My Life My Future

Evaluation of Down's Syndrome Scotland Life Story Project

Evaluation Report

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BE THE DIFFERENCE

My Life My Future

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"Life story work has been a big achievement for me.

It feels good"

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Background

My Life My Future project was developed and delivered by Down's Syndrome Scotland as an enjoyable family activity with the aim of producing an output that can serve as a valuable communication tool now and in the future. Life story work is a person-centred approach which enables an individual to focus on their past, present and future by collating images, audio or other types of memorabilia.

Aim

The aim of the evaluation was to identify short-term outcomes (one-year duration of My Life My Future) among fourteen participating families, and to consider implications for medium- and longer-term planning beyond one year.

Evaluation design and methods

The University of Stirling research team developed a logic model to focus on and visually represent the short-term (one-year) outcomes of the evaluation. Data collection methods were: pre- and post-project family interviews, pre- and post-completion of Warwick-Edinburgh Mental Wellbeing Scale, pre- and post-completion of Personal Wellbeing Index – Intellectual Disability (PWI-ID) and semi-structured interviews with two project workers and two volunteers.

Findings

Recognising that people who took part were all able to communicate verbally and that the level of available support was high, there were clear benefits for the families who took part. No significant changes were evidenced in the wellbeing of

participants, which remained high over the course of the year. Five themes were identified relating to either the process or outcomes of life story work:

- format of life story

- increased social interaction

- future planning

- responding to loss and difficult life events

- ownership and affirmation of life story

Early concerns from parents and siblings about ownership of the life story work reduced as people with Down's syndrome became more confident and knowledgeable. The value of support staff being involved in the ongoing development of life story work was recognised although questions were raised about how far this was happening in practice. Unexpected outcomes arose for parents who themselves reflected on their own past and in particular what they had been told about their child at birth, compared to the achievements and progress made in reality. A further unexpected outcome was the increase in positive engagement around bereavement and loss. At the beginning of the project many families were concerned about re-visiting upsetting memories of people who had died, yet by the end most spoke of how helpful it had been to include these memories, both happy and sad.

Conclusions

My Life My Future was reported to be an enjoyable and beneficial project for the members of Down's Syndrome Scotland who took part. The potential is evident for individuals with Down's syndrome to be at the centre of future planning or transitions through ownership of a tool that (with permission) identifies what is important to

them. Both families and paid staff have a key role to play in achieving a longer-term outcome of supporting members of Down's Syndrome Scotland to continue or begin life story work in an appropriate format.

Recommendations

Recommendations are made for research, social care practice, people with Down's syndrome, families and Down's Syndrome Scotland that include:

- development of appropriate organisational support or training that, within resource constraints, recognises the importance of sharing learning about life story work

- recognition that life story work can go beyond an enjoyable activity, it can be of benefit in the longer term should health or cognitive needs change

- recognition that family input level may be high initially, but this ownership should transfer to their family member over time

- increased evidence of use of life story work at a time of, and after, transitions in care arrangements

- increased evidence of life story work with people who have profound or complex disabilities

- awareness of the importance of social care staff increasing their role in supporting individuals with life story work (with permission)

- increased engaging with life story work as appropriate when discussing bereavement and loss

Introduction

Developing a life story can give a sense of identity and help an individual to share not only their story, but memories, experiences, life events, details of preferences, and information about family, friends, work, hobbies, holidays and favourite places. Identity is what makes an individual unique. People with learning disabilities have often been denied the opportunity to reflect on their life events and how this has affected them. The compilation of a life story can be an empowering process helping the person to feel valued and listened to, and most importantly to have 'a voice' in what should be a fun activity.

Many parents and siblings worry about what the future holds for their family member with Down's syndrome and what will happen if they can no longer provide care, yet there is often reluctance among families to plan ahead (Foundation for People with Learning Disabilities, 2013). As recently as the 1980s, life expectancy for an individual with Down's syndrome was around 15 years. Now it is above 60, which means that many people will outlive their parents. Down's Syndrome Scotland's Family Support Service has previously reported incidences where an adult with Down's syndrome has been placed in care services or received support in emergency situations (due to ill health or death of a family member) where nothing is known about the life or preferences of the person with Down's syndrome. Having a life story can not only ease challenging transitions and help the person come to terms with changes but can also help to provide a routine and have a positive effect on wellbeing, in additional to recognising the importance of enabling staff in support services to 'know the person'. Whilst this evaluation and development of a logic model was led by the University of Stirling research team, the My Life My Future

project was instigated, developed and facilitated by Down's Syndrome Scotland over a 12-month period, August 2018-August 2019. This collaborative approach with the University of Stirling, including a joint funding application and shared dissemination, was designed to maximise the resulting impact in practice.

The aim of the My Life My Future evaluation was to measure and report on the short-term (one-year duration of the project) outcomes among participating families, and to consider implications for medium- and longer-term planning beyond one year. The agreed outputs were:

University of Stirling research team:

- produce and electronically disseminate evaluation report

Down's Syndrome Scotland:

- produce and disseminate accessible life story guide for families

Down's Syndrome Scotland aimed to achieve the following through their delivery of the project:

- Aim 1 - People with Down's syndrome will take part in an enjoyable activity and develop a resource that can be a valuable communication tool as they age.
- Aim 2 - Families of people with Down's syndrome will enjoy a meaningful activity with their family member.
- Aim 3 - Down's Syndrome Scotland will extend its work with members ageing with Down's syndrome and will support families to prepare for the future.

Down's Syndrome Scotland is a parent-led national charity established in 1982 to support people with Down's syndrome and their families in Scotland. The

organisation works to achieve its mission of supporting families and people with Down's syndrome to reach their full potential by providing a range of services, influencing public policy and changing attitudes.

The Faculty of Health Sciences and Sport at the University of Stirling conduct world class research and lead the way in key areas affecting individuals and society. The Faculty's primary mission is to be the natural first choice for everyone with an interest in health, to develop global citizens through internationally relevant curricula and to deliver excellence in teaching and learning. The team of academics within Health Sciences dedicate their time to creating and discovering new knowledge in their respective fields and developing a bespoke curriculum that is at the forefront of research innovation.

