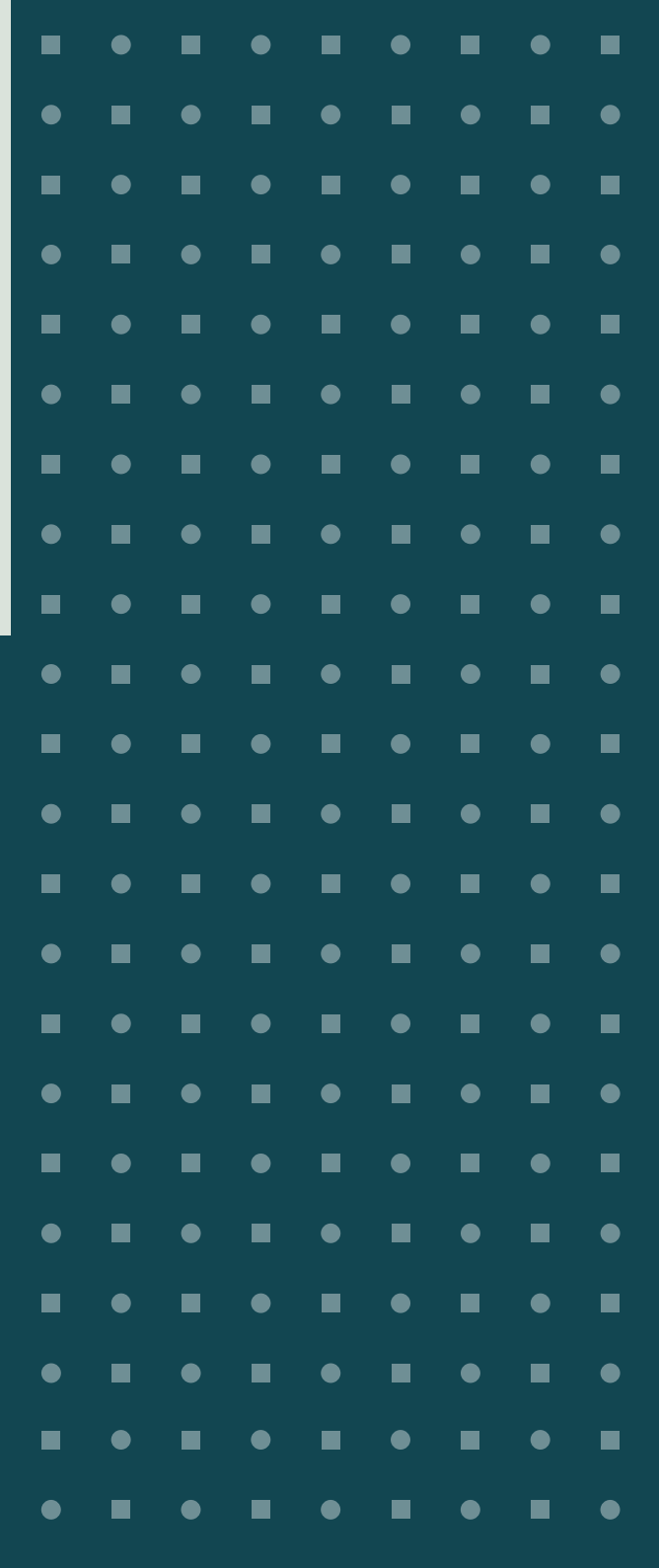
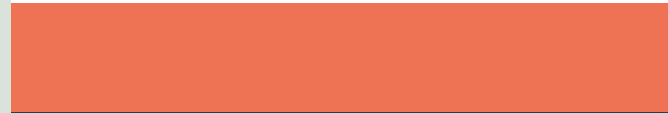


# Independent advocacy for independent lives:

A groundbreaking evidence  
base to grow inclusive support  
services for people with learning  
disabilities and autistic people

[socialfinance.org.uk](http://socialfinance.org.uk)



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# About this report, and acknowledgements

The Henry Smith Charity funded 15 organisations providing independent and non-statutory advocacy to support people with learning disabilities and autistic people across the UK. As part of the programme, the Henry Smith Charity awarded a grant to Social Finance to work as the learning and evaluation partner to build evidence and support the case for sustainable funding for the sector. Social Finance conducted research, gathered data and insights from grantees and people benefitting from advocacy, and facilitated peer learning.

This report was prepared by Social Finance and summarises key learnings from across the programme and puts forward recommendations to support the sector. It builds on an interim report published in 2024. A shorter report is also available separately which summarises key findings from this report.

The report is complemented by an Easyread summary, prepared by our programme partner Speakup.

The authors are grateful to all 15 grantees for working closely with us on data collection and case studies, participating actively in our community of practice events, and consistently sharing valuable insights. This report would not be possible without their time and commitment.

Throughout the programme, Social Finance worked in close partnership with Speakup, a lived experience partner run for and by people with learning disabilities and autistic people to help them have a voice through self-advocacy. We would particularly like to thank Geoff Doncaster, Vicky, Amy and Marshall for their constant advice and guidance, and their invaluable role in helping to shape the report's insights, providing check and challenge, and supporting the creation of Easyread outputs.

We are especially grateful to Social Finance colleagues Bex Spencer and Nadine Smith for their strategic guidance and oversight. We would also like to thank colleagues who have contributed to this project over the years, including Michael Crowder and Dan Peck.

Finally, we thank colleagues at the Henry Smith Charity, in particular Jonathan Oppé, Keith Anderson, and William Jacks, for their ongoing support and trust, and for making this programme possible.

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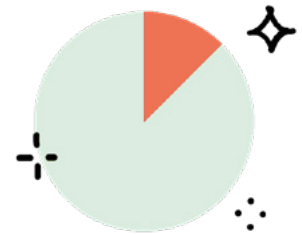
## Contribution Statement

This report was written by Fergus Hamilton (lead researcher) and Tanyah Hameed (project manager) with support and guidance from Bex Spencer and Nadine Smith (project directors).

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# Foreword from Social Finance

Today 1.5 million people in the UK have a learning disability while around 700,000 adults and children have a diagnosis of autism spectrum disorder.



This might be you, your family or friend, or perhaps this is a disability that is less visible to you. But people with learning disabilities and autistic people do show up frequently in our crisis services and are then misrepresented as too hard to help or too reliant on the system. To me that is an unacceptable narrative. The number of those who identify as having a learning disability and/or who are autistic is projected to increase in the coming years. Without independent person-led support, known as non-statutory advocacy, many of these people will risk ending up at crisis point at challenging times in their life. Yet more will be unable to reach their full potential through absolutely no fault of their own and absolutely not helped by the system.

When people do show up in statutory services, they often find they are not offered specialist help and find it difficult to have their voices heard in important decisions impacting their lives, leading to missing data and misdirected commissioning and support, which costs more money and causes unnecessary trauma. Specialist support for people with SEND drops off at 18 mostly, or at 25 years of age for some, after which people often have nowhere to turn to for support, resorting to use of crisis/frontline public sector-run services when they are no longer able to manage alone. Our work shows this leads to disengagement and despair, while also contributing to wider societal and economic challenges. Learning disabilities and

autism are lifelong conditions, but many, with the right help, go on to lead fulfilling and independent lives, without the need for lifelong intervention, and we have proven that.

With independent support delivered through partners from the VCSE sector, we have seen people like William gain the confidence and independence to turn his life around. There are plenty of stories like this in our report.

There has never been a programme like this, and we have broken new ground in being able to give the VCSE sector the clear and usable evidence they need to grow independent advocacy across the UK. But this can only be achieved in deepening and expanding partnerships with local authorities and health organisations, located alongside existing and now expanding family and person-led services, from supported employment to family hubs.

Sadly, we know the support provided by the 15 incredible grantee organisations participating in this programme only scratches the surface of the real demand for independent advocacy across the UK. We are hopeful, though, about the direction the Government is now taking to support unmet needs will change this. We are pleased to see an emphasis on shifting care from hospital to community, and ensuring everyone has access to a fulfilling job that works for them. All these government pledges provide the right environment

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## Foreword from Social Finance

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for independent advocacy to thrive, but this will need a cross-government approach and clear leadership.

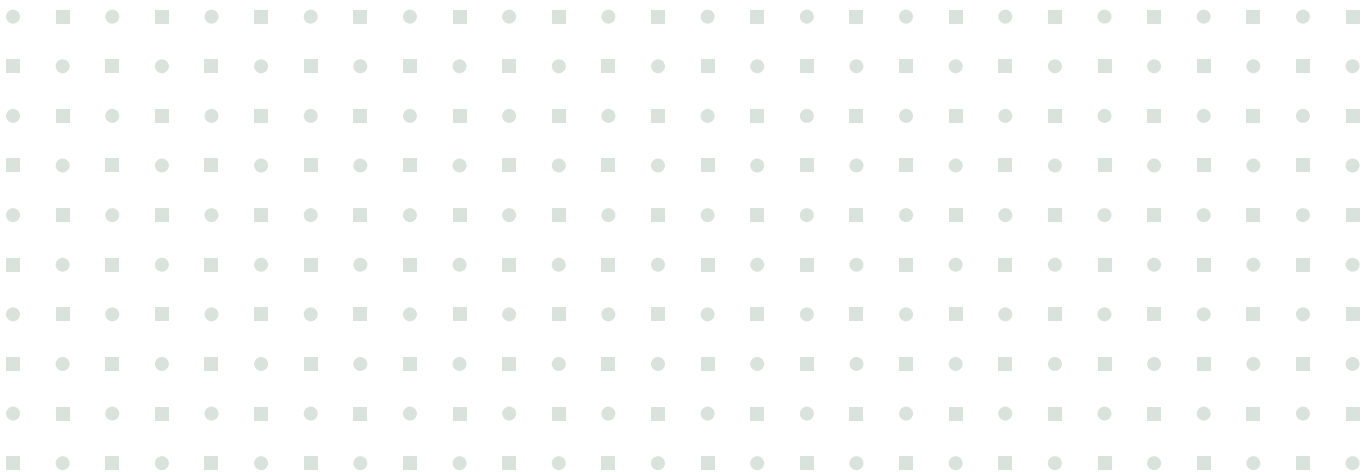
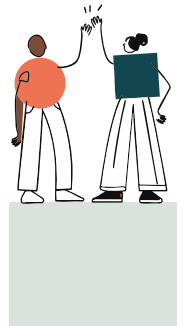
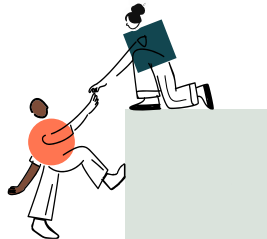
With every £1 spent on independent advocacy generating an estimated £12 of savings, it is high time that we recognise the vital role that independent advocacy can play as part of a preventive approach to health and its potential to reduce the strain on already overburdened statutory services. We need to put an end now to the chronic funding instability that means independent advocacy organisations face a constant battle to maintain the support they provide now, let alone rise to meet increasing future demand. This effort only takes their precious time away from those who need their support.

Our thanks to the grantees and to Henry Smith for making this work possible at all and to the Social Finance team that drove the learning and

partnership to work so well: Fergus Hamilton, Tanyah Hameed and Bex Spencer. The collaboration and partnership in this project we hope is an inspiration on the journey forward.

Let's make this work visible, let's help make learning disabilities more visible, and let's see independent advocacy support as not just a way through a crisis but a service that works for the benefit of everyone, no matter their age. Learning disabilities and autism should never be a crisis, should never be spoken of as too hard to help, complex or too expensive. Let's act now before it is too late and seize the potential. Government often asks, 'But does it work?' With this groundbreaking evidence and learning, we can say it most certainly does.

**Nadine Smith**  
**Executive Director, Government**  
**Strategy & External Affairs,**  
**Social Finance**

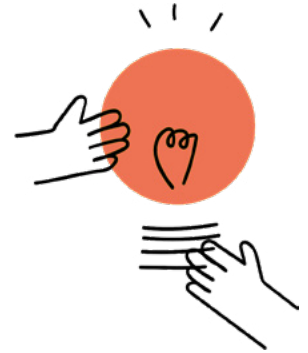


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# Foreword from the Henry Smith Charity

In recent years, the Henry Smith Charity has launched several strategic grant programmes to address critical social issues. Grounded in evidence from our open responsive grants programmes, these initiatives aim to tackle pressing challenges, raise awareness, influence policy, and amplify outcomes to create lasting change.



This report explores the impact of our grants programme supporting advocacy services for people with learning disabilities and/or autistic people. It underscores what frontline workers have long understood: advocacy services are a lifeline, empowering individuals to understand their rights, make confident decisions, and achieve better life outcomes. However, advocacy organisations face significant challenges, including shrinking budgets, difficulty demonstrating the value of their work, and escalating needs.

This programme was designed to address these issues with three clear goals:

- **For individuals:** Provide access to high-quality, non-statutory advocacy that builds confidence and supports better futures.
- **For communities:** Drive systemic change in policies, practices, and systems to foster inclusion.
- **For the sector:** Strengthen capacity, demonstrate impact, and attract sustainable funding.

We collaborated with the National Development Team for Inclusion (NDTi) to design the programme and identify exceptional advocacy organisations to support. Additionally, we partnered with Social Finance and Speakup to evaluate the programme, help grantees influence local systems, and raise the national profile of non-statutory advocacy.

The programme prioritised innovative approaches, including long-term advocacy for people with complex needs, peer advocacy, and support for those facing systemic inequities. Crucially, it linked local efforts to national conversations, fostering learning and, we hope, amplifying the impact of these services.

This report captures the achievements and insights from this ambitious initiative, illustrating the transformative power of advocacy. It highlights how strategic investment and partnerships, combined with a focus on evidence and learning, can drive meaningful change across the sector.

**Jonathan Oppé**  
**Grants Manager,**  
**Henry Smith Charity**

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# Part 1: Summary

- Approximately **1.5 million people** in the UK have a learning disability, and more than **700,000** are known to be autistic.
- The **£2.6m Strategic Grant programme** from the Henry Smith Charity funded **15 organisations** providing independent and non-statutory advocacy to people with learning disabilities and autistic people across the UK.
- Grantees used the funding to reach **1,667 people** through a variety of different forms of advocacy, including one-to-one advocacy, self-advocacy and group advocacy.
- People were supported across all age groups, with those aged 30–39 forming the biggest group (24.1%). Of people supported by grantees, 27.1% were between the ages of 18–29. There was an even split between males and females. 89.9% of the people participating in advocacy were of White ethnicity. Of these, **59% had a learning disability, 25% were autistic, and 16% reported having both learning disabilities and being autistic.**
- Participation in grantee services and groups was associated with **measurable improvement across all seven advocacy success outcomes.**<sup>1</sup> The most pronounced improvements were observed in people's self-reported feeling of being listened to, knowledge of their rights, and knowledge of local services.
- Of the people supported by grantees, **58% achieved their self-defined primary goals set out at the beginning of support** in the advocacy plan they created with their advocate. A further 35% reported making progress towards their goals.
- **Advocacy had a positive impact on people's lives** even when they were unsuccessful in achieving their primary advocacy goals. This was especially true in how people felt about their knowledge of their rights and feeling of being listened to, which saw measurable improvement through participation in non-statutory advocacy irrespective of whether people achieved their advocacy goals. Financial cost-benefit analysis shows that non-statutory advocacy generated benefits worth £12 for every £1 spent. Approximately £7 of these savings accrue to the National Health Service, with £5 going to local authorities.
- The additional system costs from better access to services may be offset by **reduced or more effective service usage elsewhere.**
- Advocacy can potentially contribute to wider economic benefits by **helping people improve their well-being, gain greater independence and participate more actively in society** (including employment). Future research could potentially use a Randomised Controlled Trial (RCT) or quasi-experimental methods to further assess the attribution or economic costs and benefits of advocacy services.

1 Participants were asked closed questions at the beginning and end of support in relation to seven topics: (1) Speaking up, (2) Knowledge of rights, (3) Knowledge of local services, (4) Good relationships, (5) Happiness with life, (6) Feeling listened to, (7) Learning new skills. Answers were converted to a three-point scale. The difference between answers given at the beginning and end of support was measured and compared to assess change.



Advocacy has helped me to live by myself. We've got more confident by learning together and going out and about. We set up the groups ourselves and set the topics. We're in our own community. We encourage each other to speak up for those who can't.



**Self-advocacy group member – grantee organisation**

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## 1.1 Summary of findings

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### **Non-statutory advocacy fills a gap in support that statutory advocacy currently does not cover.**

Non-statutory advocacy provides support for a wide range of issues that do not currently sit within the remit of statutory services.

Non-statutory advocacy can take various forms (e.g. one-to-one, self-advocacy groups, peer advocacy) and is characterised by its flexible issue-based support that relies on building long-term trust and relationships with people. Unlike statutory advocacy, it is less constrained by requirements to end support after a predetermined period of time.

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### **People used non-statutory advocacy services and groups to help them work toward a wide variety of goals.**

The most common advocacy goal types were related to accessing services (e.g. health services, social services, or other services), supporting people with accommodation-related issues (e.g. applications to move to independent living facilities or resolving disputes with landlords or neighbours), and helping people navigate family-related situations (e.g. supporting with difficult relationships with partners and parents, or navigating child protection procedures). People also had goals related to mental health and wellbeing.

Advocates played an active and important role in supporting people to prepare for and have their voice heard in meetings with professionals. They also supported people in additional ways, such as signposting to services, helping people to contact services, making information more accessible and helping people to digest it and plan next steps. Taken together, these elements of support ensured that people got the right care at the right time to prevent issues from escalating.

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### **Grantee advocacy services and groups had a positive impact on people's wellbeing, relationships and their ability to speak up.**

Services provided individuals with the skills and confidence needed to live more empowered, independent and fulfilling lives. An outcomes framework for this project was co-produced with the grantees and Speakup to capture key data. This included seven core outcomes that advocacy aims to improve (referred to as 'advocacy success outcomes' throughout this report):

- Speaking up
- Knowledge of rights
- Knowledge of local services
- Good relationships
- Happy with life
- Feeling listened to
- Learning new skills



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## Part 1: Summary

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Non-statutory advocacy had a measurable positive impact across all seven advocacy success outcomes, with an average overall score improvement of 0.69 on a scale of 0–2 between self-reported scores taken at the beginning and end of support.<sup>2</sup> This finding demonstrates the inherent value of non-statutory advocacy that goes far beyond simply supporting people to resolve their immediate issues. In many cases, this form of advocacy played a crucial role in promoting wellbeing and personal development that we believe is often overlooked in commissioning decisions.

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### **Advocacy helped people achieve self-defined advocacy goals.**

Data from this programme demonstrates the impact of non-statutory advocacy support on people's chances of achieving their advocacy goals. The vast majority of the 963 people with goal data achieved (58%) or made progress (35%) towards their goals. While grantees have stressed that success in advocacy should be measured by metrics that go beyond solely goal achievement, the combination of high goal attainment rates – with only 7% not achieving their goals – and advocacy participants' increased scores across the advocacy success outcomes (described above) makes a persuasive case for advocacy's inherent value in fostering holistic personal development. These findings strongly suggest that advocacy is often a critical factor in enabling people to break through barriers and secure their fundamental rights.<sup>3</sup>



From our point of view, somebody feeling that they've been involved and listened to and able to express their views is a huge thing for us because we would never say to somebody, okay, we'll get this fixed for you or we'll get you what you want.



**Advocate – grantee organisation**

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### **Advocacy services are creating a meaningful and lasting difference in people's lives regardless of whether they achieve their goals.**

While progress on advocacy success outcomes appeared to be positively correlated with goal achievement, the small percentage of people who did not make progress towards their advocacy goals still made substantial progress in their advocacy success outcomes. Average scores across the seven advocacy success outcomes still improved by 0.31 on a scale of 0–2 among this group. This serves as compelling evidence that participation in non-statutory advocacy resulted in wider benefits to people which were separate to their success in achieving their advocacy goals.

- 
- 2 Participants answered questions related to each of the advocacy success outcomes (e.g. 'Do you feel confident when speaking up?'). They were given a chance to respond according to a 3-point scale: 'Yes', 'Maybe/A little bit', or 'No'. The researchers then attributed scores to answers in the following way: Yes = 2, Maybe/A little bit = 1, No = 0. Scores were recorded for participants once at the beginning of support and then again at the end of support. Beginning and end scores for individuals were then compared to assess the impact associated with participation in grantee services and groups across the seven advocacy success outcomes.
  - 3 [The Advocacy Charter](#) (NDTi 2018) describes advocacy as 'taking action to support people to say what they want, secure their rights, pursue their interests, and obtain services they need. Advocacy providers and Advocates work in partnership with the people they support and take their side, promoting social inclusion, equality, and social justice.'

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### **More work needs to be done to support people from Asian backgrounds.**

Data collected through this programme suggested that Asian ethnicities were underserved by grantee organisations, which may be indicative of a wider trend in the advocacy sector. Reaching these communities may require greater prioritisation and additional funding, as well as culturally sensitive support. Grantees did well to engage with people who identify with a gender other than that which they were assigned at birth, and there might be lessons here on reaching marginalised communities.

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### **For every £1 spent, advocacy generated benefits worth £12. As part of our research, we undertook a financial analysis for advocacy services. This showed that for every £1 spent on advocacy services, there were savings of approximately £7 to the National Health Service and £5 to local authorities.**

These financial cost benefits were primarily driven by advocacy services supporting individuals to move from more costly forms of social support (such as inpatient treatment) to more appropriate and cost-effective forms of support (such as community-based supported living). This adds to a growing body of evidence that community-based social interventions that aim to address health outcomes can generate significant return on investment. The full methodology and associated assumptions are included in the body of the report and findings have been tested with relevant academics in the field.

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### **Data suggests that any additional system costs from better access to services may be offset by reduced or more effective service usage elsewhere.**

Advocacy can potentially contribute to wider economic benefits by helping people improve their well-being, gain greater independence and participate more actively in society (including employment). Future research could potentially

use a Randomised Controlled Trial (RCT) or quasi-experimental methods to further assess the attribution or economic costs and benefits of advocacy services.

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## **1.2 Background**

The Henry Smith Charity launched a £2.6m Strategic Grant programme in 2022 to support 15 organisations (see the table below for a full list) providing independent non-statutory advocacy services and support for self-advocacy groups to people with learning disabilities and autistic people across the United Kingdom. The programme ran over three years to support the advocacy sector to build an evidence base for independent non-statutory advocacy.<sup>4</sup>

Non-statutory advocacy encompasses all advocacy that is not delivered under a statutory duty to provide advocacy, coming in various shapes and sizes, including one-to-one advocacy, self-advocacy groups, peer and citizen advocacy, among others. Each of these models is designed to ensure that a person's voice is represented in important decisions related to their health, care, employment, education or housing.

But the true long-term impact of non-statutory advocacy on a person's life may be far greater. In many cases, it can lead to long-term personal growth, better social integration and improved wellbeing. At the same time, it serves a key function in giving people the tools to navigate challenging situations before their level of need escalates and they reach crisis point. This report, building on two and a half years of research and learning partnership, finds that non-statutory advocacy participation has an inherent value for people as a systems facilitator that remains largely underappreciated by commissioners making key decisions impacting its provision.

