

AUTISM SUPPORT THE SYCAMORE TRUST

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Table of contents

Executive summary	3
Foreword by Sycamore CEO Cheryl Kearney	5
The Sycamore Trust	6
Autism in the UK	15
The value of autism support	23
Conclusion	34
Further literature	35



Executive summary

Sycamore Trust

The Sycamore Trust is a charity that provides support services for autistic individuals, their parents and carers, and the wider community in Barking and Dagenham, Havering, and Redbridge, in East London.

The charity has run highly successful programmes for several years, and its work has been widely praised in the local community.

However, Sycamore is at a critical juncture. The UK's economic environment and reduced government funding mean Sycamore had to make difficult choices to continue serving the community. The charity was forced to pause or reduce some of its activities, which provide essential support in one of London's most deprived neighbourhoods.

An increasing amount of time is required to secure whatever funding is available, often plugging the gaps through short-term funding sources. This takes time and resources away from what Sycamore does best, delivering valuable support services.

The UK context

Sycamore's work reflects challenges for the UK as a whole. Autistic individuals too often experience hardship through different stages of life, including social isolation in school and difficulties in finding and holding down a job.

Their struggles are also shared by hard-working parents and carers who are often forced to cut back on work to support their families. Overall, a family can suffer thousands of pounds in costs and losses related to factors such as healthcare costs and missed work. For the UK as a whole, the costs amount to over £1bn a year.

This is partly because autistic individuals and their families are unable to get the support they need.

Even an autism diagnosis is difficult to obtain. Waiting lists for a diagnosis are growing as the recognition and understanding of autism improve. This improvement is a positive outcome, but the UK's diagnostic and support system is creaking under demand it was not designed for.

Value of autism support

The valuable work of charities such as Sycamore is increasingly important in this environment where few other options are available. Frontier Economics worked with Sycamore to demonstrate the charity's immense social value.

Sycamore is estimated to generate at least £3m in monetised social benefits per year while operating on extremely limited resources. The true value of social benefits is likely to be closer to £5m per year, but this is challenging to estimate precisely.

For every £1 in donations, Sycamore is estimated to generate at least £5 in social returns through improving the quality of life and wellbeing of autistic individuals and their families, reducing costs and creating more inclusive communities. The true benefits are likely to be higher, with £9-10 in social returns for every £1 of funding which goes to Sycamore.

The purpose of this report is to show Sycamore's social value and encourage everyone to support the charity. We hope that the report's findings can help Sycamore, where generous donations are going to have a big impact.

Foreword by Sycamore CEO Cheryl Kearney

This report highlights the significant economic and social contributions of Sycamore Trust to the wider community.

As a trusted organisation supporting individuals and families affected by autism, Sycamore Trust delivers measurable value to local health systems, local authorities, and the broader community.

Through its specialist services, advocacy, and community engagement, the Trust not only improves outcomes for service users but also alleviates pressure on public services, promotes inclusion, and enhances quality of life.

This report underscores the vital role Sycamore Trust plays in fostering greater understanding, inclusion, and acceptance within the local community.



The Sycamore Trust

Summary

The Sycamore Trust delivers a wide range of support services for the autistic community in East London. The charity's services help empower autistic individuals through support groups and skills development, provide help for parents and carers, and educate the local community.

Sycamore's finances are in a critical position due to a decline in funding. The charity was forced to pause or downsize its ambitions, and further cuts would threaten its ability to provide help for those in need.

Sycamore delivers a range of valuable support services to multiple audiences

Sycamore is a charity that supports autistic children and young adults, those with learning difficulties,¹ and their parents and carers. Sycamore provides support services in Barking and Dagenham, Havering, and Redbridge.

Barking and Dagenham is one of the most deprived boroughs in London² and in England,³ therefore, many in the community are unable to afford paid-for services. Other local organisations have often referred autistic individuals and their families to Sycamore, which shows Sycamore's key role in the local community.

Overview of support services

Sycamore provides a range of services which help develop important life skills, support employability, create a safe space where autistic individuals, their parents, and carers feel welcome and supported, and raise awareness and educate the community.

Figure 1 shows an overview of the services provided by Sycamore. Below, we provide more detailed descriptions of Sycamore's activities.

This report focusses on Sycamore's autism support services.

Trust for London (2019). Available at: <u>Poverty & Inequality Data Barking & Dagenham - Trust For London | Trust for London</u>.

Index of multiple deprivation (2019): <u>Index of Multiple Deprivation (IMD) | CDRC Data.</u>

Figure 1 Summary of Sycamore's services



- Life and social skills programme
- Communication support
- Employment support
- Peer groups



- Parent support groups
- Training and workshops
- Information and resources
- Administrative support (e.g. application for EHCP)



- CPD training courses
- Autism ambassadors
- Information drop-in service

Source: Frontier Economics based on Sycamore Trust

Empower autistic individuals



Life and social skills

Sycamore delivers a 12-month life and social skills programme for young autistic people aged 10-17 years.

The programme helps young people build important life skills and get more comfortable with socialising, which in turn supports independence and wellbeing. Topics covered include social skills, hygiene, health (including mental health), independent living, and travel.

Communication support

The Speak With A Picture (SWAP) programme develops communication skills for pre-school children aged 2-4 who experience social and communication delay. Early interventions such as SWAP are more likely to be effective compared to delayed support.⁴

SWAP uses a system of pictures and symbols to build communication skills (PECS). Parents and carers are actively involved in SWAP and receive expert knowledge and support.

SWAP was discontinued in December 2024 due to a lack of funding, after supporting over 750 families in seven years.⁵ Sycamore was able to re-launch SWAP on a smaller scale in

Early Intervention for Autism | NICHD - Eunice Kennedy Shriver National Institute of Child Health and Human Development.

⁵ Sycamore Trust - Farewell SWAP; a Sycamore success story!.

February 2025 for individuals aged 5-19 years who experience verbal communication difficulties.⁶

Employment support

Sycamore's support has helped autistic individuals in setting career goals and improving the skills needed to achieve those goals. Autistic individuals experience difficulties in finding employment, and this type of support boosts confidence and creates a sense of achievement.

The programme encourages autistic individuals to think about their strengths and career aspirations, and gain skills in areas including creating a CV, searching and applying for jobs, and preparing for interviews.

Peer groups

Sycamore has organised peer groups where participants can socialise in a supportive environment, build social skills, and form lasting connections in the community.