Collaboration has provided Down's Syndrome Scotland with a wider evidence base from which to expand the project, advice on methodology and approach, and support to generate new evidence. The University of Stirling has benefitted from gaining insight in the ability to learn directly from people with Down's syndrome and their family members.

Life story guiding principles

Adapted from Evaluation of 'Life Story' intervention: Feasibility study, (Gridley et al, 2016)

Although a planned output from the project was the production of a life story guide by Down's Syndrome Scotland, it was important that generic guidance was provided at the start of the project in order to share generally accepted good practice in life story work. This supported the development of ground rules for the project which not only provided information for families who were unfamiliar with this approach; it also ensured a safe environment in which to proceed.

Life story work can be developed for different reasons in different contexts; an individual living in an acute hospital, community setting, care home and family home may not have access to the same resources, tools or information but by placing the person at the centre of the work, the principles to the left can be applied in all contexts.

Evaluation methodology

Design

The University of Stirling research team developed a logic model to focus on the short-term outcomes of the evaluation. One of the most widely recognised uses for logic models is programme and service planning addressing the following questions:

1. What is the current situation?

2. What will it look like when we achieve a positive outcome?

3. What needs to change for that outcome to be achieved?

4. What knowledge or skills are needed for the change to take place?

5. What activities need to be performed to bring about new learning?

6. What resources will be required?

This approach enables the team to work between the points in any order, even backwards, to identify how best to achieve the desired effect.

Using a Wisconsin Programme Model (Taylor-Powell, Steele & Douglah, 1996), a logic model tells the story of a project in a diagram. This demonstrates the connection between an identified change in support (in this case the introduction of life story work), what actually happened, and how it made or could make a difference. The inputs are the resources required by the project; the outputs are direct products and the outcomes are the benefits derived (usually expressed as short-, medium- or long-term). Assumptions are the elements that are assumed to be in place in order to carry out the project whilst external factors highlight any constraints within the project that may influence the outcome.
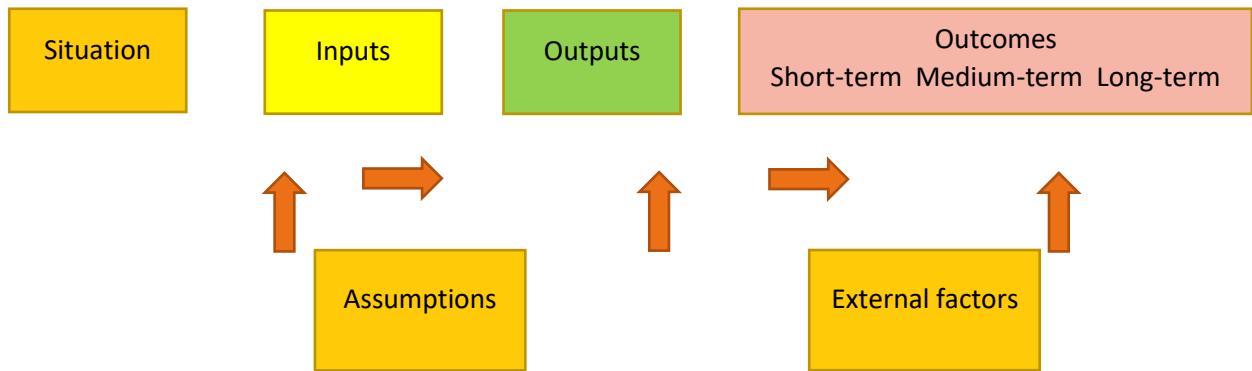
Figure 1 Wisconsin Logic Model (Taylor-Powell, Steele & Douglah (1996).

Sample

Convenience sampling was used to recruit families via Down's Syndrome Scotland organisational newsletter. Fourteen families who responded to the article and met the inclusion criteria were invited to take part. One family attended three workshops then chose to withdraw. However, they wished to take part in both the pre- and post-evaluation and stated their intention of continuing independently with life story work using the templates provided by Down's Syndrome Scotland.

It was important to recognise that the most significant person in the life of a person with Down's syndrome may not always, or only, be a family member. Consequently, it was acknowledged that the preference of the person with Down's syndrome may have been to involve a staff member to engage with their life story activities, referred to in this evaluation as 'those in the role of families'. Seven participants with Down's syndrome lived with one or more parents whilst seven lived independently with support, either alone or in shared accommodation.

Inclusion criteria for families (or those in the role of families)

- An adult with Down's syndrome and family member/person in role of family who agree to take part

- Each person agrees to be interviewed twice by a member of the research team, and to complete a Warwick-Edinburgh Mental Wellbeing Scale or Personal Wellbeing Index tool

- Each person agrees to attend as many of the monthly support workshops run by Down's Syndrome Scotland as possible, with a requirement to attend the first and last.

Whilst not all families were expected to be able to attend all ongoing support workshops, (the Down's Syndrome Scotland project worker was responsible for maintaining ongoing contact during the project) all were asked to attend the first session. This was in order to find out about and try different types of life story work in order to select a preference. Families were also required to attend the last session to update Down's Syndrome Scotland on their progress and as a fun end of project meeting. When a family expressed an interest in taking part, they were sent information sheets and consent forms with at least a week to think about their decision to take part.

Options for different types of life story work were provided at the first workshop. Once a choice was made (see Table 1), all equipment and resources were provided by Down's Syndrome Scotland depending on preference. Whilst not constrained to the selection available, the following types of life story work were provided as examples.

- a structured life story folder or scrapbook, based on a template

- an unstructured life story folder or scrapbook, with photographs and text

- a life story box (which may be individually decorated) for objects, photographs and documents

- Book of You - a digital life story accessible via a touchscreen tablet

- talking tiles - 3 dimensional tiles that enable recording and playback of speech, music or sound effects via the built-in microphone and speaker.

