SOCIAL FINANCE

Advocacy for people with learning disabilities and autistic people

An event held at the Houses of Parliament on 6th February 2025.

socialfinance.org.uk

Introduction

This is a summary of what was discussed and agreed at the launch event of the joint Social Finance and The Henry Smith Charity report, *Independent Advocacy for Independent Lives*. We've tried to include as many direct quotes as possible, but there wasn't room for everything!

At the end of the document, we've added some of the feedback we received from you after the event. Thank you so much for all the positive comments! However, if you think we could have improved anything, for example, you might have wanted people from NHS England or the Department of Health and Social Care to have been there, then please let us know.

Also, it would be useful it you could tell us what you would like to happen next, for example, do we need a campaign to push the report findings up the political agenda? If so, how do you think the 15 grantees and other interested organisations and charities work together on this? How should it be funded?

Please email one or all of us and we will continue to keep a record and re-share them with you.

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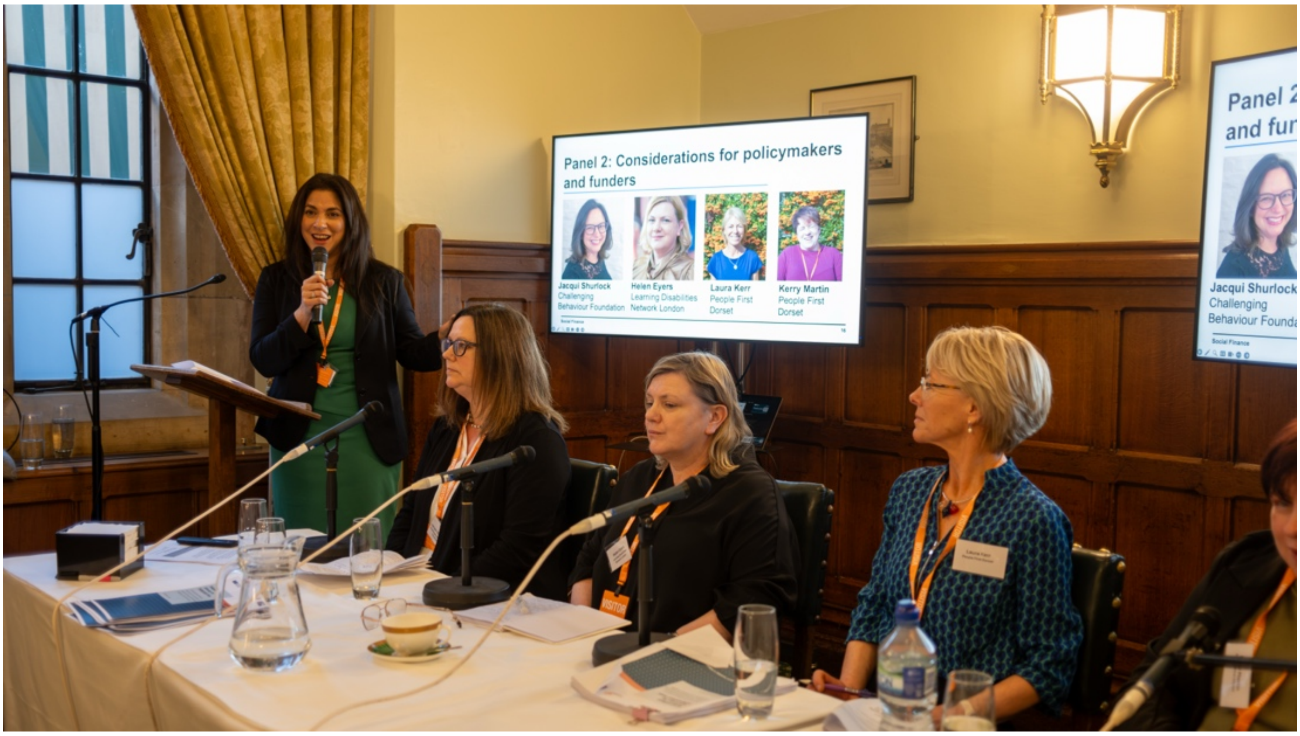
Thank you.

Nadine Smith, Executive Director Social Finance

In her opening remarks, Nadine said she wants to challenge the **“unacceptable narrative”** that people with learning disabilities and autistic people are too reliant on the integrated care system.



Nadine highlighted that education, health and care plans are reducing in number despite the number of people who might need them is projected to grow.

While pleased to see an emphasis on shifting care from hospital to community, she stressed the need for **“cross-governmental ownership and clear leadership”** for learning disabilities throughout government, the NHS and local authorities across the UK. She also said

“We need to put an end of course to the chronic funding and stability that means independent advocacy organisations face a constant battle to maintain the support they provide now, let alone rise to meet increasing future unknown demand.

“Without independent, non-statutory advocacy, people are less able to reach their goals through absolutely no fault of their own.

“We have broken new ground in being able to help the sector have the clear and usable evidence they need to grow independent advocacy across the UK, but this can only be achieved by deepening and expanding partnerships with local authorities and health organisations located alongside existing and now expanding.

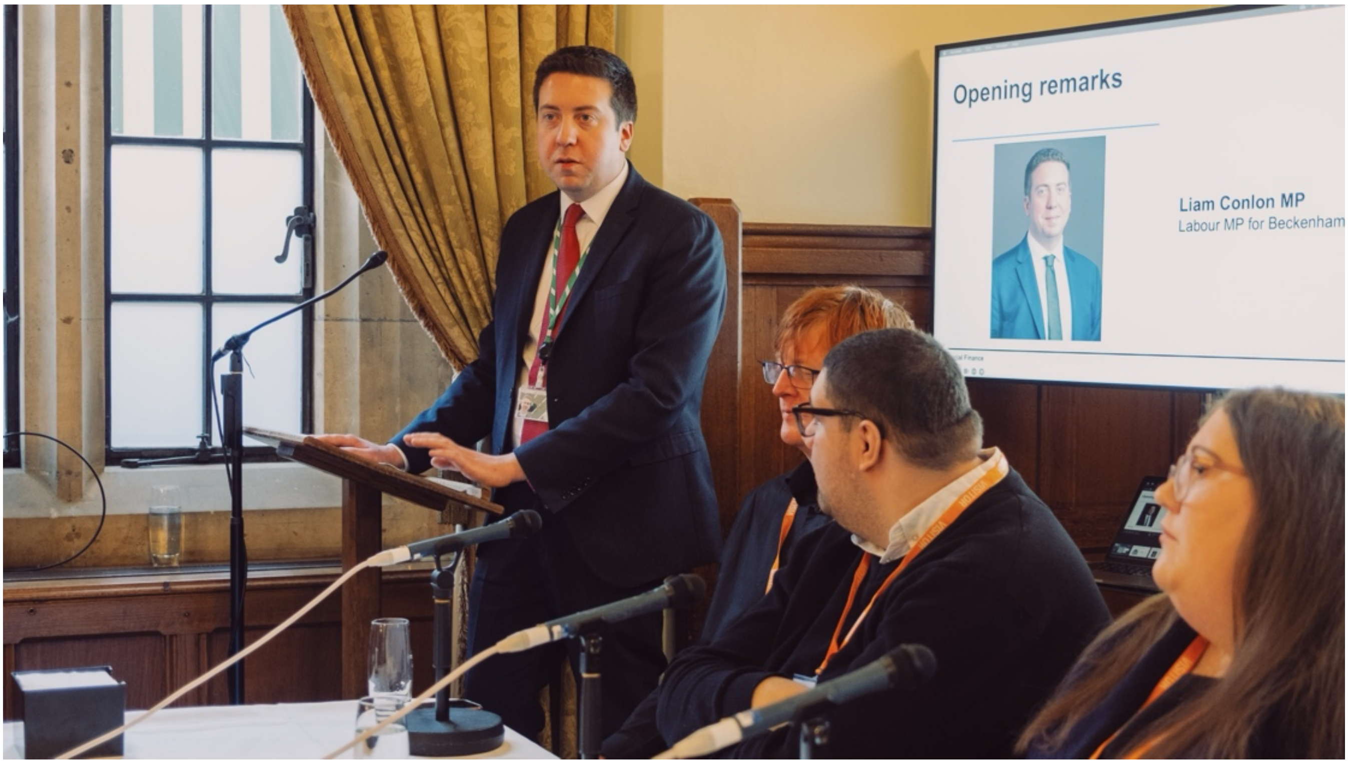
“Sadly, we know the support provided by 15 incredible grantee organisations participating in this programme only scratches the surface of the real demand across the UK.”