The groups include a Girls' Group for girls aged 10-17 and a Women's Group for women aged 18-30. Autistic women and girls are less likely than men and boys to receive a diagnosis, and receive support less often, making these peer groups particularly important.⁷

Sycamore also organises a Men's Group for men aged 18-30, and several peer groups for adults in Havering, including three regular weekday social groups and two pre-diagnostic groups for those awaiting assessments.

Support parents and carers



Parenting resources

Sycamore provides support programmes for parents and carers of autistic individuals. The offer includes a programme which supports parenting in areas such as safeguarding, stress management, and health, helps build confidence, and reduces reliance on external support.

Parents and carers can access resources that help in their daily lives with an autistic child or adult, for example, tools that help with communication.

In-person and online support groups are also available, which provide an informal setting for parents and carers to meet others in a similar situation.

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⁶ Sycamore Trust - Introducing SWAP plus.

McCrossin (2022), Finding the True Number of Females with Autistic Spectrum Disorder by Estimating the Biases in Initial Recognition and Clinical Diagnosis. Available at: <u>Finding the True Number of Females with Autistic Spectrum</u> <u>Disorder by Estimating the Biases in Initial Recognition and Clinical Diagnosis - PMC</u>.

Application support

Sycamore provides a paid-for service to help parents and carers apply for government support for autistic individuals. This includes financial help and specialist support, including via Disability Living Allowance (DLA), Personal Independence Payment (PIP), and Education, Health and Care Plans (EHCPs).

Sycamore charges a subsidised fee of £35 per hour of support for these applications to make sure this service remains sustainable.⁸

Educate the wider community



Autism ambassadors

Sycamore helps organise interactive presentations delivered by autistic young adults to local schools, employers and other local organisations.

Autism ambassadors raise awareness about and promote the understanding of autism. The experience also helps young adults develop communication skills and confidence.

Training

Sycamore also delivers accredited CPD courses which raise awareness about and improve the understanding of autism.⁹

The courses help make businesses and public spaces more accessible for autistic people and their families. Organisations benefit from the programme through staff training and site certification.

In the 2023/24 financial year, Sycamore helped organise 13 Autism Ambassador presentations and 8 training sessions for a total of over 1,300 attendees.¹⁰

⁸ All of Sycamore's other services are provided free of charge.

⁹ https://sycamoretrainingservices.org.uk/.

Based on Sycamore's 2023/24 annual report.

Sycamore is in a critical financial position

The difficulties in obtaining funding undermine Sycamore's ability to support the autistic community. Sycamore's financial position is critical, and without new funding, it risks having to cut back on its successful support programmes.

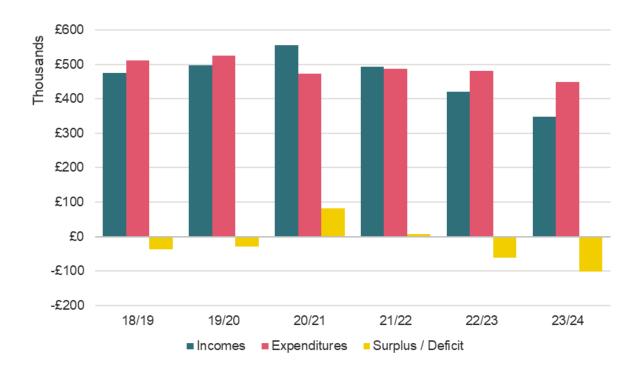
This would mean autistic individuals and their families losing support or not getting the help they need, many of whom have few or no other options.

Overview of financial position

The charity's income from donations and charitable activities has declined significantly in recent years. Sycamore's income in the 2023/24¹¹ financial year was over 20% lower than the charity's income before the Covid-19 pandemic.

This decline has contributed to increasing deficits, as Sycamore faces higher expenses compared to incomes. Figure 2 shows Sycamore's income, expenditure and deficit or surplus in each financial year from 2018/19 to 2023/24.¹²

Figure 2 Sycamore's incomes, expenditures and deficit/surplus from 2018/19 to 2023/24



Source: Frontier Economics based on Sycamore Trust Annual Accounts

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¹¹ The most recent time period for which data can be obtained publicly. Available at: SYCAMORE TRUST U.K. - 1116697.

¹² Sycamore has some reserves to use when the charity faces a deficit.

The decline was even more severe on an inflation-adjusted basis (over 40%), given the large increase in the prices of goods and services starting in 2022 (over 20% up to today). That is, Sycamore had to pay more and got less.

Grants are the main source of Sycamore's funding. Grants have typically been obtained from regional or London-based government funding sources, local authorities and charitable organisations, and a special grant during the pandemic.

Sycamore also generates income from donations and from some of its support services (e.g. EHCP application support). However, compared to grants, these sources contribute only a small share of total funding.¹⁴

Figure 3 shows Sycamore's income by source from financial year 2018/20 until financial year 2023/24. The total income is shown above the bars for each year.

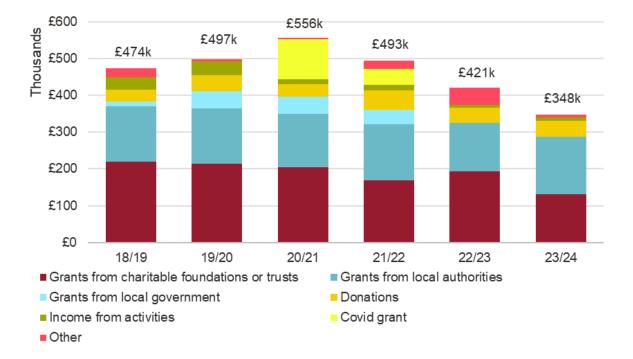


Figure 3 Sycamore's income by source from 2018/20 to 2023/24

Source: Frontier Economics based on Sycamore Trust Annual Accounts.

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¹³ CPIH inflation. Available at: CPIH ANNUAL RATE 00: ALL ITEMS 2015=100 - Office for National Statistics.

Other sources of income include the NHS North East London Clinical Commissioning Group, interest on deposits and other grants.

Reduction in funding

The grant funding landscape is increasingly competitive, as a result of the UK's economic challenges and reduced government expenditure, according to Sycamore's most recent accounts.¹⁵

Since the start of the pandemic (2019/20 financial year), grant funding has decreased by 30%. Sycamore received over £150,000 in Covid-19-related grants, spread across the 2020/21 and 2021/22 financial years, which provided temporary support for the charity's finances.