- a 'talking' photo album – a photo album with an audio record function to record audio descriptions on each page alongside photographs

Participant	Gender	Age	Family/other support	Life story work started	Life story work ongoing after 12 months
1.	F	30	Mother	Life story box Life story folder	Life story box Life story folder
2	M	32	Sibling and Mother	Book of You app Life story box Life story folder	Life story folder
3	F	30	Mother	Life story box Life story folder	Life story box Life story folder
4	F	25	Mother and Father	Life story box Life story folder	Life story box Life story folder
5	M	29	Mother and Staff Member	Life story box Talking photo album Talking tile	Life story box Talking photo album Book of You app
6	M	22	Mother and Father	Life story box Book of You app	Life story box Book of You app
7	F	30	Father	Life story box Life story folder Talking tile	Life story folder
8	F	58	Sibling and Staff Member	Book of You app Life story box Life story folder	Book of You app Life story box Life story folder
9	F	27	Mother	Life story box Talking photo album	Life story box Talking photo album Life story scrapbook Talking tile
10	M	56	Sibling and Staff Member	Life story box Life story folder	Life story box Life story folder
11	F	26	Mother	Life story scrapbook Life story box	Life story scrapbook Life story box
12	M	39	Mother and Father	Life story box	Life story box Life story folder
13	F	26	Mother	Book of You app Life story box	Book of You app Life story box
14	F	34	Mother	Life story folder Life story box	Life story folder Life story box

Table 1: Characteristics of participants with Down's syndrome and selected life story format

Methods of data collection and analysis

This was a mixed method evaluation conducted using the following data collection methods:

- Pre- and post-family interviews in months 1 and 12 (Appendix A)

- Pre- and post-completion of Warwick-Edinburgh Mental Wellbeing Scale[1] (WEMBS) (Tennant et al, 2007) with family/those in the role of family in months 1 and 12 (Appendix B)

- Personal Wellbeing Index – Intellectual Disability (PWI-ID)[2] with participants with Down's syndrome in months 1 and 12 (Appendix C)

- End of project semi-structured interview with 2 Down's Syndrome Scotland project workers and 2 volunteers (Appendix D)

Data collection was supplemented by listening to audio transcripts of monthly life story work support sessions.

Pre- and post- family interviews

Semi-structured interviews were conducted with participants who had Down's Syndrome and their family members/those in the role of family at the beginning and end of the project. Both perspectives were sought in interviews lasting approximately 30 minutes pre-project, and between 45- and 90-minutes post-project (reflecting enthusiasm to talk about and show life story work). All interviews were conducted either in the home of the individual with Down's Syndrome, or at the offices of

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[1] ©NHS Health Scotland, the University of Warwick and University of Edinburgh, 2006, reproduced with permission
[2] Cummins and Lau, 2005, reproduced with permission

Down's Syndrome Scotland depending on preferences. Data was analysed thematically and stored using NVivo data management system.

Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)

Improved mental wellbeing is a key population outcome and a fundamental part of being a healthy and resilient individual. Mental wellbeing is about having control, a sense of belonging and connection and an ability to manage change. WEMWBS enables the measuring of wellbeing as part of project evaluation before and after an intervention to establish if mental wellbeing has improved. It is acknowledged that the presence of a control group would have strengthened findings of the impact that life story work had on mental wellbeing.

The 14-item scale WEMWBS has five response categories, combined to provide a single score ranging from 14 to 70. The items are all worded positively and cover both feeling and functioning aspects of wellbeing. The scale asks the respondent to self-report their experiences over the previous two weeks with an average wellbeing score in the general population in Scotland of 49.9 (Bardsley et al, 2018). Family members completed the tool at the start and end of the life story project. Descriptive statistics were used to summarise data and paired sample t-tests were used to compare any changes in average wellbeing scores for family members between the beginning and end of the project.

Personal Wellbeing Index – Intellectual Disability (PWI-ID)

The Personal Wellbeing Index Intellectual Disability (PWI-ID) Scale is an 8-item scale that measures components of quality of life incorporating: standard of living, health, life achievement, personal relationships, community-connectedness, future security and spirituality-religion. It has been adapted from the Personal Wellbeing

Index (PWI) Scale and is specifically for people with learning disabilities. The use of the PWI-ID may assist in ensuring that the needs and preferences of people with a learning disability are informing future planning. It includes a series of outline faces (from very happy to very sad) as possible answers to questions. This gives a total well-being score out of 14. An additional optional question asks respondents how happy or sad they are with their life as a whole, on a scale from 0-10. Participants completed the scale at the beginning and end of the life story project. Repeating the scale to determine test-retest reliability was not possible due to the nature of the evaluation and participant sample size. However, a second researcher listened to the recording of the scale being administered and made separate scoring which verified the original findings. Descriptive statistics were used to summarise data and paired sample t-tests were used to compare changes in mean scores.

End of project interview with Down's Syndrome Scotland staff and volunteers

Semi-structured interviews were conducted at the end of the project with the two staff members (the project lead and project worker), and two volunteers. One of the volunteers was a long-term volunteer for Down's syndrome Scotland who provided regular support at the monthly workshops, the second volunteer was one of the participants with Down's syndrome who was invited to take on a dual role. Due to her skills, she also acted in a voluntary capacity at the workshops (across locations) to provide specific support to families who were using the Book of You digital application. She was interviewed in her capacity as volunteer to share her experience and expertise in this role. Whilst this may appear to be a conflict of interest as she was also developing her own life story at the same time, it was important to recognise her different contributions to the project and the benefit that inclusion of a volunteer with Down's syndrome brought in terms of peer support,

shared learning and role modelling. Data from the end of project interviews was stored using NVivo data management system and analysed thematically.