“We will take the recommendations at Social Finance into all the work we do with children and young people through our early inclusion collective, which looks at school transitions and childhood to adulthood.”

Nadine also said that Social Finance will incorporate the report’s findings into its work with local authorities and other partnerships.

Liam Conlon, MP for Beckenham and Penge – our event sponsor

Liam praised the work of Social Finance and The Henry Smith Charity, describing them as “fantastic advocates”. He promised to **“support in any way I can”,** including arranging follow-up meetings with the newly formed Disability Parliamentary Labour Party Group as well as with Stephen Timms, Minister of State for Social Security and Disability **“to define what we want to achieve together in the months and years ahead”.**



Liam explained that he is vice-chair of the first ever Disability Parliamentary Labour Party Group. He set this up in November 2024 with fellow vice-chair Katrin Murray, MP for Cumbernauld and Kirkintilloch, and co-chairs Marie Tidball, MP for Penistone and Stockbridge, and Olivia Blake, MP for Sheffield Hallam.

The PLP Group meets regularly with Stephen Timms, to challenge and overturn what Conlon says is government’s historically **“two-dimensional approach”** to the issues disabled people face.

He added: **“So often, government forgets the human-sized picture. And I think that's why the work that all of you are doing is so important because we know the system misses people. The question is: who should reform the system? The mantra of the disability rights movement is ‘nothing about us without us’. And that is important and powerful and true.**

“Only when organisations and everyone in this room here today steps up and makes their voices heard and empowers the voices of disabled people, will we ever see any progress.”

Liam, who has been disabled since 13 when an accident left him unable to walk for four years, said disability is **“the biggest driving force for me as an MP after my constituency, in terms of the things I want to change in this Parliament”.**

He wants to promote awareness of the **“inconsistent”** day-to-day experience of people with invisible disabilities.

“Different days and different environments can produce very different symptoms in a way that often very visible disabilities don't have. That's really misunderstood, particularly by the benefit system and by DWP and other agencies,” he said.

“The hurdles and the challenges that they often make people face are completely undignified often for the disabled person trying to access the most basic support. Constantly having to justify or explain your condition can cause huge stress and anxiety for those involved and for their families.”

Liam’s broader ambition is for this Parliament to provide **“the biggest step change for disabled people of any parliament”.** He adds: **“That only happens when disabled people put themselves forward and make their voices heard.**

“I don't think government and Whitehall had traditionally been set up to function in a way that can understand and then break down the many different barriers disabled people face, especially people with invisible disabilities, including learning disabilities.”

Liam highlighted that disabled people have not experienced the equivalent advances of those with other protective characteristics: **“If anything, the treatment disabled people experience by society has gone backwards.”**

William Jacks, Director of Research, Strategy and Engagement at The Henry Smith Charity

William outlined that the impetus for the report dates back to 2022, when he identified a low success rate for applications coming in from disability and autism charities.

“The consistent message came back to us about the impact of advocacy services, the need for the services, the lack of funding available and the need for more evidence to demonstrate the change,” he said.

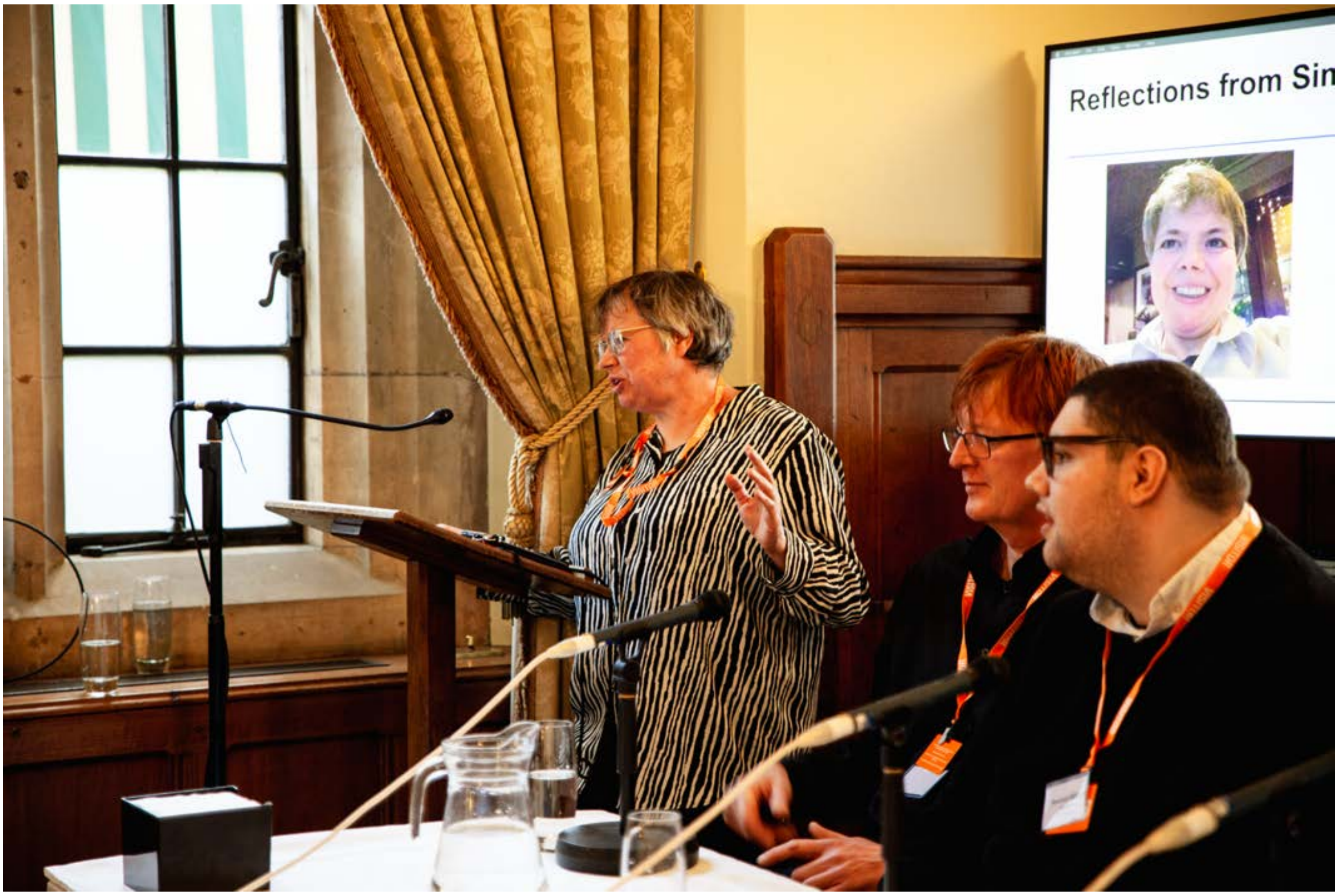
The charity has funded 15 organisations working in this area, and Jacks confirmed that it will continue to do so for at least another year. **“Empowering people and an approach focused on people's needs was really important.”**

Simone Aspis, Campaigner with lived experience and Director at Changing Perspectives

Simone has been campaigning for disability rights for more than 30 years and was on the advisory board of the HS Advocacy Fund.

She works for Inclusion London, which is campaigning against measures outlined in the Mental Health Bill that it says will keep people with autism and learning difficulties in psychiatric hospitals against their wishes.

