



Supporting SMS families for a positive future



## FIVE YEAR DEVELOPMENT STRATEGY 2024 - 2029

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 [facebook.com/SmithMagenisUK](https://facebook.com/SmithMagenisUK)  [instagram.com/smithmagenisuk](https://instagram.com/smithmagenisuk)

# INTRODUCTION

We are The Smith-Magenis Syndrome (SMS) Foundation, a small charity that supports families living with SMS in the UK. As well as helping families that live with the syndrome we also work with and support a variety of professionals who treat, educate, and care for people with SMS.

We help and support families and professionals in a variety of ways, including:



Community Events



Information and literature



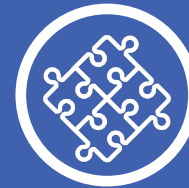
Emotional support and advice



First-contact service for newly diagnosed



Professional advisory board



Support research into SMS



Fund grants for equipment and social events

The SMS UK Foundation was started 30 years ago by a group of parents, eventually becoming a small registered charity run by trustees. In 2020 we employed a part-time staff team in line with the increasing size of our SMS community and our workload. Since then, we've seen the number of patients and families involved with the charity grow 43% and the known community has nearly doubled.

We continue to secure funding and we are supported by the incredible efforts of many supporters, making it possible to deliver important support to families and patients.

However, this growth has brought challenges. Notably, Covid-19 and

the cost-of-living crises have made fundraising very competitive. In early 2023 it made sense for us to adapt by reducing the size of our team, making the post of CEO redundant.

Despite the turbulence of the last three years, The SMS Foundation continue to operate as a staffed charity with CIO status. In the past three years we have recruited three members of staff and new board members, delivered a conference, increased our family membership, supported a rise in enquiries, provided 12 individual grants, introduced a regular giving scheme, delivered training into two schools, and supported 12 research projects.

# VISION, MISSION, AND VALUES



**VISION:** Every person with Smith-Magenis Syndrome shall have a fulfilling life within a supportive and understanding community



## MISSION

The SMS Foundation UK shall be at the heart of our community of individuals, families, carers and professionals living and working with Smith-Magenis Syndrome and we will be the first point of contact for those seeking information and support. Nobody should ever feel isolated or alone. We value every person affected by this genetic disorder and shall empower them to reach their full potential as respected members of society.

## VALUES

- Integrity
- Knowledge
- Respect
- Compassion
- Equity
- Community
- Sustainability
- Ambition

## PHILOSOPHY

An old proverb gave us inspiration... "It takes a village to raise a child".

***We understand the complex needs of a person with SMS and recognise what it takes to give them the support they need.***

It takes a community of people including family, friends, peers, doctors, nurses, practitioners, and teachers.

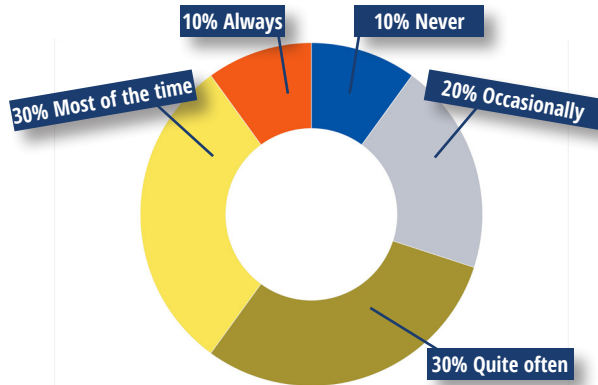
# UNDERSTANDING THE NEEDS OF THE SMS COMMUNITY

In early 2023, we took the initiative to conduct a survey among the caregivers of our SMS community to gather direct feedback on the issues and challenges they are facing. Over 100 people took part in the survey,

and the insights we gathered have been key to understanding what their needs are and developing a strategy that effectively addresses them. Below are a selection of the questions we asked our community.