Study design

The original plan was for ten workshops to take place in one location across the twelve-month period. However, membership interest came from different parts of Scotland and in order to facilitate as much involvement as possible this was revised. Ultimately, six workshops were held in Glasgow and ten in Edinburgh due to different start dates in each location. Workshops lasted approximately 90 minutes each and consisted of group-based activities with pictorial handouts. Task-based activities were provided for families to complete in between workshops aimed at stimulating discussion of potential content to add to life story work. Activities were sent to all families even if they were unable to attend. Workshop and activity topics included:

Preparation for beginning life story work:

- People with Down's syndrome shared a personal item that each was asked to bring in advance (and that they were happy to talk about)
- Discuss benefits and challenges of life story work
- Try different types of life story work
- Talk about relationship circle

Ongoing activities to prompt content of life story work:

- Talk about special family events
- Talk about special birthdays
- Christmas activity and family traditions
- Work and volunteering
- Friends
- Personal achievements

- Hobbies and interests – likes and dislikes
- Day trips and holidays
- My favourite things
- Music, television and films
- Sharing memories of a special person
- What does my week look like?
- Dreams for the future

At the request of those taking part, all participants additionally received one-to-one support sessions either at their home or in the office of Down's Syndrome Scotland. This involved one extra session for two of the families, two sessions for seven families, three sessions for two families and five sessions for two families.

Ethical issues

People with Down's syndrome typically have less cognitive impairment than individuals with other types of learning disability, this often remains stable rather than fluctuating. Despite confirmation that consent has been given to the organisation by adult members with Down's syndrome to participate in activities of the charity, the evaluation team followed the principles of the Adults with Incapacity (Scotland) Act 2000 legislation to affirm capacity for consent. Continued consent was not assumed, and the same process was followed before the post stage of evaluation.

Consent was sought from each individual taking part. For most families this was the person with Down's syndrome, one or two parents and a sibling. For three family units this also included a staff member (support worker) who was a constant in the life of the individual with Down's syndrome. All data has been fully anonymised with ethical approval granted by the General University Ethics Panel at the University of Stirling.

Findings

Pre- and post-family interviews in months 1 and 12

Five themes were identified that related to either the process or outcomes of life story work:

- format of life story

- increased social interaction

- future planning

- responding to loss and difficult life events

- ownership and affirmation of life story

Format of life story work

Participants tried a range of different types of life story, with the majority ultimately combining several types including a life story box for items that could not be readily stored elsewhere. The format selected was based on individual preference of the person with Down's syndrome and allowed them to draw on different strengths such as artistic and/or digital skills. The participants who were more creative enjoyed the process of decorating their life story boxes, life story scrapbooks, and folders. Overall, a structured approach to the process was perceived as helpful, with templates being used by members to develop and build their stories and structure the different sections within their chosen format. At the end of the project, most participants did not favour one type of life story work over another and gave positive feedback around all of the types they had chosen. There was also a suggestion that using more than one type was beneficial with associated conversations and different outputs. The exception to this was the digital life story: three of the four participants

who tried this stated that this was their preferred format. The reported advantages

and disadvantages of different approaches are recorded in Table 2.

Life Story Format	Advantages	Disadvantages
Digital life story	Highly Portable Able to incorporate sound and video clips Quick to create sections (once familiar with technology) Potential to increase digital skills and confidence	Challenges with the software Need for digital skills and confidence Potential need for support to access life story (requires a password) Potentially less creative than traditional formats (if this is preferred) Less tangible than other formats
Life story box	Able to store items that cannot be stored elsewhere Creative – can personalise the box Tangible – contains items that can be picked up, touched and looked at Easy to use independently	Less portable – heavy Durability – can get damaged
Life story folder	Able to store and organise lots of information Flexible with what can be added - new information can easily be added into earlier sections Easy to use independently	Can be less easy to share with others if too much information is stored in the folder. Less portable – heavy (if lots of information stored) Inability to incorporate audio/video recordings
Talking photograph album	Portable Easy to share with others Ability to record audio messages behind each story, including messages from significant others.	Restrictive in terms of what can be incorporated in life story – recorded message has to be brief Potential need for support to add content
Life story scrapbook	Highly creative Portable	Can be difficult to change chronological order – new information cannot be easily added into previous sections Inability to add audio/video content
Talking tiles	Ability to add a voice message	Highly restrictive in content – only one message can be recorded Only suitable as an addition to another life story format

Table 2 Reported advantages and disadvantages of different types of life story work

Increased social interaction

There were reported social benefits to the group sessions with the majority of participants and their family members/those in the role of family enjoying the opportunities that came from meeting up with other members and their parents/siblings.

> *"I've liked the whole part of it, us all coming together and working on our stories together and seeing everyone and what they've done." (Person with Down's syndrome)*

Beyond this, families spoke of additional benefits from coming together as a group, gaining insight and ideas from sharing their life stories with each other. Whilst a small number of challenges were identified (highlighted later in the 'What did we learn?' section), the group workshops were reported as enjoyable and fun.

One participant, who described herself as having depression, highlighted how the increased social activity during the project had helped her to identify gaps in her life, and her desire to become involved in more social opportunities so that she could become less isolated.

> *"It's helped me to see what my life is really like. I am suffering from depression and isolation, and I don't have that many friends. So, I'm trying to get out there and make new friends." (Person with Down's syndrome)*

Ownership and affirmation of life story

It was important for participants that they now had somewhere to store important memories and possessions. Many families spoke of how taking part had led them to bring together, and remember, past memories that they had forgotten, and how the

life story provided a place in which those memories could be stored and built on going forward.

> *"Now she's got a special place to keep special memories, that will help her as well, because she'll be thinking, oh I've been to a concert, or I really liked that film, I've got a ticket, I'm going to put that in my box. Whereas maybe she'd have put it away somewhere but wouldn't have known where she'd put it, and now she's got a place to keep special things." (Family member)*

There were initial concerns from families that they were leading the process by initiating memories or telling their family member of events that happened when they were much younger, with the potential for ownership of narratives, and therefore life story, to be contested. This was dissipated as the project developed and the person with Down's syndrome became more familiar with the process. It was also helped by the structured templates which gave the person with Down's syndrome more control over the topics or items to include or leave out.

Two families (in which both participants were living independently out with the family home) spoke of how the project had led them to become closer as they spent time together working on the life story. People with Down's syndrome were proud of their life stories and of their achievements. One participant described how her life story had shown her "*how it feels to be loved*". Another participant was reported as having fewer behaviour issues that his parents found difficult, with this being attributed to him feeling happier and more positive about himself as a result of developing his life story. Additionally, some family members spoke of how the project had helped them to reflect more on what their son/daughter/sibling had achieved in their life, and the

contrast with what they had been told to expect in that person's early years. Whilst ownership of the life story work was a key issue for people with Down's syndrome, families found the process equally affirming albeit for different reasons.