Simone believes that in driving change, **“disabled people need to set the agenda”.**

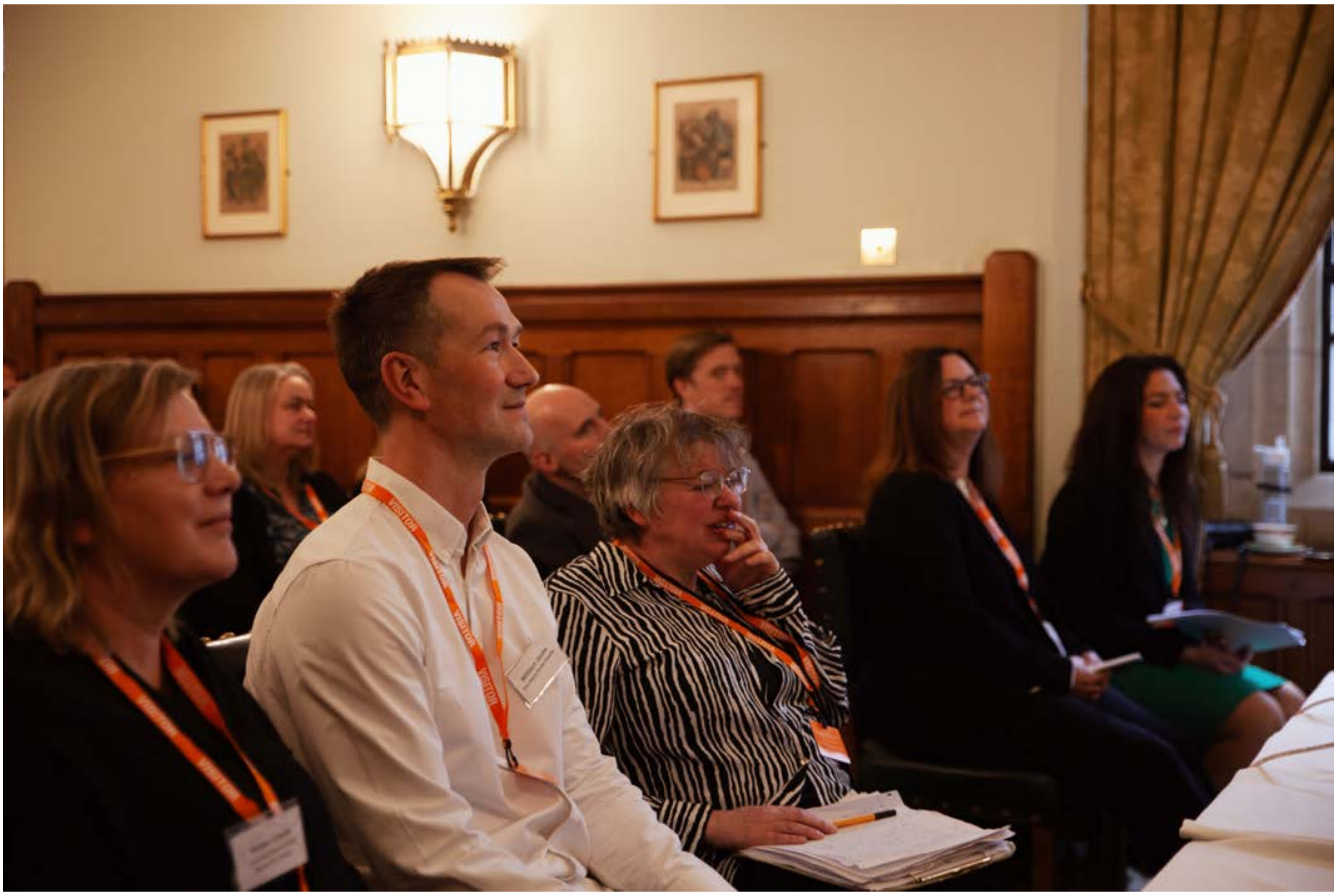


Standing by the mantra of **‘nothing about us without us’**, she called for a joined-up approach between local and national disability action groups, which she says would demonstrate the power of self-advocacy and lead to genuine change.

This needs time and commitment, Simone said.

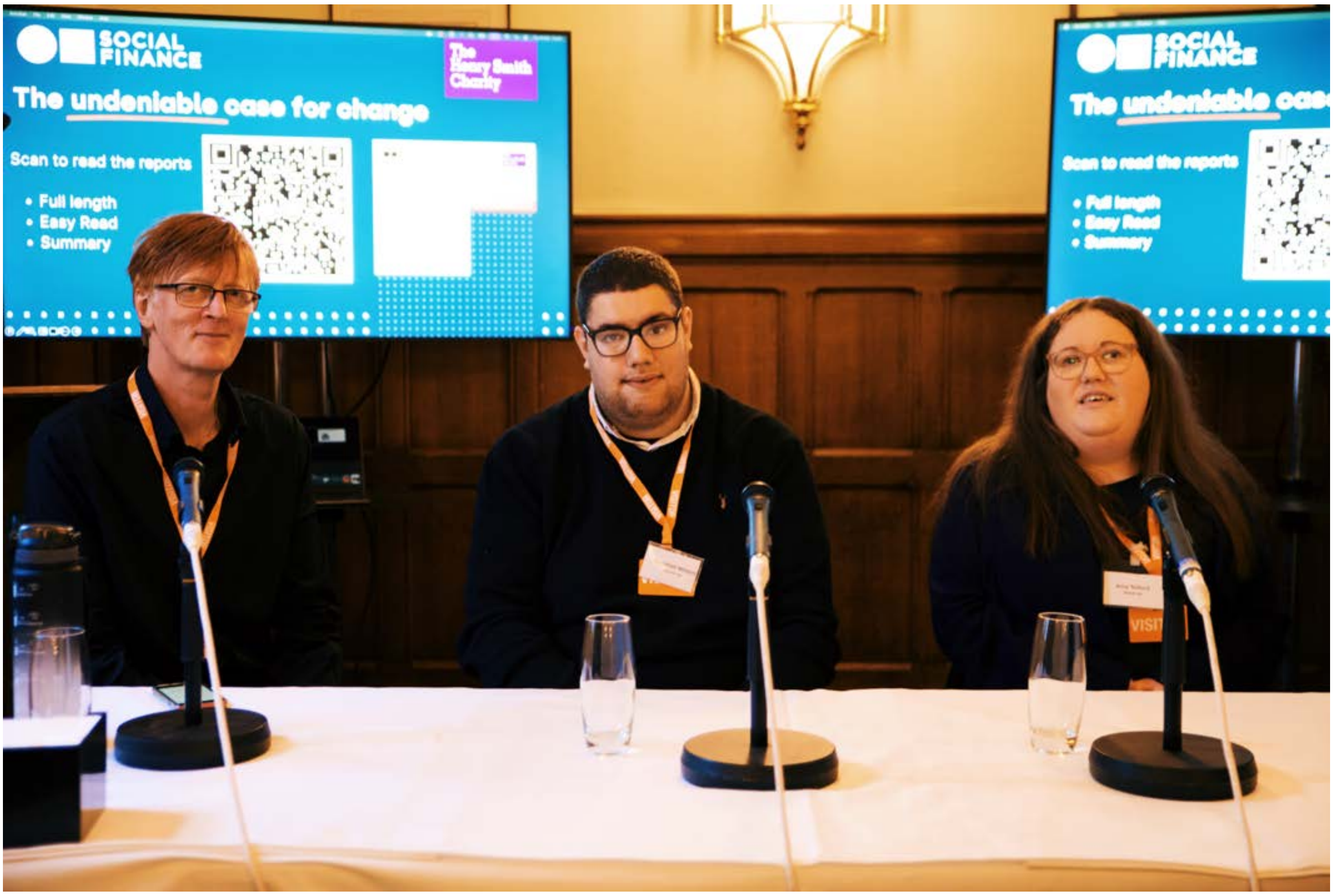
“Long-term funding is vital for work to continue, and there needs to be the political will to ensure that our voices are being heard,” she said.

“We need to make sure that our right to a voice is absolutely there in statute at every level of decision-making, both at a peer level and collectively when we need to influence policies and legislation. That’s what I feel is missing at the moment.”