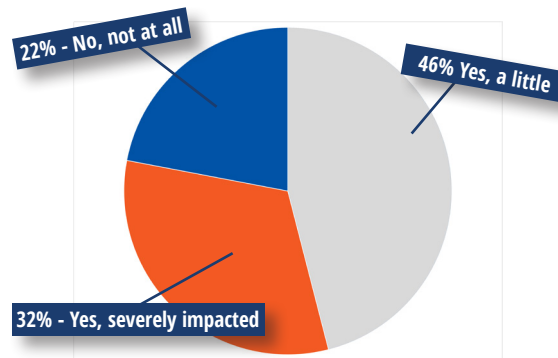
## Emotional and mental well-being impact

How often do you experience isolation and/or loneliness due to SMS?



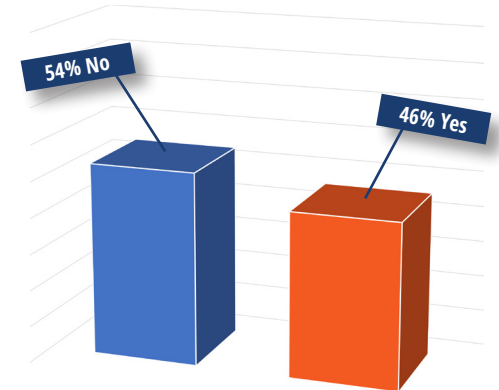
## Financial impact

Has your financial well-being been negatively impacted as a result of living with SMS?



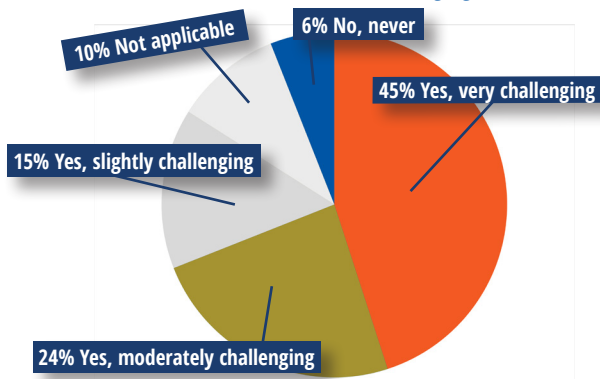
## Career and job impact

I have had to give up my job and/or career to care for my person with SMS.



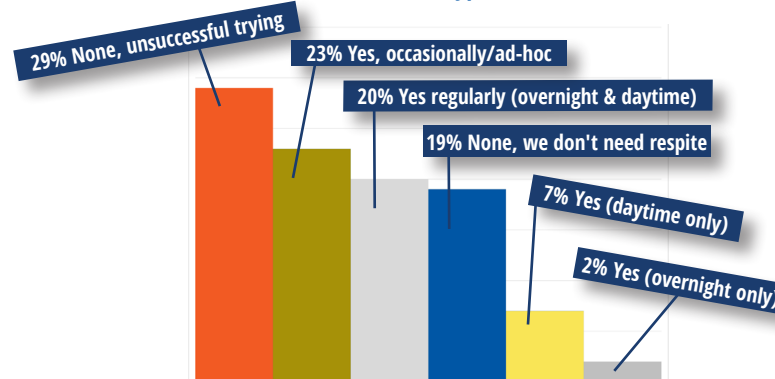
## Educational challenges

Accessing school and a quality education for our child with SMS is (or was) challenging...



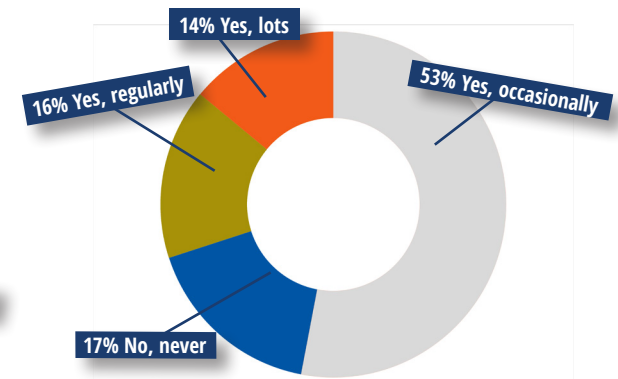
## Respite and carer support

Do you get respite support to enable you to recharge, if so what type?