"*When I think initially of the very difficult days when he was born prematurely, and how we were told he wouldn't achieve anything, just take him home and so forth, when I look at the things that he has achieved it's very very uplifting to look at that.*" (Family member)

Responding to loss and difficult life events

For some participants who were dealing with loss or other difficult life events, attending the group workshops had helped them to realise they had shared experiences with their peers, and each was able to express how they had benefitted from this peer support.

"*It was hard putting that into my story. But I've put it in, so it's kind of helped me a wee bit… the memories are there, and I can look back at them"* (Person with Down's syndrome)

At the beginning of the project a number of participants were concerned about re-visiting sad memories in their life stories, mainly of relatives or friends who had died, and expressed worries that this may be too upsetting. By the end of the project, they spoke of how it had been helpful to put those memories into their life stories and to have a means with which to talk about both sad and happy memories of that person. One person with Down's syndrome experienced a family bereavement just before the project started, and his sibling spoke of how the project had given them an opportunity to spend time as a family reflecting on those memories together. Another participant experienced a family bereavement during the project and spoke

of how important she had found it to store memories of that person in her life story. Overall, seven families volunteered information of how the life story work had provided an opportunity to talk about memories of people who were no longer alive. Only one participant with Down's syndrome found it too difficult to recall memories of his grandparents.

Future planning

Themes emerged around future planning that were related to both process and outcomes. Participants with Down's syndrome indicated that they planned to continue using their life stories by adding special events to them, looking back over them and sharing them with friends, family, and formal support. Some participants had already shared their life stories with support staff and spoke of how they felt that this had helped their workers get to know them better and to understand what was important to them. Others were planning to share their stories with staff. Families spoke of how the life stories could be shared with new members of staff in the future. Participants had either shared, or were planning to share, their life stories with friends and extended family.

In terms of outcomes, recognition of the role of life story work in future planning was evident. Families highlighted how important the life stories would continue to be, with support workers or other professionals gaining greater insight into the person, who they were as people, their identities, and what was important to them. They discussed how the resource could be used if the person moved out to live independently, moved into different accommodation or was required to stay in hospital. Nine family members spoke of the potential use of the life story if the person either developed dementia or experienced cognitive changes in future. One

participant with Down's syndrome spoke of how the life story might help her if she developed dementia. Five parents reflected on the importance of the life story as a resource for other people to get to know the person if they were no longer there to provide that information. They described this as reassuring to know that such a detailed resource about their family member was now available.

> "*You do start to think about, as we get older, and what there is for, say, your brother and sister to look at with him, when we're long gone, there'll be something there that will ground him and give a conversation point to somebody else*" (Family member)

Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)
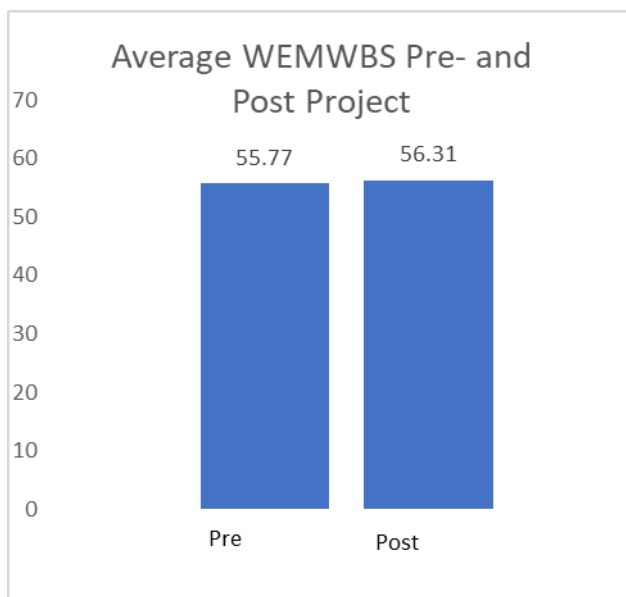
Figure 2 Average WEMWBS Scores

13 family members completed the WEMWBS at the beginning and end of the project. Average wellbeing scores were similar at both time points, rising slightly from the beginning (55.77) to the end (56.31) of the project (Figure 2; Table 3). Paired sample t-tests identified no significant change in average wellbeing scores between the time points; t(13)=-.31, p=0.76.

Findings suggest that overall subjective wellbeing was not affected by participation in the project. It should be noted however that mean scores were already high at the beginning of the project, with average scores well above the Scottish average of 49.9

(Bardsley et al, 2018). This may indicate that improved wellbeing was not a required outcome for this particular group.

WEMWBS Scores Pre and Post Project					
	Mean	N	Std. Deviation	Minimum	Maximum
WEMWBS baseline	55.77	13	6.547	45	70
WEMWBS end	56.31	13	7.631	44	70

Table 3: Descriptive statistics WEMWBS pre- and post- project

Personal Wellbeing Index – Intellectual Disability (PWI-ID)
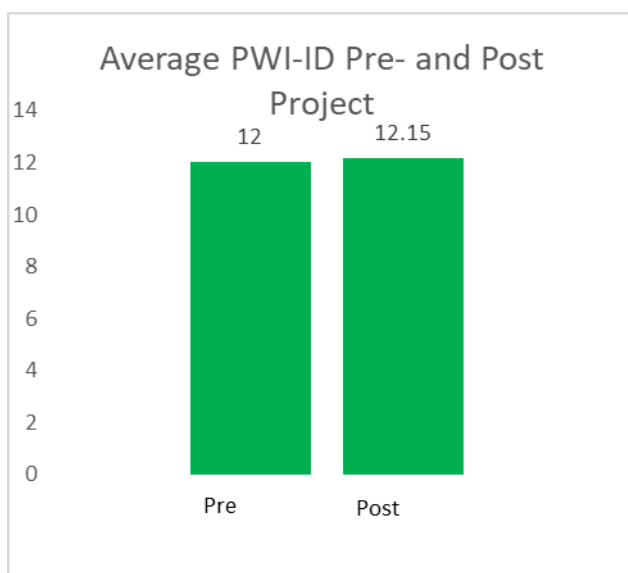
Figure 3 Average PWI-ID Scores