The non-statutory advocacy sector today faces a series of interrelated challenges. A lack of statutory protection combined with sustained budgetary pressures on local authority funders to find savings

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<sup>4</sup> Advocacy means getting support from another person (an 'advocate') to help someone express their views and wishes and help them stand up for their rights. Please see section 2.1 for a detailed note on terminology. Throughout the report we use the terms 'advocacy' and 'non-statutory advocacy' interchangeably.

## Part 1: Summary

**Table 1. Summary of grantees**

Grantee organisation	Geographical coverage	Type of advocacy	Focus cohort
Advocacy Alliance Yorkshire	North Yorkshire: Scarborough & Ryedale	one-to-one support	Adults with learning disabilities and autistic people
Advocacy Service Aberdeen	Aberdeen	one-to-one support; group advocacy	People with learning disabilities and autistic people facing life-changing decisions
Advocacy Support Cymru	South Wales	one-to-one support; other	Adults with learning disabilities and autistic people
Advocacy West Wales	West Wales	one-to-one support	Adults with learning disabilities and autistic people
Brighton & Hove Speak Out	Brighton & Hove	one-to-one support; self-advocacy; group advocacy	Adults with learning disabilities and autistic people
Central Advocacy Partners	Falkirk, Forth Valley	one-to-one support	Adults and young adults age 16+
Coram Voice	London	one-to-one support	Children with learning disabilities and autistic children ineligible for statutory advocacy, who remain living with their birth family
Darlington Association on Disability	Darlington, County Durham	one-to-one support; group advocacy; peer advocacy; self-advocacy	Adults with learning disabilities and autistic people
Disability Advice Service Lambeth (DASL)	South London	one-to-one support; peer advocacy	Adults with learning disabilities and autistic people. Parents with learning disabilities going through child protection procedures
Grapevine Coventry & Warwickshire	West Midlands	one-to-one support; peer advocacy	Adults with learning disabilities and autistic people
Impact Initiatives	East Sussex	one-to-one support	Parents with learning disabilities going through child protection procedures
People First Dorset	Dorset	self-advocacy	Adults with learning disabilities and autistic people looking for support with gaining independence, resilience and long-term planning
People First North Somerset	North Somerset	self-advocacy; group advocacy; peer advocacy; one-to-one support	Young adults (16–25 years of age) with learning disabilities and autistic people
Swindon Advocacy Movement	Wiltshire	one-to-one support; self-advocacy	Adults with learning disabilities and autistic people
Vocal Advocacy	Devon	one-to-one support; peer advocacy; self-advocacy	Adults with learning disabilities and autistic people

Figure 1. Geographical distribution of grantees



is forcing some organisations to cease services and groups. Any argument for greater commitments from local authorities to fund non-statutory advocacy is undermined by the lack of a quantitative evidence base around the impact and financial benefits brought by non-statutory advocacy. While there is a rich qualitative evidence base around how non-statutory advocacy improves lives, prevents crises, and fosters a more cost-effective use of services, quantitative and cost-benefit analysis to support the sector in making a case to both sustain and expand this valuable provision has been lacking.

Following the announcement of the programme, an invitation to apply was extended to the advocacy sectors in England, Wales, Scotland and Northern Ireland, which received 76 applications. Based on this response, there appear to be significant gaps in coverage of non-statutory advocacy support across the country. Of the total 76 applications received, grant funding was awarded to 15 organisations from England, Scotland and Wales who met the Henry Smith Charity's assessment criteria.

The grant assessment criteria were designed to assess an organisation's capacity and ability to

deliver high-quality non-statutory advocacy to people with learning disabilities and autistic people. These criteria included:

- An annual income of between £50,000 and £3 million
- A history of delivering high-quality advocacy for more than 18 months
- An ability to clearly articulate the local level of need for non-statutory advocacy
- Integration within the community, with links to other VCSE organisations and people with lived experience represented within the organisation itself

At the first assessment stage 45 applications were rejected, with a further 12 rejected at the second stage; this was due to failure to meet the assessment criteria. Eventually, 15 grantees from around the UK had their grant applications approved. The relatively small number of organisations deemed suitable for grant awards is a useful proxy for gaining an indication of the approximate depth and breadth of the non-statutory advocacy in the UK.<sup>5</sup>

The Henry Smith Charity also awarded a grant to Social Finance to work as the learning and evaluation partner. Social Finance worked in partnership with Speakup, a lived experience organisation run for and by people with learning disabilities and autistic people to help them have a voice through self-advocacy. This report presents robust qualitative and quantitative evidence on the value of non-statutory advocacy for people with learning disabilities and autistic people.

As far as we are aware, financial analysis of the value of non-statutory advocacy has been lacking. This report argues that a failure to recognise the cost-effectiveness of non-statutory advocacy represents a major missed opportunity for

policymakers and funders, especially those within the health and social care sectors. Supporting more people to access the right services at the right time has wide-ranging benefits that extend beyond the moral imperative of supporting those whose voices too often go unheard. As those working in the advocacy sector already know, these benefits accrue to systems and services with which people interact. Better individual outcomes lead to greater independence and more fulfilling lives, both of which can help reduce demands on highly stretched statutory services.

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### 1.3 Barriers to sector expansion

Approximately 1.5 million people in the UK have a learning disability,<sup>6</sup> and more than 700,000 are known to be autistic.<sup>7</sup> They can struggle to have their voices heard across a wide range of issues that impact their lives, and it is likely that a majority would benefit from advocacy support at one time or another. Whilst a complete assessment of the need for non-statutory advocacy is lacking at a national level, the numbers of people with learning disabilities and autistic people alone means that the potential demand for advocacy support is likely to far exceed existing provision levels.<sup>8</sup>

While we know that the sector hopes to sustain and, if possible, increase the scale and reach of non-instructed advocacy, there are several interrelated barriers that need to be addressed.

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#### 1. Financial strain on local authorities

Relatively few local authorities in the UK currently commission advocacy services beyond that which they are bound to under their statutory duties. In the few areas where this support is funded, non-statutory advocacy for people with learning

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5 Analysis of the geographic location of organisations that applied indicates unequal coverage of non-statutory advocacy around the UK. A relatively high number of applications that made it to the later stages of the award process were from Scotland, where the advocacy sector is supported by the Scottish Independent Advocacy Alliance (SIAA), which serves as a national voice for advocacy. Areas that produced a relatively low number of high-quality applications included London, the East Midlands, East of England, the North West, and Northern Ireland.

6 According to [Mencap research](#), based on learning disability prevalence rates from Public Health England (2016) and population data from the Office for National Statistics (2024).

7 As per the [National Autistic Society](#)

8 Grantees of this programme reported long waiting lists for support in their areas.

disabilities and autistic people is provided by a patchwork of small-scale grassroots organisations that are typically reliant on local authority contracts. In most cases, these organisations lack alternative funding sources beyond these contracts, making them highly vulnerable to any shifts in the strategy and funding priorities at the local level.

Many local authorities themselves are facing increased pressure to balance budgets. Despite an uptick in grant funding to local authorities from central government between 2020–22, grant income fell by 21% in real terms between 2009/10 and 2021/22.<sup>9</sup> This pressure is not expected to let up any time soon, with councils projected to face a collective funding gap of more than £2.3 billion for 2025/26 in England alone.<sup>10</sup> With local public sector financing severely stretched, local authorities are under mounting pressure to reduce spending on services, but are also under pressure to relieve pressure on crisis services (such as A&E) and move support to communities and partners across civil society with emphasis on prevention.

In such an environment, the funding that is naturally most at risk is that which pays for services that are not delivered to meet statutory duties, such as non-statutory advocacy. As a case in point, the grantees on this programme with local authority funding report increasing difficulty in recent years to secure reliable funding to maintain their support offering, let alone expand their reach.

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## **2. Lack of quantitative evidence**

Issues surrounding funding for non-statutory advocacy are exacerbated by a historic lack of quantitative and cost-benefit data on the impact of non-statutory advocacy. Without a firm empirical foundation, organisations can struggle to make a convincing case to commissioners on their impact and why they should continue to be funded. As a result, organisations across the country have lost or run the risk of losing the financial means to continue providing the support that people desperately need. The absence of a

statutory duty to provide advocacy beyond a narrow set of circumstances also restricts attempts to persuade local authorities to invest in new non-statutory services.

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## **3. Need for a national policy home and proactive national advocacy strategy**

While several policy teams and ministerial briefs currently cover many aspects of advocacy (e.g. there is a Disability Unit within Cabinet Office and learning disability policy teams within the Department for Health and Social Care), there is currently no policy team with a clear focus on non-statutory forms of advocacy for people with learning disabilities and autistic people. This means that efforts by and on behalf of the sector to campaign for more support and funding to increase provision of and access to non-statutory advocacy are not heard or acted upon.

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## **4. Absence of a unified advocacy sector voice**

Funding cuts have led to a reduction in services, and in some instances advocacy organisations have been forced to compete against one another for funding. This competition is one of several contributing factors that have led to the fragmentation of the sector and weakened its collective voice. The result is the erosion of the sector's collective capacity for effective representation on behalf of non-statutory advocacy services. Without this collective voice, the smaller organisations that make up much of the sector face an uphill battle to influence key policy related to advocacy at the national level.

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<sup>9</sup> [Local government finances: Impact on communities - House of Lords Library](#)

<sup>10</sup> [Further funding cuts for councils would be disastrous; urgent funding and reform is needed | Local Government Association](#)



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### 1.4 Recommendations

Our research over the past two-and-a-half-years indicates that non-statutory independent advocacy services represent value for money for both the exchequer and local commissioners, while also having lasting benefits for people benefitting from services. But most services have waiting lists, are not available across the country, and are often reliant on philanthropic funding from a minority of funders such as the Henry Smith Charity. We therefore recommend that the following steps are taken to increase provision of non-statutory advocacy across the UK:

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#### 1. Enhance policy leadership for independent advocacy for people with learning disabilities and autistic people

There needs to be greater policy ownership and understanding of independent advocacy at the central government level. At present, it is unclear whether there exists a dedicated ministerial responsibility for advocacy policy, or whether there is a central government policy team responsible for non-statutory advocacy. There is a Disability Unit within Cabinet Office and a Minister for Social Care in the Department for Health and Social Care (DHSC) charged with overseeing disabilities and SEND, but this policy area is too specific for their broad remit. There is a Learning Disability Lead within NHS England but the NHS's focus has, in recent years, been on the statutory advocacy they must provide, with less of an appetite to fund or develop policy around non-statutory, community-based services. The Minister of State in the Department for Work and Pensions (DWP) has disability policy and cross-government responsibility for disabled people under their remit but also holds broad responsibilities.

A lack of clarity here causes frustration for many in the advocacy sector as people are unsure about who to approach within government regarding advocacy-related issues.

To address this issue, a dedicated policy team should be established with the aim of growing and improving independent advocacy for people with learning disabilities and autistic people.

Consideration should be given as to within which department this team should be hosted; it is likely that they should sit within the DHSC given the strong overlap between advocacy, health, and adult social care. However, close collaboration with DWP will also be important, given the links to employment and welfare. This model could be similar (and/or adjacent) to the Joint Work and Health Unit, which is jointly led by DHSC and DWP to improve employment outcomes for people with disabilities.

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#### 2. Make funding available to support the growth of the advocacy sector

Given the constraints on local government finances, it is unlikely that areas will be able to find the resources needed to launch or grow new services without an injection of dedicated funding and policy directive from central government. We therefore recommend that a **non-statutory advocacy expansion fund** should be established by central government to test a nationwide expansion of independent advocacy support. This fund could provide catalytic capital that attracts further funding from the social impact investment market. Mayoral Combined Authorities could play a crucial facilitation role in implementing and rolling out this support.

This could follow the approach used by central government to stimulate the growth of the Individual Placement and Support (IPS) model across England. Through several pilots and evaluations, the IPS model has been demonstrated to be effective and to generate a cost benefit, helping people with disabilities find paid and competitive work through intensive, personalised support. The government then provided both a policy mandate and funding for local areas to scale up the program. The NHS Long Term Plan committed to a tenfold increase in access to IPS services over a decade. The Joint Work and Health Unit allocated funds to every CCG area in England, set access targets, and assigned local areas the responsibility for commissioning and launching services. Additionally, the Joint Work and Health Unit funded a national implementation support program to help local services maintain high-quality standards, meet staff recruitment targets, and promote shared learning.

There are similarities between IPS and non-statutory advocacy in their aims to improve people's confidence and independence to allow them to participate better in society. We believe a similar funding approach to the IPS approach laid out above could be harnessed to support a high-quality, nationwide expansion of advocacy services. To support this initiative, we intend to estimate the necessary fund size and provide a detailed rollout plan for central government.

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### **3. Build capacity for collective action across the advocacy sector**

There is a clear need for a unified approach to better represent the interests of advocacy services nationwide. This would facilitate more effective sharing of evidence with government, commissioning of research, and dissemination of best practice as the sector grows. The structure for this collaboration could take various forms – whether through loose coalitions of existing organisations, formal partnerships, or another model, such as a new membership body or sector organisation, that allows for collective representation.

To succeed, it must earn the trust and backing of the sector's diverse groups, from those offering citizenship-based models to those providing intensive one-on-one support. A design phase is crucial to explore the best way forward, with input from sector organisations (such as the National Development Team for Inclusion (NDTi) and Scottish Independent Advocacy Alliance (SIAA), and All Wales People First) and people with learning disabilities and autistic people. This process will also focus on relationship-building: restoring trust and fostering collaboration across the sector to strengthen its capacity for unified advocacy.

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### **4. Support better integration of advocacy with existing health and work-based initiatives**

The new government has pledged to support initiatives designed to help more people who face significant barriers to employment into the workplace. The announcement of government-

funded programmes such as Connect to Work<sup>11</sup> and continued rollout of the Individual Placement and Support (IPS) model alongside the Supported Employment Quality Framework (SEQF) through the NHS are pertinent examples of examples of person-centred and holistic interventions that seek to improve health by helping people overcome barriers to work.

Among those who face some of the greatest barriers to work are people with learning disabilities and autistic people. We also know that the low number of people in this demographic currently in paid employment belies the far greater number who hold aspirations to work.<sup>12</sup> For this group, additional specialised support is often a crucial step to building the confidence, skills and experience needed to increase participation in the labour market.

Here we observe some obvious overlaps between the aims and objectives of advocacy and more specialised employment support for people with learning disabilities and autistic people. Both support people to overcome barriers related to gaining more confidence and independence. These can be important steps towards greater participation in the labour market. Where people have employment-related advocacy goals, there may be opportunities for closer integration of advocacy with specialised services supporting employment, education and skills. Likewise, supported employment initiatives should be prepared to refer clients to advocacy services if they present with non-employment-related issues that may be preventing them from pursuing ambitions to gain paid employment.

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11 The Connect to Work programme aims to support around 100,000 disabled people, people with health conditions and those with complex barriers to employment in England and Wales to help them into work.

12 [Mencap and NDTi research](#) of over 200 people with a learning disability found that 86% of those not in work have aspirations to enter paid employment.



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## Part 1: Summary

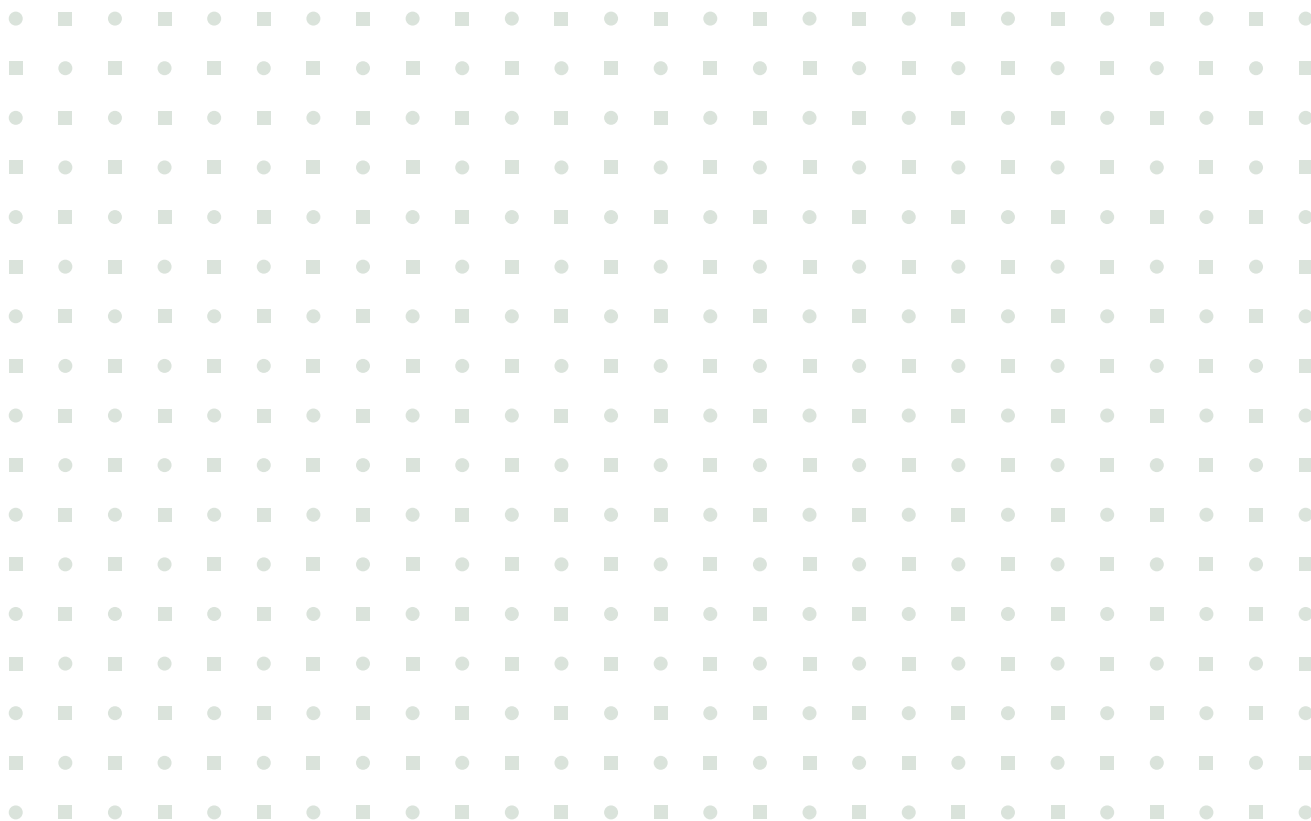
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The overall aim of these recommendations is to provide support to the advocacy sector across the UK to achieve four aims:

- Give financial stability to existing advocacy services
- Allow current advocacy providers to grow their support offer, tackle waiting lists and reach new and underserved groups:
  - People with neurodegenerative illnesses, such as Parkinson's or Multiple Sclerosis
  - Autistic people who lack social connections and are socially isolated
  - Children whose families are marginally above the financial threshold to qualify for legal aid to support in disputes around their care
  - Students with learning disabilities who exceed the threshold required for legal aid when there is a SEND tribunal and therefore find it difficult to have their voices heard

- Young people with mild learning disabilities who are in employment but who lack skills such as reading and writing
- People in residential care nursing homes who are unable to advocate for their basic needs to be met
- Autistic people and people with learning disabilities who are unable to access advocacy due to living in rural areas
- Expand provision into new geographic areas which currently do not have any advocacy provision
- Help relieve pressure on statutory services

We urge policymakers and funders to take note of the findings and recommendations presented in this report and support the sector in addressing the systemic barriers that currently prevent wider access to non-statutory advocacy. We and our partners welcome the opportunity to work together in taking these recommendations forward.



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# Part 2: Research methods and limitations

This section discusses our approach to learning and evaluation for the programme, how we worked with grantees, partners, and people accessing services to inform our research, as well as research limitations.



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## 2.1 Context to this work

The Henry Smith Charity launched a £2.6m Strategic Grant programme in 2022 to support 15 organisations (please see Table 1 on p.10 for a full list) providing non-statutory advocacy services and support for self-advocacy groups to people<sup>13</sup> with learning disabilities and autistic people across the United Kingdom. As part of the programme the Henry Smith Charity awarded a grant to Social Finance to work as the learning and evaluation partner with the grantees in a programme designed to build evidence and support the case for sustainable funding for the sector. To deliver this Social Finance worked in partnership with Speakup, a lived experience partner run for and by people with learning disabilities and autistic people to help them have a voice through self-advocacy.

Non-statutory advocacy encompasses all advocacy that is not delivered under a statutory duty to provide advocacy and can take various forms, including one-to-one advocacy, self-advocacy groups, peer and citizen advocacy, among others. Each of these models is designed to ensure that a person's voice is represented in important decisions related to their health, care, employment, education or housing.

Local authorities and the National Health Service are required by law to ensure that people have access to independent advocates in limited circumstances related to mental health and capacity to make decisions.<sup>14</sup> But many people with learning disabilities and autistic people who do not qualify for statutory advocacy benefit from advocacy support at challenging points in their lives. It is in this gap that a patchwork of smaller independent providers operates across the UK to support people to have their voices heard on key issues that impact their lives.

The non-statutory advocacy sector today faces a series of interrelated challenges. Funding for non-statutory advocacy typically comes from local authorities. However, a volatile economic climate is forcing many local authorities to navigate budget deficits by cutting services. A lack of statutory protection for non-statutory advocacy services places them at risk of losing funding, resulting in some organisations providing invaluable services and self-advocacy groups ceasing operations.

While there is a rich qualitative evidence base around how non-statutory advocacy improves lives and prevents crises, quantitative and cost-benefit analysis to support the sector in

<sup>13</sup> For simplicity, people with learning disabilities and/or autistic people are referred to as 'people' throughout this report.

<sup>14</sup> Statutory advocacy is advocacy that an individual is legally entitled to due to their circumstances. People who are eligible for statutory advocacy services are those who are being treated under the Mental Health Act 1983 or to support people to understand their rights under the Mental Capacity Act 2005, Care Act 2014 or Children's Act 1989. Statutory advocacy is completely independent from healthcare and social care providers.

making a case to both sustain and expand this valuable provision has been lacking. This programme aims to bridge this gap, taking a data-led approach to generate a body of evidence that demonstrates the value and impact of advocacy on the lives of the people who benefit from it. We hope that our findings will help make the case to strengthen and expand non-statutory advocacy provision around the United Kingdom.

## 2.2 Our approach to learning and evaluation

The overall aim of this programme was to help grantees to demonstrate their impact better and to use this to create an actionable evidence base for the effectiveness of advocacy services. This evidence base is intended to support future policy development and sustainable funding for the sector.

To achieve this aim, Social Finance developed a unique approach to learning and evaluation tailored to this programme (see Figure 2).

