposed and the common willingness to side-step people's basic needs. Service providers, commissioners and professionals similarly reported that they had a better appreciation of the role personal narrative could play in helping to understand the people they worked with. It may take some time for changes in attitudes to translate into behavioural change, especially into designing and delivering better services.

The Ambassadors' work with museums provided a direct learning opportunity for heritage staff and was said to have influenced attitudes. Mostly this was simply because it provided staff with direct contact with disabled people and an opportunity and safe place to ask questions and probe issues.

"..nothing was off limits and we were not made to feel awkward about asking question getting clarity... they removed barriers around language"

[Museum Interviewee]

The more 'fun' social events, such as Disastrous Dates, Smutslam, Drag Syndrome and film screenings also proved effective in improving awareness and attitudes. Volunteers and members of the public noted in their feedback that they had learnt to see the commonality, rather than the differences, between disabled and non-disabled people. Those with learning disabilities enjoyed participating in the same events on an equal footing and also seeing some of their issues reflected in the films and presentations. At the same time, OSN's work has also demonstrated the extensive work still required to improve attitudes, services and inclusion.

g) People will have had an enjoyable experience

All the evidence points to this being an enjoyable experience for those who participated. The people who provided oral histories enjoyed being involved in this project and having some of their day-to-day challenges formally acknowledged.

"I enjoyed doing it. I was fascinated to hear about the other contributors' experiences and again, it reinforced my own curiosity to why I was so different"

[Oral history contributor]

The OSN staff, Ambassadors and volunteers learnt a lot and enjoyed developing the different arms of the project as well as the opportunities for creativity and exploration. Many adults with learning disabilities attended social events otherwise difficult to get to. The Ambassadors enjoyed meeting others, having a job, working on inclusivity, being part of team, learning skills and travelling around Wales.

"It has helped me improve my confidence in myself and speaking out"

[Ambassador]

"I've found the whole project really great. [Staff] really approachable and the right balance of friendly but organised. It's one of the most creative projects I've been involved with as a volunteer"

[OSN volunteer]

Public visitors to exhibitions and events said they enjoyed these, and learned a lot. They appreciated OSN's efforts to make engagement fun and interactive, despite the seriousness of the topics.

"I think the most important thing is to give people the same opportunities that I have"

"It made me think about things I would never have thought about"

[Written feedback from two exhibition visitors]

The groups who the Ambassadors helped to visit museums thoroughly enjoyed the experience and indicated that they might continue to engage with heritage.

Outcomes for Communities

h) Your local area or community will be a better place to live, work or visit

OSN aimed to achieve policy and systemic changes, both within Mencap and in external agencies, and ultimately improve the lives of people with learning disabilities. Internally, OSN presented the thematic analysis and related observations to Mencap Trustees, the Chief Executive and strategic working groups. Externally, the project presented this and key policy implications to the Welsh Government's Isolation Steering Group, other policy makers, service providers and practitioners and to learning disability groups. The evidence suggests some limited immediate and incremental achievements:

- OSN supported the establishment of the Support Loving Cymru Network.
- The project increased awareness of the fact that many people with learning disabilities are unable to participate in, or enjoy, their local area or community.
- The Ambassadors' encouragement, assistance and planning enabled many disability groups and schools and individuals with learning disabilities and their carers to take advantage of their local museum for the first time.
- According to feedback given, this would not have otherwise happened and as well as being enjoyable, this may have laid the foundation for more visits.
- Further engagement may be enhanced by OSN's museum guidance.
- For those who provided their personal narratives, this project was the first acknowledgment of, or opportunity to discuss openly, the significance of friendships and relationships to them.
- OSN provided a rare opportunity for disabled people and non-disabled people to meet, attend and enjoy the same social events and evening activities and talk about relationships, on an equal footing.

i) A larger and wider range of people will engage with heritage (Save My Story & Change the Story)

OSN helped several new groups of people engage with heritage for the first time, not least:

- The people with learning disabilities, their friends and families who provided oral histories;
- Members of the public and people with learning disabilities and their families who engaged with the OSN exhibitions in the cafes, leisure centres, shopping centres and at scattered exhibitions and who attended OSN social events.
- The disability groups and special schools who were encouraged and assisted to visit their local museum.
- Many social care settings and professionals who said they would start exploring story-telling and the scope for personal narrative in their work, as a result of their exposure to OSN.

In turn this helped dismantle rigid concepts around 'heritage', and who it is for, and may have overcome some hesitancy to visit exhibitions, museums and art galleries in the future. OSN also helped museums realise that a wider range of people were interested in heritage, but that this may require facilitation.