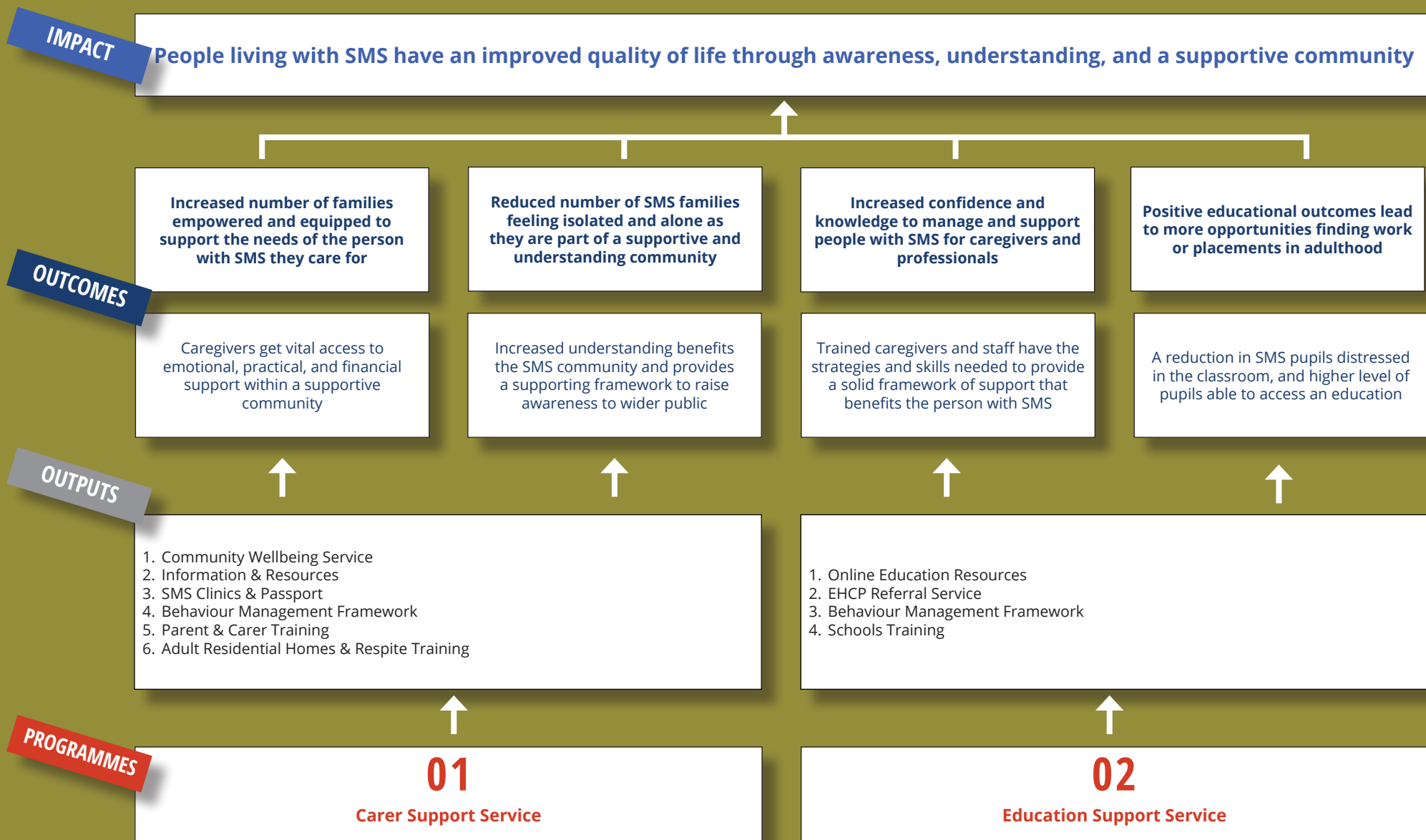


## Emotional and mental well-being impact

Do you need emotional support from The SMS Foundation?