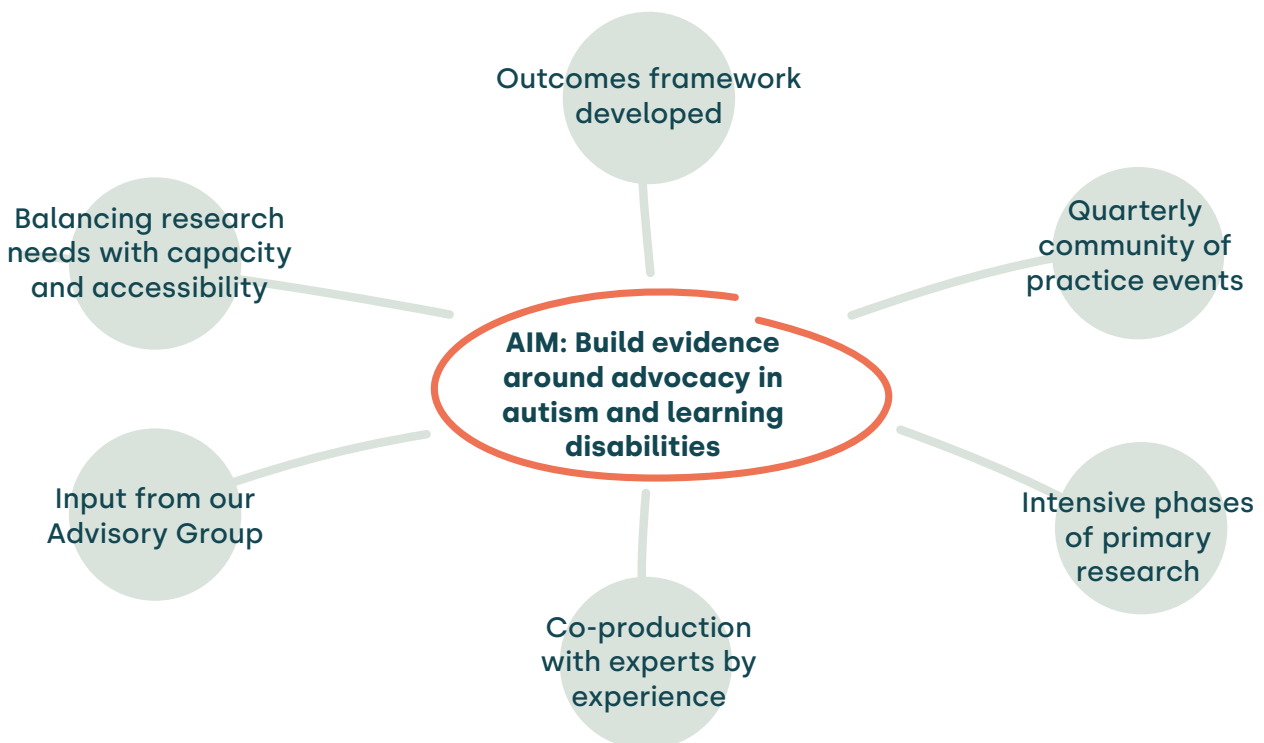
### Outcomes framework developed:

Given the lack of data in this space, we began by co-developing an outcomes framework to capture data on key fields across the programme. We spoke to all grantees as well as consulted with stakeholders in this space to come up with a simple Excel-based spreadsheet, which captures data on six key categories every six months (see the Research Methods section below for more details).

### Quarterly community of practice events:

We brought together The Henry Smith Charity, Speakup and all grantees as part of a quarterly community of practice. Each event was hosted online to encourage peer learning, share case studies, and discuss specific topics of interest to grantees, such as race equity and working with experts by experience. We also used the sessions to share and gain regular feedback on the latest findings from our work. We hosted 11 community of practice sessions by December 2024, each attended by approximately 30 people from across the programme.

Figure 2. Our approach to learning and evaluation



**Intensive phases of primary research:**

In the summers of both 2023 and 2024, we undertook deep dives into research questions informed by our data analysis and conversations with our community of practice. In each research phase, we conducted interviews, analysed quantitative data, and produced detailed outputs. These phases of in-depth primary research were complemented by light touch support (including biannual data collection and quarterly community of practice events) for the rest of the year.

**Co-production with Experts by Experience:**

From the point when the grant was awarded, we involved Experts by Experience at all stages of the programme. Our formal partnership with Speakup helped to shape the overall direction and approach to our research. For example, Speakup actively contributed to our research plan at the start of each research phase, sense-checked emerging findings, participated in our community of practice events, and provided check and challenge throughout this process. They also prepared Easy Read summaries of our reports. In addition, we incorporated user voice by seeking input from people using grantee services and groups to triangulate findings from other sources.

**Input from our Advisory Group:**

As part of this programme, we convened an advisory group of experts from across the sector including academics, commissioners, charities,

and experts by experience (a full list of members is included in the appendix). By acting as a sounding board, they helped us ensure we were asking the right questions as well as approaching research findings with a systems change lens. Their input was gathered regularly through both one-to-one conversations and advisory group meetings.

**Balancing research needs with capacity and accessibility:**

Across our work, we were careful to balance the need to build more evidence with the capacity constraints of grantees and accessibility needs. We tailored data collection to a format and frequency that suited grantees, and we were strategic in how we used their time. We developed and used Easy Read materials for all our outputs, and complemented these with more detailed versions featuring illustrative charts and graphs. All our meetings and community of practice events were tailored to participants' accessibility needs (e.g. in their duration, format, content).

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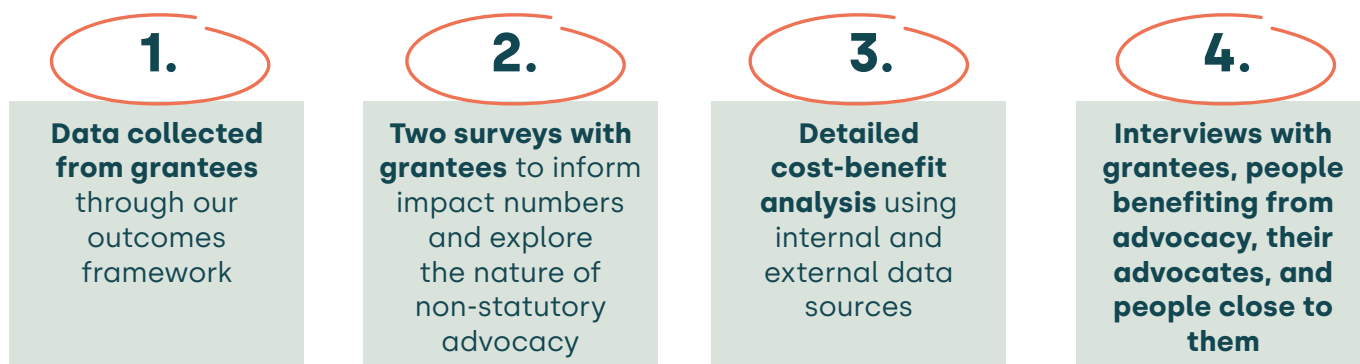
**2.3 Research questions and methods**

This report responds to five key questions (see Figure 3). These questions were informed by analysis of data collected from grantees through our outcomes framework (outlined in the appendix) and conversations with The Henry Smith Charity, Speakup, Advisory Group and grantees.

Figure 3. Key research questions



Figure 4. Sources of data used in the methodology



To answer these questions, we used a bespoke mixed methods approach that built on the findings of an interim report published as part of this programme in 2024. The approach included data from four sources, shown in Figure 4. The analyses were synthesised and triangulated, with findings used to draw conclusions on the research questions and provide recommendations for policymakers and funders.

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### 1. Data collected from grantees through outcomes framework

At the beginning of the programme, we built an Excel-based outcomes framework to gather quantitative data on grantees' work with people. Through consultation with grantees, The Henry Smith Charity, Speakup and other stakeholders in this space, we identified six data categories within the framework:

- **Demographic data:** (e.g. age, gender, ethnicity, and diagnosis)
- **Referral information:** (e.g. referral source, location at referral, social care package at referral)

- **Timing and nature of support received:** (e.g. date of referral, duration of support, description of support provided, number of contacts with services/groups)
- **Advocacy goals:** (e.g. goal category, description of goal). These goals were self-defined by people accessing support.
- **Advocacy success outcomes:**<sup>15</sup> self-reported advocacy success outcomes across seven categories (collected for those accessing one-to-one advocacy support):
  - Speaking up
  - Knowledge of rights
  - Knowledge of local services
  - Good relationships
  - Happiness with life
  - Feeling listened to
  - Learning new skills
- **End of support information:** (e.g. goal achievement information, location at the end of support)

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15 Advocacy success outcomes were co-produced with grantees and sector experts based on known 'soft' outcomes that describe some of the ways that people benefit from advocacy beyond whether it leads them to achieve their advocacy goals. Advocacy success outcomes were self-reported by people accessing one-to-one support and recorded by their advocates, once at the beginning of support and again at the end of support. We recorded scores on a scale of 0-2 where 2 = 'Yes', 1 = 'Maybe/A little bit', and 0 = 'No'. Comparing scores at the beginning and end of support revealed the impact that non-statutory advocacy is having across these categories. During programme implementation, these outcomes were known as 'process outcomes'.

We used this framework to collect individual-level data from all grantees on a six-monthly basis. Where data collection was not possible (e.g. for participants in self-advocacy groups), grantees were encouraged to provide aggregated data on as many data fields as possible. We completed five full rounds of data collection in December 2024 and analysed this data to build the figures and descriptive statistics<sup>16</sup> presented throughout this report.

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### 2. Survey of grantees to inform qualitative findings and impact numbers

We designed and ran two surveys using MS Forms with grantees. The first survey was conducted with all grantees<sup>17</sup> in 2023 to inform our qualitative findings around the nature of non-statutory support and the value that it creates for people and the different services with which they interact. The findings of this survey contributed to the interim report that was published in 2024 as part of this programme (summarised in sections 3.1–3.4 in this report).

The second survey was conducted in 2024 to gather quantitative data from grantees to help estimate the financial benefits of advocacy. As part of this survey, grantees were asked to estimate the number of cases where grantees supported an individual to move from accessing high-cost support to lower-intensity and more appropriate forms of support. All 15 grantees completed and submitted the survey, and these figures have been incorporated into the cost-benefit analysis. The survey estimated case numbers around four high-cost case categories over the 2023–24 financial year:

- Step down from hospital to supported living
- Step down from hospital to independent living
- Preventing a child or young person from going into care

- Supporting a person to move from supported living to independent living

The cost-benefit analysis section later in the report presents a detailed discussion on these high-cost categories.

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### 3. Indicative financial cost-benefit analysis using internal and external data sources

Over the past two-and-a-half years, we have worked with grantees to capture data around the impact of their services through our outcomes framework (described in the previous section), and to understand how these services make a difference in people's lives. Combining these insights from grantees with external data sources, we have conducted an indicative financial cost-benefit analysis (CBA). The cost-benefit analysis section later in this report includes a detailed step-by-step guide to our methodology.

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### 4. In-depth interviews with grantees, partners and people using services and groups

We conducted detailed case studies with two people who use grantee advocacy services and groups. Data collection for these case studies was carried out through semi-structured qualitative interviews with the person receiving advocacy,<sup>18</sup> their advocates and people close to them. The questions that guided these interviews were specifically designed to answer questions related to:

- When and why a person decided to access advocacy
- Interactions with statutory support before accessing advocacy
- The support provided by the grantee to the person and what impact this had
- Ongoing needs and support

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16 Descriptive statistics provide simple summaries about the sample and about the observations that have been made. Such summaries may be either quantitative (i.e. summary statistics), or visual (i.e. easy-to-understand graphs).

17 The survey was completed by 13 of the 15 grantee organisations.

18 An interview with 'Candice' was not possible in her case study due to her communication challenges. In this case study, we spoke only with her mother and her advocate, who were able to share information from the case on her behalf.



Questions around these topics were used to produce the two case studies featured in this report (see Section 3.6), both of which demonstrate the high level of impact that advocacy can have on people's lives to access services and address their needs. The case studies helped us to understand people's stories and their experiences with advocacy in detail, and bring to life the quantitative data captured elsewhere including in the cost-benefit analysis. The detailed case studies presented in Section 3.6 are complemented by several shorter case studies gathered from grantees throughout the programme, some of which are included throughout this report.

In 2023, we spoke to six people using grantee groups and services, using in-depth interviews to investigate how grantees work with people and the impact of their support. Their views were incorporated in findings for our interim report, which this report builds upon.

Throughout the duration of the programme, we also regularly spoke to grantees through one-to-one conversations as well as community of practice events. We conducted 14 in-depth interviews with grantees over the past two-and-a-half-years to understand how they work, and the specific facilitators and barriers they faced. Their insights have consistently informed our work, including the interim report, our theory of change, and this report.

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## 2.4 Research limitations

While our objective has been to try and build robust quantitative data and evidence in this space, there are limitations on how quantifiable some of the findings are given the nature of services. We are not aware of any counterfactual studies or Randomised Control Trials (RCTs) of non-statutory advocacy services. In their absence, it was necessary to make assumptions about attribution based on triangulating qualitative

research, academic literature and interviews with experts in the field. Where we had to make judgements, these are explicitly stated, and we have been prudent to evidence the assumptions we made.

Similarly, it remains difficult to capture detailed individual level data for people accessing self-advocacy or group advocacy through our outcomes framework (besides aggregated data). While we have been able to include some individual-level data from attendees of self-advocacy groups, some grantees did not have the capacity to capture this data, which reduced the sample size of data for analysis. Improving data collection processes could be a potential area for future capacity building so that these groups can better demonstrate their impact.

Based on feedback from advisory group members, we also sought to include perspectives from comparable statutory services in areas where grantees operate. However, we did not receive any responses to our request for contact details except from one grantee (which we followed up on). In lieu of this, we relied on the literature and online sources to understand how statutory advocacy services operate. This approach allowed us to compare and contrast the ways that statutory and non-statutory services support people.

We relied on grantees to access and speak to people using their services. This reliance could have led to biased sampling and a tendency for grantees to present more positive or 'successful' cases for interview candidates. There was also a risk of bias around the case studies presented, which were selected and shared with us by grantees. All our analysis was based on data reported by grantees and collected as part of this programme. Where possible, we attempted to triangulate findings through one-to-one conversations with people benefitting from advocacy, community of practice sessions, and wider qualitative research.

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# Part 3: Findings

This section discusses our findings on the value of non-statutory advocacy, how it helps people, and the impact it has on people's lives



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## 3.1 What support does independent and non-statutory advocacy provide?

The findings set out here are based on research carried out with the 15 grantees that participated in this programme. These organisations include representation from across the UK,<sup>19</sup> with two organisations each from Scotland and Wales joining 11 others from England. Grantees were spread across diverse geographies, ranging from smaller but highly ethnically diverse inner-city areas to larger and more rural areas presenting location-specific challenges to delivering and supporting advocacy. Grantees also differed in size and scale and whether they also provided statutory advocacy as part of their suite of services.

Across the programme, grantees delivered non-statutory advocacy across a spectrum of different advocacy models. While some focus on providing general and specific issue-based one-to-one advocacy, others provide support for facilitators of self-advocacy groups. Several of the grantees offer different forms of both one-to-one advocacy and self-advocacy:

- **General issue-based one-to-one advocacy:** Independent advocates support individuals to

access information, make meaningful choices about their circumstances and communicate these choices to others. Support is flexible and adapts to the needs of people to help them speak up on a wide range of person-led issues.

- **One-to-one advocacy in specialised situations:** Independent advocates specialised support to help people to have their voices heard in specific circumstances. For example, at least two grantees offer specialised support for parents navigating child protection procedures. Other grantees work specifically with children with severe communication challenges who were ineligible to receive statutory advocacy support and required the use of non-instructed advocacy techniques.
- **Self-advocacy groups:** Self-advocacy typically refers to groups that promote individuals' ability to have a voice to speak up for their rights and have control over their own lives. Organisations promoting self-advocacy typically aim to provide a space for people to get together and develop skills to speak up as individuals or with their peers about their experiences. The regular group sessions are chaired, and agendas are set, by people with learning disabilities.

<sup>19</sup> The Henry Smith Charity set out to include a broad coalition of advocacy organisations based around the United Kingdom in this programme, including at least one organisation from Northern Ireland. Despite efforts to identify a suitable grant candidate, this search proved unfruitful. The 15 grantees are therefore based across England, Wales and Scotland.



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## Part 3: Findings

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Although grant funding as part of this programme was awarded to support grantees to continue or expand their advocacy activities under the models above, several of them are also involved in supporting community advocacy, peer advocacy and citizen advocacy. Although there were variations in how advocacy was delivered, our survey from 2023 identified similarities in how grantees articulated their purpose and how they defined success:

- Providing free, independent and confidential advocacy support
- Supporting people to have their voices heard and to exercise their rights
- Helping people to make informed decisions about issues that are important to them
- Supporting people to access services, maintain independence and self-advocate

Grantees repeatedly highlighted how the different forms of non-statutory advocacy complemented each other, supporting people with different issues and at different points in their progress toward developing the confidence and ability to speak up. Many grantees said they wanted to expand their services to incorporate additional models of advocacy but were unable to do so due to capacity and funding constraints.

Working with grantees, we created a theory of change for non-statutory advocacy services at both a service/organisation and system level. Please see the appendix for the full theory of change model, including inputs, activities, outcomes, facilitators and barriers.

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### 3.2 How do grantees' services differ from advocacy?

Statutory advocacy is advocacy that an individual is legally entitled to due to their circumstances. Statutory advocacy services are available to individuals who are being treated under the Mental Health Act 1983 or to support people to understand their rights under the Mental Capacity Act 2005 or Care Act 2014. Statutory advocacy is also provided under the Children Act 1989, supporting the right of looked after children to make representations and complaints to a local



I think there's a real need for some sort of group advocacy in terms of [what] this group would need. And we've had these conversations in the office quite often. I've got five clients who are all having issues with the local housing provider. They're all having the same issues, but none of them want to complain. Whereas I'm the advocacy provider and I can see what's happening. Should I complain [on their behalf]? So it's this balance, and it's one of those things that at the moment we haven't got the resources and we haven't got the time to do that.



**Advocate – grantee organisation**

authority regarding their care arrangements. Statutory advocacy is independent from healthcare and social care provisioning.

Non-statutory advocacy is advocacy that is not governed by IMHA (Independent Mental Health Advocacy), IMCA (Independent Mental Capacity Advocacy), CAA (Care Act Advocacy) or Children's Act legal frameworks. Instead, it supports individuals to have their voices heard across a wide range of issues and life events, from accessing services to helping someone make a complaint regarding abuse, harassment or victimisation. Non-statutory advocates can, for example, also support a person by talking to third parties, writing letters, making phone calls, and

## Part 3: Findings

preparing for and attending important meetings with them. Like statutory advocacy, support from non-statutory advocacy is free to access.

Grantees highlighted several areas in which they felt that non-statutory services added value:

- Support in issues not covered by statutory advocacy
- More flexible and tailored support
- Longer-term support
- Greater focus on building trust and close relationships

### 3.3 Who did grantees work with?

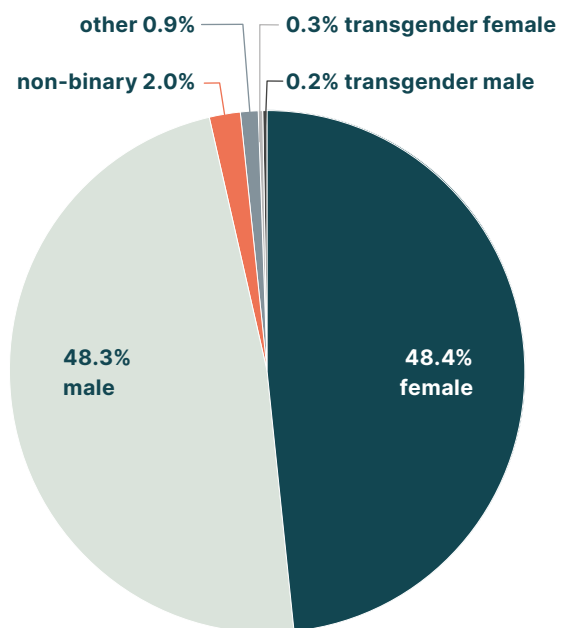
The Henry Smith Charity funding for this programme allowed grantee organisations to provide support to 1,667 new people.<sup>20</sup> The findings in this report draw on an analysis conducted on the detailed individual data for 1,626 people submitted by the grantees through our outcomes framework in December 2024. Grantees reported difficulties in completing the outcomes framework in cases where people had severe communication challenges, or when collecting data was a secondary priority when building advocacy relationships with people showing high levels of distrust of services. Likewise, there were specific challenges related to data collection for those participating in self-advocacy groups due to the group format and collective nature of goals and progress. For these reasons, it was not possible to collect individual-level data for all the people reached as part of this programme.

#### Male and female genders accessed advocacy equally

Our data reveals an equitable split in access figures for binary male and female genders. However, the percentage of people accessing grantee groups and services who identified as a gender different to the one they were assigned at

birth was higher than we would expect to see based on census data (0.5% vs 3.4%). This was not unexpected given what we know about the specific challenges faced by people at the intersection of disability, autism and trans, non-binary, gender-non-conformity or intersex (TNBI). This group is likely to be accessing advocacy at a higher rate due to a greater risk of experiencing multiple unique forms of discrimination and marginalisation that may impact on their ability to participate in education, work, and wider society.

Figure 5. Advocacy access by gender



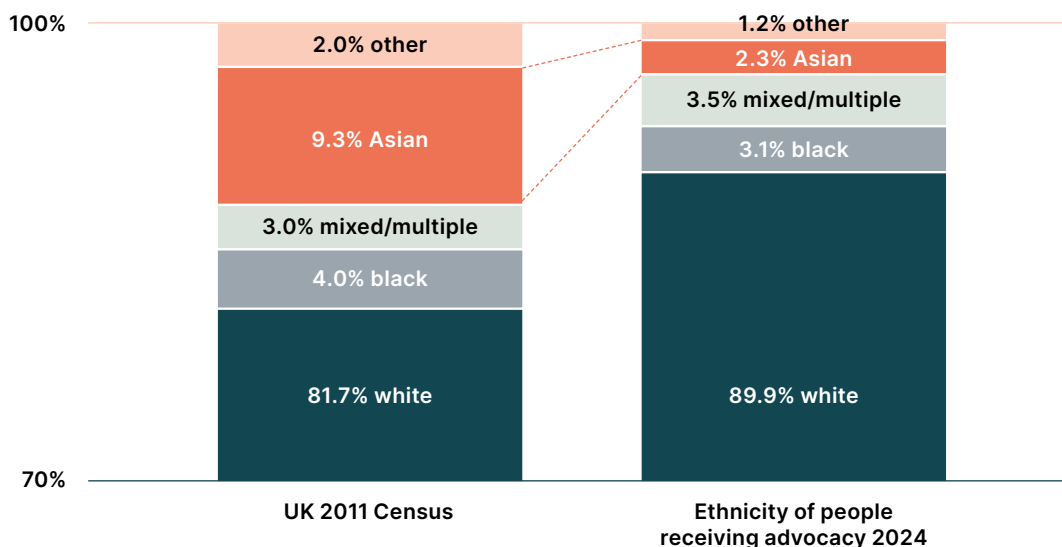
#### More work is needed to support people from Asian ethnic backgrounds

Compared with the ethnic breakdown of the United Kingdom as a whole, people of Asian ethnicities were underrepresented in grantee services and groups, based on the 2011 Census, the latest harmonised dataset for England, Scotland, Wales and Northern Ireland.<sup>21</sup> The percentage of the population self-identifying as Asian in the UK as a whole is 9.3%, whereas this percentage was 2.3% among people using grantee services and groups.

