

Full Report

Quality Checking Government

People with learning disabilities, friends, allies
and families describe the impact of
Government policy on their lives

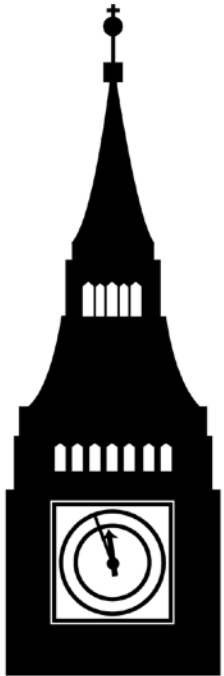


LDa

Learning
Disability
Alliance
England



Quality Checking Government



LDA England asked lots of people what they thought of the Government's treatment of people with learning disabilities. Most people thought the Government had done a very bad job.

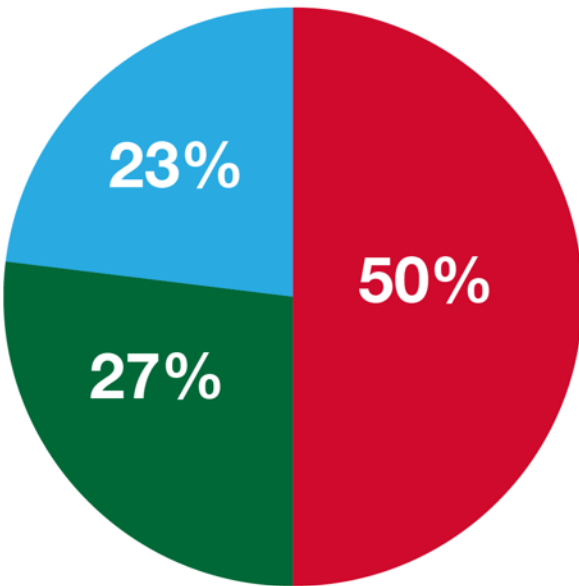
Quality Checking Government

2,000 people completed the survey to
Quality Check Government

50% were disabled people

27% were families

23% were allies or others



Quality Checking Government



We asked whether things were:

a lot better = 10 out of 10

a little better = 7.5 out of 10

the same = 5 out of 10

a little worse = 2.5 out of 10

a lot worse = 0 out of 10

Quality Checking Government

We asked people to compare
Government policies to
LDA's Manifesto for a Good Society.

To find out more about our manifesto

Go to: bit.ly/LDA-vision



Our Manifesto for a Good Society

The National Forum of People with Learning Disabilities and the National Valuing Families Forum set out our goal:

1. Human Rights

The right
to be
ourselves



2. Advocacy

Being
listened to
for real



3. Family Life

Being loved,
and able to
love others



4. Community

Being a
citizen who
is a real part
of life



5. Income

Decent income,
the chance to
save and earn



6. Education

High hopes,
help to learn
and grow



7. Work

Contribution,
value and a
fair reward



8. Home

A place of
our own,
with people
we love



9. Support

Respect
and help
to lead our
own life



10. Health

Equal access
to the best
care and
advice



11. Safety

Independence
and freedom
from fear



12. Justice

Fair treatment
and protection
by the Law



Quality Checking Government

This is the Government's score for:

Income & Taxes

69% said things were a lot worse

Work

65% said a lot worse

1
—
10

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The Government also got low marks for:

Rights - 65% said a lot worse

Advocacy - 63% said a lot worse

Family Life - 61% said a lot worse

Education - 52% said a lot worse

Home - 59% said a lot worse

Support - 67% said a lot worse

Justice - 51% said a lot worse

2
10

Quality Checking Government

The Government also got very poor scores for:

Health

46% said a lot worse

Safety

41% said a lot worse

Community life

52% said a lot worse

3
—
10

Quality Checking Government

The average of everybody's scores gave the Government
an overall score of:

2
10

This is a terrible score. It means people thought that overall the Government had made society worse for people with learning disabilities.