Panel: Lived experience and the impact of advocacy

Facilitator: Geoff Doncaster, Principal Officer at Speakup, the lived experience partner on the project



Panellists:

Kerry Martin, expert by lived experience who works for People First Dorset, one of the 15 advocacy charities funded by the programme

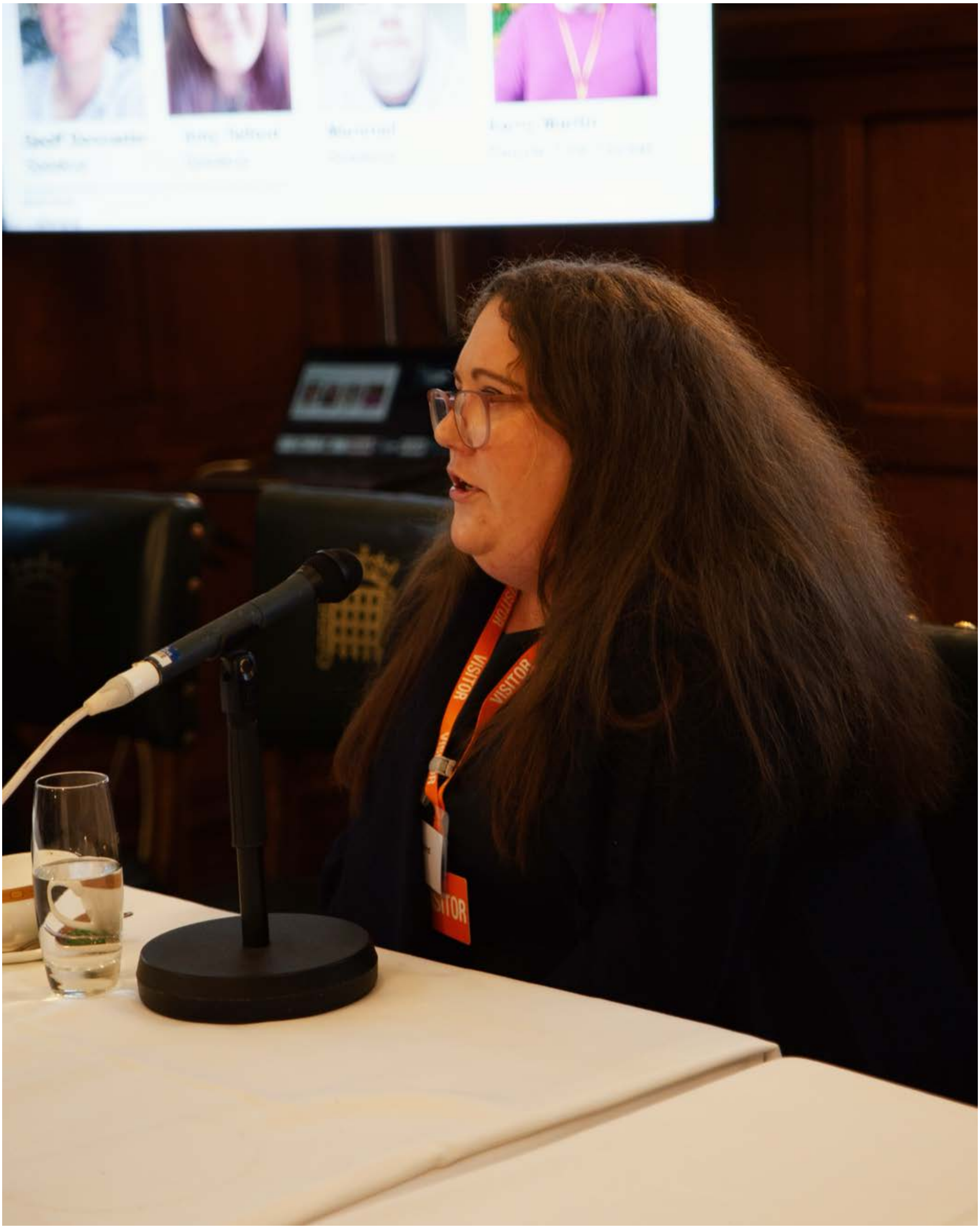
Kerry described her experience in being involved with People First Dorset's Friendship Club.

"We meet in pubs and we support each other with their well-being, with peer advocacy," she explained. **"We're well known in the community, and we're always keeping an eye on one another.**

"I don't like being in my house so I'm always looking out for others. I will talk to absolutely everybody wherever I go. If I see people quietly sitting in the corner, I'll go over to them, tap them on the shoulder and make sure they're OK.

"If we didn't have them [these clubs], it would be a very quiet and lonely world. We'd all be in mental health hospitals and really sad and lonely and I wouldn't be able to help my friends."

Amy Telford, expert by lived experience who works for Speakup



“For me, advocacy means connection,” said Amy. **“It means community. And it means being able to understand your rights, and being able to speak up.”**

“From a ‘building confidence and growing’ point of view, for me, non-statutory advocacy in grassroots advocacy is the key to the future.”

Amy spoke about the impact of her experiences as a psychiatric patient.

“I spent 11-plus years in mental health hospitals across the country and it was really hard,” she said.

“At one point, a psychiatrist said to me that I would never get out of hospital, and I would never live a fulfilling life. When you're told that on a daily or weekly basis by multiple professionals, it's hard to believe anything else. It's hard to believe that you are worthy, you are worth getting out of hospital for, that that your life matters.

“And when you go into hospital because you're suicidal and you're on the edge of life, and that's how a mental health hospital makes you feel when it's supposed to get you better, it’s just absolutely horrendous.

“Even as a sectioned patient, advocacy was very hard to come by. You'd only see an advocate maybe once a month, sometimes once every two months.”

Amy’s challenges did not stop when she left hospital.

“Coming out of hospital was really difficult for me because I'd spent all my teenage years in hospital,” she said. “I hadn't lived a normal life and I was very institutionalised. I didn't know how to be in the community.

“Non-statutory advocacy is the future to getting learning disabled and autistic people out of long-term hospital stays into the community, so they can create a group around them, so they can have friends and they can live the life that they want to live.

“For years, I believed that I had to live the life that professionals were telling me I had to live because of my disabilities. I've been out of hospital about five years now, and it's only really in the last two that that I'm at a point where I know that I can live the life that I want to live. And I don't need any professionals to tell me how to do that. I can make the choices that I want to make, within reason.

“There needs to be more positivity within mental health units in inpatient settings. There needs to be more non-statutory advocacy and grassroots advocacy within these settings to inspire and give hope to those that are stuck so they can get out of hospital and have connection within the community, so they're not alone and that they know that they've got people there for them.”

The invisibility of Amy’s condition can make it hard for others to understand what she is going through, and she described how this affects her.

“Being autistic and living in a neurotypical world is exhausting at times,” she said. It feels impossible. People don't see what you go through when you're on your own and the burnout that can come from it.

