Supporting people with learning disabilities to have a **voice** in their care

Project Report
July 2018
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Introduction

The Springwell Project brought together people with a learning disability and complex needs from across Sussex Partnership Trust to share their experiences of using specialist NHS health services, to explore what needed to change so that they become more involved and more in control of their care right through from referral to discharge.

The project has enabled us to truly hear and act upon the voices of people with a learning disability.

Our participants transformed from a disparate group of people who needed a lot of support in their daily lives and were unused to giving their opinions on any aspect of their care, into Team Springwell, a group of skilled experts by experience who are able to understand and speak up confidently about their specialist health care.

To date Team Springwell have:

- Developed a set of 4 standards for good engagement that the Trust has pledged to implement within our services.
- Made a comprehensive film in 4 parts explaining community learning disability services to help people understand and be prepared to be involved in their healthcare.
- Co-facilitated workshops for NHS and other provider staff introducing the project, the film and our standards and sharing our learning.
- Held consultation sessions on the SPFT Mental Health and Complex Health Pathways.
- Presented our Standards to the Board of Directors
- Ran a workshop on participation at SPFT Experts By Experience Celebration event
- One team member went to the NHS Positive Practice Awards Ceremony when Springwell was nominated for its work in coproduction and another spent a morning with our Chief Executive finding out more about SPFT and telling them about the project.
- Been part of a short film about Experts by Experience made by Sussex Partnership Foundation Trust and which included representatives from all care groups

We have gained so much from this project and have so much to develop. Above all we have learnt that people with learning disability and complex needs can take a central part in their healthcare.

By giving more time, creating a space that is emotionally and physically safe and respectful, tailoring communication support to individuals and being flexible and responsive, we can enable people to tell us what they need and to help us to help them.
**Context**

Sussex Partnership NHS Foundation Trust’s (SPFT) 2014 internal Learning Disability (LD) services audit found that 26% of LD patients had been involved in their care planning.

The Care Quality Commission’s (CQC) January 2015 inspection found some parts of our service were not adequately engaging patients in decisions regarding their care and treatment. We knew this was not good enough.

Nationally, CQC’s 2012 evaluation of service for people with a learning disability (PWLD) found that less than 40% of services demonstrated patients and families involved in planning their care.

Recent focus groups suggested PWLD are confused by what services offer, have little understanding of what clinicians do and often don’t feel listened to. Staff feedback that they face several barriers to engaging people in care planning; lacking the right tools, time, a risk averse culture and being unsure how best to go about it.

Springwell aimed to support PWLD and complex needs to gain skills to better manage and engage in the planning of their own healthcare. We wanted to double the number of people and carers participating in care planning in Sussex, resulting in better care, reduction in health inequalities and improved quality of life for PWLD.

Underpinning these aims was the integral importance of developing a space to hear what PWLD need and want from services. We wanted to understand how our services looked from their point of view, what impedes engagement and what helps.

**The Project**

A previous pilot project in the Trust looking at the experiences of people with a LD and behaviour that challenges found that a focus group structure yielded insightful feedback and we decided to extend and build on this method for the Springwell project.

We drew up a preliminary structure consisting of:
1. Focus groups (& other consultation)
2. Development of a set of standards
3. Access pack
4. Access film
5. Training pilot
6. Evaluation & dissemination

We wanted a truly creative and collaborative approach so we chose to assemble a group of people with learning disabilities and complex needs to work together with staff and facilitators with similar disabilities.

We knew the demographic we wanted to work with were by definition hard to reach and factored in as much flexibility as we could anticipate. Recruiting participants was a challenge and took a lot of time.
We put up easy read posters and flyers, used Community Learning Disability teams and other community networks across Sussex and eventually identified 3 willing participants for the focus group and other people to participate in one to one sessions.

Between them they had history of physical and mental health issues and expressing themselves through challenging behaviour. They all needed a lot of support in their daily lives and were unused to being in a group situation or commenting on issues.

**Focus Groups**

- **A safe space**

Our first stop was to create a space where it felt safe to build their skills and confidence. To do this we ran a series of focus group sessions over a number of months using the model of Host Leadership (*see page 18*).

This involved making people feel welcome and valued, giving of ourselves as facilitators, providing creature comforts like drinks and food and establishing emotional safety.