In the financial years 2022/23 and 2023/24, Sycamore did not receive funding from some of its biggest contributors in the past, such as the City Bridge Trust. ¹⁶ Funding from other major contributors such as BBC Children in Need and National Lottery Grant has also been reduced.

Sycamore has lost local government funding from the Greater London Authority and faced a reduction in funding from other sources (e.g. the NHS).

Income from some sources other than grants has also declined (e.g. from activities). Donations have remained stable in recent years. However, on an inflation-adjusted basis, they have declined about 15% since the start of the pandemic, as individuals struggle to keep up with donations given the increasing cost of living.¹⁷

Securing grant funding has become increasingly resource-intensive due to shorter funding cycles and longer waiting times for funding decisions, according to Sycamore.

Funding now typically covers a 12-month period compared to the previously more common three-to-five-year contracts. Shorter funding cycles and the average 6-month-long waiting time between bid submission and funding decision make planning more difficult, threaten stability and hinder expansion.

The financial challenges limit Sycamore's ability to focus on programme delivery.

Sycamore has a range of funding sources, and the charity consistently has multiple funding applications under consideration at any given time. However, the administrative burden on its staff has reduced Sycamore's capacity to focus on delivering its support programmes.

Negative impact on Sycamore support programmes

Sycamore has had to pause or downsize highly popular and impactful programmes, which has left autistic individuals and their families without crucial support.

Financial year 2023/24. Available at: <u>SYCAMORE TRUST U.K. - 1116697</u>.

While Sycamore did receive funding for the next three years to continue delivering youth services, the level of funding obtained is lower compared to previous years.

¹⁷ CPIH inflation. Available at: CPIH ANNUAL RATE 00: ALL ITEMS 2015=100 - Office for National Statistics.

The **Havering Autism Hub** closed in July 2024. For nine years, the programme provided support services including a sensory room, drop-in support for parents and carers, and a venue for peer group activities. Families described the Hub as a "very much needed service for [their] community", offering a "non-judgmental environment" and "a welcoming place". 18

While Sycamore has adapted by offering by-appointment interim services at an alternative venue, this temporary solution lacks the dedicated space, accessibility, and consistency that made the Hub effective in serving the community.

Sycamore also paused its **SWAP** programme in December 2024. SWAP was a huge success, supporting over 750 families over seven years.¹⁹ One Sycamore member of staff who oversaw the SWAP programme described it as follows:

"... SWAP, as much as it has been a communication programme it has also seen us support parent/carers with additional difficulties that their children face such as toileting, sensory needs, and restricted diets to name a few. It has been amazing to see the parents and carers grow in confidence when communicating with their children and we have had such wonderful feedback over the years."

Initially funded by BBC Children in Need, the programme was paused in 2023 due to funding gaps but briefly resumed in May 2024 with short-term grants before being paused again.²⁰

SWAP then resumed again as "SWAP Plus" in April 2025 on a smaller scale for Barking & Dagenham residents, offering five weeks of support for parents and carers with a child or young adult aged 5-19 who experiences verbal communication difficulties.

This new programme does not include any direct work with the children, which was a key part of SWAP and was seen as one of the key benefits of participating. Additionally, the programme is 7 weeks shorter than SWAP in its original form.²¹

The acute shortage of funding has also meant that existing programmes operate at or are close to full capacity. There is no realistic chance of supporting more people, despite increasing demand for Sycamore's services.

Sycamore struggled to satisfy demand for its services. For example, it could accommodate only 46 of the 50 applications for its parental support programme in 2021/22.

More recently, Sycamore faced increasing difficulty in providing support where needed. For example, there are waiting lists to join Sycamore's peer groups for autistic girls and separately

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https://www.sycamoretrust.org.uk/latest/article/End-of-an-era%21.

https://www.sycamoretrust.org.uk/latest/article/Farewell-SWAP%3B-a-Sycamore-success-story%21.

²⁰ https://www.sycamoretrust.org.uk/latest/article/Picture-this%21.

²¹ Sycamore Trust - Introducing SWAP plus.

for men. The waiting list for the life skills programme, which started in April 2025, had to close early due to high demand.

Scaling back Sycamore's ambitions has helped to control expenditures and minimise the deficit the charity faces as its expenses overtake incomes.²² However, these decisions threaten to leave many in the autistic community without the support they need.

Financial constraints prevent Sycamore from expanding or offering additional services to meet community needs.

Sycamore helps families apply for government support such as PIP, DLA and EHCPs. This service is charged at a (subsidised) rate of £35 per hour. Sycamore would like to offer this support for free to low-income families. This is not possible under current financial constraints.

Despite the financial challenges, Sycamore continues to innovate by launching new programmes to address community needs. One such initiative is the Sensory Workshop, which educates participants on supporting children with sensory needs.²³ These efforts reflect Sycamore's commitment to supporting the community, despite financial constraints.

Purpose of this report

Frontier Economics started working with Sycamore to help improve the charity's financial position. Sycamore delivers a range of vital support services for the autistic community at a critical time when funding has seen significant reductions.

The purpose of this report is to show the value Sycamore creates through its ambitious support programmes. In the next section, we show why it is crucial to support autistic individuals and their communities, who are increasingly coming forward for the support they need for healthier, happier, and more fulfilling lives.

The subsequent section estimates the economic value of Sycamore's services. This shows that supporting the charity financially is a great choice, as they deliver a significant social return.

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²² Sycamore has some reserves to use when the charity faces a deficit.

https://www.sycamoretrust.org.uk/latest/article/Sensory-Workshop%2C-back-by-popular-demand%21

Autism in the UK

Summary

The lived experience of autistic individuals is likely to include significant hardship, including challenges in school and at work, isolation and exclusion, poor mental health, and difficulties in getting and holding down a job.

This is not only costly for the individuals and their communities, but also for the UK economy as a whole. Despite these challenges, in the UK, autistic individuals are unlikely to receive sufficient support.

It is likely that in future there will be an even greater need for charities such as Sycamore, which provide crucial support for their local communities, given the increasing recognition of autism and the shortage of available support options.

Autistic individuals and their communities experience significant hardship

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition with a multidimensional impact on an individual's life quality and outcomes. Autism is a *spectrum* condition, which means autistic individuals' lived experiences and support needs vary significantly.

Someone on the spectrum might face difficulties in understanding facial expressions, while someone else might be exceptionally gifted at reading social cues. Some people are highly sensitive to sensory inputs (e.g. light or texture), while others show very low sensitivity.

