

Reach Report

Making Lives Better:

Work, Health and Disability Consultation

February 2017



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About Reach



Reach is a group advocacy project supporting adults with learning disabilities in Stoke-on-Trent.



We arrange meetings and events for people to speak up together, talk about issues, share opinions and ideas.



We support people to share their experiences of health and social care services.



We are part of Asist, Advocacy Services in Staffordshire.



You can telephone us on 01782 747872 or email us on reach@asist.co.uk

What We Did



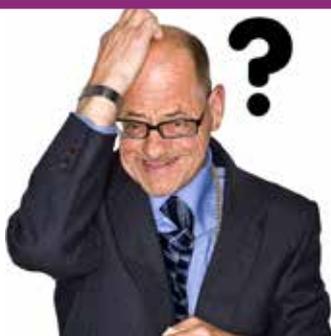
We supported people to speak up about the government's **Improving Lives** consultation.



We supported people to talk about their ideas and answer questions based on the information in the **Making Lives Better** 'Easy Read' booklets.



We made posters explaining the main points of the consultation.



We did this because there was too much information and too many questions for people to look at in one meeting.



We then invited people to a series of **2 hour focus group meetings** to talk about the consultation and share their experiences and ideas.

Who We Worked With



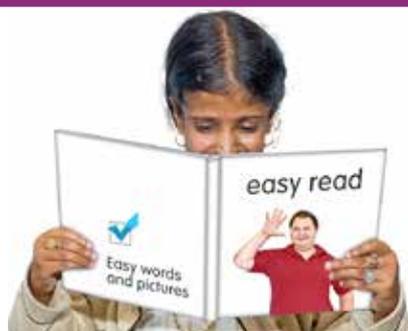
We held **4** focus group meetings, supporting a total of **32 adults with learning disabilities** to speak up about the consultation.



We supported **15 men** and **17 women** to speak up, aged from their **20s** to **70s**.



We also worked with **9 support staff** to share their thoughts on the consultation, based on their experiences of supporting people with learning disabilities in their daily lives.



This **clear information** report highlights the main things people said about the consultation, in their own words.



Most of the thoughts, ideas, experiences and questions in this report are by adults with learning disabilities. Comments by support staff are clearly marked: **(Support Staff)**.

What We Found: Employer Attitudes and Training



Almost everyone we spoke to felt the **attitude of employers** was one of the main reasons people with disabilities find it difficult to find and keep work.



Everyone said employers need **training so they can understand more** about supporting people in work.



“A lot of the time I think the problem lies with the employers and their attitudes.” **(Support Staff)**



“Employers need be trained. They want you to do too much. Rushing people, not taking people’s disabilities into account.”



“We get pushed aside. There’s not a lot of places that’ll take people like us.”

What We Found: Employer attitudes and training



“Employers need re-educating. I think most employers are scared to give jobs to disabled people.” **(Support Staff)**



“They [employers] don't want to employ people who might take a bit longer to do a job.” **(Support Staff)**



“Physical appearance. They just look at people and they don't think people can work because they look disabled.”



A few of my friends have been through that. They've been turned away and ignored.



“Employers could employ two people – one disabled, one not – and have them job share but they just want make things easier for themselves.” **(Support Staff)**

What We Found: Employer attitudes and training



“Employers don’t always have the patience. Some people don’t listen [to us].”



“Their disability. [That’s as why] they [employers] don’t give them a fair chance. They get pushed out.”



“They just don’t want to employ people who might take a bit longer to do a job.”
(Support Staff)



“Employers sometimes I don’t think are bothered about the rules [on disability discrimination]”.



“Employers aren’t as willing to employ people. They don’t want to do that. They don’t want to pay people to provide support.” **(Support Staff)**

What We Found: Employer attitudes and training



“[Employers are] worried that disabled people can’t cope, not fast enough. They [employers] don’t realise how people **can** do things.

When I was 16 I was casting in a pot bank [pottery factory]. I kept forgetting to clean my moulds.

If I’d had a bit of help to remind me to do that I could have carried on in that job.

They don’t take into consideration that if you have a bit of practice, you can do things right.”