We wanted people to be honest and unafraid to express different views. To encourage this we played games. The Marmite Game is based on the idea that the spread polarises people’s opinions! We used the idea of a giant talking mat (*see page 17*) on the floor with a visual scale of ‘like’ ‘don’t like’ and ‘don’t know’ on each end and in the centre.

Starting with Marmite, one of the facilitators called out topics likely to split the room in terms of opinion and people had to move to the relevant part of the mat for them. Examples included horror films, camping and holidays.

The participants soon became very involved, taking turns to call out topics.

The whole group including facilitators joined in, setting a collaborative and accepting tone that has endured throughout the project and beyond.
• Building confidence

We devoted the first session to getting to know each other, participants making a big wall graphic describing themselves and everyone present, including facilitators and support workers making bad day/good day posters together. This set a solid foundation of openness, acceptance and honesty.

By the end of the first session our participants had already developed a group identity, calling themselves Team Springwell.

• Responsiveness and flexibility

We were responsive and reactive during sessions, keeping the overall structure flexible so we could develop each one in direct response to the outcomes of the last.

For example at the end of one of our sessions we had begun to discuss different diagnoses. XX and XY said they were Autistic and asked what it meant. We were able to factor a proper discussion about Autism into the next session and made an information booklet for them to keep.

• Valuing input

We also paid our participants, valuing their input in a socially recognisable way. Initially they were surprised to be paid for their time, opinions and ideas but it really built their confidence as well as establishing boundaries and encouraging focus.

XX said at our SPFT board meeting presentation that one of the things he liked best about being part of Team Springwell was ‘they treat you like an adult, they pay you’ and ‘it’s like my job, it’s my job’.
• **Engagement-capable environment**

We set up carefully before each session using the same room and arrangement of furniture. We put up posters and graphics that people had made in previous sessions on the walls so they could see we valued their input. It created a sense of security and helped focus the group. We also had a quiet room for people to go to if they needed time out.

• **Inclusive communication approach**

We used an inclusive communication approach *(see page 16)* at our sessions which meant discovering the communication strengths of each person and tailoring how we presented information so they were able to understand and express themselves in the best way for them.

Visuals were our main tool: we made easy read letters to invite people to meetings, put visual timetables on the wall at each session, made posters together and graphically recorded our discussions as we talked.

• **Building skills**

At the beginning our participants were not at all clear about the services they had accessed, that they were specialist services (rather than mainstream), which professionals they had seen and why. Someone said they thought Challenging Behaviour Support was ‘what you have when you get out of prison’ another that ‘Psychiatrists brain wash you’.
We built people’s knowledge slowly using their own examples along with consistent visual support and explanation. These were later used in our standards and as extra visual support in our film.

- **1:1 sessions**

  To try to reach people who did not want or were not able to attend our focus groups we held 1:1 sessions at a venue of the participants’ choice. These were less successful than Team Springwell in that it took more time to build skills and learning enough to gain quality of feedback. We decided to put our efforts into the main focus group.

- **Carers and staff focus groups**

  We also held 2 carers focus groups and one staff focus group to gain evidence from these perspectives. The carers groups backed up a lot of what was said in our main focus groups, in particular confusion around referral pathways, services and terminology like Care Plan which was often confused with a Social Work Care Plan.

  Most people felt that they would like the person they cared for to have more of a say in their services, one that the person they cared for would not have the capacity to be more involved.

  Staff felt stymied by the amount of information recording needed versus the high number of referrals.

  Input from these groups would be worthy of full projects in themselves.
Outcomes

- **Springwell Standards**

  From our focus groups the team came up with a series of recommendations which we developed into 4 clear standards for good engagement in services for people with a learning disability. The standards act as a benchmark for what people should expect when they access our services and as guidelines for staff.

  1. Supporting communication
  2. Getting to know all about you
  3. Supporting your rights
  4. Making decisions together

- **Springwell film**

  Made with Team Springwell our access film forms part of our Easy Read Access Pack and explains specialist learning disability health services available and how to access them. It uses peoples own voices to reinforce the importance of involvement and engagement in their own care and shows ways that staff, support workers, carers, family and PWLD themselves can help.

  The film also underpinned our pilot workshop for staff.

  Our film director was involved right from the start of the project so that she could get to know the participants and she became an integral part of Team Springwell.

  The film making seemed to develop organically, some of the team were wary at first but quickly became interested and excited and then used to the filming process.

  Because of her burgeoning confidence we chose our peer facilitator to present the film and she seemed more at home in front of camera than some of the staff who were used to speaking in front of an audience.