13 participants with Down's syndrome completed the PWI-ID tool at the beginning and end of the life story project. Participants scored highly on the scale at both time points, with the lowest score 10 out of 14 and the highest score 14. Average scores rose very slightly from 12 to 12.15 (Figure 3; Table 4). There was no significant change in mean wellbeing scores between the beginning and end of the project; $t(12)=-.56$, $p=0.58$. This range, both pre and post indicates that participants' wellbeing levels began and remained within the normative range and are similar to those reported by the population generally. This supports other research findings that individuals with a learning disability do not necessarily always experience a lower quality of life (McGillivray et al, 2009). Increased use of use of the PWI-ID may ultimately help in

advocating for the needs of people with Down's syndrome to be met particularly with future planning or at times of transition.

	Mean	N	Std. Deviation	Minimum	Maximum
PWI-ID score baseline	12.00	13	1.35	10	14
PWI-ID score end	12.15	13	1.28	10	14

Table 4: Descriptive statistics PWI-ID pre- and post- project

End of project semi-structured interviews

Data collected from the project workers and volunteers again fell into themes of process and outcomes. In terms of process, project workers highlighted a number of adaptations made during the project. This included the introduction of templates to help families structure life stories and delivery of one-to-one sessions across two geographical areas. Overall, the workshops that focused on current lives and experiences were highlighted as being more accessible and productive than those which focused on the past. It was undoubtedly more challenging for some to source photographs from the past and individuals with Down's syndrome were reliant on family members for support. A suggestion for future projects was the need to consider the order of the sessions (i.e. to begin the sessions with the present day and then introduce early memories once participants were more familiar with the process). The session on planning ahead for the future, including 'future dreams', only worked well in one group. The session on 'work and volunteering' revealed inequities in experience by age, as the oldest members of the group had not enjoyed the same opportunities to be involved in work-related activities as other (younger) members of the group.

The volunteer with Down's syndrome gave positive feedback around her role, highlighting how she had enjoyed the opportunity to apply her own digital skills to support other families who were less confident in this area. Findings highlight a potential need for increased support of individuals who choose a digital format of life story work; the peer support approach used in this project worked well to support some of the practical challenges faced by families.

In one area it took group members longer to become familiar with the process of life story work. In another area (where the group sessions began at a later date) members became more engaged within a shorter period of time. It was unclear whether this was a result of different dynamics within the groups, the shorter time frame being conducive to more efficient working, or project workers being more confident in their approach in the initial sessions having already held some of the sessions in the first group.

Whilst the project had initially planned for ten families, project workers felt that a smaller group of between 6-8 families was preferable, due to the intensity of the work. Project workers also highlighted the need to consider follow on support, such as reminder letters to families to prompt continued engagement with the life stories. This may also include the development of links with Down's Syndrome Scotland family support service so that life stories could be used directly to facilitate improvements for participants with their current support providers.

Outcomes identified by both staff and volunteers related to increased confidence, increased ownership of the work and planning for change or transition. Project workers and volunteers highlighted the importance of giving participants with Down's syndrome and their family members an opportunity to spend time together and reflect on past memories, including memories of people who were no longer in the

person's life. Over time, participants with Down's syndrome were observed to have become more confident in the group setting and to be proud of their life stories and their achievements. The process of creating a life story was seen to be emotional at times for family members, reviewing the achievements of participants and the progress made in their lives. In creating life stories some participants identified gaps in their current lives and a key hope was that each would use their life stories to take steps towards making the changes they desired. This included participants choosing to share their life stories with others to help them achieve these changes and access the range of support that they wanted in their lives. A further area where it was hoped that the life story might facilitate participants to make bigger changes in their lives was in supporting those still living in the family home to both think about and take steps towards increased independence.

> *"Longer term I would like to hope that it has helped achieve things, just made them think, that it's helped to get the right support that they want. Even if they were having a planning meeting and didn't feel confident enough to talk up in the meeting but were happy to show parts of their story, you get a sense of what this person wants.*" (Project worker)

Logic model

This logic model demonstrates links between activities and the range of outcomes for the participants. It visually represents a 'theory of change' about life story work. In doing so, it demonstrates which outcomes were achieved during the project lifespan, referred to here as short-term, and which may take longer but were anticipated by participants and are recommended to form part of future planning for Down's Syndrome Scotland.

Down's Syndrome Scotland: My Life My Future Logic Model

Inputs	Outputs		Outcomes		
	Activities	Participants	Short (learning)	Medium (action)	Long (change)

Inputs
- Planning time
- Staff delivery and support time
- Volunteer delivery and support time
- Room space
- Time
- Finance
- Life story equipment and resources

Activities
- Group workshops, location 1
- Group workshops, location 2
- Ongoing individual support sessions

Participants
- People with Down's syndrome
- Paid social care support staff
- Parents and siblings of people with Down's syndrome

Short (learning)
- Increased confidence of person with Down's syndrome through an enjoyable activity
- Ownership of individual life stories and the importance of individual choice
- Increased knowledge base among paid support staff
- Validation for families of progress and achievements
- Families reconnecting with knowledge, skills and interests of individual with Down's syndrome

Medium (action)
- Enables person to share their preferences, needs and wishes when planning ahead both formally and informally
- Increased role for social care services (direct support staff) in supporting life story work – if permission given
- Support for person with Down's syndrome to discuss bereavement, loss and change
- Families become proactive and confident in support for life story work

Long (change)
- Tool to support families to plan ahead in a timely way that acknowledges change may occur, but may reduce impact of a crisis situation
- Tool to discuss health or cognitive changes in a planned rather than reactive way.
- More of Down's Syndrome Scotland members safely engaged with life story work wherever they live in a format appropriate to them

External Factors
Economic – cost of resources and support
Technical - for digital life story
Environmental – is support available where the person lives?
Health – are age-related health changes being considered as part of future planning?
Social – recognising and responding appropriately to diversity among life story participants, for example gender, age and previous lived experience

Assumptions
Level of existing knowledge base of participants is high
That participants will attend workshops or training
That ongoing support will be available
There will be access to, and funding for, materials and resources
That there is a willingness to participate on ongoing basis
That communication is verbal

The logic model demonstrates the process taken beginning with group and individual workshops over a period of time, plus ongoing support in-between sessions. This helped the evaluation team to prioritise and structure data collection and analysis in order to explore key aspects about life story work and any relationships between them. This demonstrates how use of life story work by Down's Syndrome Scotland has enabled outcomes to be achieved, or why it may not always work.