<sup>20</sup> 'New' people are those who registered during the programme and were previously unknown to grantee organisations.

<sup>21</sup> Harmonised data for more recent censuses in England and Wales (2021), Scotland (2022), and Northern Ireland (2021) is not yet available.

Figure 6. The ethnicity of people receiving advocacy support



Note: Ethnicity data from the 2021 Census has not yet been harmonised between the Home Nations.

The 15 grantee organisations in the programme operated in England, Wales and Scotland, across both rural and urban settings, all of which have discrete ethnic population breakdowns. It is unlikely that the combination of these populations was representative of the overall UK population. However, the underrepresentation of Asian ethnicities highlighted by the data comparison above supports qualitative findings from interviews conducted with grantees in which several barriers to accessing advocacy among this group were cited, including:

- Gaps in language capabilities within advocacy organisations and a low awareness of advocacy among minoritised communities
- Potential cultural misconceptions of the nature of advocacy, what it is and who it is for
- Stigmatisation of autism and disability combined with a preference for family-based support which might lead to people being cared for within families and communities

Regardless, this is clearly an area of improvement for advocacy services which requires stronger prioritisation as well as additional funding and use of culturally sensitive approaches to expand access.

### Advocacy supported people across different age groups

Our data shows a wide distribution in the age of people accessing grantee services and groups (see Figure 7), with the 30–39 age group being the most prolific users of advocacy (24.1%). Young adults in the 18–24 and 25–29 age ranges captured in the outcomes framework also accessed advocacy at high rates with 16.2% and 10.9% people falling within these age ranges, respectively. Combined, this means that 27.1% of people supported by grantees were between the ages of 18–29. The substantial number of people participating in advocacy between the ages of 18–29 likely received support with building life skills, confidence, empowerment and wellbeing at the transition points between formal education and adulthood. Given the lifelong nature of learning disabilities and autism, the role that advocacy plays at this point in a person’s life can have a dramatic impact on a person’s ability to be independent later in adult life and have long-term benefits around improving social inclusion.

It is also notable that just under half (41.9%) of people who used grantee service and groups were aged 40 or above, demonstrating the important role non-statutory advocacy is playing in supporting people throughout their life. The

Figure 7. Age distribution of people accessing grantee services

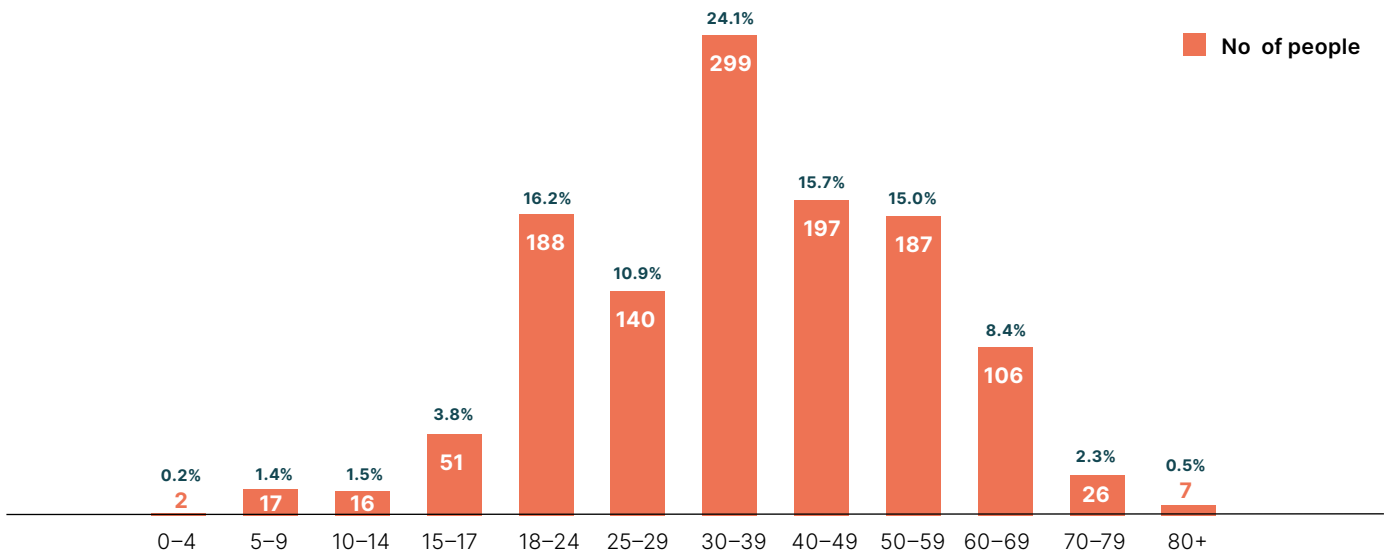
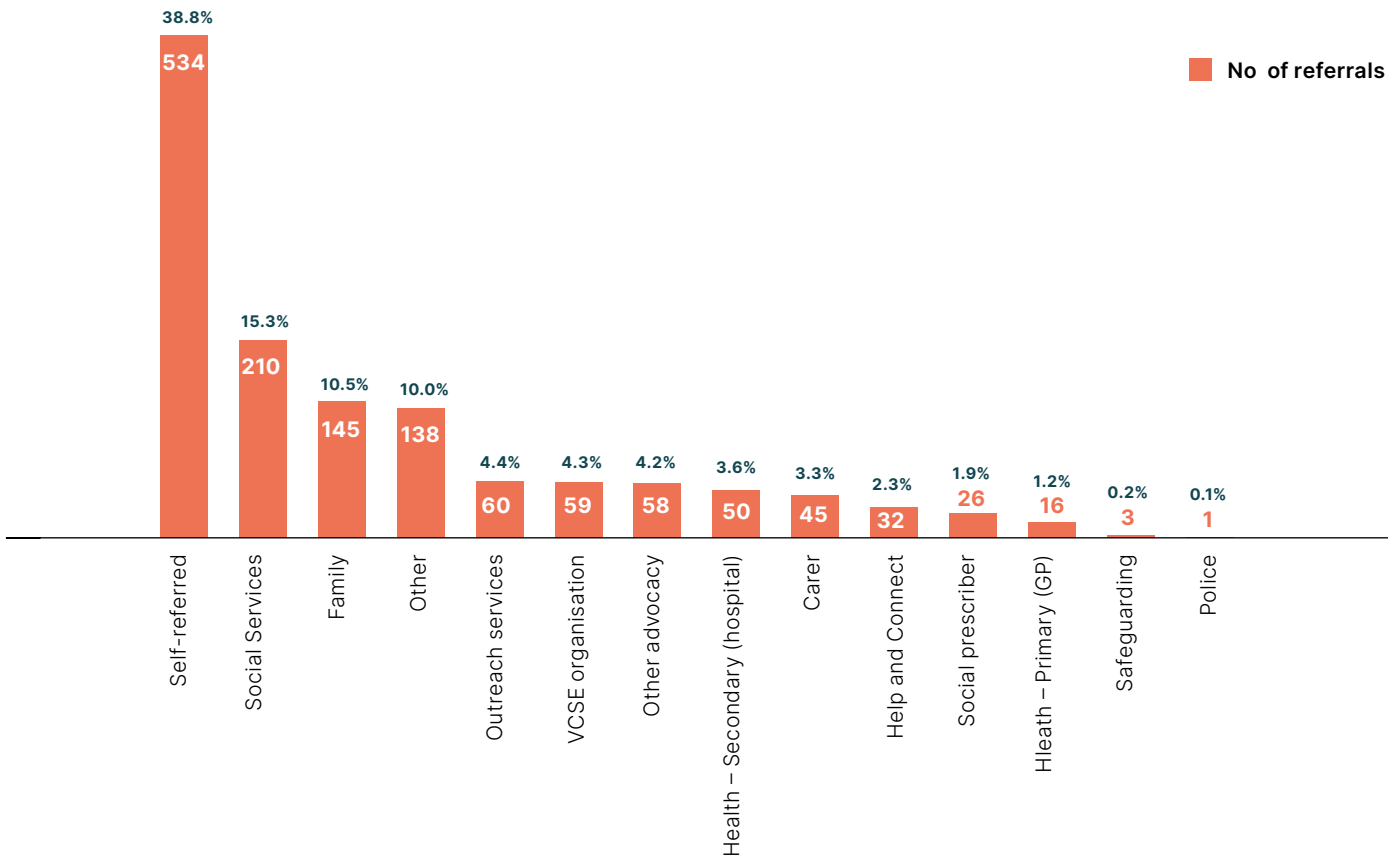


Figure 8. Referral sources



numbers of people accessing groups and services diminished progressively through the higher age brackets. This drop off was likely due to a combination of several factors, including lack of

timely diagnosis for older generations, and persistently poor life expectancy for people with learning disabilities.

### Most people came to advocacy through self-referral

As shown in Figure 8, the most prolific referral route into grantee services and groups was via self-referral (38.8%), some way ahead of the next most common referral sources, which were through social services (15.3%) and family (10.5%).

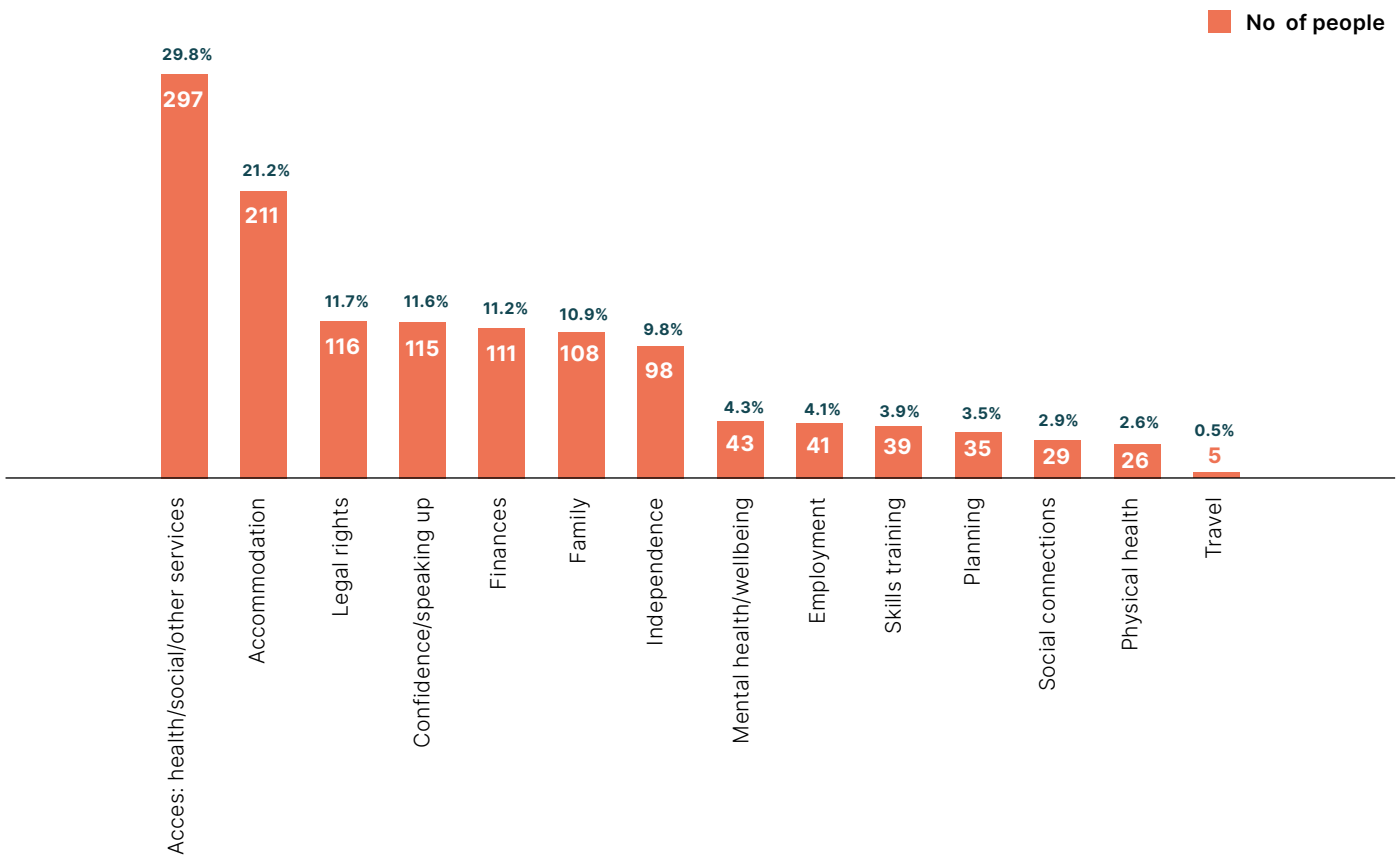
Relatively few people came to advocacy through referrals from other VCSE organisations (4.3%), health (combined primary and secondary, 4.8%), and other services. The low number of referrals from these sources is likely explained by a general lack of awareness among VCSE organisations and statutory services of the existence of non-statutory advocacy and who is eligible to receive it. This data clearly indicates a need for better integration and clearer referral pathways between non-statutory advocacy

support and health and social care services that autistic people and people with learning disabilities typically have extensive contact with throughout their lives.

### 3.4 What did people using these services need and receive from advocacy?

Data showed that the most common primary goal category for individuals using grantee services was to access health services, social services or other services (29.8%), followed closely by support with accommodation (21.2%). Legal rights goals (11.7%) and goals related to confidence and speaking up (11.6%) were the third and fourth most common goals, respectively. Primary goals related to finances (11.2%), family (10.9%) and independence (9.8%) were also prevalent. The remaining goals were relatively equally distributed across the other goal categories.

Figure 9. Primary goal categories



## Case study: 'Mary'

'Mary'\* has been known to one of the grantees for several years. She has required one-to-one advocacy on and off and has maintained regular contact with services throughout the years. Mary has experienced gender-based violence and her children were removed from her care. She is very isolated and has no support or contact from family and friends.

Last year, Mary was working intensively with her advocacy worker who was supporting her with various issues like finances, contact with her children, housing, and supporting her to speak to the police. The grantee organisation's relationship-based approach meant that her advocacy worker got to know Mary very well and started to identify changes in Mary's mental health.

Over several weeks, Mary's advocate started to observe worrying signs that Mary's mental health was deteriorating. This was also observed by other colleagues at the organisation. Mary was discussed regularly, and the team shared any concerns with her allocated advocacy worker. Unfortunately, the concerns escalated, and Mary's advocacy worker contacted mental health services and submitted an Adult Protection referral to social work. There was a slight delay in response from both services, and Mary hit crisis. Mary could not recognise she was unwell and began to feel frustrated with her advocacy worker when they expressed concerns to her. Mary refused to talk with mental health services, and they asked us for support. Working collaboratively, Mary was taken to hospital for the treatment she needed and detained under the Mental Health Act.

Initially, Mary was angry that her advocacy worker and other staff had helped facilitate her going into hospital but as she started to feel better, she began to understand how unwell she had been. Mary's advocacy worker gently reminded her about the organisation's safeguarding policy and how staff need to share information with other services when they are concerned for her well-being. Mary's advocacy worker visited her in hospital regularly and helped her understand her rights and advocated accordingly. The advocacy worker and our other staff helped to make arrangements with social work for her pets and made sure she had everything she needed whilst in hospital. When Mary was discharged, she thanked her advocate for everything they had done for her. She could understand why the organisation had been so concerned for her and appreciated that she needed to be in hospital.

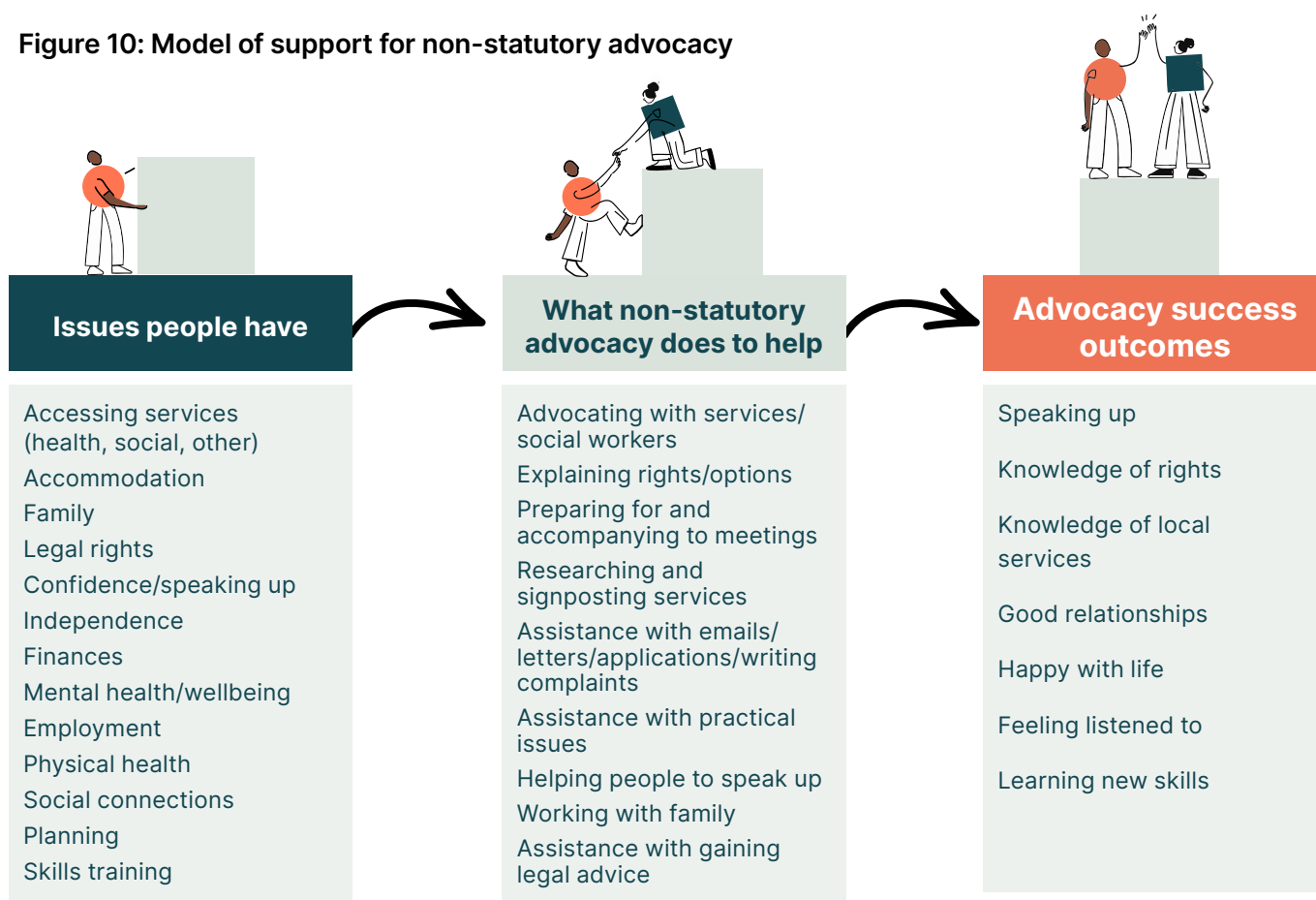
Mary's mental health has massively improved. Her advocacy worker supported her to apply for an energy grant which has paid all her debt and provided a grant for new carpets, a fridge and a mattress to help get her life back on track. She now receives regular support from the mental health team and has a package of support from social services.

\* Names in case studies in this report have been pseudonymised to protect the identity of the people concerned.

The goal categories featured in the outcomes framework were broad by design. From the outset, we were conscious that the complexity of people's lives and circumstances would mean that goals would in many instances span two or goal categories at the same time. Our outcomes framework remained flexible to accommodate this.

Indeed, we may gain a true sense of non-statutory advocacy's ability to support people by understanding goals that do not neatly fit within a single category. The qualitative data we collected on the nature of the goals themselves beyond their categorisation indicates that many of the issues for which people accessed advocacy are the

Figure 10: Model of support for non-statutory advocacy



products of complex causal factors. Such issues are often interrelated and systemic, requiring advocacy support to be delivered in a way that is highly adaptable, holistic and radically person-centred. These are qualities that are often lacking in people’s interactions with statutory services.

Figure 10 illustrates the key issues or areas of advocacy support, the nature of advocacy activities, and the advocacy success outcomes for people receiving support from grantees.

Given the wide range of different goals for which people accessed advocacy support, it stands to reason that the nature of support provided by advocates is equally broad. From the data and interviews conducted with grantees and people participating in advocacy, we observed several key elements of support being offered, including but not exclusively:

- **Signposting:** Advocates and advocacy groups generally have in-depth and first-hand knowledge of the local service environment and

can help people become aware of and access these services.

- **Contacting professionals:** Advocates and advocacy groups can assist a person by supporting them to contact professionals and helping a person to speak up regarding their wishes, views and complaints related to their current circumstances and care.
- **Attending meetings:** A key element of support relates to advocates attending key meetings with professionals. In meetings, advocates will ensure that professionals are held to account around their duties and commitments and that the conversation remains person focused. They will also typically take notes, ready to play back to a person following the meeting.
- **Debriefing and planning next steps:** Following meetings, advocates play an important role in ensuring that people they support understand the information shared in meetings and their implications. They will then assist a person to plan next steps.



## Case study – ‘Jennie’

A solicitor referred ‘Jennie’,\* a young mum with learning disabilities. The solicitor had worked with advocacy before and felt Jennie would benefit from having an advocacy worker herself. The advocacy worker met with her, and quickly established a positive trusting relationship.

The advocacy worker supported Jennie’s understanding of legislative processes involving her child, her own rights and maximised her participation in these processes. The advocacy worker also supported her to attend social work meetings, prepare for and attend children’s hearings, and arranged individual meetings with professionals to discuss the plans for her child. The social work coordinator thanked advocacy for being on board, stating that, ‘since advocacy has been involved, the mum has managed meetings much better and presented much calmer than before’.

Prior to having advocacy, Jennie struggled to attend meetings and was distrusting of services. Advocacy supported her to engage with services and repair fractured relationships. Things are looking more positive now and she has received positive feedback from others working to support her. Jennie was delighted recently to be informed that social work was now considering assessing her to have her older child, who resides in foster care, returned to her care.

\* Names in case studies in this report have been pseudonymised to protect the identity of the people concerned.

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### 3.5 What was the impact of advocacy services and groups?

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#### Advocacy success outcomes improved across the board

The advocacy success outcomes that feature in the outcomes framework were co-designed with grantee organisations to make them as user-friendly as possible to respond to as possible. The outcomes framework allowed people to self-report scores for seven advocacy success outcome categories on a scale of 0–2, where 2 = ‘Yes’, 1 = ‘Maybe/A little bit’, and 0 = ‘No’. Grantees collected beginning and end scores for 583 individuals who used groups and services.