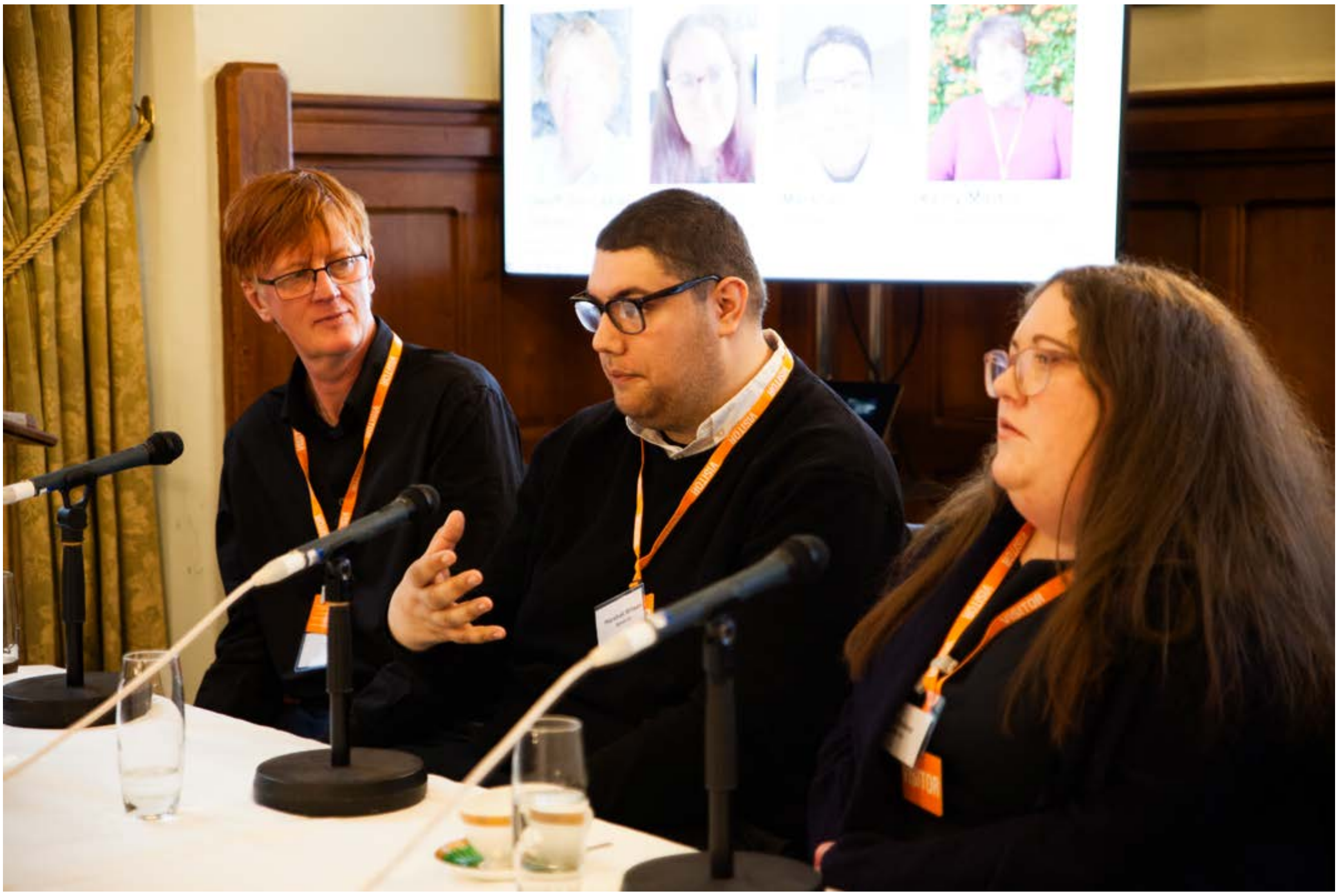
“Some days, it feels like it's just constant admin to manage my autism, to manage hospital appointments, to manage therapy, to manage all the different things that I

need to do to keep myself well - how to spin every plate at once and keep them spinning on an even keel.

“High masking makes it invisible, and people don't see what it's like behind the scenes. But you've got to mask the meltdowns, you've got to hide everything, because if you don't, it's seen as not the right way to be.

“I’m not great at making decisions – I’m working on it and self-advocacy has allowed me to improve on that. Because I'm seeing as ‘normal’, so to speak, and you can't see the autism behind me, people think that I understand everything that's said to me in professional meetings, that I'm processing it like a neurotypical person would, but actually I'm not. And it takes a lot of time with my support workers to be able to process that and understand it in a way that makes sense to me, which further adds to the feeling of burnout. It's the aftermath of these meetings that is difficult.”

Marshall Wilson, expert by lived experience who works for Speakup



Marshall Wilson works with The Henry Smith Charity and Social Finance as a lived experience provider. He is currently delivering tiers one and two of The Oliver McGowan Mandatory Training on Learning Disability and Autism for Speak Up across North Yorkshire and the South Humber.

“It gives me the confidence to tell people how to communicate,” he said. **“It shows people how to look after people and how to support people differently - reading their communication passports, sensory profiles and background information. And sharing my own story, because if people know how to support me, not just mentally but physically, it can help people in the future. That's why I'm proud to be studying it today.**

“I bring my experience of being in hospital to help people get out of hospital and have a good life. It’s shocking when I see that someone’s been in hospital since before I was born.”

Marshall told of how Speak Up has helped him adjust to day-to-day life by building his confidence, particularly when it comes to trusting people.

“When I was in hospital, I did some things that could have risked my life,” he said. “I’m grateful I’m here. If I didn’t have Speak Up around me, I don’t know what would have happened. I wouldn’t be here now.

“I’ve been in an impatient setting for six years nearly. I've had to stand my ground and tell people how I feel – to tell people who won’t listen, who are controlling me, who are trying to send me to different places in the country.

“I know what I want in life and I have the skills and confidence to show people how they should support me in the future.

“Sometimes I feel people have fobbed me off. I have struggled with people trusting me. Not a lot of people have been honest with me in the past and sometimes I felt a bit let down by the way that people have treated me over the past few years and not believing in me.

“I'm known as being a crazy kid when obviously all my life I've been having physical and mental health difficulties - it's been a bit challenging for me for growing up with my eating habits.

“I know when I've got a good group of people around me, I feel safe, secure, knowing that I can talk to them because we have a bond.

“It's about getting my confidence back. I was really confident growing up, but when I got into mental health services when I was 16, I wasn't confident to speak up.

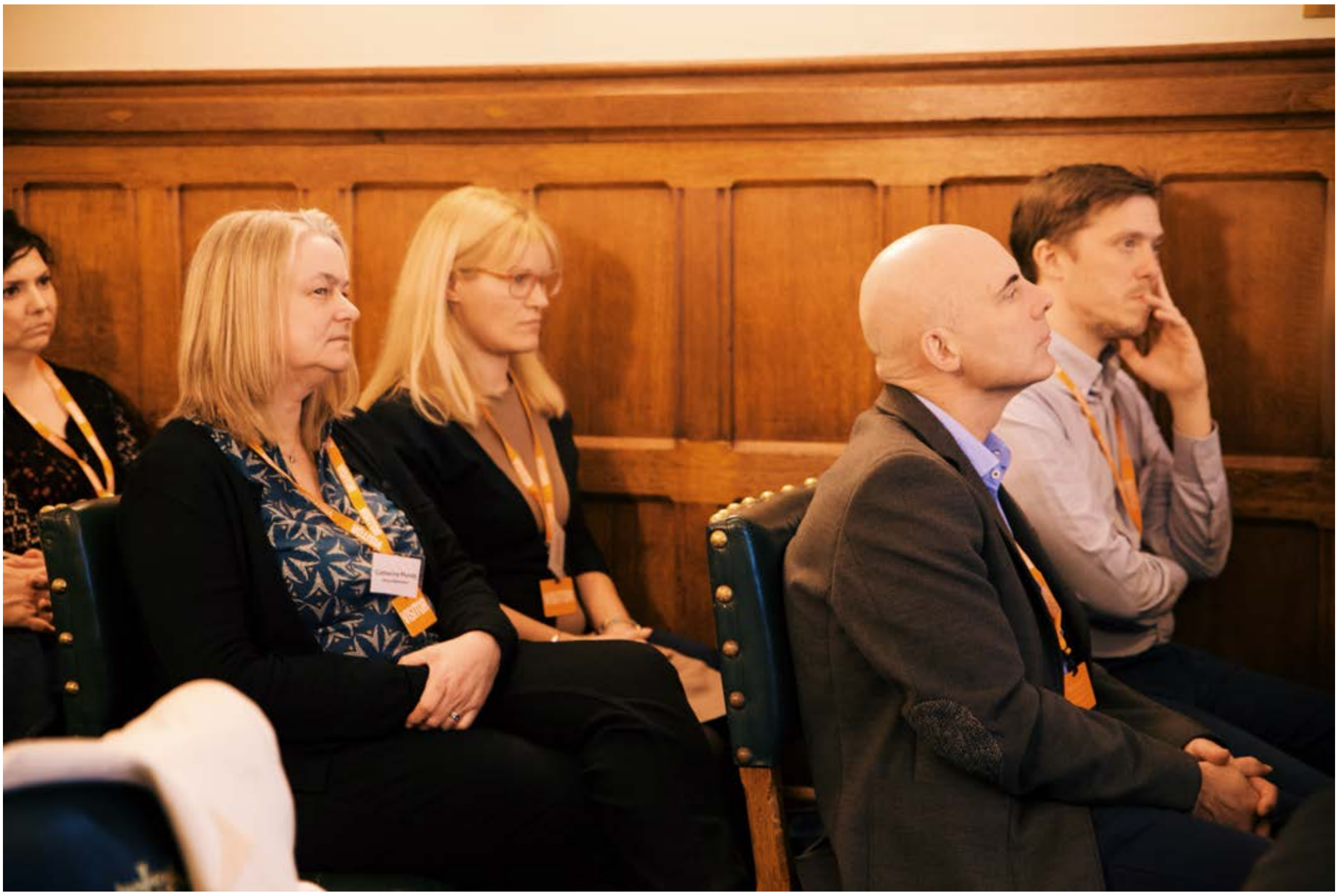
“My friends and family didn't always believe me. I would have been known as being attention-seeking, even though people knew that I was struggling.”

