

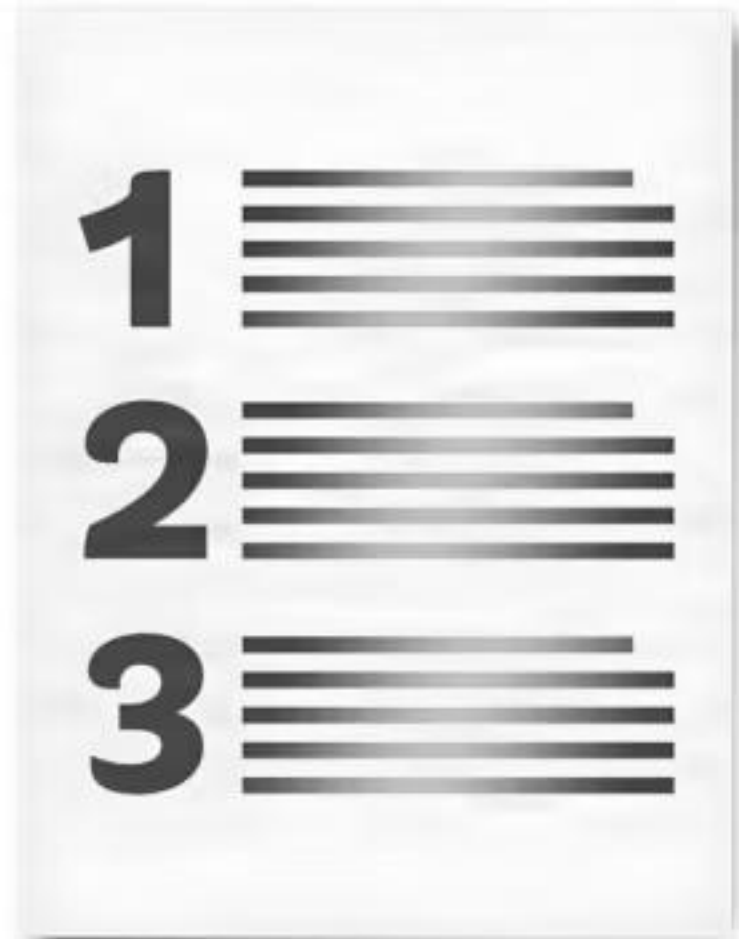
The Casey Commission's Big Conversation



Members Network Meeting



The Casey Commission



- The Casey Commission is looking at how we make social care work for everyone.
- The Prime Minister asked Baroness Casey to finish her work earlier and share their final report in the summer next year.
- Casey has already shared some ideas and the government have started working on them

The Big Conversation



When we are old or disabled, or have a serious illness, who should support us and how?

The Big Conversation



- This is stage 1 of 3
- They are collecting ideas from the public
- They will be putting a citizen panel together to think about the ideas

Getting Involved



- LDE have some seats to help certain people take part:
 - People who have recently been through transition and families
 - People with profound and multiple learning disabilities and families
 - People with severe learning disabilities whose behaviour may be described as challenging, and their families
- We are collecting people's stories
- Have a go on Make.Org



Getting Involved



LDE have written to:

- Yvette Cooper, The Health and Social Care Minister
 - Sarah McLinton, The Chief Social Worker
 - the Casey Commission and Ipsos who are leading the Big Conversation
-
- We are waiting to hear about some new ways to get involved



When we are old or disabled, or have a serious illness, who should support us and how?

We should ...

10 / 140

Read our [moderation charter](#) and our [terms of use](#)

SUBMIT

 You must be logged in to submit a proposal.



Tracey, 65 We should end the system whereby someone's spent all their money on care home fees, then they have to contribute towards them (top-ups). 1 Sep 2026	Sid, 74 We should allow people with assets to pay a chunky lump sum now to avoid the risk of having to pay much much more for care later. 1 Sep 2026
Trina, 62 We should provide a minimum of annual home visit health, lifestyle and mobility checks to all people over a certain age, maybe 80.	Clare, 51 We should have a team of health and social care workers who can support us holistically.

When we are old or disabled, or have a serious illness, who should support us and how?

 Popular proposals

Jennifer, 77

We should have a National Care Service free at point of need and this should also include palliative care and end of life care.



