SOCIAL FINANCE

Speakup Self Advocacy

The Henry Smith Charity

Independent advocacy for independent lives:

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

SUMMARY

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About this summary, 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 summary 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 full report is available separately with more detailed findings and charts.

The summary report and full report are complemented by an Easyread summary, which was prepared by 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 work 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.

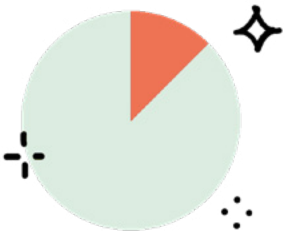
Finally, we thank colleagues at the Henry Smith Charity, in particular Jonathan Oppé, Keith Anderson, and William Jacks, for their ongoing support and trust, and for making this programme possible.

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).

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.

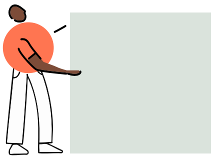
Sadly, we know the support provided by the 15 incredible grantee organisations participating in this programme only scratches the surface of the real demand for independent advocacy across the UK. We are hopeful, though, about the direction the Government is now taking to support unmet needs will change 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 for independent advocacy to thrive, but this will need a cross-government approach and clear leadership.

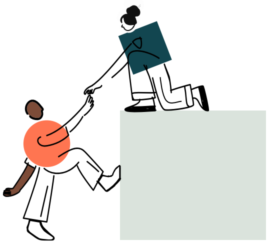
With every £1 spent on independent advocacy generating an estimated £12 of savings, it is high time that we recognise the vital role that independent advocacy can play as part of a preventive approach to health and its potential to reduce the strain on already overburdened statutory services. We need 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.

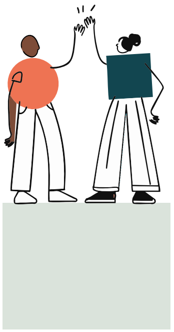
Our thanks to the grantees and to Henry Smith for making this work possible at all and to the Social Finance team that drove the learning and partnership to work so well: Fergus Hamilton, Tanyah Hameed and Bex Spencer. The collaboration and partnership in this project we hope is an inspiration on the 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







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

Executive 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**.[1] 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.

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[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**

1.1 Summary of findings

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.

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.

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

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.[2] 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.

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.[3]

> "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**

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.

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[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.'

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.

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.

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.

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.[4]

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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[4] 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 in the full report for a detailed note on terminology. Throughout the report we use the terms 'advocacy' and 'non-statutory advocacy' interchangeably.

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 disabilites 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 disabilites and autistic people
Advocacy West Wales	West Wales	one-to-one support	Adults with learning disabilites and autistic people
Brighton & Hove Speak Out	Brighton & Hove	one-to-one support; self-advocacy; group advocacy	Adults with learning disabilites 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 disabilites 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 disabilites 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 disabilites and autistic people
Swindon Advocacy Movement	Wiltshire	one-to-one support; self-advocacy	Adults with learning disabilites and autistic people
Vocal Advocacy	Devon	one-to-one support; peer advocacy; self-advocacy	Adults with learning disabilites 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.[5]

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.

1.3 Barriers to sector expansion

Approximately 1.5 million people in the UK have a learning disability,[6] and more than 700,000 are known to be autistic.[7] 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.[8]

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.

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 disabilities and autistic people is provided by a

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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.

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.[9] 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.[10] 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.

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.

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.

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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[9] Local government finances: Impact on communities - House of Lords Library

[10] Further funding cuts for councils would be disastrous; urgent funding and reform is needed | Local Government Association

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:

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.

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.

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.

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[11] 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.[12] 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.

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.

1.5 Detailed case studies

In addition to the case studies gathered from grantees and featured across the full 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._

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**

* 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.

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.

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.

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.

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 voice remained front

> “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**

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.

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 themself 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.

1.6 Conclusion

This summary report presents a detailed discussion on the value and impact of non-statutory advocacy for people with learning disabilities and autistic people. 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 people with learning disabilities and autistic people:

- 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.

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