Rohan Lowe from Brighton and Hove Speakout asked the panel whether they believed statutory advocacy would still be needed in ten years' time – and if so would it look any different.

Kelly replied: **"Yes, that's the plan. The difference would be that we wouldn't be putting so much strain on the public purse – they wouldn't need to fund our support through direct payments and everybody going through them because they haven't got any support because the advocacy is not there anymore. So their bill would be higher."**

Amy echoed Kelly's comments, adding: "It would decrease the demand on overstretched services and give back to the services that really need the funding to be able to function appropriately. I think it will allow for more connection, for more people to come together and feel valued and feel listened to and feel able to speak up for what they believe in."

Marshall added: "I hope in 10 years' time that we'll have built a big community with people, not just in London but all around the country. If we have better advocacy in place, it might support people, it might give them a chance to speak up, and give them a chance to have what they want in life. Because at the end of the day, it's all about the person and what they want in life. The person's important and whatever situation they're in, they will get through it. But I would like to hope they'd have that increase in more advocacy places and a chance for everyone to connect."

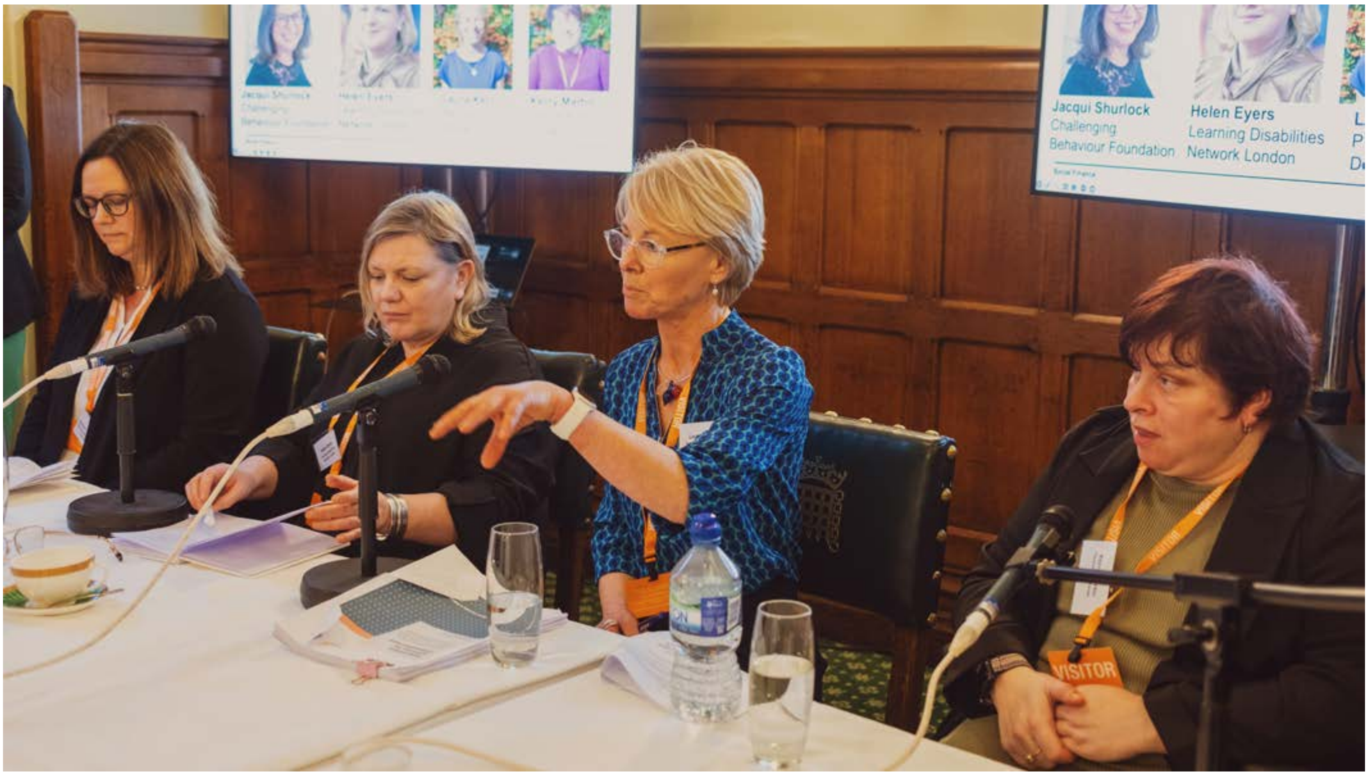


Panel: Considerations for policymakers and funders around supporting advocacy

Chair: Nadine Smith, executive director of Social Finance

Panellists:

Laura Kerr, manager of People First Dorset



“Very often, situations are very personal to an individual, so they are difficult to share in a public setting, and really hard to measure – we just get on with it,” said Laura.

“I don't know that the wider public are aware of what advocacy means. When you start understanding advocacy and how it's broken up into health advocacy, independent, self, peer - there are so many types of advocacy, all of which are important and some of which seem to get a huge amount of funding and, others completely fall off the cliff.

“You can be at least a minute into a conversation with journalists before they've even understood what you're talking about. We've got some work to do there and I'm confident this report will help us.”

“When government gets too involved, that sometimes isn't great, because sometimes they get it wrong. When they do want to open it up to community voices, those voices competing with one another. Actually, what we're talking about for government is

really a baseline first step. It's recognising the power and value of independent advocacy."

Laura spelled out the deleterious impact of conversations with people who might not have the full picture of an individual's needs.

"When people are going for their benefits and are asked if they can cook a meal, they might say 'yes' when they can't open a tin of beans, out of shame or pride," she said. **"If that assessor isn't experienced, and takes that as said, that person's benefits will be stopped. And that's when we see the crisis happening because there's a period of time between the benefits stopping and then the review, which almost always says the person does qualify. In that period, people will sink. We see that happening on a daily basis."**

Laura says the picture laid out in the report could be a lifeline for small charities like hers to make their case.

"It's taken us years to build relationships and trust. We nearly folded last year, we were literally on a lifeline. Two years before, we had so many reserves and such a big team, we weren't eligible for a lot of funding because our reserves were too high. We've seen a lot of self-advocacy groups go. It can happen so quickly and the real danger is that the trust is gone because people think it won't last. You don't know from one year to the next whether you're going to be able to sustain those services.

"People with learning disabilities will talk to us because they know our team and they know that we will get stuff done. When you lose those things, it's much more expensive to bring them back in. We don't want to lose any more. A lot of our time is spent trying to get money in to do what we do – and it would much better served if we didn't have 20 different grant funders to report to, and to write reports that sit on the shelf."