Due to difficulties in areas including socialising and communication, autistic individuals face significant challenges in settings such as school and work.²⁴

Impact on life outcomes

Autistic individuals have significantly poorer life outcomes compared to their non-autistic peers. Evidence is abundant on these difficulties, for example:

Autistic children are 60% more likely to experience social disadvantages such as bullying in school, which leads to feelings of isolation and exclusion. Between 70-95% of

According to the DSM-V diagnostic criteria symptoms must be present from early in life and cause significant difficulties. See, for example: Criteria and tools used in an autism assessment.

autistic children and young adults experience **mental health problems**, including anxiety and depression.²⁵

- Autistic adults face significant challenges in the labour market, and are less likely to be employed (30%) compared to non-disabled individuals (82%).²⁶ However, 77% of unemployed autistic individuals want to work.²⁷
- Over 3 in 4 parents of disabled children with special education needs have reported giving up work or cutting hours to support their children because their children's needs are not met in the education system.²⁸

Costs in the UK

The difficulties of autistic individuals, their families and carers translate into significant monetary costs in the UK.

Economic costs are estimated at £560 million a year for the UK through parents' and carers' reduced ability to work when they care for an autistic individual.²⁹ The UK is also estimated to lose over £1 billion a year due to autistic adults' reduced employment rate.³⁰

One study estimated significant costs, including those related to special education and parental productivity loss. The annual loss in productivity of parents who care for 4-17-year-old autistic children was estimated at £5,000 per person in 2011, or £6,800 in today's prices.³¹

Support is not always available

The challenges and costs for autistic individuals, their communities and the economy can be mitigated with the appropriate support services. These can improve health and wellbeing, overall life quality, employment prospects, and reduce costs.³²

MacLennan (2024), Mental health support teams in schools: Evidence and assumptions. Available at https://cep.lse.ac.uk/pubs/download/occasional/op063.pdf

Department for Work and Pensions (2024), The Buckland review of Autism Employment: report and recommendations.

Available at https://www.gov.uk/government/publications/the-buckland-review-of-autism-employment-report-and-recommendations

NHS England (2024) Learning Disability Services Statistics. Available at https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/at-september-2024-mhsds-august-2024

http://gov.uk/government/statistics/the-employment-of-disabled-people-2023/employment-of-disabled-people-2023.

²⁹ Page 4 of Knapp et al. (2024).

Doubling the employment rate for autistic adults (i.e. bringing it closer to the general population) would generate potential societal benefits of £900 million to £1.5 billion a year, in 2014 prices (over £1bn in today's prices). Buescher et al (2014), Costs of autism spectrum disorders in the United Kingdom and the United States. Available at https://doi.org/10.1001/jamapediatrics.2014.210.

³¹ Accounting for inflation since 2011. Ibid.

³² Knapp et al. (2024).

Early access to support is important for maximising effectiveness. For example, for younger children (at or before preschool age), interventions to improve communication, social and emotional capacity have a better chance of being effective in the longer term compared to interventions at a later stage.³³

Common support systems

The are a number of government-provided services which provide financial help and specialist support for autistic individuals and their families.

Access to Work is a government-funded programme that provides financial support for disabled individuals and those with a health condition to help them start or stay in work.³⁴

Access to Work provides funding for work accommodations such as equipment in the workplace (e.g. an ergonomic chair), travel to and from work (including vehicle modifications), and support in finding employment (e.g. an interpreter during interviews). The scheme also provides advice to employers on how best to support employees.

Education, Health and Care Plans (EHCPs) provide support for young people up to 25 years old with special educational needs (SEN).³⁵ EHCPs identify the individual's health, educational and social support needs and outline the steps needed to deliver the support. EHCPs are provided by local authorities.

However, EHCPs have not been able to provide the necessary support. According to stakeholder views and performance data compiled by the National Audit Office (NAO),³⁶ ECHPs often fail to meet expectations and statutory requirements.

For example, transitions from one education phase to another (e.g. from primary to secondary school) are not always well organised, while the special education (SEN) system is often seen by parents as "adversarial", where local authorities cannot effectively resolve complaints.

Families who disagree that the EHCP assessment meets their rights can appeal to a tribunal. The proportion of EHCP decisions appealed increased from 1.6% in 2018 to 2.5% in 2023. At the same time, the proportion of appealed cases won by families is very high, and increased from 92% in 2018/19 to 98% in 2022/23.

Local authorities also often fall short of the deadlines set by the Children and Families Act 2014, which requires the delivery of EHCPs within 20 weeks of receiving a request for

National Institutes of Health, 2021, Early Intervention for Autism. Available at: https://www.nichd.nih.gov/health/topics/autism/conditioninfo/treatments/early-intervention.

³⁴ Access to Work: factsheet for customers - GOV.UK.

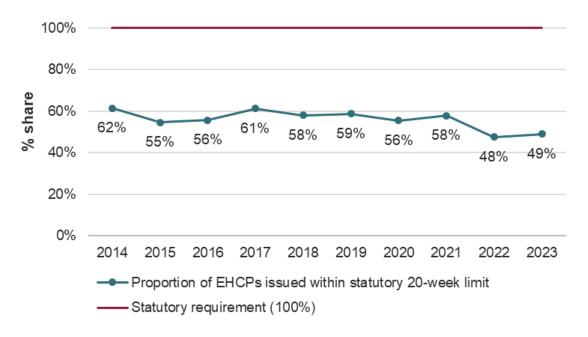
³⁵ Children with special educational needs and disabilities (SEND): Extra help - GOV.UK.

NAO (2023), Support for children and young people with special educational needs. Available at: <u>Support for children and young people with special educational needs</u>.

assessment. According to the NAO report, children experience long waiting times for specialist support (e.g. speech and language therapists).

Figure 4 shows the proportion of EHCPs issued within the 20-week requirement in England. The proportion has decreased steadily and in 2023 less than half of all EHCPs were issued on time.

Figure 4 Proportion of EHCPs that are issued within 20 weeks in England each year in 2014 to 2023



Source: Frontier Economics based on government education statistics. Available at: <u>Create your own tables - Explore education statistics - GOV.UK</u>.

There is significant geographical variation in the performance of local authorities. Figure 5 shows the % share of EHCPs issued within the 20-week limit across each of England's 150 local authorities, where data is available in 2023. The local authorities are ordered along the horizontal axis from the worst to the best performer.

