



### Transcript:

[Music Playing]

### User-led Organisations

Andrew Gardner: I think ULOs are critical actually in delivering on the personalisation agenda, because personalisation is all about the individual being at the centre of what goes on.

Margaret Heffernan: You see people that have other disabilities and you can relate. It gives you that confidence.

Bernd Sass: The greatest asset of ULOs is their credibility.

Narrator: Sustainable user-led organisations are emerging as a key force in the personalisation agenda. Managed and run by disabled people they are delivering a wide range of self directed services, and providing a representative voice in their local authority.

David Williams: It is important for authorities to have sustainable ULOs. They have to be more than just a voice, they have to be business ready.

Narrator: We are finding out about the day-to-day practices of one of the most successful user-led organisations in the UK. The Essex Coalition of Disabled People, or ECDP, is now in their fifteenth year and has over three thousand six hundred clients, fifty staff, and a current operating budget of 1.9million.

Rich Watts: We use the lived experience, the day-to-day experiences of our members, of our clients, to fundamentally inform the work that we do.

Sally-Anne Webb: *It's really good to see you again Chris?*

Chris Donn: *Very nice of you to say.*

Sally-Anne Webb: *How's it all going with Sam?*

Chris Donn: *Going great.*

Sally-Anne Webb: *Yeah?*

Chris Donn: *Yeah, we have just done six months now.*

Narrator: Sally-Anne Webb is a support planner at the Essex Coalition, and her lived experience as a carer informs the relationships she develops with her clients.

Sally-Anne Webb: *And how are the PAs is that all going well?*

Chris Donn: *Yeah, it's going okay. We will probably need a new PA come the holidays.*

Sally Anne-Webb: I work with all disabilities, but I tend to pick up people with learning disabilities with the highest support needs simply because I have got that experience of my daughter moving into independent living.

Narrator: Chris Donne came to Sally-Anne for help with a support plan for his son who has Down's syndrome. Chris' son who is now eighteen has just recently left home to begin living independently.

Chris Donn: *He is, and he is slowly improving on his life skills.*

She gave us a hell of a lot of assurance, the main reason being that her daughter had been through this, and she had been through it with her disabled daughter. So she knew how to put a support plan together, and what the process would be after that. And that was a great help to us, particularly we had the feelings of guilt, of we are going to leave him, he has been a family person. But she reassured by saying that she had always got this contact with her daughter. We started to think quite positively about it after that.

Rich Watts: I think what makes a user-led organisation different to other organisations is that disabled people are fundamentally involved at every part of the organisation; right from the very top, setting the strategic direction of the organisation, through the management and into the management that deliver the services on a day-to-day basis. What that gives you is the experience, it gives you the knowledge, it gives you the expertise of disability throughout the whole of the organisation.

Narrator: As a user-led organisation, the Essex Coalition provide a voice for disabled people in their local authority, and are influencing policy and strategy at the earliest stages.

Rich Watts: At the very top level, just as the ideas are emerging, we can be sitting next to Essex County Council, and help shape their thoughts. But ultimately we have to make sure that that's linked in with the values that we have as an organisation as well.

Narrator: With the wide range of services the Essex Coalition are providing, from information and payroll to peer mentoring and support planning, they recognised they needed a workforce ready to share a range of skills and life experiences.

Rich Watts: We don't have constraints in terms of the way that we think. We are a bit more nimble, we are able to respond and think a bit

more creatively. And one really crucial part of that is making sure that we have got the staff available to do that.

Narrator: Elizabeth Bird was working as a personal assistant and carer until Essex Coalition hired her and trained her up to work as one of the support planners.

Rich Watts: Elizabeth herself doesn't have direct lived experience, but that doesn't mean that she can't therefore get involved in our support planning work. So being a user-led organisation the other members of staff that we have got who do have direct experience are constantly in contact with Elizabeth. It means that Elizabeth can take all of those experiences on board and apply that in her support planning work.

Elizabeth Bird: So when I joined on with Sally she helped me by talking about her own experiences, because her daughter has got learning disabilities herself and has her own personal budget, and I shadowed Sally on quite a few visits. And I got to understand how it was that she talked to people, to relate to them, to get them to open up, and to realise their own dreams and ambitions.

Narrator: One of the first people Elizabeth has helped with their support plan is Margaret Heffernan, a young disabled woman who has spent most of life dependent on her mother. Margaret wanted to use her personal budget in ways that would enable her to begin to live a much more independent life.