74 votes

Favourite

Obvious

Realistic

NEXT PROPOSAL

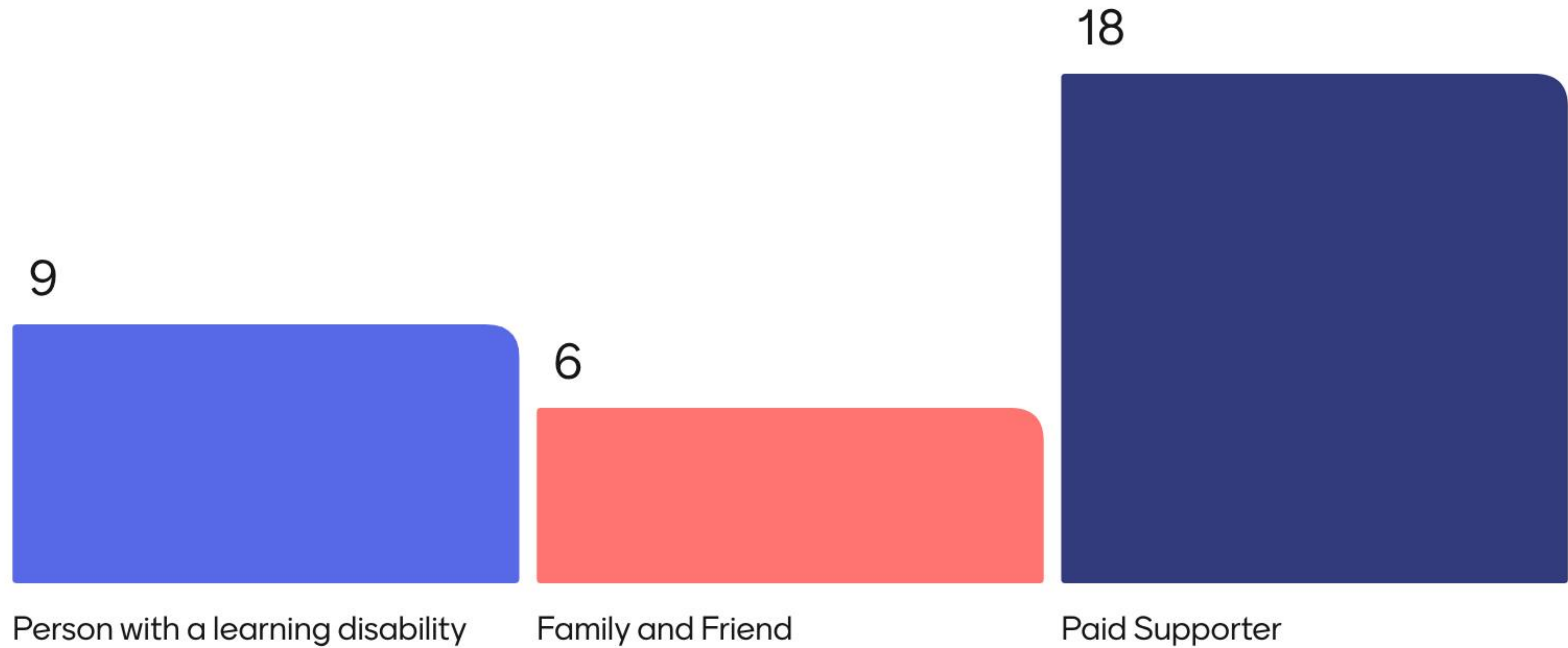


The Big Conversation



Who should support people with learning disabilities and how?

Tell us what kind of member you are?



Brain Dump!



**What are the big things that
stop support from working
well?**

What are the big things that stop support from working well?



Think about...

What are easy changes we can make to make things better?



Think about:

- Things that are obvious
- Things that could be done quickly

What are easy changes we can make to make things better?

tackle reasonable adjustments

trust that people know themselves best and allow them to make decisions about how to use their budgets

social care free like the NHS but that is not a quick fix

NHS and social care should work together better

Have the same social worker for life - since Covid 19 had 6 or 8 different social workers and changing disrupted things a lot. I'd get used to one person and someone else would take over

lots of organisations need to do better from housing to job centres

respite care, amount needed linked to DLA. Stopping people getting multiple assessments. Can system speak to each other to stop reassessment

hard to find local help that can be accessed by phone or come to your house

What are easy changes we can make to make things better?

Focus on consistency of support workers - High turnover is really difficult, inconsistency of support means repeating things, worrying things will get lost, starting with new support relationships

Communication between organisations

Trust the people and families to use self-directed support, people aren't trying to cheat the system

regulation of private providers who are making big salaries when frontline are making minimum.
Private equity too!

ICBs work together to
commission services
that work for everyone

Consistency and trust in support - getting to know people and trusting them is made harder when there's a high turnover rate. Longer term fixes is recruitment and retention but must be easier fixes

Really truly co-producing support with people and their families, with clear outcomes.

Being clear what funded support looks like



What are easy changes we can make to make things better?

support people to manage their budgets - having a budget is like running a small business but no one gives help for this

more information

More flexibility in support, beyond "basic needs"

Listening to what people want their support to look like.