Short-term outcomes were evidenced during the project as part of participant learning, whilst medium term outcomes were raised by families, staff and people with Down's syndrome as something they intended to do, recognising that life story work is an ongoing process. Long-term outcomes move into wider change that may consequently occur and can be aimed for. This expands on individual, family or staff actions and demonstrates the viability and potential benefit of embedding life story work in organisational strategy.

The model includes assumptions of what needs to be in place for the project to achieve its aims. Whilst levels of existing knowledge could be increased at the workshops, it relies on people actually attending the workshops to benefit. Due to the nature of the project, a high level of support was available along with funds to enable choice of format of life story work, neither of which may be the reality in the future. External factors can be mitigated to a certain extent with planning, but the technical ability of the family or staff member will have an impact, recognising too that this may also be inferior to the technical ability of the person with Down's syndrome. Where the person with Down's syndrome lives now and in the future is a major factor in determining how the life story work is developed and indeed used in a proactive way.

What did we learn?

The life story project was an enjoyable shared experience for both participants with Down's Syndrome and their family members/those in the role of family, with a number of short-term outcomes evidenced at the end of the project. Inevitably, limitations and challenges were identified in addition to the creation of opportunities for the families who took part.

Limitations

The project was aimed primarily at supporting future planning within families, it is acknowledged that the outcomes may be different if the purpose was specifically to improve care or services out with the family. Similarly, ongoing support was available from Down's Syndrome Scotland which should not be assumed as the typical scenario either for families or services. Conversely, the high level of support available may have increased motivation and willingness to continue. Whilst the project had the flexibility to offer one-to-one meetings, this was a significant additional demand on resources that may not be available in future similar projects.

The structure of the group sessions required adaptation, with the project workers finding that too much information had been planned for the initial sessions. This was pared back in subsequent sessions to focus on an 'ice-breaker' group activity followed by work on individual life stories. Templates were subsequently produced to provide families with a more structured approach to help guide the life stories. This had not been anticipated at the start however proved helpful, particularly in the earlier stages of the project to support individuals to build a structure to their life story.

No participants with Down's syndrome had profound or multiple disabilities and all involved were able to communicate verbally. One family withdrew from the life story project after three sessions. Whilst an alternative social commitment was given as the reason, it was noted that the individual with Down's syndrome had more complex communication needs than other members of the group. However, the family were able to reflect on the benefits of life story work in terms of future planning and were planning to build on this in the future. Further research is required to identify how life story work may be adapted to meet the needs of people with adapted communication methods.

Three families noted that the presence of parents in the group may have inhibited the involvement of their relative with Down's Syndrome. One participant with Down's Syndrome began the group sessions attending with his parent and support worker, however his parent subsequently stopped attending the group sessions and felt that this led to a more positive outcome for the participant as it helped to promote his independence. Another participant with Down's syndrome (and his parent) reported that it would have been preferable if the parent had not attended the group. However, this must be balanced with the need for appropriate support when engaging with life story work.

Some families reflected on the time required to support the participant to complete their life story, the process appeared overwhelming in the early stages and required a high level of ongoing commitment. For participants who lived independently and not with family, it was difficult to co-ordinate time to work on the life stories.

There were vast differences between ages of participants with Down's syndrome with the youngest being 22 and the oldest 58; most participants were in their early

30s. Inevitably, this involved differing life experiences, for example one participant grew up in a long-stay hospital and had different childhood and early life experiences requiring sensitivity in approach.

There were a number of ongoing difficulties highlighted by families with the digital version of life story work, including technical difficulties around uploading images and text. There were also difficulties with developing and sharing work in this format during the workshops when internet access was required but not available which proved frustrating for group members. One participant subsequently changed to a more traditional life story folder as a direct result of lack of internet access.

There were variable experiences of paid support staff engaging with the life story process. Three participants with Down's syndrome were accompanied by support workers with, or occasionally in place of, family to attend the workshops. As a result of taking part, one of those workers had introduced life story work with other residents receiving support within the same organisation. Another family member was hopeful that a staff member would take forward and share her learning within her organisation. However, a small number of families reported that support workers had not engaged as hoped in supporting the participants to develop their life stories, and did not recognise this as a task that they could be involved in.

Opportunities

For seven families, the life story provided an opportunity to talk about and reflect on memories of people who were no longer alive; participants found it helpful to talk about and store memories. Whilst wellbeing scores for the PWI-ID did not change from the beginning to the end of the project, there were positive indicators for a number of families. Two families (in which the participant with Down syndrome lived

independently) spoke about how taking part in the project had helped them to become closer as a family. Three participants were described as more confident, two participants more independent, and one participant was reported by his parent as having fewer behavioural difficulties as a result of the project, which he also acknowledged made him feel happier and more confident.

Family members and people with Down's syndrome referred to themselves and each other as being the most likely to engage in developing life story work. However, there is an opportunity to connect across the persons wider networks if this is desired. For example, depending on the strength of the relationship with each, Community Learning Disability Nurses, community links such as faith groups and leisure activities, friends and partner, Allied Health Professionals, voluntary sector groups or care homes may be able to offer support with development of life story work.

The different ages and living situations of participants in the groups meant that families spoke of different ways in which they were planning to use the life stories in the future. Of the seven participants who were still living with family, three families spoke of how the life stories could be used in future if the person decided to move out to live independently. Of those already living independently with paid support staff, their families highlighted how the life stories could be used both with current members of staff, to help them get to know the person better, and future new members of staff.