Full Scores - Part 1

TOPIC	A Lot Worse	A Little Worse	The Same	A Little Better	A Lot Better	Overall (Out of 10)
Rights	65%	14%	9%	8%	3%	2
Advocacy	63%	13%	11%	9%	4%	2
Family	61%	18%	12%	7%	2%	2
Community	52%	16%	13%	13%	5%	3
Income	69%	14%	11%	4%	2%	1

Full Scores - Part 2

TOPIC	A Lot Worse	A Little Worse	The Same	A Little Better	A Lot Better	Overall (Out of 10)
Education	52%	18%	19%	9%	3%	2
Work	65%	17%	12%	5%	1%	1
Home	59%	15%	15%	7%	4%	2
Support	67%	7%	14%	9%	4%	2
Healthcare	46%	18%	19%	13%	4%	3

Full Scores - Part 3

TOPIC	A Lot Worse	A Little Worse	The Same	A Little Better	A Lot Better	Overall (Out of 10)
Safety	41%	21%	21%	15%	3%	3
Justice	51%	15%	27%	6%	1%	2
OVERALL	58%	15%	15%	9%	3%	2

The overall score was achieved by averaging all the scores. The overall score **out of 10** is simply the average percentage expressed to the nearest whole number.

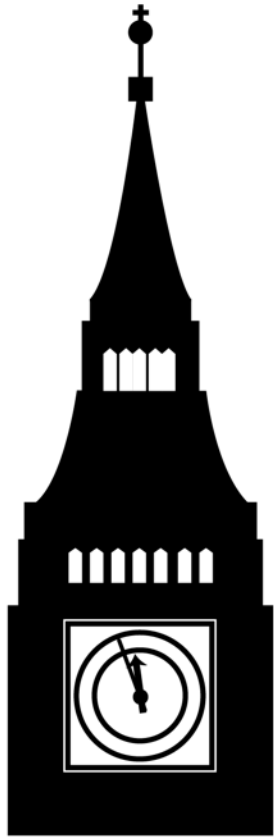
Quality Checking Government



If you want to find out more about the Government policies that are harming people with learning disabilities and their families go to:

bit.ly/wrong-list

Quality Checking Government



Many of those who completed the survey also shared stories or feelings about Government policy towards people with learning disabilities.

Below are just a few of these quotes, which reflect people's **real life experiences.**

1. Rights

“ We are sometimes scared of challenging the bad policies our county council has brought in because we think they will make things worse for us. ”

1. Rights

“ We are forever fighting, screaming, shouting and crying because we find it so hard to get equipment and support. We don't want medals, or to feather our own nests; we just need support so we can do our best to help our children be the best they can be. I want my child to be an active member of society not dependant on the state but to be able to give back and to support our economy. ”

1. Rights

“

I have been written off by this government as a burden. I am no longer a professional teacher who contributes, but someone who the government says is a leach on society. They didn't say that while collecting my taxes and contributions over the last 35 years.

”

1. Rights

“

I believe that the rights of all minority groups have been diminished by this Government.

”

1. Rights

“

A prime example of destroying our human rights is zero hours. How can anyone budget for all their living costs, when they have no idea how much money they will have coming into the household? This also causes stress and anger and depression. What kind of life is that?

”

1. Rights

“The unborn disabled have no human rights as they can be aborted almost up to the point of birth. This has not improved. Whilst the theory regarding the human rights of the disabled is good, the practice is being undermined by funding cuts year after year.”

1. Rights

“

I am concerned about the reduction in Legal Aid to prevent people being able to challenge inequalities. The benefit system is also very punitive to people with a learning disability.

”

2. Advocacy

“

There were a lot of advocacy services available and now the majority are having their funding cut or being replaced by sub-standard organisations who are 'cheaper'.