At the start of support from advocacy services and groups, people reported average scores of 0.80 across the seven advocacy success outcomes. This means that people were generally responding with either ‘No’ or ‘Maybe/A little bit’ to questions such as ‘Do you feel happy with life?’ By the end of support, average scores had improved to 1.49, meaning that participants were answering either ‘Maybe/A little bit’ or ‘Yes’ to the same questions.

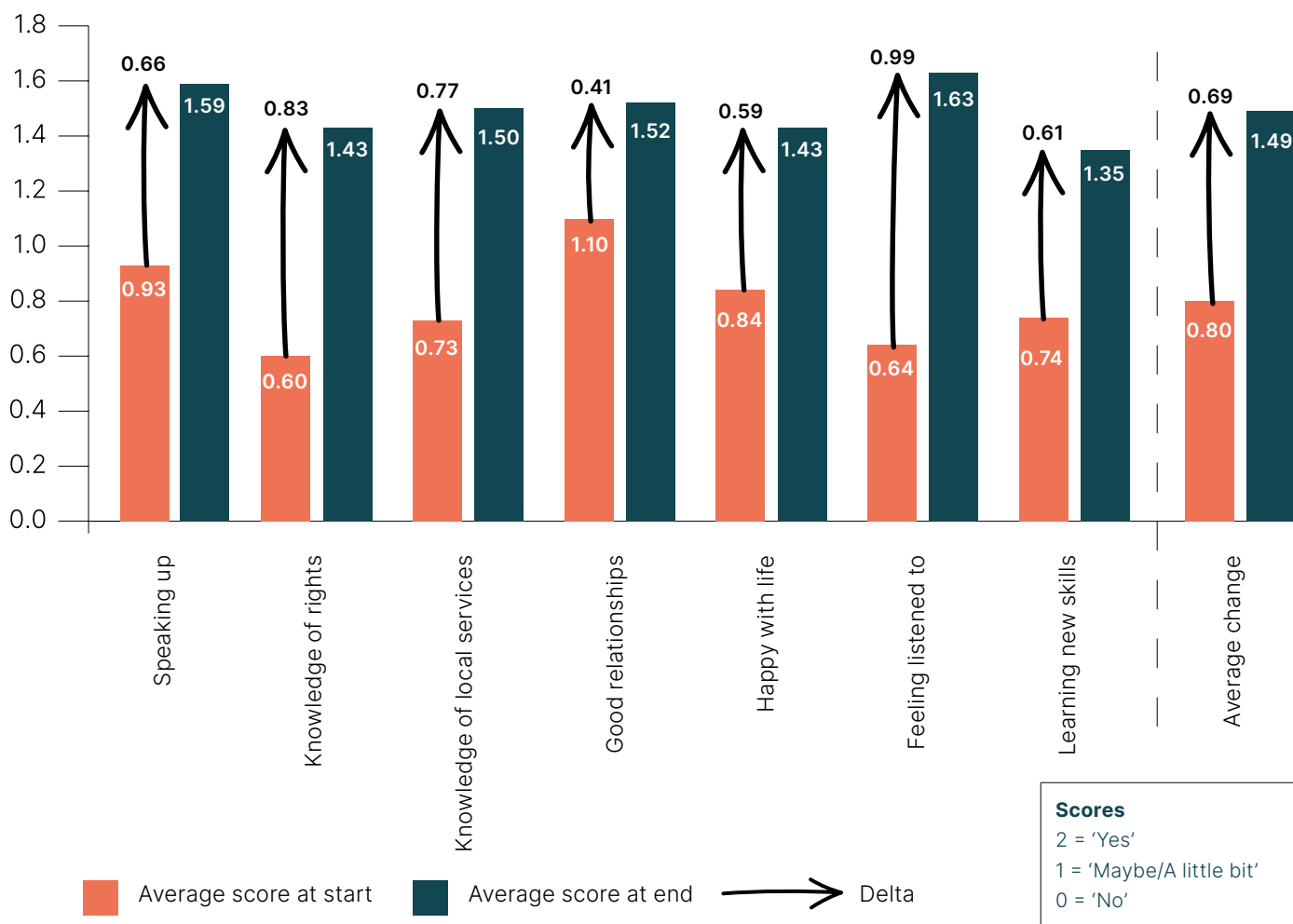
The three advocacy success outcomes that saw the greatest positive change were ‘Feeling listened to’ (+0.99), ‘Knowledge of rights’ (+0.83), and ‘Knowledge of local services’ (+0.77).

Meanwhile, advocacy success outcomes that saw relatively smaller positive changes were ‘Good relationships’ (+0.41), ‘Happy with life’ (+0.59), and ‘Learning new skills’ (+0.61). These three outcomes are likely impacted by advocacy in a more indirect way than other outcomes that saw greater positive changes. Therefore, we might logically expect them take a longer period of time to see an impact compared with outcomes that address acute issues such as gaps in knowledge and feeling that you are not being heard.

A notable gap exists in the average score changes between the ‘Feeling listened to’ (+0.99) and ‘Speaking up’ (+0.66) outcomes. The greater improvement in ‘Feeling listened to’ relative to ‘Speaking up’ corroborates findings from interviews with grantees and the people they support. By their nature, advocacy services and groups aim to help people to have their voices heard, which applies to people who are already speaking up but feel like they are not being listened to. As grantees and the people they



Figure 11: Change in average advocacy success outcome scores from start to end of support



support pointed out, in some cases, people first engaging with services and groups are already capable of expressing their choices and desires (as demonstrated by the relatively high starting score of 0.93 for 'Speaking up'), yet can feel that their voices remain unheard until they are supported by an advocate.

For these people, the issue is not one of feeling ill-equipped to speak up but rather a feeling that one's choices and desires do not play apart in decision-making processes. We heard in interviews with advocates, people benefitting from support and their family members that a core benefit of advocacy often lies in simply having someone independent with greater perceived authority in the room (i.e. an advocate). This can motivate professionals to start paying attention to what a person has already been saying.

In other cases, people often do not feel able to speak up, especially in the early stages of advocacy, and it is often their advocate who speaks up on their behalf. The confidence and ability to speak up on their own may take longer to develop, with the act of speaking up itself not necessarily the only way that someone can feel like their wishes are being listened to.

Scores at the end of support for both 'Speaking up' and 'Feeling listened to' are similar, indicating that advocacy is helping people to feel equally that they can express their needs and opinions, and feel like these are having a real impact on decision-making processes. This is positive as it suggests that advocacy is playing a role both in equipping people with the skills to convey what they want and to engage with services and professionals in a way that increases their ability to be heard.

## Case study – ‘Mario’

As part of the project funded by Henry Smith, a grantee organisation advocated for ‘Mario,’\* a 20-year-old autistic young person, with selective mutism. Mario was referred to the grantee following an education health and care plan (EHCP) tribunal. At a tribunal hearing, an order had directed that Mario should have an independent advocate to find out his views about education and his learning support needs.

Timescales were tight for the tribunal, so the advocate arranged to visit Mario at home. Mario agreed to the meeting. However, it was very challenging to gather Mario’s views during the visit due to his selective mutism: People with selective mutism will generally only be able to speak once they have established rapport with someone and feel comfortable. Initially Mario was reluctant to even enter the room when the advocate was there. The advocate offered a range of communication options including writing, typing, and using visuals. Mario agreed to remain in the room and indicate his feelings using the visual aids. This then prompted a wider conversation about Mario’s previous experiences and challenges at college, and what provision he wanted in the future. Mario was willing to speak at this point, though only with a family member in the room to support him.

Following this visit, the advocate was able to create a ‘wishes and feelings report’ for tribunal, which Mario agreed could be shared with his solicitor and the judge. The tribunal outcome was that Mario did not have to return to college, and that the Local Authority would provide online tuition, which is what Mario had wanted.

It was felt that if the advocate had been given more time, she would have undertaken more visits, with a view to reaching a point where Mario might agree to speak to her alone. Nevertheless, given the short timescales, it was positive that Mario’s views were represented via the advocate’s report: it is highly unlikely he would have been able to attend the tribunal hearing and speak for himself. It is also positive that judges and local authorities want to hear directly from young people about their educational aspirations, rather than relying on parents’ and carers’ views. However, without Henry Smith Charity funding, the grantee stated that they would not have been able to undertake this work, and they were not aware of any other fully independent service that existed exclusively to support children and young people to put forward their views during the SEND tribunal process. They have since taken a second referral for another young person, who needs support to give their views for an EHCP tribunal.

\* Names in case studies in this report have been pseudonymised to protect the identity of the people concerned.

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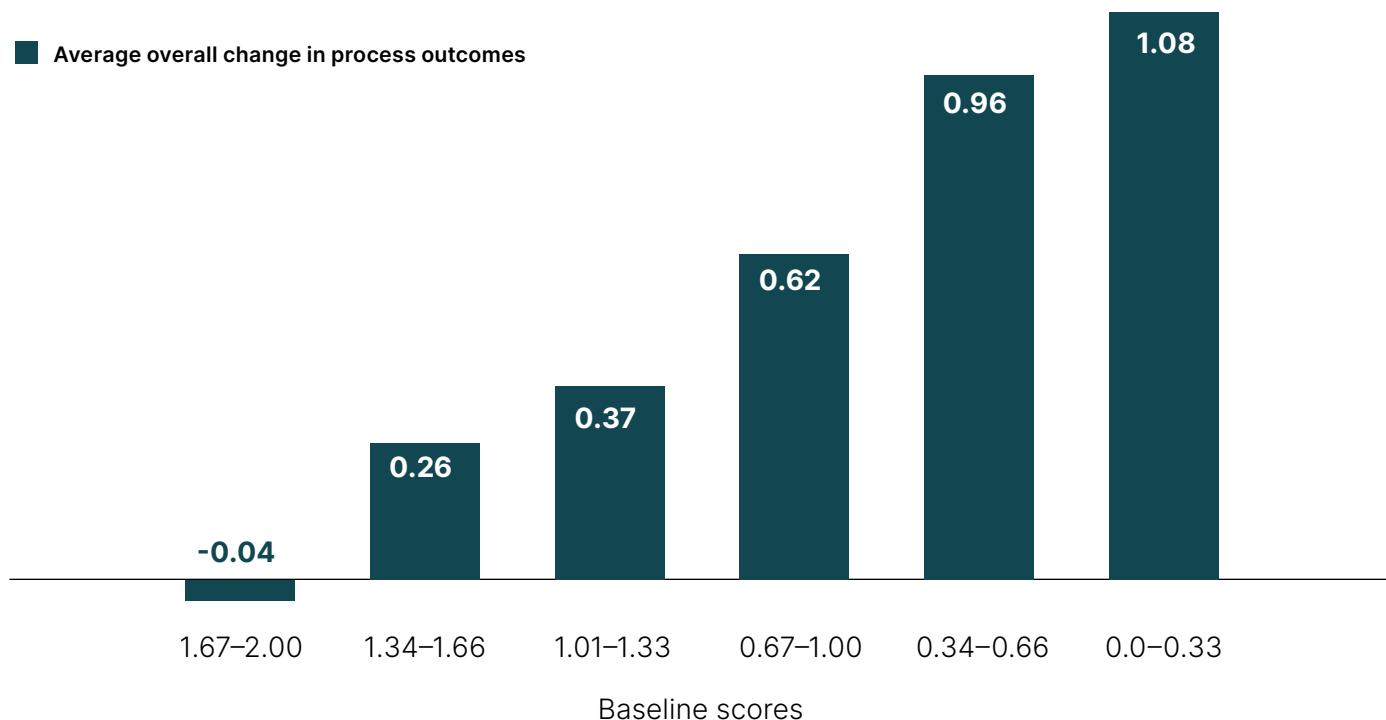
### **Advocacy was helpful for those with high levels of need**

Analysis shows that individuals who entered advocacy services with the lowest scores in advocacy success impact indicators such as ‘Speaking up’, ‘Feeling listened to’ and ‘Knowledge

of local services’ were those who saw the largest benefits throughout their engagement with the programme. As part of our analysis, we stratified average baseline scores<sup>22</sup> across the seven advocacy success outcomes into equal groups. From this, we observed that the most profound change in average success outcome scores from the start to end of support were reported by those

22 Self-reported scores collected by grantees at the beginning of advocacy support.

Figure 12: Average overall increase in advocacy success outcomes vs baseline scores



individuals whose initial needs were greatest (average baseline scores of 0.0–0.33). For this bottom group, average outcome scores increased by +1.08 during the support period.

Self-reported average advocacy success outcome scores improved across all groups except for that with the lowest initial level of need (1.67 – 2.00), albeit with diminishing returns across groups as need reduced.<sup>23</sup> This indicates that advocacy had the greatest impact for people whose ability to have their voices heard was the lowest, bolstering the case for its use as a targeted intervention for those most in need of support.

The top stratum comprises the people reporting the highest average baseline advocacy success outcome scores (1.67–2.00) and is the only group to exhibit a negative change in scores by the end of support (-0.04). This negative change could be the result of natural variance caused by external factors in people’s lives, circumstances and their own feelings of how they were progressing across the areas recorded by the advocacy success outcomes. We recognise that progress toward personal goals and objectives is by nature non-linear, and this slight regression in scores may reflect setbacks as well as advances experienced while participating in advocacy.

23 The average rate of change in advocacy success outcome scores across the six groups determining initial levels of need was 0.17.

## Case study – ‘Debbie’

‘Debbie’\* made a self-referral to an advocacy service. Debbie felt overwhelmed, frustrated and ‘at the end of her rope’. Debbie is a mum of 2 daughters, at the time of referral one daughter was awaiting diagnosis of Autism and ADHD (which she did receive) and one daughter had a diagnosis of autism and a learning disability.

Debbie had reached out to social services for support, as a single mother with a history of trauma and mental health diagnosis and limited support she said she was ‘crying out for some help.’ By the time advocacy got involved Debbie felt let down and distrusted social services. Due to COVID, limited and changing workers and lack of information Debbie had not built trusting relationships with the Children with Disabilities team. They had not worked in a trauma informed way, and she felt humiliated and patronised.

Debbie wanted support to speak to social services and be able to express her family needs to social services, to understand the Self-Directed Support budget, to find more appropriate housing and get information about Motability.

Once allocated, advocacy discussed and wrote an advocacy plan. Firstly, advocacy contacted social services to find out if and who the allocated worker was. One of Debbie’s daughters had an allocated worker. A meeting was arranged to introduce Debbie and the new worker.

During the subsequent months Debbie had the opportunity to share her concerns regarding the previous support, the Self-Directed Support (SDS) budget and what she wanted going forward. These were difficult interactions for Debbie; however, she felt able to have these conversations because advocacy was present. Over the course of eight months, Debbie was able to get the reassessment for her daughter she felt was needed, and the social worker did an assessment of need for her other daughter.

Advocacy and Debbie took time to go through the assessments to ensure they reflected the needs of her daughters and shared feedback with the social worker. The daughters were both provided with SDS budgets. Advocacy supported Debbie to complete housing applications, medical questionnaires, question decisions by allocations and ensure that the family was at the highest possible priority they could be.

Debbie was sleeping on the lounge floor and as the grantee had some funding available to support victims of crime, they were able to buy Debbie a bed of her choice. Debbie said this was life changing, to be able to get a night’s sleep. Debbie applied for and received the high-rate Adult Disability Payment and advocacy supported her to get information about the Motability scheme and driving instructors.

Advocacy continues supporting Debbie to work alongside social services; however, relationships are improving. Debbie feels more hopeful about the future.

\* Names in case studies in this report have been pseudonymised to protect the identity of the people concerned.

### Advocacy helped people achieve their self-defined goals

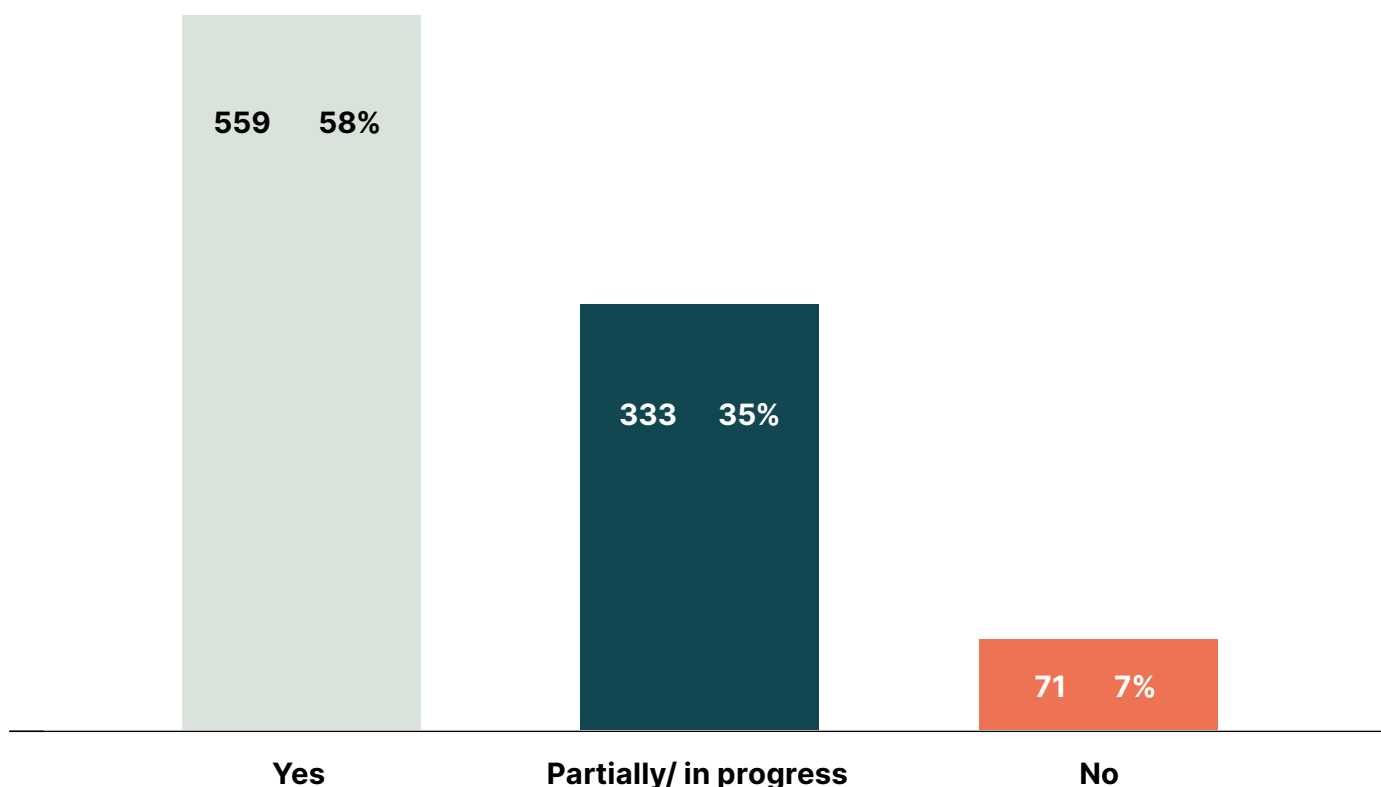
Throughout the programme, we heard from grantees that the success of advocacy is determined by how effectively it helps a person to speak up and feel like their voice is heard. While the eventual achievement of advocacy goals in individual cases is certainly linked to a person’s ability to make their voice heard, it is also distinct from the fundamental objective of the advocacy itself: helping people to express their views, access the services they need, and secure their rights.

While we are cautious about pointing to rates of goal achievement of people supported by grantees as a key indicator of their impact, the self-reported

goal achievement data collected through our outcomes framework shows that the majority (58%) of the 963 people for whom we have goal data achieved their primary goals. A further 35% of people reported the status of their goals as ‘Partially/In progress’, with just 7% of people described as not achieving their primary goal.

While goal achievement is potentially impacted by a wide range of factors besides participation in advocacy, we know from interviews we conducted with grantees and people participating in advocacy that people tend to access advocacy only after being unable to resolve issues alone, despite sometimes persistently trying to do so for an extended period. Although it is not possible to fully assess attribution, advocacy support is likely to have played at least some part in people achieving their goals.

Figure 13: Self-reported goal achievement (number of people)



## Case study – ‘Sarah’

‘Sarah’\* made a self-referral to one of the grantees as she wanted to regain control of her finances. At the time of the referral, aside from her day-to-day money, all her financial matters were managed by the local authority Court of Protection (CoP) Team. Sarah found this intrusive and said she felt she was being treated ‘like a kid’. This had been the case for many years, Sarah felt she now had a better understanding of her finances and wanted more control.

After meeting Sarah and hearing what she wanted to achieve the grantee organisation spent time looking at easy to understand information on the Mental Capacity Act. Looking at the principles of the Act, Sarah built up an understanding of how the decision had been made to remove control of her finances and importantly what safeguards the Act gives her. She recognised that she had a right to ask for the decision to be revisited, she now knew that decisions must be ‘time specific’ and that the ‘least restrictive option’ must be followed.

Sarah was supported to make a referral to the social care team and was allocated a social worker. Advocacy support was provided during the meeting with the social worker and Sarah was able to clearly voice her request and what she now understood about the Mental Capacity Act. Initially, this was met with challenge from the social worker as she felt the arrangement with the CoP team continued to be in Sarah’s ‘best interests.’

The advocate supported Sarah by highlighting the specifics in the law that meant the social worker had to complete a ‘time and decision specific’ assessment of her ability to manage her finances and that a ‘best interest’ stance could not be taken until it was deemed that she currently lacked capacity in this area. When pointed out, the social worker agreed that a long time had passed since the assessment and agreed to re-visit this.

The social worker completed up-to-date Mental Capacity Assessments in relation to financial matters and Sarah was deemed to have capacity in all areas. The social worker said she had been left with ‘no doubt’ about this after the assessment process. An application, containing the new assessments, has now been submitted to the Court of Protection to bring the court order to an end and return full control of finances to Sarah.

\* Names in case studies in this report have been pseudonymised to protect the identity of the people concerned.