“[This is] pipe dreams! Employers need more training if they’re going do any of this.

I’ve worked before and the employers didn’t understand about learning disability at all.

It’s all about reasonable adjustments.”

What We Found: Rights



Everyone we spoke to felt that people with disabilities have the **same rights as everyone else** and should get support to work if they want to.



"Disabled people have got the same rights as people who aren't disabled. We want the same things."



"Yes everybody should have the chance get a job, same rights."



"I agree [with the government]. It's important. Working. Good for you."



"I think this is good. It [work] gives you confidence. Do things. Get involved. I would like to work."

What We Found: Rights



“Disabled people want jobs. But it’s hard to find jobs. You ought to have a choice.”



“It’s easy to say ‘I’d like to work’ but they [employers] need put things in place that’ll help ‘em do the job.”
(Support Staff)



“Everybody’s got a voice. You have to speak up for yourself. Your own choices. Everybody has something to say.”



“Yeah, of course they [employers] should give jobs to people with disabilities. They [the government] should help people get jobs.”



“You’re entitled to try things out, with the right support.”

What We Found: Support



Everyone we spoke to said support was **very important** in helping disabled people into work.



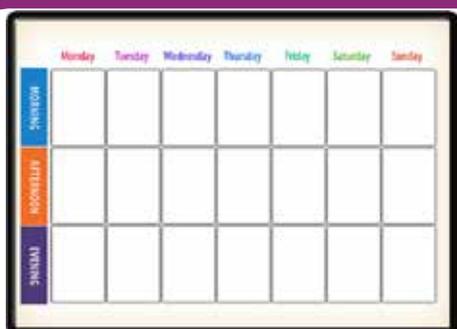
Many people, including all the support staff we spoke to, felt there is **not enough support** to help adults with learning disabilities to find, and keep paid jobs.



“Support is very important. And they [support services] need to listen to the person.”



“Getting support for people at night time is a big problem. There are very few support services that will work with people in the evenings.”
(Support Staff)



“I always have support off my staff. Where I live [in a small group residential home] there's staff 24 hours a day.”

What We Found: Support



“They [employers] need learn what support they should be giving people and not push disability people out.”



“There’s just not a lot [of support] for people.”
(Support Staff)



“You’ve got key workers. They get you back on track.”



“Support with feelings and emotions. I get support from Duke Street [a support service for adults with learning disabilities in Stoke-on-Trent]. Important!”



“It is hard. You want more support.”

What We Found: Support



“Here [at Riverside Employment Training for adults with learning disabilities] there’s generally 6 to 12 weeks of support for people on placements.

Then there’s a review and people continue in the job but there are still regular reviews, and the support can come back in if people need it.”

(Support Staff)



“I’ve done 7 years job coaching and I think where it falls down is the support.

The training and the support isn’t there or just comes way too late.

The support people do have in in place is usually short term, a few weeks or so.

Then it goes away and even if the person can do the job they can’t without that little bit of support.”

(Support Staff)

What We Found: Support



“[You] get help from carers. More support. Carers are giving people more support.”



“Support, I’d need more to help me.”



“I don’t get as much support [as I need].”



“[Support services should] ask people what support they need, everybody’s different.”



“The job training and support is really important.”

What We Found: Support



“Support needs be personalised – It should be for just you.”



“Need make sure people have proper support.”



“We had someone with a learning disability come and learn how be a carer [at the service I go to]. She had another person to support her while she learned the job.”



“Social care should be providing support. Your GP should be part of it, too.”



“Sometimes you get good support, sometimes not.”

What We Found: Barriers



People talked about the barriers (problems) that get in the way of people with disabilities working.



The main barriers people talked about were:

- public transport
- peoples' fears
- family attitudes
- disability and health issues.



People said **public transport** is not reliable and can cost a lot of money.



"Buses. People who want find jobs need go on the bus but if they're not on time you can't work. You're late."



"If you have to go to the job centre every day, how do you afford the travelling to get there?" (**Support Staff**)

What We Found: Barriers



“Buses are a nightmare [and] you’ve not got the money – paying out for buses or taxis every day.”