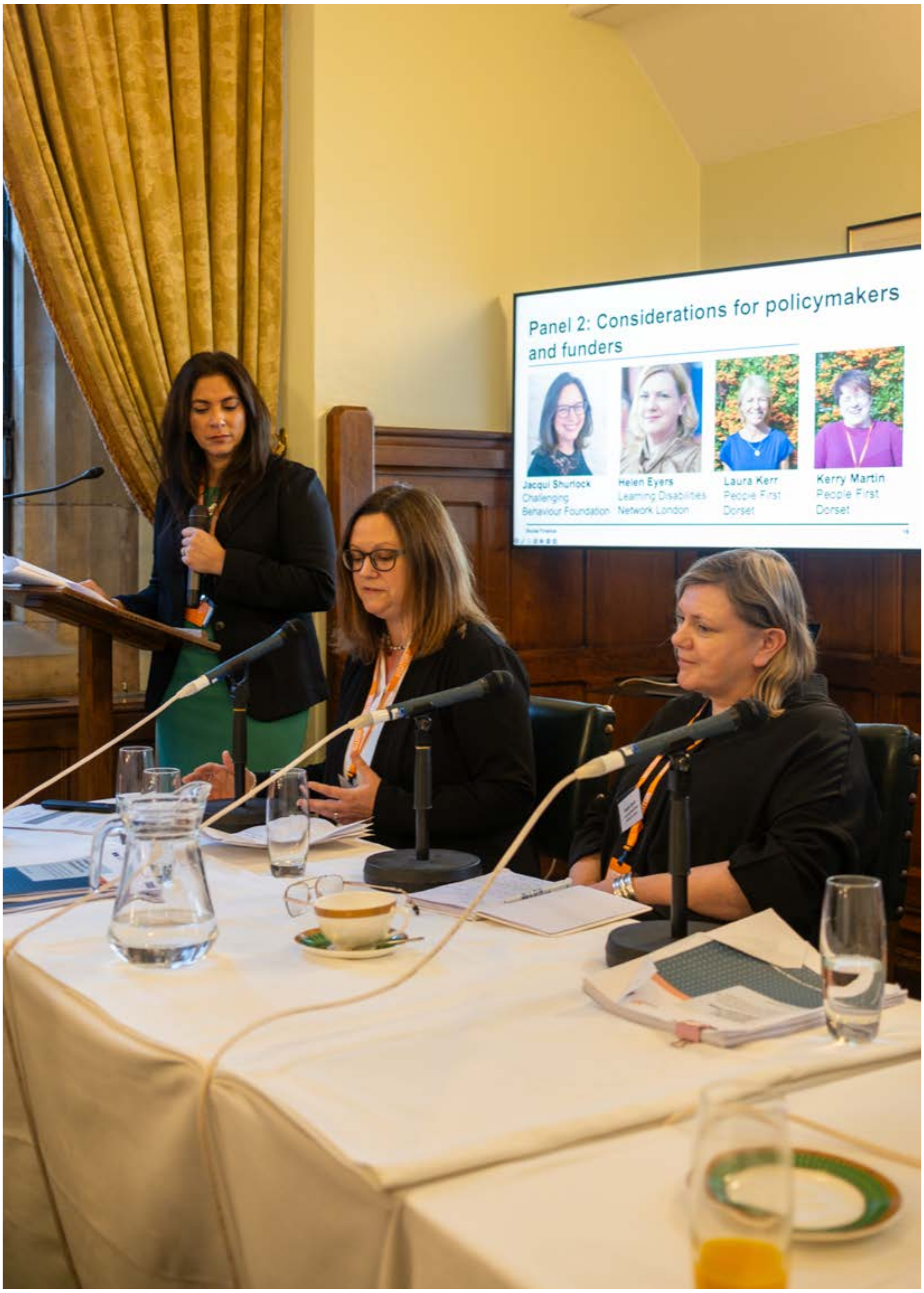
Laura believes the report is important because it empowers small charities like hers by evaluating the work they are doing

"The brilliant thing about Social Finance and The Henry Smith Charity is that they have understood and we have now got a cost to what we do," she said. **"We've got a report. Let's not let it sit on a shelf because we've ticked the boxes. We really need to come together and drive this forward.**

"We've never been able to put a value on what we do. We know it saves money, we know it changes people's lives, but we're so busy doing it, we can't actually evaluate it. And now they have. What they've said in this report is that for every £1 that is invested in the work we do, that makes an estimate saving of £12. That's massive.

"Social Finance has put forward a case for an advocacy fund in the next spending review in March. We've got a government that's said it's really committed to a preventative and partnership agenda with civil society and charities. This is what we're doing. You want a quick win? This is how we can do this. We've never had a platform before and the biggest message is we're not going to be here if we don't get that funding platform."

Jacqui Shurlock, Chief Executive of The Challenging Behaviour Foundation



The Challenging Behaviour Foundation is a UK-wide charity specifically focused on people with severe learning disabilities and helping their family carers to understand how to fight for their rights.

“We are really excited by this report, particularly the new evidence around cost savings and the evidence that good advocacy has a really big impact on people who

have higher support needs," Jacqui said. "If we had that better non-statutory advocacy, hopefully we then wouldn't need the statutory advocacy, because people wouldn't be in an inappropriate restrictive setting."

Noting that there has been no response to a Department of Health and Social Care review of advocacy regarding mental health, and that budget constraints have scuppered the Child Safeguarding Practise Review Panel's proposal of a national framework for advocacy around disabled children, Jacqui said she believes the report can help make the case for the **"massive policy imperative"** to progress with something that will change people's lives and save money.

She outlined four principles that should be born in mind when considering the proposed advocacy expansion fund:

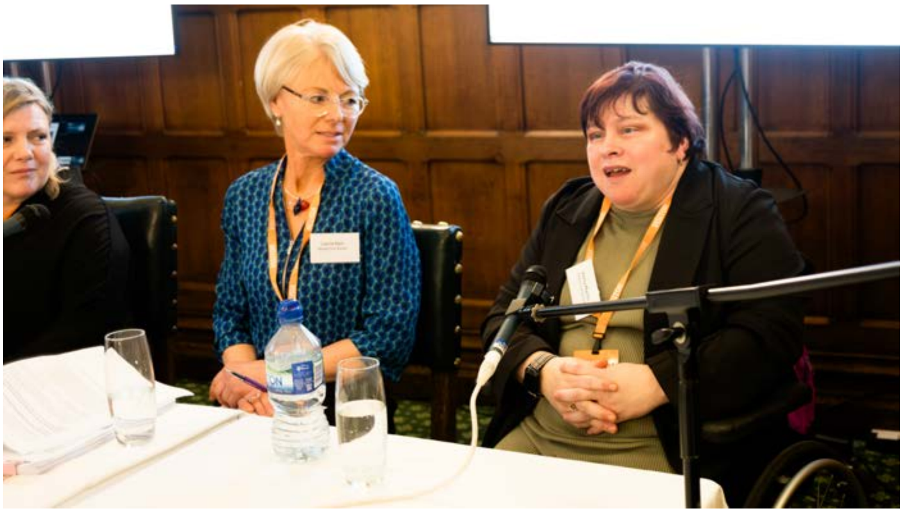
1) Advocacy needs to work for everyone, from people who cannot communicate verbally to those with more hidden disabilities.
2) It must consider the role of family carers where appropriate.
3) Advocacy must apply at all ages, from children through to older adults.
4) It must address statutory advocacy, not just assume it's there.

Helen Eyres, Director of Quality and Compliance at Learning Disabilities Network London

Learning Disabilities Network London provides supported living services and hosts Family Services support groups for people with learning disabilities and autistic people support to self-advocate.

"There need to be some really clear referral pathways because it's really difficult to get people to help people refer to advocacy support," said Helen**. "Without a policy in place, let's be really honest, it won't be commissioned because we've got local authorities in health that are struggling for cash and struggling to provide statutory services."**

Kerry Martin, People First Dorset



On her second panel appearance, Kerry opened by talking about her past experience as co-chair of the national forum, which used to feed concerns raised at regional disability forums to government.

"We'd like to have something like that in this policy ownership but be listened to, more because they that that door is shut now," Kerry said. "Apart from today, when we're bringing in a new door [with this report]. We don't have anywhere to feed everybody's voices now."