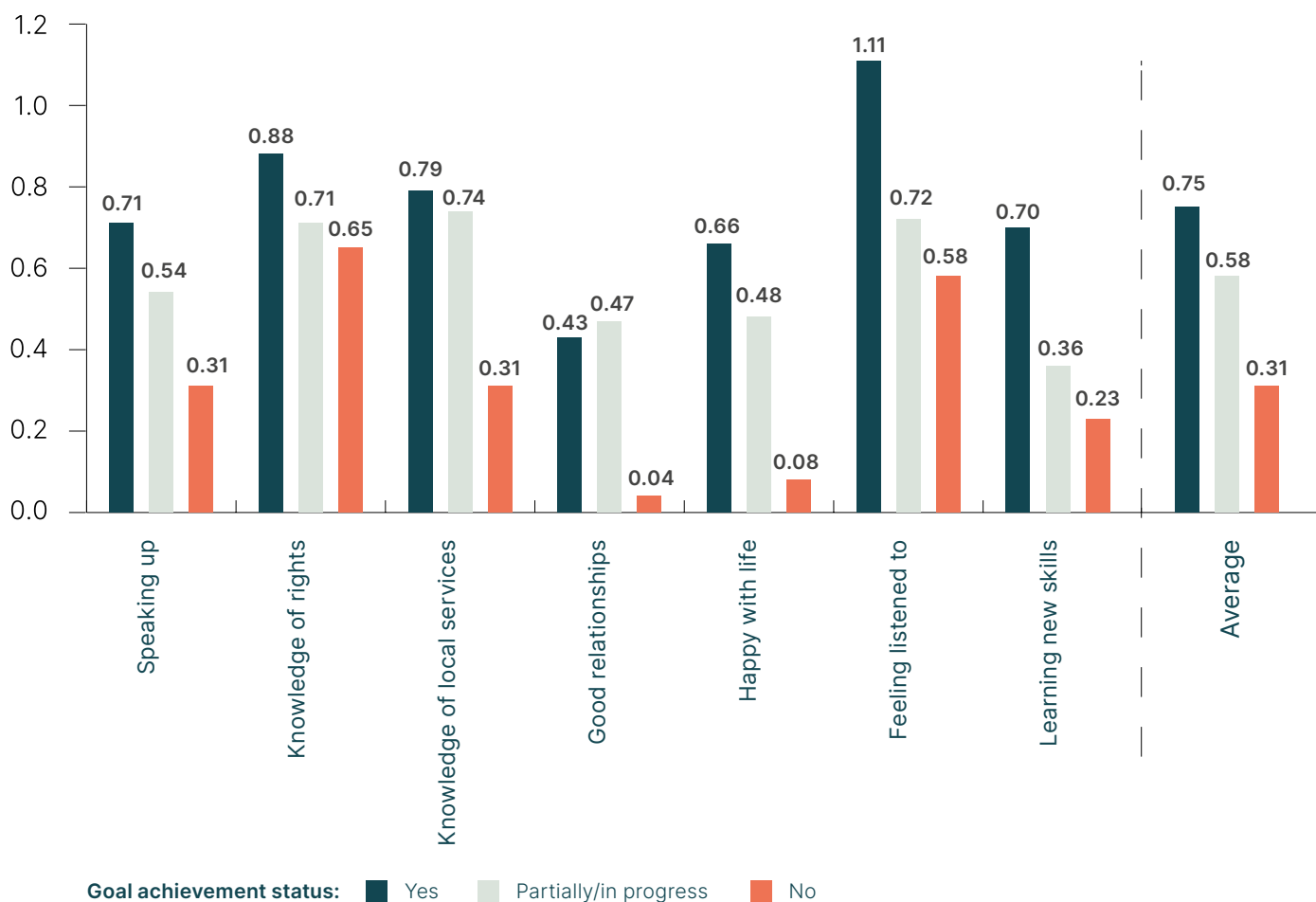
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### **Advocacy had a positive impact even when people did not achieve their self-defined primary goal**

Through our research, we undertook analysis to explore the relationship between advocacy success outcomes and goal achievement. We were interested in whether goal achievement impacted the degree of change in advocacy success outcomes. As demonstrated in Figure 14 below, advocacy success outcomes scores showed an average increase irrespective of whether people achieved their advocacy goals.

For those who achieved their goals, the average increase in outcome scores was 0.75. But even for people who reported not having achieved their goals, participation in advocacy was still positively related to increases in scores across a broad range of the outcomes. This was most notable across the outcomes related to ‘Knowledge of rights’ (0.65) and ‘Feeling listened to’ (0.58). People who reported not achieving their primary advocacy goals also reported improved scores for ‘Knowledge of local services’ (0.31) and ‘Speaking up’ (0.31). Although the dataset this analysis draws upon is relatively small, these figures show that participating in advocacy has inherent value,

Figure 14: Average advocacy success outcome score change (beginning to end) by category



Note: Our data contains records for 428 people with both start and end advocacy success outcomes and data on goal achievement status.

regardless of a person’s ultimate achievement of their advocacy goals.

Average advocacy outcomes score changes were not as profound for ‘Good relationships’ (0.04) and ‘Happy with life’ (0.08), especially for those who did not achieve their advocacy goals. As noted earlier in this report, these outcomes are arguably ones which advocacy does not seek to directly and immediately impact. Instead, positive changes in people’s relationships and their happiness with life might be viewed as secondary effects deriving from contact with an advocacy service or self-advocacy group over the longer term.

The analysis in this section supports decision-making around commissioning non-statutory advocacy. The long-term holistic benefits for individuals brought by participation in these forms of advocacy are, in many cases, not being accounted for by traditional performance metrics and notions of value for money that inform commissioning decisions. As this report argues in Section 3.7, there is a compelling financial case for commissioning ‘softer’ advocacy success outcomes featured in this analysis; one that sits alongside the moral case for funding services that increase societal inclusion for people whose voices so often remain unheard.

### 3.6 Detailed case studies

In addition to the case studies gathered from grantees and featured across the report, we fleshed out two case studies in more detail and have presented them in this section. These case studies help provide a complete picture of two people's journeys, including their needs and experiences before accessing advocacy and how these have evolved since. They are informed by detailed interviews with advocates, family members or social workers, and where possible the person accessing advocacy.

## Case Study 1: William\*

William is in his mid-fifties, and he lives in Dorset. He has a mild learning disability. Over the past 16 years, he has been on an inspiring journey towards building a more independent and fulfilling life for himself.

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### Support needs and previous interactions with statutory services

William lived with his parents until 2008, when he moved into supported living in Dorchester. William was sometimes bullied and experienced behavioural problems. He told us that kids would throw things at his windows and call him names in the street, which he found upsetting.

By this point, William had lost contact with people he knew at school and had only one friend whom he saw once or twice a month. He found it difficult to speak up, which led to feelings of loneliness and isolation. Most of his days would be spent at home,



I was lonely. I only had one friend. I was having trouble with antisocial behaviour. Kids annoying me... throwing things at my windows. They're calling me names in the street.



William



[When I met him] William was still living at home with his parents. He struggled with low mood and anxiety, he was unoccupied and unhappy. At times this presented as bouts of agitation and stress for William. Being out in the community was particularly difficult for him and there were episodes of him being exposed to bullying and ridicule. Here was a young man living with his parents, with hopes and aspirations to move on from home and live independently. Yet probably feeling quite stuck, bored and isolated as he lived in a rural village in West Dorset. William did not really fit into the type of day services on offer for adults with learning disabilities at that time. He lacked friends and didn't really have a natural peer group. So I think he was under-stimulated, under-occupied and feeling vulnerable and lost.



William's former community nurse

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\* Name used with the person's permission.





I think what Friendship Club gave William was a sense of inner confidence, self-esteem and self-worth. He found and identified with a peer group, and it facilitated him meeting other younger adults with similar life experiences and ability. So, he met and could identify with other young adults with a learning disability who were also socially isolated, didn't really fit into day services, didn't necessarily have a commissioned care and support in place. They too lacked some confidence to go into those social settings that they wanted to experience; a pub or bowling alley or a coffee shop...and William made those networks, not only within Friendship Club, but he then went on to meet those people outside...and they met independently of Friendship Club as a group of friends. They set their own social agenda, went to places, did activities, explored together shared a growing sense of confidence, supported each other.



**William's former community nurse**

watching television on his own. Sometimes, William would go to the local bowling alley to try and meet friends. He would have a beer but did not feel able to talk to anyone and no one approached him either. He would have another beer and go home, and said that these experiences made him feel 'not good.'

Through most of his adult life, William has needed support with activities of daily living around cooking, washing, managing finances and managing his health. He had never taken public transport on his own and did not know how to do so. William was receiving support around managing these needs from his parents and from the community learning disabilities team with visits from a community nurse and an occupational therapist. At points these visits were required weekly.

William was also receiving care from a GP around management of his anxiety and stress and was on medication which helped him to a degree.

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### **Support received from advocacy and its impact on William**

In 2008, William discussed with his community nurse the opportunity to attend events organised in the community by People First Dorset (PFD), a user-led charity focusing on self-advocacy skills. He began to attend Friendship Club, which had just started, and later, the Speaking Up groups, organised by PFD. Initially he was anxious about



I have more confidence to speak up more in public... I'm a lot happier now than I used to be.



**William**



The more included and valued William feels by the community, taking on roles that give him meaningful activity, the more his confidence grows, and we see him go from strength to strength. Our role at PFD has, and continues to be, enabling William to maintain and develop this confidence, be it through making and managing friendships; developing his self-advocacy skills at Speaking Up groups; helping oversee the charity as an active member on the PFD Management Committee; or the ever-critical 'ongoing soft support' that we offer. For example, this has included helping William take on, and successfully sustain new activities, such as the newspaper column or writing and promoting Not Lost. These enable William to become increasingly visible and appreciated in the community and by his peers, who 'look out' for each other. This means that when issues or problems arise – we recognise this happens in life for everyone, including our members – they are picked up quickly and addressed at an early stage, before escalating into a crisis.



**Representative from People First Dorset**

attending on his own and was accompanied by his community nurse, who helped facilitate conversation and provide emotional reassurance. By attending their activities, he gained more confidence and made friends, which he has sustained. Every Monday, William and his group of male friends meet up independently to have lunch together.

He also learned how to take public transport, which helped him to start attending PFD's Weymouth events as well as participate in activities with his friends, e.g. by going to a disco together.

During this time, he secured four volunteering placements through his parents and PFD, and has successfully maintained these. These included volunteering at a film club, borough gardens, garden centre and EuCan volunteering.

Within a couple of years of being signposted to Friendship Club, William required far reduced input and direct support from his nurse and occupational therapist. He remains informally in touch with his former nurse as they both live in the same small town and sometimes meet at Friendship Club events.

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### **Current and future support needs**

Over time, William has gained confidence, built independent friendships, and learned how to manage his emotions. He is able to self-regulate his emotions in response to triggering situations. He can do his own cooking and washing up now, and says that overall, he feels much happier. Some of his favourite dishes to cook are spaghetti bolognese and chili con carne. While his mother and a cleaner still visit and help manage his house occasionally, the need to do so is substantially reduced and William has not interacted with statutory services in this time.

William has learned to actively participate in society. He gradually started participating in Friendship Group's steering group and assumed more responsibility at PFD events, for example by helping count donation box money at events. He has also helped give presentations on Friendship Club activities, including speaking to a whole school. He is now a member of PFD's Management Committee, an elected group of people who sit alongside trustees and are responsible for overseeing the organisation's governance. They meet monthly.



I think a combination of local volunteer employment opportunities and Friendship Club has opened William's world really. It's given him confidence and self-belief in his abilities to test and push his own boundaries. He lives without any need for statutory service input although his parents of course remain very supportive. William travels, he's spoken in public, he writes for a newspaper, he's written a book, he's been to the palace. On reflection I think the young William I first met probably would have felt those were all completely unachievable goals.



**William's former community nurse**

William was introduced to a local journalist as part of an article she was writing on PFD's work. He started writing a weekly column for the Dorset Echo with two friends and they have since written over 500 columns in the past 10 years. This year William co-authored an illustrated book entitled

*Not Lost* about a famous local cat who brings people together. The book is helping to raise funds for PFD and has already sold over 1000 copies. In recognition of his community work, William was invited to, and attended, a garden party at Buckingham Palace in 2022.

## Case Study 2: 'Candice'

'Candice'\* is 15 and lives with her parents in South East England. She has profound and multiple learning disability needs and lives with a rare genetic disorder. Candice experiences severe daily seizures, must be monitored with regards to oxygen levels, and is tube-fed a liquid diet. She is nonverbal and requires round-the-clock care.

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### Support needs and previous interactions with statutory services

Candice's case was first referred to Coram Voice by her parents at the beginning of 2023 in relation to an ongoing dispute with both Health and Children's Social Care about the level of support they were receiving to care for their daughter. During this dispute, Candice's parents were not entitled to legal aid since they exceeded the means-tested threshold for this support.

Candice had a night-time care package funded through NHS Continuing Healthcare, aimed at people with complex medical needs that cannot be met by existing universal or specialist services alone. In Candice's case, this package is funded through the Integrated Care Board (ICB). The ICB decided to step down her nighttime package, arguing that Candice's care could be provided by carers rather than specialised nurses. Due to the complexity of Candice's condition and her increasing needs, the family disagreed with this decision.

\* Names in case studies in this report have been pseudonymised to protect the identity of the people concerned.



When there were action plans and when there were outcomes to be achieved, she very much held professionals to them. So, if a social worker said, 'Oh yeah, I'll chase that,' in the next meeting, the advocate would say, 'This was the action plan and the things that you said you were going to do from last month's meeting. Have they been achieved?' It's about holding professionals to account so they can't just promise and then never deliver.



**Candice's parent**

Candice was also in receipt of a social care package that funded short breaks and a daytime care package. Despite Candice's increasing level of need and several safeguarding incidents, social care was reluctant to provide funding to pay for extra nursing care that the family argued was necessary to ensure her safety. Social care stated that their assessment would be 'led by' the judgement made by health professionals. This meant that instead of challenging the health assessment, social care used the outcome to justify providing the same level of support for Candice.

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### **Support received from advocacy and its impact on Candice**

Candice is limited in how she can express herself. She does not have clear facial expressions or use visuals or Picture Exchange Communication Systems. She also has a high pain threshold and

will only signal discomfort if she is experiencing extreme levels of pain. As a result, Candice is unable to self-advocate for her own needs.

In advocating for Candice, the advocate followed a person-centred and rights-based approach to build an in-depth knowledge of Candice's circumstances, relationships and needs. As well as speaking to family members and observing Candice in her home and school environment, the advocate spoke to Candice's social worker and other professionals to formulate an independent picture of Candice's unique perspective and rights. She found that an increasing number of people were expressing concerns for Candice's safety in relation to the reduced nursing support she was receiving.

This approach and the advocate's specialist knowledge of Candice's rights were crucial in building an independent picture of the adequacy of support in meeting these. The advocate attended regular meetings on Candice's behalf, in which professionals were making important decisions around her care. The advocate observed disagreements between the family and professionals around the level of care that Candice needed.

Candice's parents felt that it was useful to have the advocate in the room on these occasions as their views, the views of others at her school and the hospice, and evidence provided by neurologists, had been consistently disregarded by the ICB and local authority over several years. In sitting in on these meetings with the parents, the advocate was able to ensure that Candice's



The happiness and the interaction and the quality of life for Candice has been massively improved by the care package.



**Candice's parent**



This case has revealed to us how much more challenging this kind of non-statutory advocacy can be: We believe that had Candice been a looked after child, it is unlikely she and her family would have been left with so many gaps in support for so long. Had Candice been a looked after child, she may also have been assessed for legal aid in her own right, rather than her parents' income being taken into account, so she would likely have been able to access legal support. Nevertheless, this also shows how vital this project is, in supporting children who would otherwise slip through the net.



### **Candice's advocate**

voice remained front and centre, and professionals were held to account on their commitments to her care.

Since support from Coram Voice began, Candice and her parents have been able to successfully argue the case to retain funding for nursing care at home from 10 hours a week to 48 hours a week. This has helped to alleviate the intense pressure on her parents to balance commitments around Candice's care with work and caring for their other child. This in turn ensures that there is a sustainable package of support for Candice. The advocate made supporting representations on Candice's behalf, when her parents requested this, in a request to the local authority for support with

transportation to and from school in a medically equipped vehicle. This journey had previously been flagged as a safeguarding risk by the parents due to their inability as a single driver to both drive the vehicle and ensure that Candice was safe. Appropriate and safe transport has now been agreed in a medically equipped vehicle, supported by professionals who are trained to respond to Candice's medical needs.

The extra support has had a big impact on Candice and her family, increasing Candice's social interaction and reducing safeguarding risks. In a recent Children in Need review, people in Candice's network were asked to provide scores across several metrics designed to gauge her quality of life. The outcome of this review indicated that Candice's wellbeing and quality of life had improved since the increased care package had been put in place.

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### **Current and future support needs**

Candice has a life-limiting condition that means that she will need a high level of ongoing support for the rest of her life. Without this support, serious safeguarding issues could have serious implications for her health and safety, if her carers lack the specialist skills to ensure that her condition is managed properly. When this is the case, the situation is unjust for Candice, her family, and also for carers.

It is all too common for a person's voice to be overlooked in conversations about their care, especially when multiple agencies are involved and the young person is unable to speak up for themselves or understand their rights. Candice's case is a clear example of the powerful role that advocacy plays in amplifying a young person's voice in forums where health and social care professionals make key decisions that have an impact on their health and wellbeing. Her case also reveals a desperate need for greater commitment and funding for services like that provided by Coram Voice to support children whose family circumstances mean that they are unable to access the support that they so desperately need.



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### 3.7 Cost-benefit

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#### Background

Policymakers and funders have noted a gap around data which quantifies the impact of independent advocacy, especially in terms of benefits to the public purse. Over the past two and a half years, as learning partner to the Henry Smith advocacy programme, we have worked with grantees to capture data around the impact of their services, and to understand how these services make a difference in people's lives. Combining these insights from grantees with external data sources, we have conducted an indicative cost-benefit analysis (CBA).

The Henry Smith programme for learning disabilities and autism supports advocacy services across England, Wales and Scotland, which has allowed us unique insight into the costs and benefits of advocacy. We believe that the grantees in the programme are broadly representative of non-statutory advocacy services across the UK due to the small size of the sector – as far as we are aware there are limited non-statutory services across the country who are not part of this programme. Therefore, we have used programme data to extrapolate the costs and benefits of advocacy to the general UK context. We hope this piece of work can help inform future policy and funding decisions and lend greater support to independent advocacy services.

This section provides a summary of the key figures and findings from our CBA, followed by a step-by-step guide to our methodology and implications for policymakers and funders. We have included detailed calculations in the appendix and have referenced them in this section where relevant.

It is important to note that our CBA is a financial analysis based on self-reported outcomes, and due to the absence of randomised control trial data in this field, we have had to make sensible and informed assumptions about how we attribute outcomes to advocacy, drawing on published reports and qualitative data. All our assumptions are

clearly outlined in this section and the appendix. Where assumptions have been made, we have been prudent and cautious to avoid overstating the impact of advocacy services, and we have also sense-checked these with relevant academics in the field of advocacy. While we would like to see a more comprehensive economic analysis completed too, we hope that this indicative financial analysis will provide enough evidence to policymakers that this is a policy area that generates social and financial benefits and is worth investing further in.

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#### Key figures

We estimate that advocacy generates substantial benefits relative to its costs:

- We estimate that it costs £2,400<sup>24</sup> to provide independent advocacy to a person, which is in line with other intensive social interventions for this cohort e.g. supported employment and individual placement and support (IPS) interventions. While cost data for social interventions is not widely available, we believe these are good comparator benchmarks. As programme costs can vary based on the size of the individual services, all our figures are in per-person terms. Two-thirds of service costs ranged between £143–184 per person with an average of £165 per person.
- Advocacy generated net benefits (total benefits less total costs) per person of over £28,200 per year. Two-thirds of net benefits ranged between -£45,820 and £1,507,192 with an average of £704,896, which shows that the range was representative. These benefits calculations were based on estimations around how advocacy services can prevent and reduce reliance on particular areas of 'high cost' support. The four high-cost categories identified by grantees and advisory group members were:
  - Supporting an individual to step down from hospital to supported living
  - Supporting an individual to step down from hospital to independent living

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<sup>24</sup> Summary figures in this document have been rounded to the nearest significant figure. These figures are based on the calculations and assumptions that follow.



Figure 15: Key figures from cost-benefit analysis



- Preventing a child or young person from going into care
- Supporting a person to move from supported living to independent living

We know that while these categories do not encapsulate the bulk of the support offered by independent advocacy services, they feature regularly in the lives of the people they work with and can generate substantial costs for the system. With the right support and early intervention, some of these can be either prevented or reduced in duration and intensity.

- The Henry Smith Charity programme cost around £926,000 per year and generated financial benefits of £11.5 million per year. This means that for every £1 spent, it generated benefits worth £12. Most social interventions are seen to be effective if they produce more than £1 of benefits for every £1 spent, which means that our estimated benefits are substantially higher than many social interventions. However, we know from recent research<sup>25</sup> that social interventions that aim to address health outcomes can have higher returns on investment than other types of intervention. Advocacy services are working with people who have complex, long-term needs and are helping to prevent the costliest types of support from

being needed, so it seems reasonable to expect that it would generate a high level of savings. This finding has been tested with grantees and our expert advisory group that includes academics and commissioners in this field, who confirmed that it is in line with their experience of the nature and impact of advocacy services.

- The cost-benefit ratio for grantees varied greatly based on their focus on these high-cost cases. Advocacy services generate a range of benefits in addition to these high-cost cases which we have not quantified at this stage, and there is a risk that advocacy becomes seen purely as a cost cutting exercise, whereby funding becomes conditional on supporting solely these high-cost categories. This CBA therefore presents the average cost saving that a service is likely to generate. Individual advocacy services will show a range of cost-benefit ratios.
- Most grantees offered a mix of one-to-one and other forms of advocacy e.g. self-advocacy, peer advocacy or group advocacy. There were no clear trends in how the nature of support influenced costs of individual services or their cost-benefit ratios.
- For every £1 spent, there are savings of approximately £7 for the NHS and £5 for local LAs, while there is a cost of £0.40 to DWP.

25 Research by the NHS Confederation and Carnall Farrar: <https://www.nhsconfed.org/news/investing-more-prevention-could-deliver-ps11-billion-return-investment>

We are conscious that the high-cost categories used in our calculations are a small part of the overall support provided by advocacy services. Our calculations do not account for other costs avoided due to more effective use of services (e.g. a reduction in use of GP services due to reduced isolation) as well as early intervention, which is expected to have prevented people's needs from escalating and requiring statutory intervention. These are often by-products of the bulk of the support provided to people, but not all these can be quantified or recorded.

Advocacy services also play an important role in helping people access services that they are entitled to and accessing appropriate support early to prevent escalation of issues. This inevitably has a financial implication and increases costs to the system. However, our qualitative research has shown that these additional costs are often in the context of supporting someone to access more appropriate, or preventative support (for example accessing community-based befriending support which reduces the number of GP visits due to poor mental health resulting from loneliness).

In addition, we also acknowledge that not all the benefits expected can be fully attributed to the work of these services and have taken this into account in our calculations (see methodology section below). All our calculations are based on data reported by grantees and collected as part of this programme.

As mentioned earlier, in the absence of Randomised Controlled Trial (RCT) data in this field, we have not been able to fully assess the attribution or economic costs and benefits of advocacy services. However, the qualitative and quantitative data we have collected suggest that any additional system costs from better access to services may be offset by reduced or more effective service usage elsewhere, as well as wider economic benefits from improved well-being, independence and participation in society (including employment).

We recommend that any future expansion of advocacy services include funding for a comprehensive economic benefit analysis or Social Return on Investment (SROI) assessment to complement our indicative financial analysis.

Most importantly, we realise that it is hard to place a number on the value of advocacy and this is just one way of showing its impact. This is why our CBA is complemented by case studies and other qualitative findings to demonstrate the full value and impact of advocacy.

