**

Transcript: Laurence Clark – Self-Directed Support in the USA

*[A number of people in wheelchairs are gathered together for a demonstration in Washington D.C.]*

Laurence Clark:

I don’t think I’ve ever seen so many wheelchair users in one place at the same time. It’s quite an amazing sight. I’ve come to America to find out about independent living here.

Today I’m joining some disabled people who are marching to the White House to demand Self-Directed Support.

*[Laurence joins a long line of people in their wheelchairs]*

Laurence Clark:

I’ve never had to drive in a straight line before [laughs]

*[Laurence sits with a man demonstrating who is in a wheelchair]*

Laurence Clark:

Can you tell us what ADAPT stands for?

Demonstrator 1:

It just means ‘Adapt Knowledge,’ it’s an acronym, but what it stands for, you know, philosophically and for me, is addressing the most important issues, starting with things that really mean something to the people that have the least that need the most.

*[A number of other demonstrators give their opinions]*

Demonstrator 2:

Well, I’m here because we’re trying to change long term care policy in this country so that people can have the choice to live in their own homes instead of having to live in an institution.

Demonstrator 1:

It’s the most important issue when it comes to disability because it’s getting people in their communities and until you do that you can’t do much else. Public transit doesn’t matter, buildings accessibility infrastructure doesn’t matter if you’re not free and in your community, that comes before everything else.

Demonstrator 3:

We have services that are much less expensive in a self directive manner, through personal assistant services.

Demonstrator 4:

Now that the US Federal Government has spent millions of dollars to study this question, they have learned what we told them years ago, that when we as people with disabilities are in charge of who touches us, how we’re touched, what for, what our services are, we are in fact not only happier but our quality of service is better, safety is far better, and to that, you know, thanks for spending money to learn that.

*[The demonstrators chant outside of the White House]*

Laurence Clark:

It’s a little bit scary, there are lots of police all around.

Demonstrator 2:

The way it is right now, I mean the system is totally turned upside down - if you’re eligible for Medicaid, the state have to pay for your long term care in an institution like a nursing facility, but if you want to get the help in your home, there are optional programmes.

Demonstrator 1:

I come from Chicago and Obama was the senator there, as you know, from Illinois and he did not sign on to the community choice act and about a week before Adapt showed up in Chicago Obama became a sponsor. So he was a reluctant supporter to begin with, I don’t think that he’s necessarily against it, I just don’t think that he has the guts to do what it takes to make it happen.

Laurence Clark:

In the UK the unions have been one of the strongest opponents…

Demonstrator 1:

Why?

Laurence Clark:

Because they see it as people losing jobs. The jobs are still there, they’re just going to be done in a different way.

Demonstrator 1:

Exactly. And we would be all in favour of our workers getting pensions and things like that, we certainly stand with them on that. But their solution is you know, this might happen so therefore you guys have to remain locked up forever and ever and you know, we’ll never get anywhere.

Demonstrator 3:

We have a workforce, meaning personal attendants that are out there ready and able to provide that support and we have consumers whose lives can be greatly enhanced by virtue of being able to have that service provided in their own homes, to make decisions for themselves and basically to be a contributing member of society.

Demonstrator 5:

In all the states around the country, when they have these budget cuts, the first thing that they cut is home services, and then that leaves people no choice to live in the community.

*[Laurence explains how his support works, to Demonstrator 4]*

Laurence Clark:

The way my support works is, I get and individual budget, I get an amount of money every year from the state, I write a support plan that says what I’m going to spend that on and how that’s going to keep me healthy and safe and give me choices. Then they agree it and I go away, I have the money in my bank account, I spend it and at the end of that time I fill in a form to say what I’ve done with it and then we start again.

Demonstrator 4:

So isn’t it too bad our healthcare reform didn’t come anywhere close to getting us that. Thanks. Now I’m really mad *[laughs]*. All that work for not what we needed.

Laurence Clark:

Yeah.

Demonstrator 2:

I mean that’s all it is, it’s purely politics. If you could take all the political crap out, take all the greed out, it makes perfect sense.

Demonstrator 1:

As soon as George Bush became president, the democrats weren’t in office anymore, the Democrats said ‘we love this bill and we endorse it’ and now that Bush is gone and the Democrats can do something about it, they don’t want to talk about it anymore and that’s the sort of game they play, they all love it when they can’t do anything about it, but when it comes time to do something, they don’t want to talk about it anymore.

Demonstrator 4:

It’s so obvious here that when people say ‘we just don’t get why the Administration doesn’t appreciate how much less expensive it is for the Administration as well as how much happier people are,’ well it’s pretty obvious why they don’t – the corporations that run the nursing homes aren’t going to give up easily on their cash cows.

Demonstrator 5:

It’s such a violation of our Civil Rights, you know, the US Supreme Court said that we have a right to live in the community and not be forced into facilities and yet still, it goes the wrong way.

*[The police address the chanting demonstrators]*

Policeman:

…Ok, thank you for listening to me, ok...

Laurence Clark:

The guy was basically saying, because there’s different police, different jurisdictions, he was giving them a warning that if they don’t get off this land soon then they’ll get locked up. I think we may have to leave.

*End*