



## Easy-Read Summary

### **The Victoria & Stuart Project:** End-of-life care planning with people with learning disabilities



#### **What is the project about?**

The project is about planning ahead for when someone gets to the end of their life.

It's about helping people with learning disabilities to think about what they would like to happen:

- in the last days, weeks or months of their life,
- and when they die.



#### **Why are we doing the project?**

People with learning disabilities don't always get the right care and support when they are ill and going to die.

They can find it hard to understand what is happening, and to say what they want.

Many staff who support people with learning disabilities have said that they find it very difficult to help people prepare for dying.

They want to know how best to help.





## What are we going to find out?

- **What helps** people to plan ahead for the end of life, and **what stops** them?
- **When** should people with learning disabilities start planning ahead?
- **Who** should be involved?
- **How** can they help?

## What will we do?

We will do 5 things:

1. **Find out what people are already doing** to help people with learning disabilities plan for the end of life.

- Look at reports on the internet about plans for the end of life.
- Ask care providers that work with people with learning disabilities what they are doing.  
We will send them a questionnaire.

2. **Find out what people think about planning ahead**

Talk with groups of:

- people with learning disabilities
- families
- staff in learning disability services
- healthcare staff
- commissioners (who make decisions about funding)
- policy makers (who decide the rules about how we do things)



### 3. Get a team together to look at everything we found.

On the team are:

- 8 people with learning disabilities
- 2 family members
- 2 support workers
- a learning disability nurse
- 3 project researchers
- 3 other people

We will meet 6 times to decide:

**The best ways** to help people with learning disabilities plan for the end of their life.

**The best resources** that can help (such as pictures, documents or videos, for example).

### 4. Test the method and resources:

30 staff working in learning disability services will test some different ways of planning with people they support.

Afterwards, we will ask them if they think it was good.

We may have to make some changes to the resources and guidelines.

We will then put it on the internet, so everyone can use it.





## 5. Make sure people who need it, know about it:

Ask for help and advice from lots of people, including:

- People with learning disabilities
- Families
- Learning disability services
- End-of-life care services



Write articles and reports. Some of these will be easy read.



Hold webinars and presentations.



Use the internet and things like Facebook and Twitter.

## Who is doing project?

Working together on this project are:



1. Two universities (including researchers with learning disabilities)



MacIntyre  
Providing support...your way

2. Organisations that support people with learning disabilities



Voluntary Organisations Disability Group



3. A hospice



People with learning disabilities have helped to prepare this project.

We will employ 4 researchers with learning disabilities.