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### Methodology

We followed five key steps and drew upon several data sources to estimate a cost-benefit model:

#### 1. Estimate programme costs

We began by defining programme costs for each grantee, based on total grant values in budget documents submitted by grantees to Henry Smith. The structure of these costs varied across grantees but typically included overheads, building costs, salaries, events, and training costs. We feel that these costs are representative of the actual costs incurred to deliver additional support to the individuals worked with. We divided these cost figures by the number of people supported by each grantee and converted these figures to annual terms. Two-thirds of costs ranged between £53,784 and £69,137 with an average of £61,776, which shows that the range was representative.

#### 2. Estimate programme impact numbers

Next, we established the total number of people supported by each grantee as part of this programme over the past two years. These figures were based on data collected from grantees every six months using our outcomes framework. A total of 375<sup>26</sup> new cases were supported across the programme each year.

We also designed and ran a short survey using MS Forms with all grantees to estimate the number of 'high cost' cases each grantee had supported over the 2023–24 financial year. As described in the

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<sup>26</sup> This figure is derived from data captured in June 2024 during the cost benefit analysis exercise. This number has since grown but has not been updated for the CBA to ensure consistency with other data sources used in our calculations.

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## Part 3: Findings

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previous section, the four high-cost categories identified were:

- Step down from hospital to supported living
- Step down from hospital to independent living
- Preventing a child or young person from going into care
- Supporting a person to move from supported living to independent living

All 15 grantees completed and submitted the survey. Figures for these categories were generally low as expected but varied across grantees. Table A1 in the appendix summarises impact figures across the programme.

### 3. Estimate unit costs and duration of costs

Using external sources (e.g. GMCA unit cost database, Mencap and LA data), we assigned unit costs to each of the four high-cost categories mentioned above and estimated the duration that these costs would apply for (e.g. average length of stay in hospital for a person with a learning disability). We also assigned costs to ongoing support and alternative provision that we assume people would be receiving (e.g. community social care packages and housing benefits). We have used housing benefits in our calculations as individuals are likely to be eligible for some aspects of other benefits even in hospital or supported living. Singling out housing benefits enables us to focus on benefits entitlements that change significantly depending on accommodation type. Please see Table A2 in the appendix for details on unit costs and relevant sources.

Using inflation rates from the Office for National Statistics (ONS), we converted all figures to 2024 prices (see Table A3 in appendix). For consistency, we also converted all figures to annual terms (see Tables A4–A7 in the appendix).

### 4. Apply assumptions to calculations

For each of the four high-cost categories, we added assumptions based on external sources and our own learnings from the programme (see Tables A8–A11 in the appendix):

- Deadweight estimates (ranging from 20% to 50%) to account for people who would have achieved these outcomes without support from

advocacy services and to acknowledge the challenges of fully attributing these outcomes to advocacy services.

- Years of effect to estimate the number of years the outcome would be effective for each person

### 5. Conduct cost-benefit calculations

Based on the data and figures estimated above, we conducted calculations to estimate a cost-benefit analysis:

We multiplied impact numbers by unit costs (which had been adjusted for inflation, deadweight and years of effect incorporated) to estimate benefits across grantees, cost categories, and across the programme.

We subtracted benefits from relevant costs to arrive at net benefits and divided this figure by the number of people to arrive at per recipient/case figures.

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### Implications for policymakers and funders

As a further step, we have also calculated how a reduction in the use of high-cost services would impact key funders, including Integrated Care Systems (ICSs) in the National Health Service's (NHS), relevant local authorities (LAs), and the Department for Work and Pensions (DWP).

We estimate that the NHS is likely to save £18,360 per person per year in costs if people are stepped down from hospital-based care.

LAs are likely to save £13,200 per person per year, factoring in spending to help people in supported living, spending on community social care support packages, and savings from preventing children from going into care.

Meanwhile, the DWP is likely to incur a cost of over £960 per person per year due to spending on housing benefits.

Overall, advocacy is likely to save over £30,600 per person per year across the system though the implications vary from funder to funder. In other words, for every £1 spent, there are savings of approximately £7 for the NHS and £5 for LAs, while there is a cost of £0.40 to DWP. Please see Table A12 in the appendix for more details.

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## **3.8 Recommendations**

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### **System-level recommendations**

Our research over the two-and-a-half-year lifetime of this programme indicates that non-statutory independent advocacy services represent value for money for both the exchequer and local commissioners, while also having lasting benefits for people benefitting from services. But most services have waiting lists, are not available across the country, and are often reliant on philanthropic funding from a minority of funders such as the Henry Smith Charity. We therefore recommend that the following steps are taken to increase provision of non-statutory advocacy across the UK:

#### **1. Enhance policy leadership for independent advocacy for autistic people and people with learning disabilities**

There needs to be greater policy ownership of independent advocacy at the Central Government level. At present, it is unclear whether there exists a dedicated ministerial responsibility for advocacy policy, or whether there is a Central Government policy team responsible for non-statutory advocacy. There is a Disability Unit within Cabinet Office and a Minister for Social Care in DHSC charged with overseeing disabilities and SEND, but this policy area is too specific for their broad remit. There is a Learning Disability lead within NHS England, but the NHS focus has, in recent years, been on the statutory advocacy they must provide, with less of an appetite to fund or develop policy around non-statutory, community-based services. The Minister of State in DWP has disability policy and cross-government responsibility for disabled people under their remit but also holds broad responsibilities.

A lack of clarity here causes frustration for many in the advocacy sector as people are unsure about whom to approach within government regarding advocacy-related issues.

To address this issue, a dedicated policy team should be established with the aim of growing and improving independent advocacy for autistic people and people with learning disabilities.

Consideration should be given as to within which department this team should be hosted; it is likely that they should sit within the Department of Health and Social Care (DHSC) given the strong overlap between advocacy, health, and adult social care. However, close collaboration with DWP will also be important, given the links to employment and welfare. This model could be similar to the Joint Work and Health Unit, which is jointly led by DHSC and DWP to improve employment outcomes for people with disabilities.

#### **2. Make funding available to support the growth of the advocacy sector**

Given the constraints on local government finances, it is unlikely that areas will be able to find the resources needed to launch or grow new services without an injection of dedicated funding and policy directive from Central Government. We therefore recommend that a non-statutory advocacy expansion fund should be established by Central Government to test a nationwide expansion of advocacy support. This fund could provide catalytic capital that attracts further funding from the social impact investment market. Mayoral Combined Authorities could play a crucial facilitation role in implementing and rolling out this support.

This could follow the approach used by Central Government to stimulate the growth of the Individual Placement and Support (IPS) model across England. Through several pilots and evaluations, the IPS model had been demonstrated to be effective and to generate a cost-benefit, helping people with disabilities find paid and competitive work through intensive, personalised support. The government then provided both a policy mandate and funding for local areas to scale up the program. The NHS Long Term Plan committed to a tenfold increase in access to IPS services over a decade. The joint Work and Health Unit allocated funds to every CCG area in England, set access targets, and assigned local areas the responsibility for commissioning and launching services. Additionally, the Work and Health Unit funded a national implementation support program to help local services maintain high-quality standards, meet staff recruitment targets, and promote shared learning.

There are similarities between IPS and non-statutory advocacy in their aims to improve people's confidence and independence to allow them to participate better in society. We believe a similar funding approach to the IPS approach laid out above could be harnessed to support a high-quality, nationwide expansion of advocacy services. To support this initiative, we intend to estimate the necessary fund size and provide a detailed rollout plan in a briefing note for Central Government.

### **3. Build capacity for collective action across the advocacy sector**

There is a clear need for a unified approach to better represent the interests of advocacy services nationwide. This would facilitate more effective sharing of evidence with government, commissioning of research, and dissemination of best practice as the sector grows. The structure for this collaboration could take various forms – whether through loose coalitions of existing organisations, formal partnerships, or another model, such as a new membership body or sector organisation, that allows for collective representation.

To succeed, it must earn the trust and backing of the sector's diverse groups, from those offering citizenship-based models to those providing intensive one-on-one support. A design phase is crucial to explore the best way forward, with input from autistic people and people with learning disabilities. This process will also focus on relationship-building – restoring trust and fostering collaboration across the sector to strengthen its capacity for unified advocacy.

### **4. Support better integration of advocacy with existing health and work-based initiatives**

The new government has pledged to support initiatives designed to help more people who face significant barriers to employment in the workplace. The announcement of government-funded programmes such as Connect to Work<sup>27</sup> and continued rollout of the Individual Placement

and Support (IPS) model alongside the Supported Employment Quality Framework (SEQF) through the NHS are pertinent examples of examples of person-centred and holistic interventions that seek to improve health by helping people overcome barriers to work.

Among those who face some of the greatest barriers to work are autistic people and people with learning disabilities. We also know that the low number of people in this demographic currently in paid employment belies the far greater number who hold aspirations to work.<sup>28</sup> For this group, additional specialised support is often a crucial step to building the confidence, skills and experience needed to increase participation in the labour market.

Here we observe some obvious overlaps between the aims and objectives of advocacy and more specialised employment support for autistic people and people with learning disabilities. Both support people to overcome barriers related to gaining more confidence and independence, and there may be potential opportunities for closer integration of advocacy with specialised employment-focused services and education and skills services for autistic people and people with learning disabilities in cases where people have employment-related advocacy goals. Likewise, supported employment initiatives should be prepared to refer clients to advocacy services if they present with non-employment-related issues that may be preventing them from pursuing ambitions to gain paid employment.

The overall aim of these recommendations is to provide support to the advocacy sector across the UK to achieve three aims:

- Give financial stability to existing advocacy services
- Allow current advocacy providers to grow their support offer, tackle waiting lists and reach into new and as yet unsupported but high-risk cohorts

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27 The Connect to Work programme aims to support around 100,000 disabled people, people with health conditions and those with complex barriers to employment in England and Wales to help them into work.

28 [Mencap and NDTi research](#) of over 200 people with a learning disability found that 86% of those not in work have aspire to enter paid employment.



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## Part 3: Findings

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- Expand provision into new geographic areas which currently do not have any advocacy provision
- Help relieve pressure on statutory services

As our research has highlighted, non-statutory advocacy services are essential in ensuring that individuals with learning disabilities and autistic people have a voice in decisions affecting their lives. Expanding and strengthening this sector will ensure that more people receive the support they need to lead independent and fulfilling lives.

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### Service-level recommendations

Throughout the course of this programme, grantees highlighted several additional groups who may benefit from participating in advocacy but who are currently unable to access targeted support. These gaps exist either due to these groups not meeting the eligibility criteria for existing advocacy services or due to a lack of specialist support that might be needed. The groups include:

- People with neurodegenerative illnesses, such as Parkinson's or Multiple Sclerosis
- Autistic people who are isolated and lack social connections

- Children whose families are marginally above the financial threshold to qualify for legal aid to support in disputes around their care<sup>29</sup>
- Students with learning disabilities who exceed the threshold required for legal aid when there is a SEND tribunal and therefore find it difficult to have their voices heard<sup>30</sup>
- Students with learning disabilities who exceed the threshold required for legal aid when there is a SEND tribunal and therefore find it difficult to have their voices heard
- Young people with mild learning disabilities who are in employment but who lack skills such as reading and writing
- People in residential care nursing homes who are unable to advocate for their basic needs to be met<sup>31</sup>
- Autistic people and people with learning disabilities who are unable to access advocacy due to living in rural areas

Further research could help develop a more nuanced understanding of the specific advocacy requirements for the groups identified above.

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29 Grantees highlighted cases where children with learning disabilities who live with their families are not entitled to the same advocacy support provided to care experienced children. In many cases, access to advocacy would be beneficial in cases where families do not qualify for legal aid and are unable to afford legal advice.

30 Perversely, ineligibility is sometimes caused when receipt of disability/student benefits takes a family/individual over the financial threshold.

31 Grantees reported how staff at nursing homes can sometimes treat advocates with suspicion, making it hard to engage with individuals in these settings.



### 3.9 Conclusion

This report presents a detailed discussion on the value and impact of non-statutory advocacy for autistic people and people with learning disabilities. We found that grantee organisations' support played a role in helping individuals express their needs, secure their rights, and access wider services. Our findings emphasise the crucial role of non-statutory advocacy in promoting social inclusion and equality for people whose voices struggle to be heard on key issues impacting their lives.

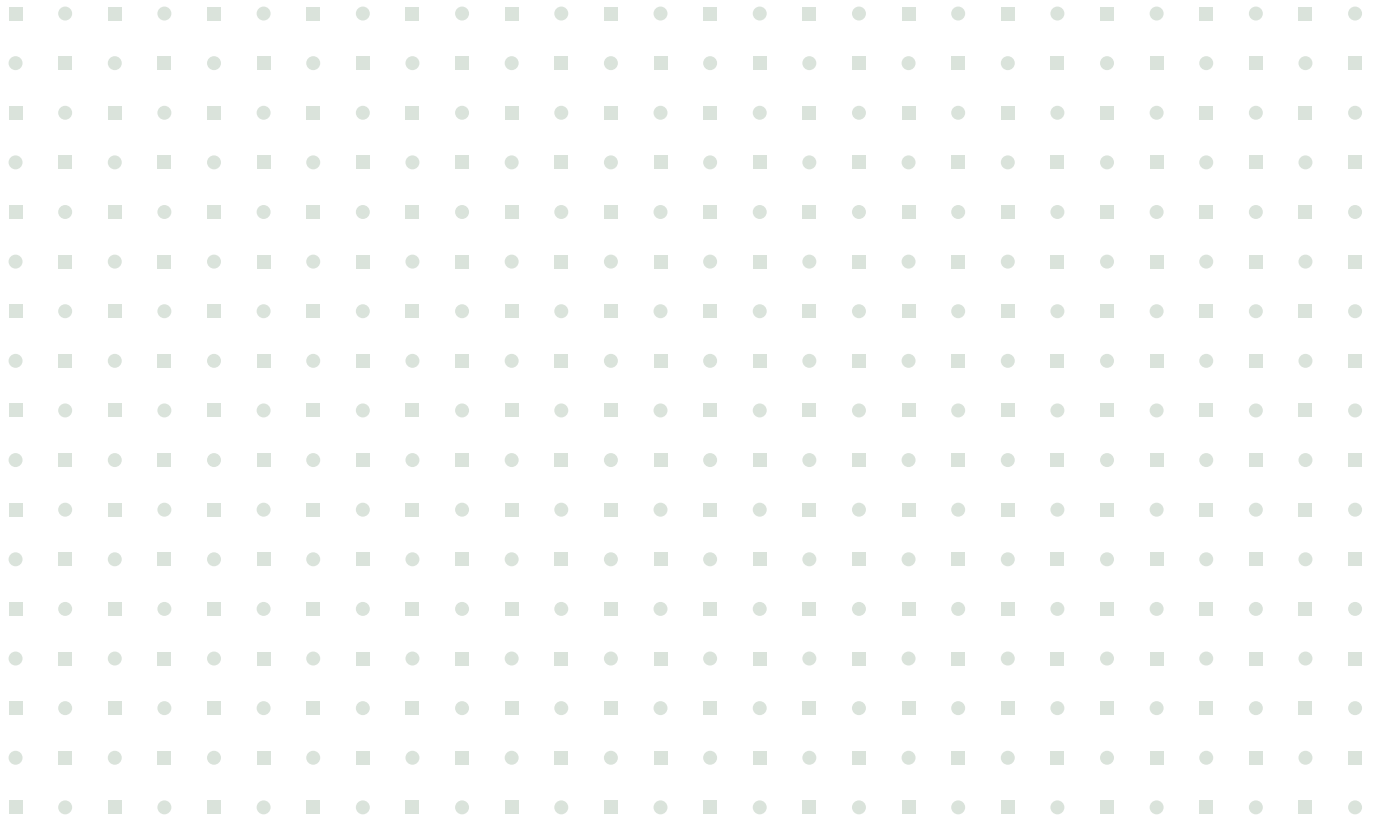
There is a powerful moral imperative to ensure that all individuals have the opportunity to live empowered, fulfilling lives and actively participate in society. Alongside this, there is a strong financial argument for expanding the non-statutory advocacy sector in the UK. Non-statutory advocacy not only reduces demand on statutory services but also aligns with the government's current focus on a prevention-led

approach to health and social care. As our cost-benefit analysis highlights, investing in non-statutory advocacy could generate significant savings for both the NHS and local authorities.

We have four key recommendations to strengthen non-statutory advocacy provision for autistic people and people with learning disabilities:

- Enhance policy leadership
- Create dedicated funding
- Build sector collaboration
- Improve integration with employment and health initiatives

We urge policymakers and funders to take note of the findings and recommendations presented in this report and support the sector in addressing the systemic barriers that currently prevent wider access to non-statutory advocacy. We and our partners welcome the opportunity to work together in taking these recommendations forward.



# Part 4: Appendices

## 4.1 Detailed assumptions and calculations for cost-benefit analysis

**Table A1. Annual figures for the total number of people supported and high-cost categories across grantees**

Grantee	Total number of people supported (annual)	# Step down from hospital-based care to supported living (annual)	# Step down from hospital-based care to independent accommodation (annual)	# Moves from supported living to independent accommodation (annual)	# CYP prevented from going into care (annual)
Impact for whole programme – all grantees	375	10	7	29	51

**Table A2. Unit costs for high-cost categories and alternative provision with sources and years of estimate**

Cost category	Estimated cost (£)	Year of estimate	Source/notes- unit costs and duration
Mental health unit in-patient admission for autistic person/person with learning difficulties (per year)	237,000	2022	Mencap: <a href="https://www.mencap.org.uk/press-release/over-half-billion-pounds-year-spent-locking-people-learning-disability-and-or#:~:text=The%20new%20analysis%20estimates%20the%20average%20cost%20of,this%20cost%20rises%20to%20%2C%2A31.2%20M%20per%20person">https://www.mencap.org.uk/press-release/over-half-billion-pounds-year-spent-locking-people-learning-disability-and-or#:~:text=The%20new%20analysis%20estimates%20the%20average%20cost%20of,this%20cost%20rises%20to%20%2C%2A31.2%20M%20per%20person</a>
Cost of supporting adults with learning difficulties in residential placement (weekly)	1,760	2018	Mencap: <a href="https://www.mencap.org.uk/sites/default/files/2018-04/2018.052%20Housing%20report_FINAL_WEB.pdf">https://www.mencap.org.uk/sites/default/files/2018-04/2018.052%20Housing%20report_FINAL_WEB.pdf</a>
Child taken into care – average across all settings (per year)	67,877	2022	GMCA unit cost database and Gov.uk: <a href="https://explore-education-statistics.service.gov.uk/find-statistics/children-looked-after-in-england-including-adoptions">https://explore-education-statistics.service.gov.uk/find-statistics/children-looked-after-in-england-including-adoptions</a>
Children in need average cost of case management (6 months)	1,865	2022	GMCA unit cost database and Tower Hamlets Children's Services: <a href="https://www.proceduresonline.com/towerhamlets/cs/p_cin_plans_rev.html#:~:text=A%20Child%20in%20Need%20Plan,for%20example%20children%20with%20disabilities.">https://www.proceduresonline.com/towerhamlets/cs/p_cin_plans_rev.html#:~:text=A%20Child%20in%20Need%20Plan,for%20example%20children%20with%20disabilities.</a>
Community social care support package for people with learning disabilities (weekly)	398	2022	GMCA unit cost database
Housing benefits- average weekly award across all tenure types (weekly)	120	2022	GMCA unit cost database

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**Table A3. Inflation rates for 2018–2023, based on figures from the Office for National Statistics (ONS)**

Year	Inflation Rate	Source/notes
2018	2.30%	CPIH ANNUAL RATE 00: ALL ITEMS 2015=100 – Office for National Statistics ( <a href="https://ons.gov.uk">ons.gov.uk</a> )
2019	1.70%	
2020	1.00%	
2021	2.50%	
2022	7.90%	
2023	6.80%	
2024		

**Table A4. Unit costs for in-patient admissions for autistic people and people with learning disabilities, adjusted to 2024 prices**

### 1. Mental Health in-patient admission for person with learning disabilities or autistic person

	Estimated cost (£)	Source/notes
Cost of in-patient treatment per year (2022–3)	237,000	Mencap: <a href="https://www.mencap.org.uk/press-release/over-half-billion-pounds-year-spent-locking-people-learning-disability-and-or#:~:text=The%20new%20analysis%20estimates%20the%20average%20cost%20of,this%20cost%20rises%20to%20%C2%A31.2%20M%20per%20person">https://www.mencap.org.uk/press-release/over-half-billion-pounds-year-spent-locking-people-learning-disability-and-or#:~:text=The%20new%20analysis%20estimates%20the%20average%20cost%20of,this%20cost%20rises%20to%20%C2%A31.2%20M%20per%20person</a>
Cost of in-patient treatment per year (2024)	253,116	
Average length of stay (years)	5	As above

**Table A5. Unit costs for residential placements for people with learning disabilities, adjusted to 2024 prices**

### 2. Cost of supporting adults with learning disabilities in residential placement

	Estimated cost (£)	Source/notes
Cost of supporting adults with learning difficulties in residential placement (weekly), 2018 prices	1,760	Mencap: <a href="https://www.mencap.org.uk/sites/default/files/2018-04/2018.052%20Housing%20report_FINAL_WEB.pdf">https://www.mencap.org.uk/sites/default/files/2018-04/2018.052%20Housing%20report_FINAL_WEB.pdf</a> .
Average length of stay (years)	5.3	The National Elf Service: <a href="https://www.nationalelfservice.net/learning-disabilities/challenging-behaviour/high-cost-placements-for-people-with-learning-disabilities-and-complex-and-challenging-needs/">https://www.nationalelfservice.net/learning-disabilities/challenging-behaviour/high-cost-placements-for-people-with-learning-disabilities-and-complex-and-challenging-needs/</a>
Cost of supporting adults with learning difficulties in residential placement, weekly, 2024 prices	2,184	
Cost of supporting adults with learning difficulties in residential placement, annually, 2024 prices	113,593	

**Table A6. Unit costs for supporting people with learning disabilities in independent accommodation, adjusted to 2024 prices**

**3. Cost of supporting adults with learning disabilities in independent accommodation**

	Estimated cost (£)	Source/notes
Housing benefits – average weekly award across all tenure types (weekly) – 2022 prices	120	GMCA unit cost database
Housing benefits – average weekly award across all tenure types (weekly) – 2024 prices	128	
Annual cost	6,240	
Community social care support package for people with learning disabilities (weekly) – 2022 prices	398	GMCA unit cost database
Community social care support package for people with learning disabilities (weekly) – 2024 prices	425	
Annual cost	22,103	
Total cost	28,343	