Margaret Heffernan: *This is lovely, because even though Frinton is gorgeous it is very isolated.*

Elizabeth Bird: *Yeah.*

Margaret Heffernan: *And it does make it really difficult ...*

Elizabeth Bird: *There's not a lot to do there for you is there?*

Margaret Heffernan: *Yeah, no.*

Elizabeth Bird: *Especially now that your mum is not as well as she was.*

Margaret Heffernan: *No there's not, there's not a lot to do.*

Elizabeth Bird: It was important to try and put her at ease, and to make the process really empowering for her; this whole process about choice and control, and giving the person control of their own life, and making the most of it.

Narrator: Over the years Margaret's physical dependence on her mother left her feeling frustrated, and with few independent life skills.

Margaret's Mother: Life was really bad for her, really bad, and the isolation.

Margaret Heffernan: You do need to have opportunities like everybody else; everyone should be able to do what they want to, everyone has dreams, and goals and ambitions.

- Elizabeth Bird: We started talking about the few basic things, short term goals that you wanted to do. But when we really started developing and talking about the future, and where you want to be. And then you started to realise all of things that you could do, like going to Ireland to see your family, and developing the skills and possibly living independently in the future.
- Narrator: One of Margaret's goals was to find ways to build her confidence. And Elizabeth felt that peer mentoring at the Essex Coalition would offer Margaret an opportunity to start to fulfil her potential.
- Elizabeth Bird: They are running this pilot scheme at ECDP, it is all about the new generation of support planners. And they asked me to think of somebody that I thought would be good at this, and I immediately thought of Margaret because I knew her words could be quite powerful. Margaret was very excited, she was up for the challenge; she wanted to come to share it with people.
- Margaret Heffernan: It is very difficult to put it into words, its very emotional to think that you can have this impact on someone, but knowing that only you can do it. You think well you are quite honoured to actually do that.
- Narrator: Margaret is coming into the Essex Coalition to share experiences with some of the up and coming support planners and peer mentors.
- Bernd Sass: Peer mentoring is crucial, because communication is not just about what we say, sometimes just seeing someone doing something that we have not expected ourselves.
- Elizabeth Bird: *Okay, well this is Margaret, and I have asked her to come in to talk to you all today. About three months ago I worked with her to create her own support plan for her personal budget, and I thought it would be really useful if she came in and talked through her experience of the process.*
- Support Planner: *I find that coming in here and seeing people with disabilities actually working, it must be such an achievement.*  
  
*My personal budget has helped me to achieve; and one of my achievements was to be able to work. And now as a support planner, hopefully in the making I can encourage other disabled people like yourself who think that they can't work for whatever reason.*
- Margaret Heffernan: Because nobody ever said to me what would you like for the future, because I never ever had a choice, and then when somebody offers you this choice – oh you can do this, you can do that – I think now I have always been dreaming it, because it's in your head, but you have never ever said it.
- David Williams: I think the Essex Coalition has been at the forefront of recognising that change, recognising the opportunities of the potential to not only have a very powerful voice, but to also underpin that with a

delivery model that is a true partnership, a true co-production model, with the local authority, and just how powerful that is.

Rich Watts: One of the key areas for us is how we can expand that service, so that we can offer it to far more people.

Narrator: The Essex Coalition are now expanding their work by mentoring a number of smaller user-led organisations, like the embryonic Cambridgeshire one set up by Chairman Andrew Gardner. The expertise and experience of the Essex Coalition is proving to be an invaluable resource.

Andrew Gardner: One of the things that we have taken from the ECDP, which has been really helpful was around strategy; so how we feed back on issues at a local level, how we run consultations, and how we support people to have a voice back to statutory authorities about the types of service that they are providing. And that, at a strategic level, has been really helpful to talk to ECDP, and have their input all the way through, to see how they have developed that particular model. Because we are very much in the infancy of how do we get there, so it's really nice to have your end goal mapped out really, and what we are trying to do is work out the process by which we get there.

Rich Watts: And for me, if there is a good user-led organisation in that area, I think presents huge opportunities for the ULO to work with the local authority to face those challenges together.

Bernd Sass: ULOs can facilitate new ventures, even new enterprises.

Andrew Gardner: It's not just about talking, it's about doing as well.

[End of Recording]