Listening to families

'Kent Card' to manage direct payment didn't work, you had to go back to ask for money. Direct Payments should put people in control

make sure people who make decisions understand the care act law and stick to it!

Flexibility in support and teams, so they can be empowered beyond compliance and to find the joy in life

What are easy changes we can make to make things better?

Staff feel limited when there's no real reason

time based support planning should be ended - budgets should be based on needs not hours The care act needs to be properly funded so that it can be implemented properly and councils held to account

light touch or self directed reviews when things are going well

More accountability

nationally agreed social care strategy that follows the care act that people have to stick to

Bring back local housing associations

Accessible information - to understand SC and to communicate with social workers

More information and support to understand how social care and other systems work so people can learn themselves and know what standards to hold professionals to

What are easy changes we can make to make things better?

better monitoring of social care services

Put people first before profit

listen to families if they say it isn't working - full partners in care

Respect people may struggle with trust, having strangers entering their home, change, and other potentially traumatic events

People having choice of who supports them

Listen to people drawing on social care and their families

health and social care need to work together. a shared pot of money not competing over the same money

nationally accredited training for care and support workers - different levels where people can climb when they gain more skills

What are easy changes we can make to make things better?

Better identify where people need support to have a better life instead of relying on potentially outdated support plans and notes

Have clear measurable outcomes for people

I can't find where to raise my hand! But I agree with Hannah and think there should be joint foundation training for nursing and social care workers.

better joined up working health and social care

Focus on inclusion

people with 'complex needs' don't fit into boxes

Training for Family Carers/advocating friends

better support during transition to adulthood

What are easy changes we can make to make things better?

Creating community inclusion from primary school (not from 18+/post education)

have a check in system instead of waiting until things reach crisis

people shouldn't be labeled, we are all equals

Have a central point for information, e.g. what you're entitled to.

Person Centred planning training & culture (rolling).

make sure that lived experience is always involved in developing policy strategy services and monitoring including commissioning and reviews

Systemic capturing (positive) of a person's history that travels with them and develops, after leaving the family home.

Commissioned services requiring additional asks - e.g. void payments, social values, office requirements removing the focus on spending on people and innovation

What are easy changes we can make to make things better?

real clarity on the care act,
everyone working to the
same standads.

Lack of proactive and
preventative support - usually
provided from organisations.
Their funds are tighter and
therefore forcing
transformation programmes

National standads for
commissioning

Those in charge understand
how values translate into care,
sometimes frontline staff are
the ones best practicing of the
values we want to see in care

Everyone should know what
their rights are in health and
social care

Lack of choice - being
influenced into one
option

KNowing what you can
expect

Consistent annual reviews that
have action plans at the end of
it - we recently took part in a
research that showed action
plans should be given but
Leanne has not heard of these

What are easy changes we can make to make things better?

Advocates to know people better, including communication

Accountability to ensure provision to meet people's needs

make sure that everyone can be included and the conversation is accessible, people with lived experience at the centre

Boundries of ICBs and LA, should be the same

Professionals being accountable

Also they should have SMS text and easy read and not just use jargon

Transition staff in schools to ensure smooth access to adult services. So many parents I meet do not know that there is no easy access to physio, SALT, etc.....

Values based recruitment

What are easy changes we can make to make things better?

Focus on inclusion

Properly raise the status of both social work and support work. This would also help give more jobs for young people that can't be replaced by ai

Training for Family carers

make a community inclusion thread from primary school (not post 18+)

Make sure the review doesn't mainly focus on older people. Young people with a learning disability need different support

Person centred planning training & culture (rolling)

Digital systems that cross supports, reducing repeated assessments and improve inter-agency collaboration

Make feedback easier and less intimidating than complaining

What are easy changes we can make to make things better?

Value based recruitment

stop putting people in boxes

I think young people are beginning to recognise that social work is a job that cant be replaced by AI. The government investing in social work and social care could help with the youth jobs crisis

An initiative to promote work in social care as a career - with specialisms and a proper trade union type body to raise standards of work and also standards of care

Local Authority do not follow Acts of Parliament

Long-term sick leave is an issue with the ASC team in the area where we are, I can only imagine that the role is challenging in a way that means that such workers experience 'burn-out' - not an easy w

What are your Big Ideas?



How would things work in a perfect world?

Think about:

- What would your support look like if money wasn't a problem
- How would you start from scratch?



How would things work in a perfect world?