  As well as more than meeting the brief of supporting access to our services, the finished product is a joyful and authentic representation of service user involvement within the project.
• Springwell Access pack

We have developed an access pack template drawing together the best of existing welcome packs with the addition of our new easy read initial assessment form and easy read Service User Engagement Charter.

The pack is an accessible referral support tool to help PWLD, their family and friends to understand and prepare for the referral and assessment process.

We presented our draft pack at pilot workshop session where it met with positive feedback, especially for the initial assessment form. The pilot workshop group also felt that there needed to be more mention of Social Workers and their place in referrals for integrated services in particular but in general they felt this was an omission.

We will continue to develop this pack over the next 6 months in response to feedback from the workshops we are rolling out across Sussex.

• Training

We had originally planned a one off training day for each part of Sussex but instead have piloted a workshop using our standards, access pack and film to start a conversation about service user engagement and work with clinician’s knowledge to troubleshoot and begin an action plan.

The decision was in response to our increasing certainty that creating and supporting a culture of service user participation needs ongoing work. We wanted to ensure we were creating a structure for sustainable service user participation and that meant continued consistent input rather than a ‘quick hit’ of training sessions.

Our pilot had great feedback particularly in relation to the film which staff felt was very helpful and much needed support for referrals to services.

We aim for this to become part of upcoming SPFT training on Care Pathways in order to reach a wider audience and more sustainably feed a culture of service user participation for Learning Disabilities.

• Evaluation of project

In response to the change in our planned training the evaluation component of the project has also had to evolve.

We have recruited a Psychologist one day a week between July 2018 and Dec 2018 to undertake evaluation of the project.
Benefits of the project

• Peer facilitator

We employed a co-facilitator with complex needs and training in advocacy whose confidence developed rapidly over the course of the sessions. XZ sat quietly drawing at the table during our first couple of sessions and we discovered she had a real talent for it.

In session 3 we asked if she would like to help graphically record and by session 4 she was drawing in front of the group.

Having a peer in this position became a kind of bridge between participants and staff. We have had a strong sense that we are all working together, rather than having a facilitator/participant relationship.

The whole group went on a tangible journey during the project, becoming skilled, knowledgeable and confident.

• Therapeutic element

Often during discussion about people’s experiences some participants became upset. Although we had factored such situations in with an available quiet room, the group set up seemed supportive here and we recognised that out focus group sessions might also have an element of therapy.

We now begin all our sessions with a brief check asking what we’ve been doing since we last met to reiterate the tone of acceptance.

This unforeseen benefit was very welcome although it was necessary at times to balance them with the purpose of the project.

• Positive Practice Awards Nomination - for co-production in the Springwell Project.

Team Springwell member XY and her support worker came to the awards ceremony in November 2017.

We were all very excited and happy to be nominated. Although we didn’t win a prize, XY said ‘let’s go for it next year!’
● **NHS England Film** – sharing learning and celebrating co-production

The Springwell project was one of 8 out of 169 proposals to gain funding to support the team to share our project and learning.

We made a reedit of our film to illustrate how our process works in the hope that other organisations may use it as a template or guide for implementing good service user engagement in their services.

Link to film [https://youtu.be/5VJ70eoLztg](https://youtu.be/5VJ70eoLztg)

● **Permanent Learning Disability Service User Participation Lead post**

Throughout this project it has been consistently clear that time is one of the main enablers of engagement with the people who use our services.

One of the project’s successes has been the recognition and commitment from Sussex Partnership NHS Foundation Trust that continued work to facilitate service user participation needs to be intrinsic to LD Health Services.

The appointment of a service user participation lead allows us to embed our learning in the organisation more sustainably.

● **Team Springwell EBE group**

As a result of the focus groups, Team Springwell is now a skilled group of experts by experience in SPFT services.

They are represented on our Clinical Academic Group and have so far undertaken 2 consultations on the proposed Care Pathways for Mental Health and for Complex Physical Health.

The teams learning from the Springwell project helped them to understand and comment on the pathways.

The project highlighted that work to develop a culture of participation and involvement must be consistent and ongoing.

Springwell’s standards and guidelines will support this and the new Service User participation Lead post will facilitate it along with the continuation and expansion of Team Springwell.

We will continue to support the current Team Springwell membership along with ‘satellite’ members who are happier with 1:1 or alternative consultation.