Overall, the project illuminated an enormous gap around inclusion and access in the heritage sector, the low likelihood of people with disabilities visiting museums because of access challenges and the presumption of such barriers, and the limited appreciation of disability access in general or of the specific considerations which would to help different groups access heritage.

Conclusion

This was an ambitious and innovative project, both in its aims and methods of delivery. OSN set out to address major barriers currently faced by people with learning disabilities, not least the limitations on their scope to pursue meaningful social and emotional lives, friendships and relationships. The project highlighted deep-seated prejudices and misconceptions and presented new insights and realities, especially the importance of friendships and relationships, and the challenges people face when trying to participate in society or access heritage or employment.

OSN tackled serious issues using creative ways to share first-hand accounts from people directly affected by negative attitudes and discrimination. There is no doubt that those who viewed the films, exhibitions or social media posts and/ or listened to people's personal accounts found these narratives and the issues raised compelling, distressing and transformative. In addition, OSN demonstrated the value of personal narrative, in terms of capturing insights which are usually hidden from view or not even sought, and improving understanding of those who are generally excluded from British society. It also showed the value of using narrative as a process to help people present their own perspectives and priorities and its enormous scope within social care services.

As well as original perspectives and content, OSN was inventive in its design and delivery of this project and in its agile response to emerging challenges, not least the Covid-19 pandemic. Visitors to the exhibitions and those who listened to the oral histories online found them extremely inspiring. While the siting of the exhibitions in community venues may in hindsight have been over-ambitious, especially given the unfamiliar and thought-provoking content and limited time and budget to publicise these and get them set up, evaluation interviewees praised the aim to cover all of Wales and to reach out to the general public, rather than confining the exhibitions to an art centre demographic. It might have proved simpler to work more intensely in fewer areas, making more use of existing heritage agencies, venues and staff.

Mencap Cymru is a small constituent of the Royal Mencap Society and normally have proportionately less influence. However, in this project they appear to have '*punched above their weight*'. OSN demonstrated the potential for similar projects across the UK, not least because of the universal themes addressed, such as love, friendships, loneliness and autonomy and their framing within power, wellbeing and human rights. OSN also highlighted the potential for services to shift their approach, to use personal narrative as a method to improve the type and delivery of care, not least by prioritising the discovery of someone's individual identity and paying attention to inherent power dynamics.

Everyone who provided feedback reported that they had learnt something and that they got a much better understanding about the need for, and significance of, friendships and relationships for people with learning disabilities, as well as the major obstacles people face day-to-day. Participants with learning disabilities felt gratified that these issues were being shared and discussed openly and seriously. The people who shared their stories and those who participated in conferences and seminars enjoyed the process and having their voices heard, as equals. OSN's framing of issues within a human rights context, and as determinants of individuals' happiness and health, proved

influential with policy and service providers. Professionals and service providers interviewed felt inspired to use this evidence to improve service design, in particular to facilitate friendships and relationships and use personal narratives within services.

The adults with learning disabilities employed as Ambassadors and Project Officer got a lot from working on this project, including valuable personal and work related skills. Through this work, Mencap Cymru developed more understanding about employing disabled people with little or no previous work experience, not least the need to provide enough hours, support and continuity and to help embed learning and personal growth.

The work with five regional museums illustrated an enormous gap in the appreciation of access and application of disability law and guidance and a continued failure to consider cognitive, sensory and communication needs, or the social model of disability. Put bluntly, a wheelchair accessible lift is not enough. It was shocking to hear that many people never visited museums because they are inaccessible, or because of anxieties that their child's disability could not be accommodated and would prove too challenging. Despite difficulties faced, this work provided significant learning, which can be built on. More than anything, OSN showed the enormous potential to be gained from collaborating with disabled people, including local groups, not least in gathering and sharing views and ideas; that switching attitudes is just as important as physical changes; that the sector needs substantially more advice and detailed guidance; that even small budgets can effect worthwhile changes; that the process is continuous and that any adaptations, including lifts, need to be maintained.

For many professionals this was a new experience and their feedback on OSN was extremely positive. However, the professionals who engaged most with this project may have been those who were already more interested in these issues: it is unknown how well they represent the wider service sector. The practical challenges highlighted in professional mindsets, service design, training and guidance and the responses from some staff and other gatekeepers, indicate that there is quite a way to go to make OSN's aspirations a reality. It is too early to assess impact, and it will take time to see concrete outcomes in relation to making services more encouraging, enabling and facilitative, let alone improvements in people's social and emotional lives and wellbeing.

The project team responded to the challenges of Covid-19 in their typical creative fashion, designing films, social media take-overs and other outputs. They successfully engaged commissioners, service providers, policy personal, other professionals and others through online conferences and presentations, despite lockdowns and restrictions. Moreover, the feedback indicates that OSN has established good foundations with many agencies to help work continue in this area.