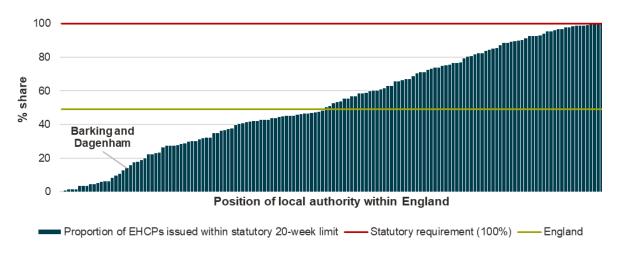
For example, in local authorities such as Westminster, close to 100% of EHCPs were issued on time. However, most local authorities are significantly below the statutory requirement. In Barking and Dagenham, where Sycamore operates, only about 14% of EHCPs were on time.

One study from the London School of Economics and Political Science (LSE) (2023) found that individuals in more deprived areas are less likely to receive the EHCP support they seek.³⁷

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Inequalities in provision for primary children with special educational needs and/or disabilities (SEND) by local area deprivation (2023), Centre for Analysis of Social Exclusion at the London School of Economics and Political Science, November 2023. Available at: https://sticerd.lse.ac.uk/dps/case/cp/casepaper231.pdf.

Figure 5 Proportion of EHCPs that are issued within 20 weeks in England in 2023 – by local authority (average shown for England)



Source: Frontier Economics based on government education statistics. Available at: <u>Create your own tables - Explore education statistics - GOV.UK</u>.

Local authorities' ability to support individuals depends on the authorities' financial resources. The NAO report finds that local authorities are expected to accumulate close to £3bn in deficits in their "high-needs" budget used for EHCPs. In the absence of reform, the NAO finds that local authorities' spending on EHCPs is unsustainable.

The increasing recognition of autism requires further support

There has been a significant rise in the number of autism diagnoses and the number of people looking for a diagnosis, with an increase in waiting times for diagnostic services.

It is estimated that there are around 700,000 autistic children and adults in the UK, or about 1 in 100.38 A 2023 study found that 1 in 57 (about 2%) of all UK children are on the autism spectrum.39

The 700,000 estimate for the number on the spectrum does not include about 750,000 autistic people aged 20 and above in England who remain undiagnosed, which would mean the autistic population in England exceeds 1.2 million people.⁴⁰

Increasing numbers of diagnoses and referrals

The number of individuals with an autism diagnosis has increased significantly in recent years, and autism is seen as increasingly common.

One study found that the number of autism diagnoses in the UK increased more than 8x between 1998 and 2018.⁴¹ The rise in diagnoses was greater for females than males, and greater for adults compared to children.

NHS data shows a significant increase in the number of individuals referred for an autism diagnosis who are waiting too long for a diagnosis.

Figure 6 shows the number of open referrals for an autism diagnosis in England per 100,000 population. The chart shows that in 2025, there are around 8 times as many referrals as there were in 2019, relative to the population.

The chart also shows that the overwhelming majority of referrals were open for at least 13 weeks. That is, most people would need to wait at least 13 weeks for an autism assessment, and the share of those waiting this long has increased from under 70% in 2019 to about 90% in 2025.

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The national strategy for autistic children, young people and adults: 2021 to 2026. Available at: https://assets.publishing.service.gov.uk/media/60f72556e90e0764c6eb39f5/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026.pdf.

Roman-Urrestarazu et al. (2021), Association of Race/Ethnicity and Social Disadvantage with Autism Prevalence in 7 Million School Children England. Available at https://jamanetwork.com/journals/jamapediatrics/fullarticle/2777821.

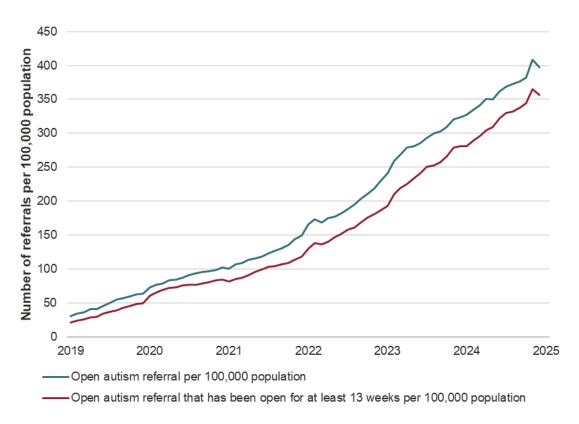
O'Nions et al. (2023), Autism in England: assessing underdiagnosis in a population-based cohort study of prospectively collected primary care data. Available at https://www.thelancet.com/journals/lanepe/article/PIIS2666-7762(23)00045-5/fulltext.

Russel et al. (2021) Time trends in autism diagnosis over 20 years : a UK population-based cohort study. Available at https://acamh.onlinelibrary.wiley.com/doi/10.1111/jcpp.13505

For some, the waiting can be significantly longer. For example, in Oxfordshire, adult autism diagnostic services recently had an 18-year waiting time.⁴²

National Institute for Health and Care Excellence (NICE) guidance recommends that no one should wait for over 13 weeks for a diagnosis.⁴³

Figure 6 Referrals for autism diagnosis per 100,000 population in England in 2019-25



Source: Frontier Economics based on NHS England Autism Statistics, available at: https://digital.nhs.uk/data-and-information/publications/statistical/autism-statistics/april-2024-to-march-2025#resources.

Rising recognition

Autism is recognised and understood better today than ever before. The improvement in the understanding of autism over time contributed to changes in its diagnostic criteria to capture a larger number of individuals for whom a diagnosis would help provide support.⁴⁴

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⁴² Oxfordshire: Eighteen-year wait for adult autism assessments - BBC News.

⁴³ Autism assessment waiting times.

What's behind the UK's increase in autism diagnoses? | Autism | The Guardian.

Increasing diagnosis numbers are therefore to be taken as a positive sign that the system is working as intended, in that it is at least flagging the need for support.

The increase in the number of people seeking a diagnosis is expected to continue. This is because individuals from backgrounds where autism was historically underdiagnosed are now more likely to come forward: for example, women and girls, adults, and individuals from minority ethnic groups.⁴⁵

Indeed, one study shows a greater increase recently in the number of diagnoses for women and girls compared to men and boys, and a greater increase for adults compared to children.⁴⁶

Given the increasing understanding and recognition, in future, there will be an even greater need for support services provided by charities such as Sycamore, especially where governments lack sufficient systems and resources to support autistic individuals to help them lead happy, healthy, and fulfilling lives.

