As prime author of Valuing People in 2001, former national director for learning disability and now chief executive of the National Development Team for Inclusion, Rob Greig knows a thing or two about the issues facing people with a learning disability. Jenny Darwent met him.

What were your hopes for Valuing People?
My biggest hope was that it would herald the start of a sustained change in the culture of how society viewed people with a learning disability. Within that, there were specific things I hoped for – the end of long-stay hospitals, an increase in direct payments, and person-centred planning becoming an understood way of working.

Were you happy with the results?
The aspirations were incredibly high – you don’t change centuries of societal discrimination in five years.

In some places, we have changed the culture for good. The idea that people with a learning disability are equal citizens and should be involved in decision-making about services is now understood. There are other areas where the principles are understood, even if the practice is not what it should be – like person-centred working and people with a learning disability working.

But in other areas, we are still a long way from real change. The fact that the people with the most complex and challenging needs are still not properly included is disappointing, and that many public bodies still think that people with a learning disability can be ignored when the going gets tough.

What did Valuing People Now (published in 2009) add?
Valuing People’s focus was achieving cultural change and supporting the voices of people with a learning disability and families to be heard. Valuing People Now shifted the focus to government actions.

If we’d had more resources in 2001, people would have put in place more of the same services that hadn’t delivered what people needed. We needed to change the culture, so when money came, it could be used creatively.

Unfortunately, we made significant progress in achieving social change but investment didn’t follow. From around 2005/06, government did not accept the evidence about increased numbers of people with a learning disability. And, at the same time, was turning away from the idea of ring-fenced money.

Were you concerned when the central Valuing People Now team was disbanded in March 2011?
I didn’t necessarily think ending the team was a problem – it was that it wasn’t replaced. I would have put some of that...
money into other resources to help ensure momentum can be sustained. I don’t accept we’re at the end of Valuing People – it is owned by people with a learning disability and family carers. It’s not up to the government to switch the policy on or off.

When disbanding the team, the government promoted local leadership. Has the agenda been picked up locally? I think it’s happened where local people have wanted it to happen. To think that you can withdraw national funding and support and local people will suddenly say “I’ve never prioritised people with a learning disability, but I’m going to start now” is not grounded in reality.

There are some places where partnership boards do a good job. But one of the reasons is because the local authority and the NHS listen to them. There are some partnership boards that have stopped operating.

I’m not saying there should be a national model, but the concept that every local area should have a structure whereby people with a learning disability and their families work alongside the people responsible for public services is really a no-brainer.

Families were at the heart of Valuing People – are they still fighting? It’s important to differentiate between the minority of families involved in delivering Valuing People and the majority, who seek to get by. The latter probably wouldn’t have noticed whether the national team was there or not.

Some families feel the momentum has gone out of Valuing People, because people aren’t pushing it. They will be lacking support and there is a risk they may lose heart. However, many families and self-advocates are still fighting – I’m not saying they can’t do it without national support.

Some self-advocates, and families, took information from IHAL [the Improving Health and Lives Learning Disabilities Observatory] on health checks to their local NHS and local authorities and said “why are our rates on health checks lower than neighbouring counties?” and the authorities are doing something about it.

But not everywhere has self-advocates who are sufficiently resourced and experienced to take on those responsibilities.

The Office for Disability Issues is developing a new disability strategy. What do you hope it will include? I hope it builds on the past rather than starting again. And I hope government remembers that one of the things that has enabled disabled people to make progress is their solidarity. Some government agendas focus on the individual rather than the collective group.

The disability review has got to ensure that people with a learning disability can fulfil their place as equal citizens, and not just expect people to do it off their own bat. There must be adequate resourcing for self-advocacy and family support organisations and a clear requirement on public service bodies.

What advice would you give people with a learning disability? Speak up, but don’t do it alone. It’s a cliché, but together we are louder and have a greater chance of success.

Key points

- Rob Greig wrote a learning disability plan called Valuing People.

- He says things are better than they used to be, but people need to keep fighting for change.