Despite frustrations with internet access, most participants with Down Syndrome gave positive feedback around the digital life story, with particular emphasis attached to the ability to incorporate favourite music and audio links. The oldest member of the group learned new digital skills and preferred her digital life story to the more

traditional life story box and folder that she had also created. The digital version was the preferred option for the member who already had strong digital skills and some families highlighted how their relative with Down's syndrome proved to be more digitally adept than they were.

Recommendations

For Down's Syndrome Scotland

- Dissemination of life story guide for members with information about different formats and availability of templates
- Development of appropriate ongoing organisational support whether face to face or virtual that, within resource constraints, recognises the importance of sharing information about the process and potential outcomes of life story work
- To consider the addition of life story work to the current training programme to extend work with people with Down's syndrome, families and professionals
- To provide training in life story work to Down's Syndrome Scotland Family Support Service staff in order to maximise the reach and ongoing work of the project
- To seek further funding for expansion and continued development of life story work among the membership

For individuals with Down's syndrome

- To maximise the opportunity for increased social activity or engagement with friends or family

- To take increasing ownership of life story work with control over preferred format, choice of content and who it is shared with

- To refer to life story work at meetings with staff if this helps to share wishes and preferences

For families

- To recognise that their input level may be high initially, but this ownership should transfer to their family member over time

- To be proactive in supporting the development of life story work

- To recognise the potential of life story work when talking about loss and bereavement, even if this is a number of years later

For future research

- Effectiveness and impact of life story work at a time of, and after, transition in care arrangements or accommodation settings

- Opportunities and barriers to life story work within health and social care services

- Theoretical and conceptual issues in both traditional and recent types of life story work

- Outcomes of life story work over a longer time period

- Life story work (case studies) with people who have profound or complex disabilities

For social care practice

- For staff to attend training on life story work in order to embrace an increased role for social care services in supporting individuals with life story work (with permission)

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Appendices

Appendix Ai Interview schedule – families

<u>Pre-Project Interview Schedule Family and Individuals with Down's Syndrome</u>

1.   What are you looking forward to about the project?

2.   Is there anything you are worried about?

3.   What do you want to happen as a result of the project?

4.   What do you want to get out of the project as a family?

Appendix Aii

<u>Post Project Interview Schedule Family/Members with Down's Syndrome</u>

- What is your experience overall of taking part in the life story project?
- What type(s) of life story did you use?
    - What did you like/not like about each type you tried?
    - Did any work better than the others? Why was this?
- What have you liked about taking part in the project?
- What did you not like about taking part in the project?
- Is there anything that you found difficult about the project?
- Are you going to keep using your life story?
- If yes, which method and what will you do? If not, why not?
- Has the project helped you personally in any way?
- Has the project helped you as a family in any way?
- Has it been helpful for you all in thinking about the future? How?

Additionally, for parent/sibling of person with Down's syndrome:

- What has been the impact of the life story work on your relative?
- Can you identify any potential longer-term benefits of the life story work?
- Have there been any unintended consequences of taking part?
- How will you use the life story in the future?
- Do you have any concerns going forward?
- Would you recommend life story work to others?

Appendix B

**The Warwick-Edinburgh Mental Well-being Scale
(WEMWBS)**

Below are some statements about feelings and thoughts.

Please tick the box that best describes your experience of each over the last 2 weeks

STATEMENTS	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	1	2	3	4	5
I've been feeling useful	1	2	3	4	5
I've been feeling relaxed	1	2	3	4	5
I've been feeling interested in other people	1	2	3	4	5
I've had energy to spare	1	2	3	4	5
I've been dealing with problems well	1	2	3	4	5
I've been thinking clearly	1	2	3	4	5
I've been feeling good about myself	1	2	3	4	5
I've been feeling close to other people	1	2	3	4	5
I've been feeling confident	1	2	3	4	5
I've been able to make up my own mind about things	1	2	3	4	5
I've been feeling loved	1	2	3	4	5
I've been interested in new things	1	2	3	4	5
I've been feeling cheerful	1	2	3	4	5

Appendix C

Personal Wellbeing Index -ID

Participant code:

Date:

Code	2 faces (2pt)	3 faces happiness scale (3 pt)	
	Sad = 0 Happy = 1	Sad = 0 Neither Happy nor Sad = 1 Happy = 2	
Part 1: Happy with Life as a Whole (Optional) *"How happy do you feel about your life as a whole?"*			
Part 2: Personal Wellbeing Index – ID		**2-pt (0-1)**	**3-pt (0-2)**
"How happy do you feel about…?"			
1.the things you have? Like the money you have and the things you own?			
2.how healthy you are?			
3.the things you make or the things you learn?			
4.getting on with the people you know?			
5.how safe you feel?			
6.doing things outside your home?			
7.how things will be later on in your life?			

Happiness scale   Outline Faces for PWI-ID
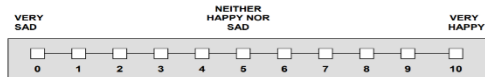
Appendix D

Interview Schedule for Project Workers/Volunteer

- What has been your experience of facilitating the life story project?
- Which sessions worked well or not so well? Why?
- Did participants use a structured approach?
- What do you think the effects of the sessions were on members and family members?
- What do you hope for in the medium and longer term?
- Tell me what your impressions were of the different types of life story format that people used – advantages and disadvantages of each
- Did you need to make any changes to the sessions/process?
- Did you need to suggest any changes to the type of life story used?
- Do you think the life story work contributed towards future planning for families? If so how? (ask for examples) Were there any barriers to this?
- Were there any difficulties for families in doing their life stories?
- Were there any other challenges that you faced in the project? If so, how did you overcome these challenges?
- Would you make any changes if the project was repeated?
- Did anything surprise you?

Interview Schedule for Volunteer with Down's syndrome

- What support did you provide as a volunteer?
- What difficulties did people have with their digital life stories?
- How did you overcome this?
- What are the benefits of digital life story work?
- Did anything surprise you about the project?

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