In the next section, we show how Sycamore delivers a significant economic impact, and we economically evaluate the magnitude of this impact.

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See, for example: <u>Autistic women and girls</u>.

Russel et al. (2021) Time trends in autism diagnosis over 20 years : a UK population-based cohort study. Available at https://acamh.onlinelibrary.wiley.com/doi/10.1111/jcpp.13505

The value of autism support

Sycamore is expected to generate social impact through four mechanisms, which together help improve autistic individuals' life quality, reduce costs, and create positive spillovers to wider society through employment and a more inclusive community.

The economic evaluation finds significant monetary benefits from Sycamore. Given conservative assumptions, every £1 of donation to Sycamore is expected to generate at least £5 in social returns, and likely more.

Sycamore creates economic impact via a wide range of mechanisms

As a first step in economic evaluation, we need a clear theory of how Sycamore is expected to generate impact. Figure 7 uses a "logic model" to show the mechanisms that an evaluation could seek to evidence.⁴⁷

The logic model was produced through a desk review of Sycamore's programmes and targeted discussions with Sycamore staff. We have identified four distinct mechanisms through which Sycamore is expected to generate impact. Each of these mechanisms is described in turn.

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⁴⁷ Magenta Book - Central Government guidance on evaluation.

Figure 7 Mechanisms through which Sycamore is expected to generate impact

Programmes

Autistic individuals

- Peer groups
- Employment support
- Life and social skills
- Autism ambassadors

Parents and carers

- Communication skills
- Information and resources
- Support groups
- Application support

Wider community

- Autism ambassadors
- Awareness training/workshops
- Steering group
- Community outreaches

Impact mechanisms

- 1) Developing important life skills
- 2) Creating a supportive environment for autistic individuals and families
- 3) Improving the understanding of autism
- 4) Supporting employment

Outcomes

Autistic individuals

- Gain skills and more understanding of autism
- Experience reduced isolation and enhanced social integration
- Improve financial, physical and mental wellbeing

Parents and carers

- Receive practical support
- Engage with a supportive environment
- Benefit from improved overall wellbeing

Employers and local organisations

- Enable more inclusive workplace environments
- Provide better support for employees

Impact

Improved life quality: Increase in life quality and wellbeing for autistic individuals

Reduced public and private costs: Lower cost for supporting autistic individuals e.g. privately and through local authorities or the NHS

Spillovers to wider society

- Positive impact on the labour market: through supporting autistic individuals, parents and carers, and employers
- More inclusive society

Source: Frontier Economics based on Sycamore Trust

Mechanism 1: Developing important life skills



Sycamore Trust offers a range of programmes to help autistic individuals build important life skills in areas such as communication, independent living and social interactions.

Sycamore's programmes help increase life quality and wellbeing through improved confidence, independence and self-esteem, and reduced isolation. On a broader level, Sycamore's programmes promote social inclusion through helping autistic individuals practice social interactions and become more engaged members of their communities.

Learning life skills can also help reduce care needs and the associated costs for autistic individuals and their families, and for the public sector.

Mechanism 2: Creating a supportive environment



Sycamore helps create supportive environments for autistic individuals and their families through peer groups and support networks.

These programmes help foster social interactions and a sense of community, belonging and acceptance. Autistic children and adults are often "othered", while their parents or carers can feel isolated in the face of everyday challenges.

Sycamore also provides a paid-for service (at a subsidised rate of £35 per hour) which helps parents and carers apply for financial help and specialist support via Disability Living Allowance (DLA), Personal Independence Payment (PIP), and Education, Health and Care Plans (EHCPs).

Sycamore delivers practical support such as parental training, information and resources. These programmes reduce feelings of isolation and help make autistic individuals and their families more informed and feel more supported.

The supportive environment created by Sycamore helps address everyday challenges, reduces isolation and improves resilience. Overall, this improves the well-being of both autistic individuals and their families and reduces care costs.

Mechanism 3: Improving the understanding of autism



Sycamore's work helps improve public understanding of autism through programmes such as training sessions and outreach initiatives (e.g. the Autism Ambassador programme).

These activities promote practices which reduce barriers for autistic individuals, for example, in the workplace. Raising awareness among employers encourages workplace adjustments such as flexible working or sensory-friendly environments, which help autistic individuals thrive in their roles.

These adjustments improve individuals' well-being and enable them to participate more fully in the community and labour market.

Sycamore's skills programmes, parental resources and training also help autistic individuals and their families learn more about autism.

Mechanism 4: Supporting employment



Currently, only 30% of autistic individuals are employed, substantially lower than the employment rate for all non-disabled people (84%).⁴⁸ Sycamore helps address the employment gap faced by autistic individuals via programmes such as "Career Ready".

These programmes help autistic individuals gain a clearer understanding of their career options and skills, and the confidence necessary to make informed decisions about their future, which in turn improves their wellbeing.

Research suggests that an autistic person transitioning from unemployment to employment could gain £9,200 annually, even after accounting for the loss of state benefits, with additional positive outcomes such as improved life satisfaction and stronger social relationships.⁴⁹

Supporting the employment of autistic individuals also provides broader socio-economic benefits, including increased economic activity and tax revenues, and lower government spending.

Department for Work and Pensions, 2024, The Buckland Review of Autism Employment: report and recommendations. Available here.

⁴⁹ https://www.autistica.org.uk/downloads/files/PBE-improve-autistic-employment-report-Autistica.pdf

Our evaluation method estimates economic benefits conservatively

Choosing the mechanism of focus

Sycamore delivers a wide range of programmes to different audiences. The ultimate beneficiaries of Sycamore's programmes are likely to include autistic children and adults, parents and carers, employers and other organisations, local communities, and others.

The programmes are expected to result in a diverse mix of outcomes, including skill development, improved wellbeing, and better workplace environments for autistic individuals. Some of the benefits (e.g. from improved communication skills) are likely to be realised over a long time horizon where many socio-economic factors interact.

These challenges make precise economic evaluation for autism support difficult. According to a recent report from researchers at the London School of Economics and Political Science (LSE), the evidence base to make an economic case for autism support is currently limited.⁵⁰

We have focused on a single impact mechanism from the four identified above: skills development (impact mechanism #1 above). Figure 8 summarises the impact mechanisms and shows which of them are included in the quantitative evaluation.