”

2. Advocacy

“

We work hard on consultations from the county council and health services but they usually ignore what we have said so it doesn't make any difference. Now we have to keep applying for funding from different charities which wastes a lot of time and means we can't plan ahead and help our members as well as we should.

”

2. Advocacy

“

We used to have money through Valuing People so we could support each other really well. We are scared of our groups closing as some of us don't have any other support.

”

2. Advocacy

“

We don't feel that existing advocacy provision is able to address everyone's issues. Advocates don't always have adequate understanding of mental capacity.

”

2. Advocacy

“ We are having the opportunity to speak, but we don't feel we are listened to. ”

2. Advocacy

“ I'd like to know where the advocacy services are for people who have complex learning disabilities or no ordinary means of communication. We have always advocated for our son and he has a small team of supporters who now have the confidence to take over our role. Others are not so lucky. ”

2. Advocacy

“ Case advocacy is working well,
but there are not enough staff.
Our self advocacy group is
working well but we are unsure
about future funding.

”

3. Family

“ Families will only be able to cope if they are at least supported by the minimum help and services. Cutting groups, services and respite will only lead to crisis within families and end up costing a lot more money.

”

3. Family

“

My husband tried to kill himself and did irreparable harm to himself. He died five months later, leaving me a widow and a mother working full time, myself suffering from health problems on my own. It is nice to know that if I have to finish work to look after my son, I will get paid less than someone on job seekers or who has never worked in their lives.

”

3. Family

“ Some of us have to live at home with elderly parents because we can't get help to move out. It is very bad for us and it is bad for our parents. One member said: 'These are terrible times.' ”

3. Family

“ I am my husband's carer, which really means my life doesn't matter and the stress just gets worse. I never sleep, I am ageing way before my time. I have lost all friends, I am very depressed. I can see no future in front of me. If anything happens to my husband I won't even have enough money to survive, and I have to hide all this stress from my husband - any stress to him just causes his condition to become much worse. ”

3. Family

“

Cuts mean families are more likely to end up in a crisis rather than prevent a crisis.

We would have expected a lot more understanding from a PM with first hand personal experience in these matters.

”

3. Family

“

I had my kids taken from me
because I have a learning
disability. No one explained why.

”



3. Family

“

Families have less and less say in what happens to their disabled family members. Decisions are made by the councils depending on what funding is available.

”

3. Family

“

The local Learning Disability team will now only support people in emergencies. Their budget has been so drastically cut, they can't do anything else.

”

3. Family

“

Families are under pressure as individuals - meaning they're working harder whilst services are either not fit for purpose or aren't there.

”



4. Community

“

Because people are having their budgets cut this means it is more difficult for them to access community life.

”

4. Community

“

More prejudice around as people with learning disabilities are seen as burdens and scroungers whose welfare should be cut.

”

4. Community

“

My daughter would love to access her local park but is unable to because there is no play equipment that is suitable. This would make a massive difference to a 6 year old that is already getting the picture that having a disability means you don't matter.

”

4. Community

“Until people with learning disabilities are included in all aspects of schooling, socialising, education and employment then they will not be accepted into society.”

4. Community

“ We feel more threatened when we are out in our community now. Two of us have been robbed in the last year. There are fewer things for us to do so sometimes we just have to wander around because that is all there is to do. ”

4. Community

“

Lack of staffing has meant less opportunity to go out into the community. Less person centred activities, instead when residents go out they have to go in a group due to staffing constraints.

”

4. Community

“

It depends very much on
the area you live in.

”



4. Community

“

Government cuts have led to hardship, hunger and distress - and in many cases, suicide. Adult Social Care is wrecked with many people left prisoners in their own homes.

”

5. Income

“ As for the assessments, my sister was 'assessed' by someone who had never even met her. Not one of her doctors, support workers, family members or anyone who knew her were consulted. ”

5. Income

“

Having to choose between heating or food or paying the rent used to be shocking, a real horror story in terms of quality of life. Now it's just a commonplace, everyday fact of life.