Social Care wouldn't be a postcode lottery and there would be much more consistency in local authority funding for it

You need management to be broad minded and not just think about making money and profit

Carers wellbeing needs to be prioritised, people shouldn't be pushed to breaking point. Prevention should be central

Forward thinking

Legal Protections: Codify non-discrimination protections across employment, education, housing, healthcare, and public accommodation.

doing more activities and having more freedom

Enforcement Mechanisms: Establish independent oversight bodies (e.g., human rights commissions, disability ombudsmen) with powers to investigate claims, penalize non-compliance, and enforce equal rights

professionals need to understand how to listen to family members, abuse by care workers needs to stop today, care workers need respect for people with learning disabilities,

How would things work in a perfect world?

focus on support for social connection is missing and wanted

International Standards Alignment: Ratify and align national laws with international frameworks like the UN Convention on the Rights of Persons with Disabilities (UNCPRD).

Stop listening to outdated advice and misinformation everywhere

- Better paid staff - No time restrictions on calls - Specialist equipment is funded by local authority or NHS - One portal for all information around one person - People can choose where they want to live

Have respect for everyone

pulling together who are in the support and care network and having them involved in your support

Systematic training scheme for support workers. Common foundation with nurses before branching off with additional training

care staff need training, so they can be held accountable for all their actions

How would things work in a perfect world?

Less exclusion

Professionalisation and professional body for support workers

having an OT, self advocate, discussing what I need and having people to understand how best to support me, so it is planned together and not separately

- People matching when offering places to residents - Those that control the purse strings need to see the person as not just writing on a piece of paper on a score sheet

Able to choose where you live and who supports you

Training to staff to work with people with learning disabilities and autistic people

paying more tax is not difficult to do when it means people and their families get good support and people and organisations are held accountable

Proper wages for staff

How would things work in a perfect world?

Keeping contact with friends and family throughout life (support for that gets lost with GDPR etc)

More accurate information provided during decision making, to form a clearer picture for all organisations

Digital systems across agencies talk to each other securely to reduce professional assessments and improve communication and support

Funded support is focused on quality of life and not just basics

Stop institutionalisation

Accessible information as standard - trained to use

Support for people with more complex needs to have meaningful daily activities - such as good support to have a self-employed business

designed so you don't have to fight - people need social care!

How would things work in a perfect world?

Training for families in advocacy and personalisation

services and systems should naturally work together

Find a way to include non-verbal people in communications to gather written evidence - accurately produced records and before any assessment know what you are being asked and why

Ensure that there are all forms of communication during assessments

focus on the person

Its not a 'fight'

People like my son wouldn't be trained to be compliant (by school etc) and be more able to self advocate

People need to listen more not just hear say , without evidence

How would things work in a perfect world?

There's be
accountability
throughout he whole
system

clear identified needs, not
about one size, but
catogories for budgets
(currencies)

Adult social care system
wouldn't have to undo what
has happened in education,
and education would be
preparing people for
adulthood

Support staff to take time to
get to know people, to
understand them and
understand limitations

Listen to people with
disabilities with lived
experiences as each one is
unique as individual people.

equal access to social
care

The whole family circle (not
just mum) would be able to
advocate for their person
and the system wouldn't be
so opaque

We need to play by the
same rules around the
country

How would things work in a perfect world?

eligibility shouldnt be so high - it should be fair . stop people falling through the gaps

There would be better understanding and skills to communicate with neurodiverse people and families

Oliver McGowen training - I don't see the value in level 1 it isn't very detailed; all staff should receive level 2. There is a lack of practical details to support people and understanding

There would be better communication between services, the person and their families/supporters

consistent standard of high quality support wherever you live - every citizen knows what is possible to support them to live their life

Suggestions: Look at Skills4Care training certificate has a break down of information that could be useful for what is missing from Oliver McGowen

Everyone would be able to quickly find and access the information and support they need. And get the right support from the right people at the right time

No-one would be denied mental health support

How would things work in a perfect world?

Funding - skilled and experienced people it wouldn't cost most. 4:1 could be reduced if people were skilled. Helps people be understood

Given choice of where to live, who supports them, why and how

Sensory Integration Training would be easily available and free to everyone

There is not aftercare or support after diagnosis - courses and support should be offered for this after diagnosis

There would be a solution to how people are diagnosed and the flags they need for reasonable adjustments - across systems

Quality of services should be really good

The same social worker, same support workers, additional funding for all social care, more choice, more decisions. My life. My voice

proper accountability for local authorities combined with actual funding to do their jobs

How would things work in a perfect world?

social workers
conducting
assessments

Deinstitutionalisation

More consistency including
jobcentres so we don't have
to repeat our stories.

Early help before
diagnosis

Life Skills

Lack of understanding. All
staff must be qualified with
photo id and high visibility
name badge. Verbal
message is unsafe

Keep in touch



- Thank you for coming today!
- Keep sharing your ideas and thoughts
- We will share updates as we find out new things about the work



Email: info@LDEngland.org.uk