“How will disabled people get to their workplaces if they don’t have their own transport?”



Adults with learning disabilities and their support staff said that **peoples’ fears, worries and past bad experiences** get in the way of finding and keeping work.



“This is all going to be a negative for a lot of people especially with mental health and learning disabilities. A lot of worry.”



“What if it all goes wrong? People are off their benefits and the job goes wrong – it takes ages to get back on their benefits again.”

What We Found: Barriers



“This is all very worrying for people who've tried work, like me, and they've had negative experiences with employers and with other employees.”



“Pressure-wise it can be exhausting for the person, trying it out, doing new things.”



“I think I'd be frightened going into a workplace I'd never been to before, frightening experience.”



“You're putting more pressure on people. Stresses them out, and their parents/carers, too.”



“Work. This is what I want to do. But my downfall is I don't know money. I don't know figures. So that's my problem.”

What We Found: Barriers



The Support Staff who came to the meetings were concerned that the **attitude of peoples' families** sometimes gets in the way of them working.



None of the adults with learning disabilities that we spoke to said this was a problem for them.



“At times you're battling [over-protective] families that don't want their disabled children to have jobs or learn anything.”
(Support Staff)



“It's down to the parents and carers to explain these things [opportunities to work or be out in the community] to people. But they don't always do that.” **(Support Staff)**



“People end up getting frustrated. It makes you so angry when it fails like that.”
(Support Staff)

What We Found: Barriers



People told us they were worried how working could affect peoples' health, and that their disabilities or health problems might make working difficult for them.



“What about people with more severe disabilities? Are the government going to make them work?”



“Employers want you to do too much. Rushing people, not taking people's disabilities into account.”



“Physical disabilities – how are people going to work in buildings that aren't accessible?”



What about people with mental health? If they can cope with working I think it can be good for them but what about where they won't cope in some situations?

What We Found: Healthcare Experiences



Good quality healthcare, and NHS services being part of helping people get into work, stay in work or get back to work are an important part of the government's plans.



People shared their thoughts and experiences of healthcare services.



“Once a year, adults with learning disabilities are meant to have a review [annual health check] but that doesn't happen for everyone. Some do, some don't.”

(Support Staff)



“Sometimes you get the right time for the appointment but sometimes you wait ages.”



“I think sometimes, services like the NHS, they're not listening to people.”

What We Found: Healthcare



“My doctors are helpful. When people are bad and you make an appointment they’re helpful.”

NHS
England

“The NHS has fallen already. Things are getting dangerous.”



“Yeah – I agree with them [the government] there. It should be people looking after their own health.”



“It’s no use doing things if you don’t look after your health.”



“Doctors are bad. You make an appointment but it takes ages, waiting around. And at A&E it takes forever. And hours at the walk-in centre as well.”

What We Found: Healthcare



"I went up the hospital and they were very good. I had visit because you know you have to visit sometimes but they were very good."



"I don't think people get enough support with their health. They need more support. Lots."



"People need support at the [Royal Stoke University] Hospital. Helping them to find their way around."

(Support Staff)



"I went up to the hospital to visit my friend. There was somebody show us where the ward was."



"There isn't the support for people after they come out of hospital."

What We Found: Healthcare



“How can you be healthy and fit for work when the system is so bad?”



“All this is about health. And you just have to look at the news to see how bad things are in the NHS.”



“Look at what’s going on in the NHS, people are dying on trolleys waiting for beds. Healthcare for people with learning disabilities – it’s all part of being employed - but it’s not working for people.”



“I keep having appointments cancelled at the last minute. People aren’t getting the support they need.”



“At the moment the NHS has gone tits up.”

What We Found: Job Clubs and DEAs



We spoke to people about the government's plans for Job Centres, Work Coaches, Job Clubs and DEAs (Disability Employment Advisors).



We found that very few people knew anything about these services or have never used them.



In one of the focus groups, 11 of 14 adults with learning disabilities had never been to a Job Centre and don't know where their local Job Centre is.