*'the potential ..is massive...cutting edge...Important for relationships,
but also for other services'*

[Policy interviewee]

Key Recommendations

These recommendations were made by the evaluation interviewees and respondents, but have been combined and condensed by the Evaluator.

Recommendations for Mencap Cymru and RMS around friendships and relationships

- Build on this project's expertise and findings to develop Mencap Cymru's and RMS's existing policy and practice work and resources around friendships, relationships and sexuality.
- Progress the connections OSN has established across Wales with service providers, local groups of people with learning disabilities, other agencies and networks to further develop this work.

Recommendations around increasing the scope of personal narrative

- Use the OSN experience to inform Mencap Cymru's proposed storytelling development role.
- Support staff to build on relationships with those they support and to encourage people with learning disabilities to talk about themselves and define their own priorities in assessments.
- Make use of diverse methods, including personal narratives and videos, to elicit and record people's views. In services this could improve understanding of individuals' needs, more so if they have limited vocabulary. On the heritage front, OSN demonstrated the gap and scope to find out about the lives of groups of people whose narratives are currently missing.
- Employing key workers and a key working approach within services was advocated to maximise trust, communication and understanding and ensure that support and advice was sufficiently individualised and nuanced to match someone's needs.

Recommendations for the learning disability sector at large around friendships and relationships

- Ensure friendships and relationships are included meaningfully in the Welsh Government's Learning Disability strategy, 'Improving Lives', and are linked to the SSWA outcomes framework.
- Give friendships and relationship the same priority as other needs, e.g. skills and employment.
- Commissioning and inspection should prioritise support for friendships and relationships.
- Make ongoing relationship and sex education (RSE) training mandatory across all care and education settings for all staff, to improve awareness, ethos and practice. Include consent, friendships and relationships in the broadest sense.
- Promote detailed staff support and supervision on RSE, so that they understand the need for fundamental change, feel safe in their practice and are able to explore and challenge ideas.
- Training and guidance could use some OSN narratives and needs to be co-produced with people with lived experience, and framed within a rights, values, equality and wellbeing perspective.
- Agencies such as the Supported Loving Network, which have already developed good training in this field, could be commissioned to run more training across Wales.
- Such training and information needs to build incrementally to develop insight and skills and be empowering, without reinventing the wheel.
- Use a champion model and recruit a core group in each organisation to push the new approach.
- Offer families training, guidance and additional professional and peer support.
- Help develop more opportunities for people with learning disabilities to meet other people (disabled and non-disabled) and enable them to do so safely, whether in person or online.

Recommendations around promoting access in the heritage sector

- Overall, the model of co-producing access improvements through the collaboration of people with disabilities and heritage sector staff was shown to be well founded.
- However, the project design would benefit from modifications. For example, a joint introduction to, and discussion of, disability access would help secure a common understanding early on. Such an introductory stage could set out existing thinking and models to best practice around inclusion in the sector, as well as sharing available audit tools, training, templates and other resources. This would save time and limit duplication, and ultimately reduce the onus on individual Ambassadors to develop solutions from scratch.
- More time needs to be allocated to locate and engage with local disability groups.
- Focus on just one or two museums at a time to develop relationships and effective models.
- Resources for staff time, within the heritage sector and partner projects need to be realistic and allow for unforeseen issues. Access changes will always require some budget.
- An initiative like this would benefit from a pilot to help identify likely challenges early on and incorporate potential solutions to these in the planning.

Recommendations emerging around employing people with learning disabilities

- Projects need to be clear on the balance between targets and meaningful outcomes.
- An incremental selection process might work best, possibly with a trial period to help the individual and projects decide what they need. Assessments need to be individualised to gauge strengths and support requirements: pro-forma assessments are unlikely to capture sufficient detail, especially when the applicant has little previous employment or life experience.
- Someone's personal and employment support needs have to be addressed before they can start project work.
- Initial and ongoing training is essential, e.g. on general employment expectations, IT skills and the requirements of the role in question, in this case the social model of disability and inclusion.
- Hours need to be adequate to do the job, settle in, attend training and meetings, etc. Support staff need additional time for planning.
- Many people with no previous work experience might find it easier to begin their working life in a relatively structured job, with a fixed place and hours of work, set tasks, and a team and colleagues to provide informal structure, support and companionship.
- Mencap Cymru's and RMS's processes and systems, not least their IT and training need to be reviewed so that they accommodate, rather than undermine, employees with learning disabilities, and enable them to gain a positive employment experience.

