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

**Easy Read Summary**
July 2018
People with a learning disability told Sussex Partnership NHS Foundation Trust (SPFT) that they did not feel involved in their specialist health care.

We wanted to find out what needed to change so that people can be more in control of their care.

The Springwell project brought together a group of people with a learning disability to share their experiences of using specialist health services.

Services like:

- Psychiatry
- Psychology
- Counselling
- Behavioural specialists
- Speech & language therapy
- Learning disability nursing
- Occupational therapy
- Physiotherapy
The group called themselves **Team Springwell**.

The team did lots of work to tell SPFT what learning disability health services are like for them.

They worked out how SPFT can make services work better for people who use them.

Team Springwell has made a list of actions to help these services to support people with a learning disability to be a part of their care.

The list is called the **Springwell Standards**.

SPFT have promised to do the actions on the list.

Team Springwell made a **film** about SPFT learning disability services.

The film will help **people who use services** and their families and carers to be prepared to be involved in their care.

The film will also help **staff** working with people who have a learning disability to be prepared to support people to be involved.

The film works together with an **easy read access pack** with useful information..
Team Springwell are now a permanent group of skilled **experts by experience** in specialist learning disability health services.

They have run **workshops** for SPFT staff and other staff who work with people with a learning disability and for experts by experience in other area.

They have worked with SPFT **Clinical Academic Group** for Learning Disabilities on their Mental Health and Complex Physical Health Pathways.

They have presented our Standards to the **SPFT Board of Directors**.

One team member went to the **NHS Positive Practice Awards** when the project was nominated for work in coproduction.

Another spent a morning with the **SPFT Chief Executive Sam Allen** finding out more about the Trust and telling them about Springwell.

A Springwell member was also part of a short film about **Experts by Experience** made by SPFT.
SPFT want Team Springwell’s work to carry on. They have made a new job called **Learning Disability Service User Participation Lead**. The job is to support Team Springwell.

We have found out a lot of useful things from this project and we have a lot to work on.

We have learnt that people with a learning disability and complex needs can be involved in their healthcare.

We have learnt that staff and services need to:

- Give people enough **time**
- Make a **safe respectful space** for people to say how they feel
- Support people’s **communication** in the best way for them
- Be **flexible** and **responsive**. That means meeting people’s needs as they arise.

Then we can support people to tell us what they need and help us to help them.