Most of the people we spoke to who have paid jobs or voluntary work placements found them, and get support from, specialist services like Riverside Employment Training.



"Finding out about jobs – I'd find it very difficult without good support."

What We Found: Job Clubs and DEAs



“There needs be more of them. It doesn't seem to be enough. What about people who have to travel long distances to get to them?”
(Support Staff)



“The problem is there's not many job centres – not central. Mine is miles and miles away.”



We spoke to people about the government's plans for Work Coaches to help disabled people to find and keep work.



Only a few people had ever heard of Job/Work Coaches but some people do get help from support staff in specialist learning disability services.



“A Work Coach is there to support people. Someone who understands you.”

What We Found: Job Clubs and DEAs



We asked people about the government's plan to have 71 new Job Clubs for disabled people.



"71 Job clubs? That's a good idea. Bt where? And is that the whole country?"



"Run by disabled people? That's good. They can help other people because they understand about disabilities."



Who's going support people with learning disabilities to get involved?"



"But where are they going to be? Do people with learning disabilities know about them? How do they find out?"

What We Found: Job Clubs and DEAs



We spoke to people about the government's plans to employ 300 new DEAs (Disability Employment Advisors).



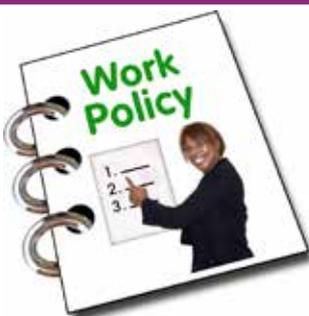
Only one person with a learning disability who spoke to us knew what a DEA is.



"I've worked with some DEAs in the past. They were a waste of space."



"They don't understand about [how to work with and support] people with learning disabilities."



"They're advisers but they just go by what's on their paperwork, not what personalised support you need."

What We Found: Job Clubs and DEAs



Other people shared their thoughts about about the plans to employ 300 new DEAs (Disability Employment Advisors).



“Do they work with people with a disability – who needs support with a job, needs a help along?”



“300 in the whole of the UK? Not much is it?” **(Support Staff)**



“It isn't a lot when you think about how much time they might need to spend with people and how many people need help.” **(Support Staff)**



“Where's the funding come from for all this? How long will it last?”

What We Found: Services helping people at work



We spoke to people about 3 different services that support people to find, keep or get back to work after an illness.



We asked people what they knew about, or thought of:

- Occupational Health Services
- Vocational Rehabilitation Services.



We also asked people about the Specialist Employability Support Programme which the government are planning to end in 2018.



Most of the people we spoke to had never heard of any of these services.



“They basically all sound really similar to each other. I think they’ll just end up scrapping these like they are with everything else.”

What We Found: Services helping people at work



Comments on Occupational Health Services and Vocational Rehabilitation Services...



“Yeah, I’ve heard of them but can you get appointments? And how long will they be around? Where’s the budget for them? All these cuts to services, especially in health.”



“Yes, they should work together like the government says. What happens if they don’t work together? What happens then?”



“Work together? They just pass the buck from one service to another.” **(Support Staff)**



“People might have had these services as part of a care package but it’s not been explained to them.”
(Support Staff)

What We Found: Services helping people at work



Comments on the Specialist Employability Support Programme...



“The what? I have no idea what that is. If this is already there, how come nobody’s heard of it? I’ve never seen any information about it.”



“There’s no use having it. If people don’t know about it - 2018, that’s next year. It’s not far off. I don’t think it’ll be missed if nobody’s ever heard of it.”



“So in 2018 that’ll finish will it? How are they [the government] telling people that?” **(Support Staff)**

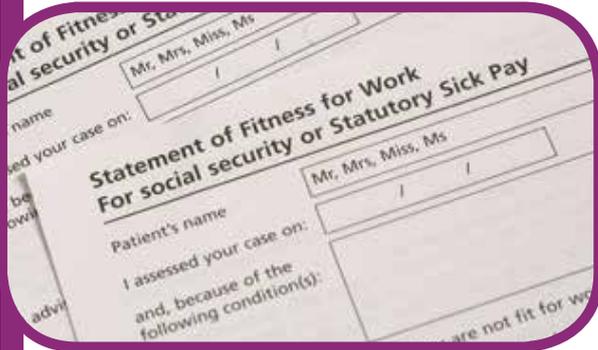


“They should keep it on for people who need support with working but they need to advertise it better as well.”