**Table A7. Unit costs for supporting children in care and children in need, adjusted to 2024 prices**

**4. Cost of child entering care**

	Estimated cost (£)	Source/notes
Child taken into care – average across all settings (per year) – 2022 prices	67,866	GMCA unit cost database
Child taken into care – average across all settings (per year) – 2024 prices	72,481	
Average length of care placement (years)	1.6	gov.uk: <a href="https://explore-education-statistics.service.gov.uk/find-statistics/children-looked-after-in-england-including-adoptions">https://explore-education-statistics.service.gov.uk/find-statistics/children-looked-after-in-england-including-adoptions</a>
Cost of children in need case management (per year) – 2022 prices	3,730	GMCA unit cost database
Cost of children in need case management (per year) – 2024 prices	3984	
Average length of children’s services intervention when child in need plan is in place (years)	1	Tower Hamlets Children’s Services: <a href="https://www.proceduresonline.com/towerhamlets/cs/p_cin_plans_rev.html#:~:text=A%20Child%20in%20Need%20Plan,for%20example%20children%20with%20disabilities">https://www.proceduresonline.com/towerhamlets/cs/p_cin_plans_rev.html#:~:text=A%20Child%20in%20Need%20Plan,for%20example%20children%20with%20disabilities</a>

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**Table A8. Assumptions for in-patient admissions for people with learning disabilities, including years of effect and deadweight**

### 1. Mental Health in-patient admission for person with learning disabilities or autistic person

	Annual Saving	Rationale
Step down from hospital-based care to supported living (£)	139,523	
Years of effect	2	Research from Mencap shows that the average length of stay in an inpatient setting for someone with a learning disability or autism is 5 years. We prudently assume that the support of the advocacy service helps to reduce the length of the placement on average by 2 years (in reality this may be higher as we know that advocacy services often intervene early with clients in in patient settings)
Deadweight (% of individuals who would have stepped down without support)	20%	We assume that only 20% of individuals helped by the advocacy services would have left hospital without the advocate's support, based on the literature base showing that the average length of in-patient stay is 5 years, and that many individuals remain in inappropriate inpatient settings for many years. Research by <a href="#">Glasby et al (2024)</a> found that most autistic people and people with learning disabilities in the study remained in hospital 12 months after being admitted. Given that these people did not receive advocacy support, this research further supports our assumption that it is difficult for people to leave hospital settings without support.
Benefit per case	223,237	

**Table A9. Assumptions for residential placements for people with learning disabilities, including years of effect and deadweight**

### 2. Cost of supporting adults with learning difficulties in residential placement

	Annual Saving	Rationale
Step down from hospital-based care to independent accommodation (£)	224,773	
Years of effect	2	Research from Mencap shows that the average length of stay in an inpatient setting for someone with a learning disability or autism is 5 years. We prudently assume that the support of the advocacy service helps to reduce the length of the placement on average by 2 years (in reality this may be higher as we know that advocacy services often intervene early with clients in in patient settings)
Deadweight (% of individuals who would have stepped down without support)	20%	We assume that only 20% of individuals helped by the advocacy services would have left hospital without the advocate's support, based on the literature base showing that the average length of in-patient stay is 5 years, and that many individuals remain in inappropriate inpatient settings for many years.
Benefit per case	359,636	

**Table A10. Assumptions for supporting people with learning disabilities living independently, including years of effect and deadweight**

**3. Cost of supporting adults with LDs in independent accommodation**

	Annual Saving	Rationale
Step down from supported living to independent accommodation (£)	85,249	
Years of effect	2	Research from The National Elf Service shows that the average length of stay in a residential setting for someone with a learning disability is 5.3 years. We prudently assume that the support of the advocacy service helps to reduce the length of the placement on average by 2 years (in reality this may be higher as we know that advocacy services often actively intervene to help people with their living situation/accommodation- one of the most prolific primary goals stated by people in our data)
Deadweight (% of individuals who would have stepped down without support)	20%	We assume that 20% of individuals helped by the advocacy services would have moved to independent accommodation without the advocate's support. We aren't aware of other support for individuals around achieving this step down.
Benefit per case	136,399	

**Table A11. Assumptions for supporting children in care and children in need, including years of effect and deadweight**

**4. Cost of child entering care**

	Annual Saving	Rationale
Preventing children from entering care (£)	68,497	
Years of effect	1.6	Research from gov. uk shows that the average length of care placement for a child is 1.6 years before they are adopted. We prudently assume that the support of the advocacy service will help prevent this from happening.
Deadweight (% of individuals who would have not entered care without support)	50%	We assume that 50% of individuals helped by the advocacy services would have not gone into care without the advocate's support, as there are often other services supporting the child. Recent research from <a href="#">Burch et al (2024)</a> suggests that more advocacy support and training for advocates is needed to support people through pre-proceedings and after care proceedings.
Benefit per case	54,798	



**Table A12. Estimated net savings/costs per year for each funder (per person per year)**

	NHS (ISC)	Local Authority	DWP	Total
Step down from hospital-based care to supported living (£) (including years of effect and deadweight)	4,049,856	-1,817,484	0	2,232,372
Step down from hospital-based care to independent accommodation (£) per year (including years of effect and deadweight)	2,834,899	-247,557	-69,888	2,517,454
Step down from supported living to independent accommodation (£) per year (including years of effect and deadweight)	0	4,245,108	-289,536	3,955,572
Preventing children from entering care (£) per year (including years of effect and deadweight)	0	2,794,688	0	2,794,688
Per year benefits	6,884,755	4,974,755	-359,424	11,500,086
Per person benefits	18,359	13,266	-958	30,667

## 4.2 Outcomes framework

The outcomes framework was designed following several rounds of consultation with grantee organisations, stakeholders and experts in learning disabilities and advocacy. The following fields feature in the outcomes framework:

### Aggregate level data

- New cases (monthly)
- Ongoing cases (monthly)
- Number of cases closed (monthly)
- Total clients (monthly)

**Individual level data**

Framework categories	Data fields
General	Advocacy organisation Client ID
Client Demographics	Age banding Gender Ethnicity Learning disability and source of diagnosis Autism and source of diagnosis Other disability
Timing of support	Date of referral Referral source Location at referral Social care package from LA at referral Date when support began Date advocacy plan filled in (if applicable) Level of engagement with client Date when support ended (if applicable)
Advocacy goals & outcomes (repeated for to capture data on a maximum of 5 goals per person)	Goal category Description of goal Support given to help achieve goal Was the goal achieved? Details on goals achieved
Advocacy success outcomes – Start of support	Speaking up – start Knowledge of rights – start Knowledge of local services – start Good relationships – start Happy with life – start Feeling listened to – start Learning new skills – start
Advocacy success outcomes – End of support	Speaking up – end Knowledge of rights – end Knowledge of local services – end Good relationships – end Happy with life – end Feeling listened to – end Learning new skills – end
End of support	Location at end of support Social care package at end of support Destination after end of support

### 4.3 Grantee survey – June 2023

Theme	Sub-Questions
<b>Nature of independent/ non-statutory advocacy</b>	What is the purpose of your service? Please restrict your response to 2–3 sentences. (free text)
	Which of the following categories do your services fall under? Please select all options that apply. <input type="checkbox"/> One-to-one support <input type="checkbox"/> Group advocacy <input type="checkbox"/> Peer advocacy <input type="checkbox"/> Self-advocacy <input type="checkbox"/> Other (please specify) (free text) <input type="checkbox"/> We provide more flexible support <input type="checkbox"/> We provide better quality support <input type="checkbox"/> We provide support for longer <input type="checkbox"/> Other (please specify)
	What are the primary issues your service assists clients with? Please select all options that apply. <input type="checkbox"/> Accessing services <input type="checkbox"/> Independence <input type="checkbox"/> Mental health <input type="checkbox"/> Physical health <input type="checkbox"/> Housing <input type="checkbox"/> Finances <input type="checkbox"/> Relationships and social connections <input type="checkbox"/> Skills and employment <input type="checkbox"/> Other (please specify) (free text)
	When engaging with your service, to what extent do you agree or disagree that people’s goals change over time? <input type="checkbox"/> Strongly disagree: Goals never change <input type="checkbox"/> Disagree: Goals tend to be fixed and unchanging <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Agree: Goals tend to change over time <input type="checkbox"/> Strongly agree: Goals almost always change over time <input type="checkbox"/> I don't know
	In your experience, what are the top three strongest influences on people’s changing goals? Please rank the top three. <input type="checkbox"/> Their relationship with their advocate <input type="checkbox"/> Personal growth & development <input type="checkbox"/> Changes in life circumstances <input type="checkbox"/> Shifts in priorities & values <input type="checkbox"/> Other (please specify)
	In your view, what are the main reasons that people use your service instead of statutory services? Please select all that apply. <input type="checkbox"/> We provide broader support on areas not covered by statutory services <input type="checkbox"/> We provide more tailored support

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<b>Advertising and outreach</b>	<p>Where do you advertise your services? Please select all options that apply.</p> <p><input type="checkbox"/> Online <input type="checkbox"/> Through public services (e.g. schools, hospitals, police) <input type="checkbox"/> VCSE organisations</p> <p><input type="checkbox"/> Other (please specify)</p> <p><input type="checkbox"/> I don't know</p>
	<p>How would you describe 'advocacy'? Please restrict your response to 1-2 sentences. [free text]</p>
	<p>Please list any alternative terms you may use besides 'advocacy' to describe your services (e.g. in advertisements) [free text]</p>
<b>Referrals and Eligibility criteria</b>	<p>Does your service have a defined eligibility criterion?</p> <p><input type="checkbox"/> No (please describe why not in 1-2 sentences)</p> <p><input type="checkbox"/> Yes (please describe what this is in 1-2 sentences)</p>
	<p>When reviewing referrals, how often do you adhere to the eligibility criteria?</p> <p><input type="checkbox"/> Almost always <input type="checkbox"/> Most of the time <input type="checkbox"/> Some of the time <input type="checkbox"/> Rarely <input type="checkbox"/> Never</p> <p>If you answered 'Some of the Time,' 'Rarely' or 'Never,' please provide a 2-3 sentence explanation of why</p>
	<p>How do you decide which referrals to engage with first? Please select all that apply.</p> <p><input type="checkbox"/> First come, first served</p> <p><input type="checkbox"/> Level of need [please describe how you may assess this in 1-2 sentences]</p> <p><input type="checkbox"/> Level of vulnerability [please describe how you may assess this in 1-2 sentences]</p> <p><input type="checkbox"/> We don't follow a set process for this</p>
	<p>How often do you receive referrals that should otherwise be handled under statutory advocacy? These types of referrals may include 'hybrid' cases where some of the advocacy should fall under the statutory category and other the rest under your work</p> <p><input type="checkbox"/> Almost always <input type="checkbox"/> Most of the time <input type="checkbox"/> Some of the time <input type="checkbox"/> Rarely <input type="checkbox"/> Never</p>
	<p>In your experience, how are people matched to their advocate? Please select all the factors that apply.</p> <p><input type="checkbox"/> Advocates are assigned by the grantee organisation</p> <p><input type="checkbox"/> Advocates are assigned by the grantee organisation, in consultation with the person using the service</p> <p><input type="checkbox"/> Advocates are assigned based on preferences stated by people using the service (e.g. someone with a similar cultural background)</p>
	<p>Are you ever forced to turn away people who approach your service for support?</p> <p><input type="checkbox"/> No <input type="checkbox"/> Yes [please describe why]</p>
	<p>What would you need to support additional people that you may have turned away in the past? Please select all options that apply.</p> <p><input type="checkbox"/> More funding <input type="checkbox"/> More staff/advocates <input type="checkbox"/> Better outreach/advertising/awareness</p> <p><input type="checkbox"/> An expansion of our current scope/range of services</p> <p><input type="checkbox"/> Other (please describe)</p>

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<b>Service delivery</b>	<p>For people accessing 'standard support' through your service, how often did you engage each person over the past 7 days? (e.g. in-person or virtual meetings, phone calls, etc.) Your best estimate is fine. [choose one]</p> <p><input type="checkbox"/> 1 – 5 times   <input type="checkbox"/> 6 – 10 times   <input type="checkbox"/> 11 – 15 times   <input type="checkbox"/> 15 – 20 times</p> <p><input type="checkbox"/> 20 times or more (please specify)</p>
	<p>For people requiring more intensive support through your service, how often did you engage with each person over the past 7 days? (e.g. in-person or virtual meetings, phone calls, etc.) Your best estimate is fine. [choose one]</p> <p><input type="checkbox"/> 1 – 5 times   <input type="checkbox"/> 6 – 10 times   <input type="checkbox"/> 11 – 15 times   <input type="checkbox"/> 15 – 20 times</p> <p><input type="checkbox"/> 20 times or more (please specify)</p>
	<p>Choose the 3 most common ways in which you support people you work with [choose 3 from list]</p> <p><input type="checkbox"/> one-to-one contact (via phone/ in-person/online)</p> <p><input type="checkbox"/> Signposting to other services</p> <p><input type="checkbox"/> Giving advice</p> <p><input type="checkbox"/> Organising events and training</p> <p><input type="checkbox"/> Other [please specify]</p>
	<p>Are your services helping people avoid crisis (including e.g. preventing hospital and other in-patient admissions)?</p> <p><input type="checkbox"/> Yes (Please explain why in 1-2 sentences)</p> <p><input type="checkbox"/> No (Please explain why in 1-2 sentences)</p>
	<p>In your experience, why might some people you work with choose not to access help through existing LA services? Please select all options that apply.</p> <p><input type="checkbox"/> Fear of social services/ hesitation   <input type="checkbox"/> Poor professional approaches by LA services</p> <p><input type="checkbox"/> Lack of access or awareness   <input type="checkbox"/> Stigma   <input type="checkbox"/> Other (please specify)   <input type="checkbox"/> I don't know</p>
	<p>How often do you engage with C(E)TRs? Please choose one option.</p> <p><input type="checkbox"/> Very frequently   <input type="checkbox"/> Often   <input type="checkbox"/> Sometimes   <input type="checkbox"/> Rarely   <input type="checkbox"/> Never   <input type="checkbox"/> I don't know</p>
	<p>What is your experience of using C(E)TR? Please choose one option.</p> <p><input type="checkbox"/> Excellent   <input type="checkbox"/> Good   <input type="checkbox"/> Fair   <input type="checkbox"/> Poor   <input type="checkbox"/> Very bad   <input type="checkbox"/> I don't know</p>
<b>Gaps</b>	<p>Are you aware of any underrepresented groups or minorities who use your service?</p> <p><input type="checkbox"/> No   <input type="checkbox"/> Yes [please specify who they are likely to be]</p>
	<p>Are there people whom you would like to work with, but are currently struggling to access? (e.g. people with certain needs or characteristics such as race/age/geographical location, etc.)</p> <p><input type="checkbox"/> No   <input type="checkbox"/> Yes [please describe who they are likely to be]</p> <p>If yes, why do you think you struggle to access these groups of people? [free text]</p>
	<p>Are there gaps in service delivery that are not being addressed by current forms of advocacy? This includes advocacy services offered by your organisation as well as others in the sector.</p> <p><input type="checkbox"/> No   <input type="checkbox"/> Yes [please describe]</p>

## 4.4 Grantee survey – September 2024

### Questions

1. What is the name of your organisation?

2. Which of the following categories do your services fall under?

3. How many individuals did you help to step down from hospital-based care to supported living in the 2023–24 financial year?

4. How many individuals did you help to step down from hospital-based care to independent accommodation in the 2023–24 financial year?

5. How many individuals did you help to move from supported living to independent accommodation in the 2023–24 financial year?

6. How many children and young people did you prevent from being separated from their family and going into the care system in the 2023–24 financial year (in cases where this was the desired advocacy outcome)?

7. Are there any other examples of support provided through different forms of advocacy which you think can generate substantial cost savings for the system? (e.g. related to health, social care, education or other areas). These examples can be drawn from multiple people and do not have to relate to the same person.

8. How many individuals did you help to step down from one-to-one support to peer advocacy or self-advocacy in the 2023–24 financial year?

9. Do you currently employ any paid lived experience employees? If yes, how many of those individuals originally accessed your advocacy service?

10. If you answered yes to Q9, how many of those individuals originally accessed your advocacy service?



## 4.5 List of grantees

Grantee organisation	Geographical coverage	Type of advocacy provided as part of this programme	Focus cohort of advocacy provided as part of this programme
Advocacy Alliance Yorkshire	North Yorkshire: Scarborough & Ryedale	one-to-one support	Adults with learning disabilities and autistic people
Advocacy Service Aberdeen	Aberdeen	one-to-one support; group advocacy	People with learning disabilities and autistic people facing life-changing decisions
Advocacy Support Cymru	South Wales	one-to-one support; other	Adults with learning disabilities and autistic people
Advocacy West Wales	West Wales	one-to-one support	Adults with learning disabilities and autistic people
Brighton & Hove Speak Out	Brighton & Hove	one-to-one support; self-advocacy; group advocacy	Adults with learning disabilities and autistic people
Central Advocacy Partners	Falkirk, Forth Valley	one-to-one support	Adults and young adults age 16+
Coram Voice	London	one-to-one support	Children with learning disabilities and autistic children ineligible for statutory advocacy, who remain living with their birth family
Darlington Association on Disability	Darlington, County Durham	one-to-one support; group advocacy; peer advocacy; self-advocacy	Adults with learning disabilities and autistic people
Disability Advice Service Lambeth (DASL)	South London	one-to-one support; peer advocacy	Adults with learning disabilities and autistic people. Parents with learning disabilities going through child protection procedures
Grapevine Coventry & Warwickshire	West Midlands	one-to-one support; peer advocacy	Adults with learning disabilities and autistic people
Impact Initiatives	East Sussex	one-to-one support	Parents with learning disabilities going through child protection procedures
People First Dorset	Dorset	self-advocacy	Adults with learning disabilities and autistic people looking for support with gaining independence, resilience and long-term planning
People First North Somerset	North Somerset	self-advocacy; group advocacy; peer advocacy; one-to-one support	Young adults (16–25 years of age) with learning disabilities and autistic people
Swindon Advocacy Movement	Wiltshire	one-to-one support; self-advocacy	Adults with learning disabilities and autistic people
Vocal Advocacy	Devon	one-to-one support; peer advocacy; self-advocacy	Adults with learning disabilities and autistic people

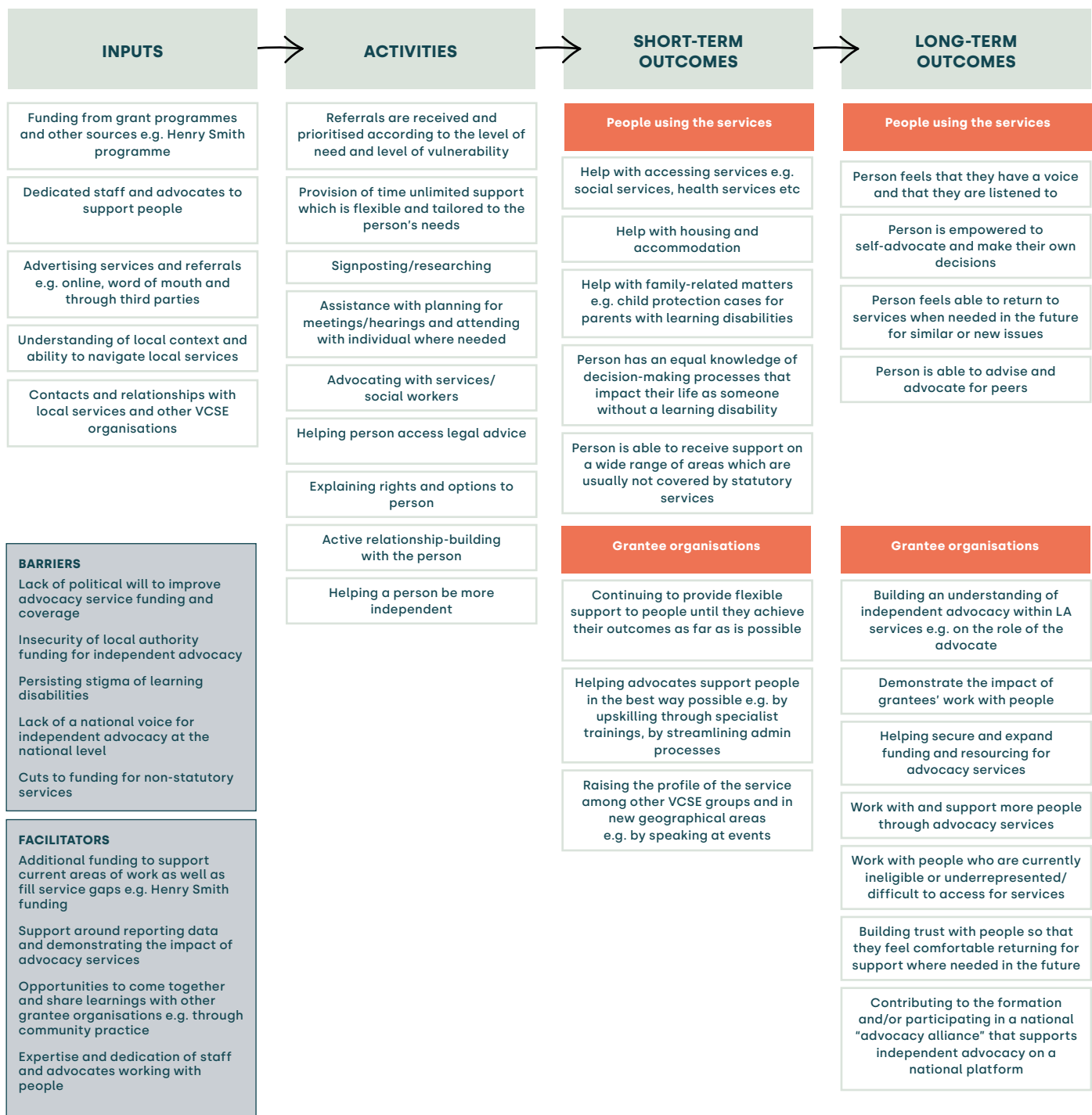
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## 4.6 Advisory Group members

Name	Organisation
Rachael Hall	Learning Disability England
Gary Bourlet	Learning Disability England
Anna Balding	Learning Disability England
Maggie Graham	NHS England
Rhona Wilder	Scottish Independent Advocacy Alliance
Suzanne Swinton	Scottish Independent Advocacy Alliance
Elizabeth Tilley	The Open University
Joe Powell	All Wales People First
Geoff Doncaster	Speakup
Marshall Wilson	Speakup
Vicky Taylor	Speakup
Amy Telford	Speakup
Simone Aspis	Changing Perspectives
Heather Barfoot	Brighton & Hove County Council
Stephen Beyer	Cardiff University
Jabeer Butt	Race Equity Foundation
Gail Petty	NDTi

## 4.7 Theory of change for advocacy services

**OVERALL AIM: TO HELP PEOPLE WITH LEARNING DISABILITIES AND AUTISTIC PEOPLE HAVE A VOICE IN DECISIONS THAT IMPACT THEIR LIVES**  
 A provisional theory of change for the interaction between grantee organisations, people with learning disabilities and autistic people



**Social Finance Ltd**

87 Vauxhall Walk  
London  
SE11 5HJ

—

[info@socialfinance.org.uk](mailto:info@socialfinance.org.uk)

+44 (0) 20 7770 6836

[socialfinance.org.uk](https://socialfinance.org.uk)

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