Figure 8 Impact mechanisms in the quantitative evaluation

Included in quantitative evaluation



1. Developing important life skills

Not included in quantitative evaluation



2. Creating a supportive environment for autistic individuals and families



3. Improving the understanding of autism



4. Supporting employment

Source: Frontier Economics based on Sycamore Trust

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⁵⁰ Page 6 of Knapp et al. (2024).

This allows us to more precisely highlight the pathway through which Sycamore's work creates positive outcomes and impacts. This also means that our quantitative results are going to underestimate the true benefits realised from Sycamore's work.

Estimation methodology

Sycamore collects some quantitative evidence on the impact of its programmes, such as the number of attendees, and for certain programmes, it collects qualitative evidence in formats such as surveys and testimonials of parents and carers.

For example, for the SWAP programme, all of the 19 respondents to a survey of participants in 2022-23 responded with "Yes" to the following question: "Do you feel that you have a better understanding of how to communicate with your child since starting the SWAP programme?".⁵¹

However, comprehensive quantitative evidence, which would allow us to evaluate the programmes' economic impact, is not available directly from Sycamore. The charity is operating on extremely limited resources, which means the type of data recording and processing necessary for having a comprehensive primary evidence base is not possible.

We focused on secondary evidence from programmes similar to Sycamore's and applied these estimates to Sycamore. This introduces some uncertainty in our estimates as the other programmes are unlikely to fully mirror Sycamore's offerings. However, given the similarity in programmes, this gives us a robust estimation tool.

Programme choice

For the estimation, we have selected Sycamore's **SWAP** programme (Speak With A Picture), which works together with parents to improve communication skills of autistic pre-school children. The choice of SWAP was based on the following criteria:

- Scope of programme. Some of Sycamore's programmes (e.g. autism ambassadors) are more open-ended in their intended outcomes than others.
 - SWAP focuses on communication skills development for pre-school children aged 2-4 who experience social and communication delays. This specific goal makes comparison with other programmes in the literature feasible.
- 2. **Intensive and persistent support**. Programmes which provide regular support for a long period of time are more likely to show a clear impact, all else equal.
 - SWAP sessions are held every week over a 12-week period, and the programme is delivered 3 times per year (term time only).
 - The programme includes parent-only sessions and informal coffee afternoons to discuss topics such as transitioning to school. Sycamore also works with pre-schools and nurseries when necessary to help in the child's communication development.

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Data shared by the Sycamore Trust.

3. Availability of comparable programmes in the literature. The validity of the economic estimates depends on the similarity of the programme for which evidence is available in the literature. That is, the programme whose impact estimates were applied to SWAP. We have used the findings of a 2023 study on Preschool Autism Communication Trial (PACT) based on evidence from multiple European countries, including England.⁵² PACT is an intervention aimed at improving social communication for young autistic children. The PACT sessions took place biweekly for a total of 6 months, during which parents and carers were also involved. Participants in the study who received PACT treatment were aged around 2-5 years, similar to the age profile of children supported in SWAP.

Limiting our focus to a single programme makes the resulting economic impact estimates more conservative, as Sycamore's other programmes are also expected to provide benefits. It was not feasible to consider multiple programmes at this time due to the complexity of estimation, and SWAP has properties (see above) which make estimation feasible.

Estimation inputs

After choosing to focus on SWAP for our evaluation, we needed certain inputs for the quantitative estimation of economic benefits. These are described in turn:

Number of individuals supported. SWAP has supported over 750 families with pre-school children aged 2-4 years in 2018-24, according to Sycamore.⁵³ We understand from Sycamore that SWAP has the capacity to support around 100 children a year.

Magnitude of impact. The PACT study estimates the decrease in costs for a family with a supported child in England as over €47,000 in 6 years, or over €7,800 per year⁵⁴ relative to the 'control' scenario, where no PACT support was provided and the children only received "treatment as usual", which included hospital and community services.

In current £ terms, this amount is equivalent to around £9,400 per person per year.55

Table 1 below shows the breakdown of the change in costs for each category due to PACT in the 2023 study. The table shows that the costs of community health, education and social services increase, and there is some cost increase due to the impact on parental productivity.

Tinelli et al. (2023). Available at: https://pmc.ncbi.nlm.nih.gov/articles/PMC10594363/#refs1.

⁵³ Sycamore Trust - Farewell SWAP; a Sycamore success story!.

Excluding the cost of PACT itself, which is €6,198 per person. This amount is excluded to later allow for the comparison of benefits to costs for Sycamore.

The benefits in the PACT study were evaluated in euros for 2020. We use the average 2020 £/€ exchange rate from the European Central Bank (ECB) to convert euros to pounds. Money received in 2020 is worth more than in 2025 because of the interest rate or return the funds can earn over time when deposited, in other words, the time value of money. Money received in 2020 is also worth more than 2025 due to inflation, the decrease over time in the amount of goods and services a given amount of money can buy (purchasing power). To reflect the time value of money, we apply the 1.5% rate typically used in health settings as outlined in the Government guidance available in the Green Book: The Green Book (2022) - GOV.UK. We also adjust monetary values with inflation using CPI inflation data available from the ONS.

However, these increases are outweighed by the large decreases for education and childcare costs, and costs of parental informal care. The PACT study attributes the decrease in costs to "improved parent-child communication, positive family life experiences, and enhanced parentchild interactions". This in turn helps increase life quality and wellbeing.

Table 1 Change in costs by category due to PACT – in current £ terms, per person per year

Change in annual costs per person	£ increase (- dec in costs	crease)
Community health, education, and social services*		£490
Hospital-based health services	-	£345
Education and childcare	-	£1,270
Parental productivity losses		£351
Parental informal care	-	£8,584
Total	-	£9,358

Source: Frontier Economics based on Tinelli et al. (2023). Available at: https://pmc.ncbi.nlm.nih.gov/articles/PMC10594363/#refs1.

Note:

Persistence of impact. Children supported in programmes such as PACT or Sycamore's SWAP are likely to benefit from the programme's impact through improved communication for a long time after the programme ends.

The PACT study found significant long-term impacts 6 years after the intervention, and we understand from Sycamore that SWAP can also have long-term benefits. For the economic evaluation, we use two scenarios: one in which the benefits persist until the 6th year (i.e. 5 years after the intervention, similarly to PACT) and one where the benefits persist for 3 years.

The 3-year scenario provides a lower bound for our estimates, which reflects that benefits for 2-4-year-old children might decline at the start of their next life stage of starting primary school, at which point they might require a slightly different mix of skills and support.