”

5. Income

“ The Government has no idea about the daily struggles that we endure on very, very limited money. Hardship, exclusion, discrimination, no one understands or cares; they simply see people with disabilities as a drain on society. ”

5. Income

“

I personally had to run my rented home on £71 per week for 2 years while I waited for an appeal. I had all my bills to pay: gas, electric, water, TV licence, phone, not forgetting the bedroom tax plus food, which my children provided. It is impossible.

”

5. Income

“ I believe that assessments for benefits should be carried out by properly trained people. Far too often the person assessing you does not understand the disability that you suffer from, and how it will effect you on a day to day basis. ”

6. Education

“ My son currently goes to a special needs school that is supposedly fit for my son's needs. Yet they have said they cannot cope with or support my son and his needs and they admit to making great errors with my son and his needs and education... When we complained about how our son is being treated to the local education authority we were told there's nothing we or they can do. I pointed out the law re schooling to be told that basically "tough" there is nothing you can do even though the law states children must attend school and follow the curriculum. It seems we and our son have no rights at all for him to get a just and fair education even though he has a statement of special needs!... Another son of mine was also turned away from our local college because of his disabilities. He was heart-broken and gave up. ”

6. Education

“ Inclusion was supposed to be the way forward but this Government has severely let a whole generation of children down by continuing to send them to special schools instead of properly supporting mainstream schools towards integration. There are also too few opportunities for appropriate mainstream college courses. ”

6. Education

“ Many of my colleagues with learning disabilities have been excluded from college courses against their wishes. One man was offered litter picking in the local park as a substitute for his literacy course.

”

6. Education

“

There is not enough forward planning of services for young people in transition. There are fewer NTAs in schools to support people. We still have segregated 'special' schools.

There needs to be more choice in education. Local authorities need to meet their financial responsibilities to meet children's care and support needs in schools.

Transport to FE is a problem. Accreditation is restrictive and limits the potential of people with high support needs.

”

6. Education

“ My learning disabled son left mainstream secondary school with a clutch of GCSEs & BTEC level 2 passes in 5 subject areas. Not a single FE college would offer him a place on the level 2 course of his choice (Performing Arts). His school refused him a place in 6th Form despite the fact that his GCSE results met their entry requirements - they redefined the entry requirements in order to justify their decision. He spent year 12 on a Foundation Learning course along with around 40 other learners. He was better qualified than all of them. One college told us when justifying their refusal, "His results are great - you must be so proud. But they don't count: he has Down Syndrome.”

6. Education

“

People should remember that just because you have a learning disability this does not mean that you are not capable of doing great things.

”



6. Education

“

I haven't heard anything but complaints about the new EHCPs. Families are having to resort to legal help to ensure their relation receives appropriate education and this is if they have the energy, know-how and funds. The right to an appropriate education should not be a battleground.

”

6. Education

“

SEND reforms are a total mess - introduced too early and not thought through - and again impacted too much on school budgets rather than the needs of the child. Post 16 provision is patchy and poor nationwide. Once a child has left school, they can only continue to get statutory support if they go to a sixth form. This is not always the right option, they often need more vocational courses at colleges or other training providers - but they then lose all entitlement to support.

”

7. Work

“

The Government has only one objective and that is to reduce benefits payable and to reduce the number of claimants. They are not worried about how or who it affects.

”

7. Work

“

My son is desperate to do some work to feel valued. He has a lot to offer but we have tried every avenue and he is at risk of losing his benefit and could be made homeless.

”

7. Work

“ As an organisation that supports people with learning disabilities or autism we took the decision to employ people from these groups. We try to lead by example but find we are still a lone voice. ”

7. Work

“

The reality is that large companies are happy to let clients do 12 week work placements for nothing, but very few offer a few paid hours at the end of it. Most people end up volunteering in charity shops for years.

”

7. Work

“

The whole system needs to change to take account of people with disabilities. If someone wants to work more than 16 hours but not full time this can cause difficulties with benefits.