Kerry also said: **"It's society that's not built for us. We're just all people at the end of the day, whether we have a disability or not. I've just had reassessment for some more support, and changing my benefits over has been a complete minefield. If I didn't have my support, and all the knowledge I've learned, I wouldn't be able to navigate the benefit system and wouldn't be able to get the support that I needed."**

Shiv, who has autism and works with Social Finance, asked the panel what more could be done to address the shame that leads an autistic person not to tell the truth when talking to representatives of the benefits system.

"So many times as an autistic person, you are scared about saying the truth, and therefore the repercussions are really bad for you," Shiv said. **"But then, at the same time, if the shame could be reduced within those systems and within people, then life could be so much better as an autistic person."**

Laura Kerr replied by outlining the aims and impact of setting up People First Dorset's Friendship Clubs in 2008, after being approached about running a dating agency.

"There had been no collaboration or inclusion with people with learning disabilities in this discussion, so I went round all the day centres and spoke to a lot of people. They all wanted friendship in the community. The cost of running a dating agency and doing it well and follow-up was astronomical. I think we had about £20,000 at the time to run this. It would have lasted about six months doing it properly. And that's how the Friendship Club started, because that's what people wanted.

"They want real friendships in the community, they want to go to pubs like everybody else, but it's really difficult as an adult with a learning disability to do that, especially when those friendships are lost when people leave school and go into adulthood.

"We work with people with learning disabilities to go and check out which pubs and cafes are welcoming, how much is a pint of beer and a pint of coke, and find the places that might be welcoming or inclusive.

"On a Tuesday night, there might be 30 or 40 of us turning up in a quiet time in the pub. You can see the couple sitting there going 'oh, God' - and I guarantee by the end of the night, they're probably volunteering for us. That reduces shame by being visible, by being seen by people, getting to know people with a learning disability. There's that still stigma and discrimination. The more we're out there, sharing stories, the more we'll break that down."

Feedback on event

Jacqui Shurlock, Chief Executive, The Challenging Behaviour Foundation
“It was a great event and there is such a huge need for advocacy and seemingly a huge appetite to work together to influence national policy. Definitely keen to keep in touch on this.”

William Jacks, Director, the Henry Smith Charity
“Thank you so much for all the work you put into the event today. It was brilliant to get so many stakeholders in the room to launch the research. It all went smoothly and was a great mix of introducing the research, hearing from experts by experience and discussing the policy challenges.”

Madeline Cooper, Programme Director- Equal Lives, NDTi
“Great to be at the launch and even better to hear that the multiple different advocacy projects supported by Henry Smith Charity have had such an impact on people’s lives. Advocacy can make a huge difference where people need support to put their own voices forward and be heard.”

Jonathan Oppe, Grants Manager, the Henry Smith Charity
“I thought the event was excellent and a really great way to launch the report.” -

Catherine Mundy, Chief Officer, Vocal Advocacy
“What a brilliant afternoon, thank you all for arranging. Looking forward to getting the report out there and see what we can all do to keep the momentum going.”

Elizabeth Tilley, Professor of Learning Disability Studies, The Open University
“Just to say thank you for a great event yesterday and for all the hard work pulling together this excellent report. I am sharing it through my networks.”

Geoff Doncaster, Speakup
“It was great to meet you all in person and thanks for sending over the links. Look forward to seeing what responses we see from this work in the coming weeks.”

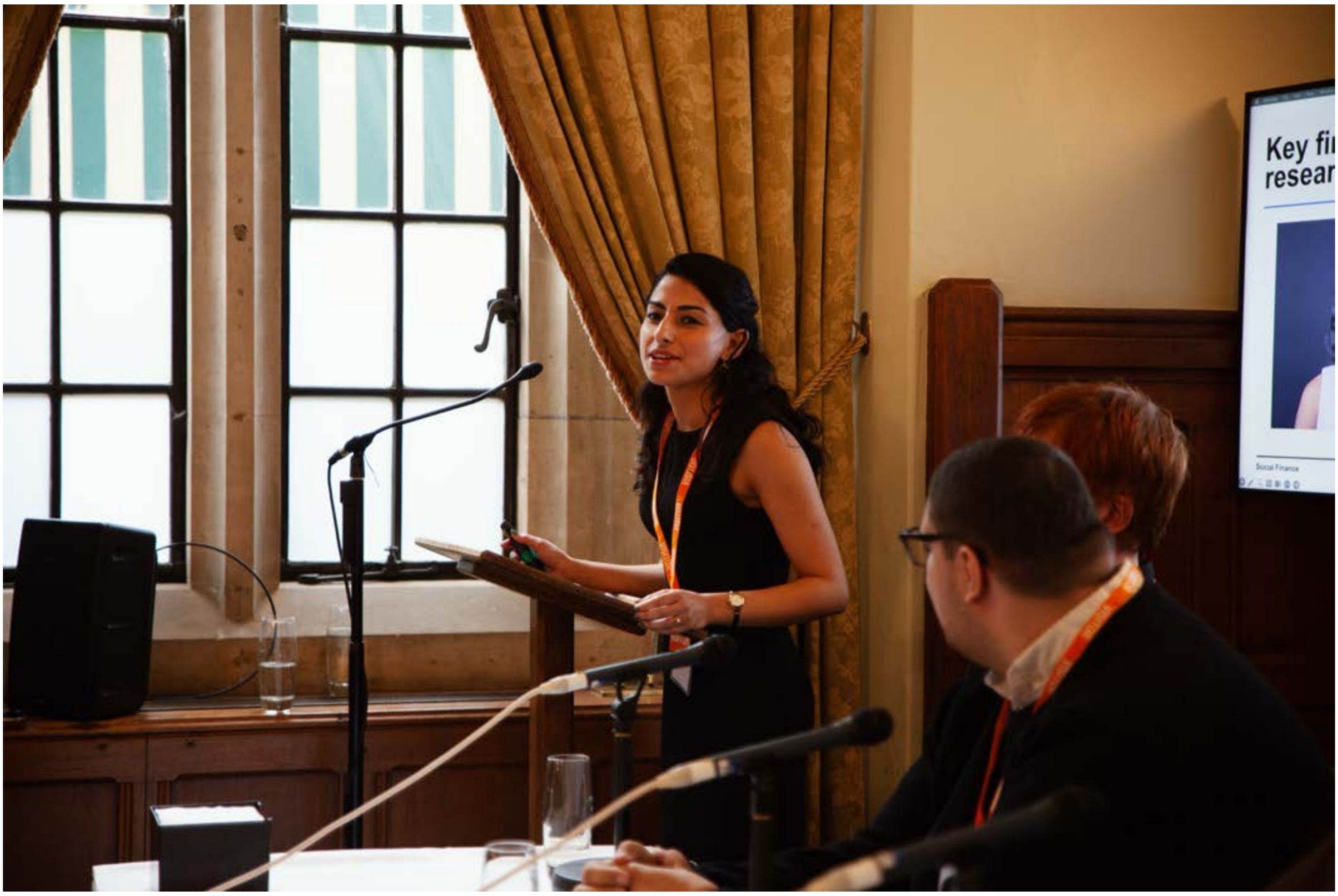
Helen Kidd, Lead Care Act Advocate, Vocal Advocacy
“Thank you for our invite to the houses of parliament last week - it was amazing to see the report launched and exciting to see what comes next.”

Carmel McKeogh DFN Project SEARCH
“I just wanted to say thank you so much to your team at Social Finance and to the Henry Smith Charity for the invitation to the event.

I have come across the work of Social Finance several times and always been incredibly impressed by the professionalism of your organisation and your commitment to ensuring that you live and breathe the ‘nothing about us without us’ philosophy.

It was indeed an inspiring event, and I know that you have shone a very bright light on the value and importance of advocacy in this sector and the difference it makes both to the individuals who shared their impactful stories on the day and the very strong economic case.

Many thanks again for extending an invitation to DFN Project SEARCH – it was a real honour to join you.”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