What We Found: Fit Notes



We spoke to people about the government's plans to change how **Fit Notes** work.



"I don't know what that is. I know about a sick note. It says how many days you're off and when you're fit to go back to work."



"I bet it's easier said than done. It might take ages for people get back to work. It sounds helpful but it depends how sick the person is."



"Will employers really wait for people to be fully fit and able to come back to work?"
(Support Staff)



"Medical records and fit notes can show an employer what you're capable of and what you can do."

What We Found: Fit Notes



“That’s a good idea, take your time to get back to work. Do it properly.”



“That’s a good idea. Somebody at the hospital doing it [signing a Fit Note]. Not just your GP.”



[Whoever signs the Fit Note] They should listen to you. If you’re able to go back to work and if you can do full time. You might need start again part time, build up to it.”



“And also it depends if they can put any of that [in the Fit Note] into place. If it’s practical.” **(Support Staff)**



“It shouldn’t just be health professionals. What about your social workers? Other professionals who know all about you, about your support that you need.”

What We Found: Not Trusting the Government



Some of the people we spoke to said they didn't trust the government to do things properly, or to do what they say they are going to.



Other people said they didn't trust the system for assessing (checking) if people are fit for work and giving them support.



"Sometimes I feel like they're forcing it on people even when they can't [work]."



"In my experience people are exploited and taken advantage of. They're entitled to get a wage but they're just used in voluntary placements."
(Support Staff)



"I think the government should do more because they're not doing much to help people."

What We Found: Not Trusting the Government



“If people are working four days a week then they’ve proved they can do a job and they should get paid for it by companies.” **(Support Staff)**



“The government say they’re collecting all this information but they’re not going get all the figures correct are they?”



“What about peoples’ personal information? Will they be able keep it safe?”



“They like keeping secrets from you, the government do.”



“People can be exploited or treated badly [because] when they go for assessments the assessors just don’t have the expertise to make judgements about people.” **(Support Staff)**

What We Found: Not Trusting the Government



"Sometimes the government, they'll say one thing and then do another."



"Who's going to be assessing whether people can work? How qualified are they to do that?" **(Support Staff)**



"Who's suitable for working? Some people can't work. Will they be getting pressured to do things they can't?" **(Support Staff)**



"I think this consultation is a waste of time. Not enough people know about it."



"I think they're just hoping get people off whatever benefits they're on."

What We Found: Spending Cuts and Benefits



People told us they were worried about spending cuts and changes to benefits. Other people said the benefits system doesn't work properly.



"Government are having to save all this money, cutting services. How are they going to put money into this?"



"There's something wrong with the benefits system. Doesn't always encourage people to work." **(Support Staff)**



"Lots and lots of benefit changes. I think it's wrong. All these benefits changes. It's confusing for people."



It's a good idea get more disabled people in work. Some people aren't really disabled but are on benefits anyway.

What We Found: Services Working Together



The government want health, social care and employment services to work together to help disabled people find, get and stay in work.



We asked people for their thoughts on whether services work well together now and what they think will happen in the future.



“Services working together, some do, yes. But not all.”



“That does NOT happen with health and social care services, not now. No.”



“People [staff in different organisations] not getting on, not talking, relationship between services breaking down. Bad for people.”

What We Found: Services Working Together



“Services working together, that just doesn’t happen.”



“They would [work together] if they communicated better but they don’t. Communication, I think is the problem.” **(Support Staff)**



“Services don’t work together.”



“The multi-agency communication is important but you have to remember these are vulnerable people.” **(Support Staff)**



“Some social care services work together well.”



Reach would like to thank everybody who took part in this consultation.



Thanks to PHOTO SYMBOLS for the images in this report



You can telephone us on 01782 747872 or email us on reach@asist.co.uk