”

7. Work

“

Our group agreed that it is harder for people with learning disabilities to get a job. No members are currently in paid employment. More support is needed to access work and all employers should have a duty to employ a diverse group of people regardless of disability.

”

7. Work

“

Not many employers are prepared to offer any kind of work due to the commitment that is needed to ensure that the premises are suitable for the needs of everyone. Specially adapted work stations, toilets, access and parking are all considered negatively.

”

8. Home

“

I have a bedroom tax
of £34 per week.

”



8. Home

“ To reduce costs, services (in my experience an inner city LA) are openly stating that they are securing larger housing for learning disabled individuals. This demonstrates a very worrying return towards institutional life for learning disabled people. Supported tenancies are being run more like mini institutions.

”

8. Home

“

A lot of people with disabilities have no choice over where they live. They live where the funding body decides they go. I have seen friends with disabilities being moved to a different shared flat because that was 'cheaper'.

”

8. Home

“

The loss of the Independent Living Fund is clearly going to destroy any idea of disabled people being able to have their own home.

”

8. Home

“

Being a disabled person it is hard to actually get a house that is suitable for me and some landlords don't like disabled people living in their properties because they think they won't be able to pay their own way.

”

8. Home

“

Supported housing is in desperately short supply; often miles away from families. Those who choose to live with families but who need live-in carers are financially penalised by the bedroom tax.

”

8. Home

“

Even if we get to live where we want to, we then do not get the support we need to make sure we keep well and stay healthy.

”



8. Home

“

People with learning difficulties can't get mortgages any more. If you won't go where the local authority want you to, your capacity will be questioned. Accommodation and support are still too often tied together. Nominations Panels decide where people live, all you can do is turn it down - it's not a real choice.

”

9. Support

“

Cuts have made
support a pipe
dream.

”

9. Support

“

Support staff often have little time to spend supporting people, so quality of care suffers. Support staff are paid very poorly for the work they do. In residential care, paper work seems to be more important than personal care. This has increased hugely in the last 5 years.

”

9. Support

“

People with learning difficulties struggle to access personal budgets or direct payments. They get the care they are seen to need not the care they want. Lots of money is spent paying agency carers who do relatively little. They play on their phone or even fall asleep. Carers are often patronising and lack empathy.

”

9. Support

“

Self-directed support seems to be going out of the window. Decisions are not person centred any more, they are money driven. This is how bad decisions are made and they are not cost effective in the long run if a crisis occurs. Winterbourne still looms.

”

9. Support

“Cuts to local authorities have had a dramatic effect on the access to support for families needing social care.”

9. Support

“ My son is being charged £47 per week for his social care. In 21 years of my son's life we've only had support from social services since he was 17, and that support is extremely limited.

”

9. Support

“

Social Workers are run off their feet by the effects of the cuts. Support is not joined up - my GP didn't know we got home care. Home visits are regimented into 10 minutes where we have to choose between eating or washing.

”

9. Support

“

I could write a book! There is such a mismatch between the rhetoric and the reality! Though some people have benefited and this is usually because they have great families to support them to get the best from the system.

”

10. Health

“

The learning disability nurse at our local hospital is brilliant. She can explain what may happen, provide reassurance and answer questions. However, there is only one of her.

”

10. Health

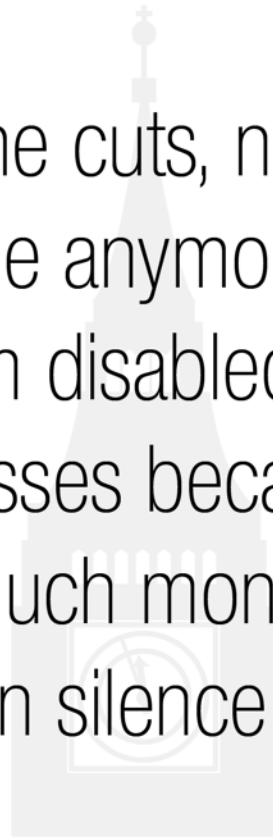
“ Post 18 it seems that care and health support decreases dramatically. ”

10. Health

“

Because of all the cuts, nobody has the time or patience for me anymore, I'm too scared to mention that I'm disabled or talk about any added illnesses because I cost the taxpayer too much money as it is, I would rather suffer in silence than be judged.