We are also using learning from the project to enable harder to reach people to be part of upcoming consultations.
• Employment for people with a learning disability

We have begun to work with the Trusts Equalities team on realising the potential for employment of a PWLD to assist the SU Participation Lead.

Successes

• Our ethos of service user involvement has underpinned every part of this project. Our peer facilitator was on the interview panel for a director. We consulted with the team on each step of development of their standards and access pack, they have presented on the project and co-facilitated workshops.

• An Inclusive communication approach. This has been a very visual project using large scale drawing (graphic facilitation), poster making, pictures and symbols. These methods have helped us to individualise our communication e.g. one person was unable to read/write, others had low skills in this area, others were able to draw.

• An iterative approach worked with our Inclusive Communication to build skills and embed learning.

• A flexible structure has allowed us to respond to ongoing learning experiences and to meet challenges as they have arisen.

• Team Springwell coalesced quickly, 3 very different people with very different versions of their diagnoses got to know each other and were able to interact with one another.

They have become a mutually supportive group with a strong team identity.

They feel their experience is valued, they have time and a safe space to be heard and are supported to express themselves in their own way.

Challenges and lessons learnt

• Participation

Reaching hard to reach people has by definition been a challenge. We learnt the value of creating and maintaining professional relationships across learning disability teams in Sussex and of forging new links with other teams and providers.

A large percentage (find stat) of the learning disability population, particularly older people, do not use social media or email. Younger PWLD do seem have more access to social media so in the future we need to use all available platforms to reach out to PWLD and hear their voices. However we also need to make sure we continue to send easy read letters and make phone calls and visits.
• **Carers involvement**

It has also been a challenge to engage carers some of whom showed interest and accepted invitations but did not attend either of the carer’s focus groups.

SPFT does have specific work going on with Carers and family carers and Springwell will link in with these groups as it continues its work.

• **Timescales**

Delivering the stages of the project on time has been a challenge for various reasons:

- Recruiting participants (see Participation)

- Working with separate organisations e.g. BSUH Clinical Media department is small and busy, with one editor/cameraman so we have had to accommodate their other priorities.

- Meeting the availability and needs of participants, for example one of the Aldingbourne Powerful trainer co-facilitators was only available on a Friday.

In terms of sheer volume of work the project would have benefitted from an assistant to support the part time coordinator.

Although we built flexibility into the project, we have learnt that more time at the beginning of the project to set up and recruit participants would have helped us keep to our timescales more successfully.

We anticipated the Springwell project would develop in response to its progress and one of our key learning points has been the need to continue to take this approach with PWLD. Right from the beginning it has allowed time for building and embedding learning.

However, it has meant that we have had to respond by extending our timescales and we are grateful to HEKSS for supporting this flexibility.

The project was originally due to end October 2017 but was extended to December 2017 with funding from SPFT.

During the final quarter we lost film editing time during August and November due to the editor’s and director’s schedules and other commitments which had a knock on effect on our training and the project was extended to June 2018.

Our pilot workshop was delivered in June 2018 and our evaluation stage will now run from July 2018 to December 2018.
• **Working with PWLD and complex needs**

As mentioned previously it was difficult to recruit PWLD and complex needs to our focus groups. For example one person was interested but was struggling to adjust to his new medication and could not get up in time to attend the sessions.

Time and space have been crucial and more was needed than we anticipated.

The mix of people in the groups meant we have been aware and ready to support people on ‘bad days’. Having had time to really get to know the group and for them to get to know us and their peers was a great advantage here. We were working with people with mental health difficulties and complex needs on often emotionally sensitive subject matter and were able to manage very well the times when people felt they had ‘had enough’.

• **Working with 3rd sector partners**

It has been extremely rewarding working with different organisational cultures and at times a challenge to accommodate people’s schedules and agendas but have developed strong and lasting bonds with the Aldingbourne Trust and also with Brighton and Sussex University Hospital Trust (BSUH) and the other service providers with whom we worked.

Next steps

• **Film premiere event**

Team Springwell thoroughly enjoyed making our access support film and were keen to have a premiere at a ‘real cinema’ so we are arranging a showing at the Duke of York Cinema, Brighton in October.

• **Sharing the learning**

Over the coming months we will be running our workshops across Sussex.

Eventually we anticipate service user participation will be part of SPFT training on Care Pathways in order to reach a wider audience, embed our standards in clinical work and more sustainably feed a culture of service user participation for Learning Disability Services.