Other recommendations around the project design and development

- Both Mencap Cymru and funders need to be more realistic about what a short-term project can achieve in a limited time in terms of major shifts in attitudes, professional practice and services.
- Arguably a complex and ambitious project would benefit from developing a logic model at the start to help interrogate assumptions and provide a more effective basis for learning. Such a process helps to agree a concise number of incremental, as well as achievable and measurable outputs and outcomes. That is not to deny a place for ambition, but as OSN has demonstrated achieving major changes often relies on gaining numerous smaller steps and stages first.
- Many aspects of this project would have benefitted from an initial pilot to test theories and models, not least how best to work with museums, engage the public in community based exhibitions, employ Ambassadors, recruit volunteers and embed a learning environment.
- Evidence requirements need to be proportionate, not too onerous and use metrics which provide useful learning.

Appendix

OSN feedback and evaluation data sources

- Participants in evaluation interviews and focus groups**

The table below provides details of the numbers who participated in qualitative interviews and focus groups for the final evaluation over the three years. In Year 3, this was limited by Covid-19. For example, the evaluator could not conduct any fieldwork in person, only 2 museum personnel could take part, as others were furloughed, and as the 2 project managers were suddenly placed on furlough their interviews had to be speedily converted to providing written feedback.

In the first and second years most interviews and focus groups were in person and some by telephone. In the final year all were conducted by video conferencing or by telephone to comply with social distancing and travel rules.

Overview of qualitative evaluation participant	Number of people		
	Yr 1	Yr 2	Yr3
Paired interviews with Ambassadors and supporters	0	0	6
Focus group With Ambassadors and supporters	6	6	0
Focus Group with Supporters alone	0	0	3
Individual interviews with Supporters alone	0	0	2
Individual interview with Project Officers	2	2	1
Paired interview with Project Officer and Supporter	0	0	2
Focus groups or interviews with OSN volunteers	4	6	2
Interview with OSN Project Manager	1	1	0
Interviews with OSN Programme Manager	1	1	0
Interviews with MC Head of Strategic Programmes and Head of Operations	1	1	1
Interviews with policy personnel, internal and external	0	0	2
Interviews with learnings disability service providers	0	0	2
Interview with Senior Heritage staff in participating Museums	4	0	2
Written feedback from OSN Programme and Project Managers*	0	0	2
Total	19	17	25

*Both went on furlough just before the scheduled interviews

- Surveys and other feedback collected by OSN & shared with the evaluation over the 3 years**

Activity / event	Timing	Numbers involved /participating	Format (Online survey, feedback form, other)	Number of feedback responses
People who gave OHs	Years 1-3	62	Face to face & written	24
People who donated artefacts	Years 1-3	21	Original photos and objects for exhibitions (190)	0
Feedback from community partners	Years 1-3	18	Paper feedback forms	5
Feedback from volunteers	Years 1-3	47	Feedback forms, focus groups	18
Exhibitions				
Bangor - Pontio Arts Centre	June 2018	85		

Wrexham - Plas Madoc Leisure Centre	July 2018	81	Feedback forms	34 across all exhibitions
Treorchy - High Street Social Cafe	September 2018	192		
Abergavenny Community Centre	October 2018	42		
Bangor, Deiniol Shopping Centre	April 2019	172		0
Cardiff Chapter Arts Centre	June 2019	194	Voting & feedback forms	25
Wrexham scattered exhibition	Spring 2020	6 Community partners	Feedback forms	3
Events & activities				
Disastrous Dates Treorchy	2018	12	Feedback form	3
Disastrous Dates Cardiff	June 2019	25	Feedback form	0
Smutslam Cardiff	June 2019	100 general public & 25 staff	Survey, written feedback, social media	10
Drag syndrome, Cardiff	June 2019	180 general public & 70 PWLD, carers & staff	Written feedback, social media	0
Wrexham	October 2019	16	Feedback forms	13
OSN seminar Glyndwr University	October 2019	34 (PWLD & staff from LA, residential college & health	Recorded discussion	34
Abergavenny Seminar - Melville	December 2020	4 Service providers & 3 PWLD	Postcard to selves	4
Learning Disability Awareness Training Cardiff Story Museum	January 2020	14	Recorded discussion	10
Abergavenny Disastrous Dates	January 2020	12, including 4 PWLD	Feedback form	12
Simema Sadwrn Llansadwrn	January 2020	33	Feedback form	3
Presentation Mirus Ceredigion	January 2020	8 Mirus staff and 3 PWLD and 1 parent	Feedback form and recorded discussion	6
A Life More Ordinary Webinar - online	November 2020	50 Participant's	Survey Monkey	19
			Whiteboard and chat at event	50
Bangor	December 2020	11 student nurses	Survey Monkey	7
Other	Late 2020		Survey Monkey	17