Limitations

The economic benefits of such a complex intervention are estimated imprecisely. This is true in every economic evaluation, and especially in the present case where only limited primary evidence is available.

To interpret our findings, the following caveats need to be taken into account:

^{*} Including speech and language therapy.

- Limiting the scope of the estimation to a single mechanism (skills development) and a single programme (SWAP) means that we produce a **lower bound** estimate of the economic benefits of Sycamore's autism support programmes.
- We apply the benefits (cost reductions) of the PACT programme to the number of people supported by SWAP. It is possible that PACT has a larger per-person per-year impact than SWAP due to access to better resources compared to Sycamore. This would lead to an **upward bias** in our estimates.
- The estimated benefits from PACT are relative to a counterfactual of "treatment as usual" (hospital and community services). A large number of the families supported by Sycamore are unlikely to have access to many alternative treatment options, which means for them, the benefits from SWAP are likely to be even higher.

Overall, the methodology provides a reasonable estimate of economic benefits given significant uncertainty. The estimates are expected to be a lower bound of the "true" benefits, mainly as a result of the limited scope of the estimation relative to Sycamore's offering.

Sycamore delivers significant benefits

Estimation results

Figure 9 shows the estimated economic benefits and costs in current £ terms.⁵⁶ The benefits show the monetised value of the positive impact on communication, well-being and life quality.

Benefits are estimated in line with the methodology above. Costs are taken from Sycamore's most recent accounts (2023/24).⁵⁷ Costs are shown for a year, and benefits are derived from the intervention in that 1-year period.

Separate estimates are shown depending on whether the benefits are assumed to persist for 3 years or for 5 years. Given these assumptions, Sycamore is estimated to generate between £2.8-4.5m per year in economic benefits for less than £500k in annual costs.

We use these estimates to calculate the benefit-to-cost ratio. Sycamore generates **5-8.7x** as much in benefits as the total costs. Put another way, on average, every £1 of donation to Sycamore is expected to generate at least £5 in social benefits and likely more.

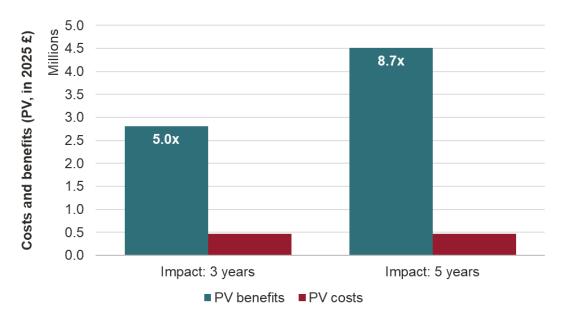


Figure 9 Estimated benefits and costs – in current £ terms

Source: Frontier Economics calculation.

frontier economics | Confidential

That is, accounting for the time value of money received in future and inflation: see the section on estimation inputs above for more information. Present value (PV) in the chart reflects the time value of money, i.e. that we have evaluated the *current value* of *future benefits*. To account for inflation, future benefits were evaluated using inflation expectations and the Bank of England's inflation target, available respectively at: Monetary Policy Report - February 2024 | Bank of England and Monetary policy | Bank of England.

⁵⁷ The most recent time period for which data can be obtained publicly. Available at: SYCAMORE TRUST U.K. - 1116697.

Interpreting the results

Costs

The economic benefit estimation only includes a single programme (SWAP), whereas the costs included relate to all activities of Sycamore. In this conservative scenario, it is implicitly assumed that the other programmes generate no benefits, an unrealistic outcome.

When instead costs are prorated by the number of individuals supported in a year in SWAP within the number supported by Sycamore as a whole (about 70%, a reasonable assumption⁵⁸), the benefits are 6.8-11.6x as large as the costs.

Benefits per person

The total benefits of £2.8-4.5m per year generated by Sycamore can be divided across all 100 beneficiaries, i.e. across the 100 families supported each year on average.

This means that each individual supported by Sycamore is expected to gain around £28,000 to £45,000, depending on how long the benefits persist. During that time, monetised benefits are around £9,000 per year in current £ terms.⁵⁹

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Assuming about 30 individuals supported in the life skills programme and that there are overlaps with other programmes.

That is, accounting for the time value of money received in future and inflation: see the section on estimation inputs above for more information.

Conclusion

The Sycamore Trust plays a critical role in supporting autistic individuals and their communities in East London.

This report shows the mechanisms through which Sycamore helps autistic individuals develop skills, provides a supportive environment, raises awareness about autism and the best ways to support those on the spectrum, and facilitates the employment of autistic individuals.

Sycamore's support is especially valuable given the hardship autistic individuals experience throughout their lives, and the increasing recognition and understanding of autism, which means increasing demand for Sycamore's services.

Our economic evaluation shows that Sycamore is delivering significant social value of at least £3m per year in monetised benefits, and more likely closer to £5m per year. All economic evaluations include an element of uncertainty, but on balance, these estimates are likely to be closer to the lower bound of the 'true level of benefits'.

This means that for every £1 of donations, Sycamore is estimated to generate at least £5 in social returns through improving the life quality and wellbeing of autistic individuals and their families, reduced costs and more inclusive communities. The true 'benefit to cost ratio' is likely to be higher, around £9-10 for every £1 of donations.

Sycamore staff work hard to deliver vital support from extremely limited resources. The charity is in a difficult financial position, which threatens to leave those in need without help, at the same time as demand for Sycamore's support services is increasing.

We hope this report encourages everyone to support Sycamore financially, given the great social value generated by the charity.

Further literature

Literature consulted beyond the specific footnotes referenced in the report:

Middleton, E. (2023). Unmasked: The Ultimate Guide to ADHD, Autism and Neurodivergence: https://www.penguin.co.uk/books/457703/unmasked-by-middleton-ellie/9780241651988.

National Institutes of Health (NIH), National Institute of Mental Health, Autism Spectrum Disorder: Autism Spectrum Disorder - National Institute of Mental Health (NIMH).

Knapp, M., Cyhlarova, E., Salehi, N., Stubbs, E., Walbaum, M., Jadoolal, S., and Shah M. M. (2024). The Economic Case for Prioritising Autism in Policy and Reform. Care Policy and Evaluation Centre (CPEC) London School of Economics and Political Science (LSE). Available at: https://www.lse.ac.uk/cpec/assets/documents/Autismeconomics.pdf.



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