”



10. Health

“ I had no idea that my autistic son should be getting an annual health check! Who knows this stuff? No-one tells you anything and busy GPs with five minute appointment slots don't exactly go out of their way to inform you of anything, assuming they know in the first place. ”

10. Health

“ Support for people to attend medical appointments is being withdrawn. Some GP practice's are stopping Annual Health Checks in spite of the evidence that properly done Health Checks save lives. ”

10. Health

“

Unless you can evidence the help or services your child or young person needs, you will definitely not get it. I learned to shout very loud a long time ago.

”

10. Health

“

My daughter is a Mental Health Nurse in the NHS and has told me some really horrific stories about the scandalous shortage of nurses, facilities and available beds.

”

10. Health

“ Doctors don't make the time to understand, it is hard to get an appointment and some people need support to go and don't get it. ”

11. Safety

“

Far more devastating cuts to the Police Services, the CPS, Courts, Probation and Prisons are due in the next financial year. You think it's bad now!

”

11. Safety

“

The demonisation of benefits claimants in the media is inevitably going to make hate crime worse.

”



11. Safety

“ We do not feel safe going out by ourselves - especially at night. ”

11. Safety

“

We don't see police around in the streets any more. Some police understand how to work with us but some of them don't and they make us feel frightened.

”



11. Safety

“

People with learning disabilities in our town have worked with the local police to help them work with people in a more appropriate way. They feel a bit less threatened about having contact with the police now.

”

11. Safety

“ My husband is in a wheelchair, I am visually impaired, my grandson has autism. The public seem to form their opinions via the media who echo the Government's attitude that every one on any benefit is a scrounger and this has left us, in our locality, being openly treated with derision and bullying behaviour. Surely we have the right to be as socially included as more 'able' people? ”

11. Safety

“

Society has been encouraged to stigmatise the disabled; the level of violence and hate is out of control. I blame the Government for this.

”

12. Justice

“

Cuts in Legal Aid make it incredibly difficult to challenge benefit decisions. This is an incredibly cynical move from a government which has massively cut benefits.

”

12. Justice

“

The cut backs in Legal Aid will impact on how disabled people obtain it. I am worried about the bullying of people with a disability and the police not acting to stop it, because of cut backs in their resources.

”

12. Justice

“

The use of advocates is still frowned upon by the legal profession and the judiciary. Information is not always available in an accessible format and there is no-one available within the court system to either take the time or who have the skills necessary to undertake this function. There is still too little trust about the reliability of people with learning disabilities as witnesses.

”

12. Justice

“

Getting Legal Aid is a joke. Even when you do get legal aid the restrictions on the solicitors as to what they can do means that there is no help - just endless stress which ends in no resolution. You can't have a judicial review now on legal aid so what's the point of going to a solicitor?

”

12. Justice

“

We have been denied representation in tribunals! We have no knowledge of the law, we are in pain and confused and intimidated in a court room, where we beg and plead for money! How fair is this?

”

12. Justice

“

The lack of legal support available effectively means that justice is only available for the very rich. I am very worried about the erosion of judicial review as a way of challenging poor public decision making.

”

12. Justice

“ The absence of a support network and the ignorance of the Police suggests to me that the rest of the justice system will play out to the negative perception of disabled people propagated by this Government.

”

Conclusion



Government is **not working**
for people with learning disabilities
and their families.

So LDA England will keep building
the widest and strongest alliance
possible to **defend our rights**.

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