• **Website**

We are currently working with SPFT Communications Team to create a central online place for people to be able to access our access pack and films, the pack, the standards and various other supports and links e.g. a glossary of symbols used in the film and access pack and links to other useful communication resources.
• **Social media**

We set up a twitter account in the name of our Service User Participation Lead to reach as many people as possible for invitations to our NHS England event and Springwell film premiere. So far we have linked with NHS staff, other learning disability providers and learning disability advocacy services amongst many others. It is proving to be a great tool for awareness raising, networking and building support.

• **Expert by Experience (EBE) training**

The Participation department at SPFT have been extremely impressed by the work of Team Springwell and as a result have looked at the reasonable adjustments they will need to make to ensure PWLD can undertake the Trust's EBE training.

One of our team will be undertaking EBE training shortly and so will learn a range of additional skills such as interview skills and how to sit on an interview panel. Once trained he will be on a database of people who will be called on to be an EBE representative at Trust interviews and at consultation events etc.

Team Springwell
July 2018
Glossary

- **Inclusive communication**

An approach to communication support enabling and facilitating people with different expression and comprehension by using all appropriate and relevant resources, tools and methods.

Tools can range from scents and objects of reference to talking mats and easy read information.

It is important to use the whole range of human communication abilities.
• **Talking Mats**

An interactive communication support tool to enable people to express their thoughts, opinions and concerns.

The mat is a rectangle of fabric, card or paper with 3 sets of picture symbols, topics, options and visual scale.

**Topics** are what you want to talk about e.g. daytime activities, how you are feeling today, what's for dinner etc.

**Options** relate specifically to each topic e.g. different activities, emotions, foods.

**Visual scale** allows participants to indicate their general feelings about each topic and option e.g. whether they are happy, unsure, unhappy.

![Talking Mats Diagram](https://www.talkingmats.com/)

Once a topic is chosen e.g. ‘what do you want to do today?’ the participant is given the options one at a time and asked to think about what they feel about it. They can then place the symbol under the appropriate emotion to indicate their feelings.

**Advantages**

- Provides a structured framework for asking open questions
- Avoids confrontation
- Can be used across a range of ages and impairments
- Reduces memory demands
- Helps people what have word finding difficulties
- Helps distractibility
- Helps people to say “no”

**Uses**

- Allows people to reflect about their lives
- Elicits issues to be explored in more detail
- Feeds back to carers and professionals
- Compares people’s views over time
- Allows client/patient involvement in life planning, meetings, goal setting

Originally a lo-tech tool developed by Joan Murphy and Lois Cameron in 2002, Psychology Department, University of Stirling, talking mats are now available as apps for tablets and phones. Visit [https://www.talkingmats.com/](https://www.talkingmats.com/) for more information.
Host leadership

McKergow and Bailey, 2014: Host – Six new roles of engagement

Host Leadership can be described as like hosting a party: as a host you need to provide for food, drinks, music, i.e. you have some duties to support your guests and you do that because you are interested in creating a great party, where people have fun.

At the same time you are responsible to ensure the party is running according to the basic rules of a civilised being together and if somebody goes out of some boundaries, as flexible as they might be, your role as the host will eventually be to intervene to ensure the rest of the party does not get ‘damaged’ by the action of some.

For further information visit http://hostleadership.com/
Springwell film links

- Our standards: https://youtu.be/QsMQ9NAN5Fw
- Our service: https://youtu.be/z3tQYutS5Uw
- Initial assessment role play: https://youtu.be/8k4SD6_QZR8
- Questions and Answers:
  1. Introduction: https://youtu.be/4rxzoi3MQTI
  2. How do you make sure my care is all about me? https://youtu.be/QiQuBN7eD9o
  3. What if the person finds it difficult to communicate or understand things? https://youtu.be/oxrxVWupbJ8
  4. What if I don’t understand my care plan? https://youtu.be/_GBYzxbUynU
  5. What if I don’t want anyone else to see my careplan? https://youtu.be/Y33lE9qJBis
  7. What happens after I have got my careplan? https://youtu.be/Yb8k4oj0jCM
  8. Why do I also need a risk assessment? https://youtu.be/alAKB4ZF5eM
  10. Will I be part of every decision about me? https://youtu.be/enzUe3Mwg-o

Appendices

Supplied separately

- Springwell Easy Read Standards
- Springwell Standards
- Springwell poster
- Easy read report summary