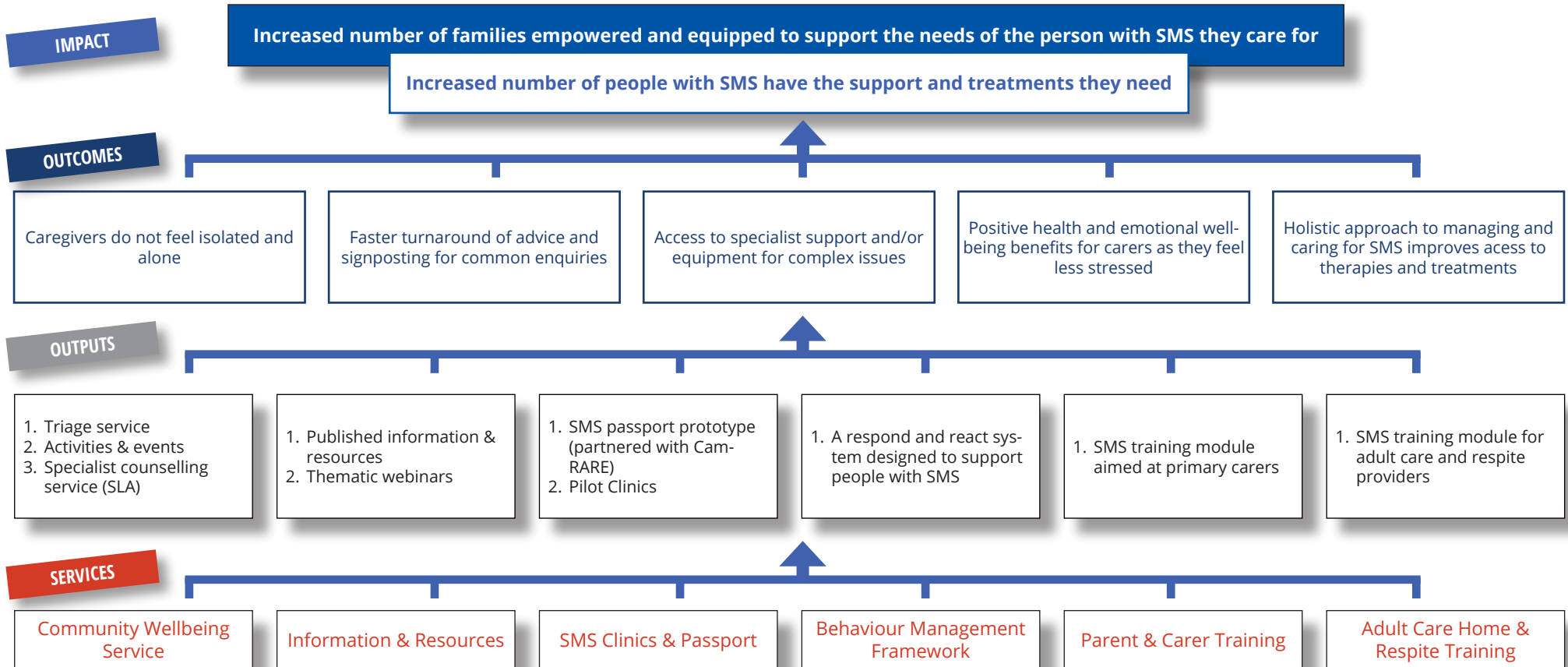


# IMPACT AND PURPOSE THEORY OF CHANGE



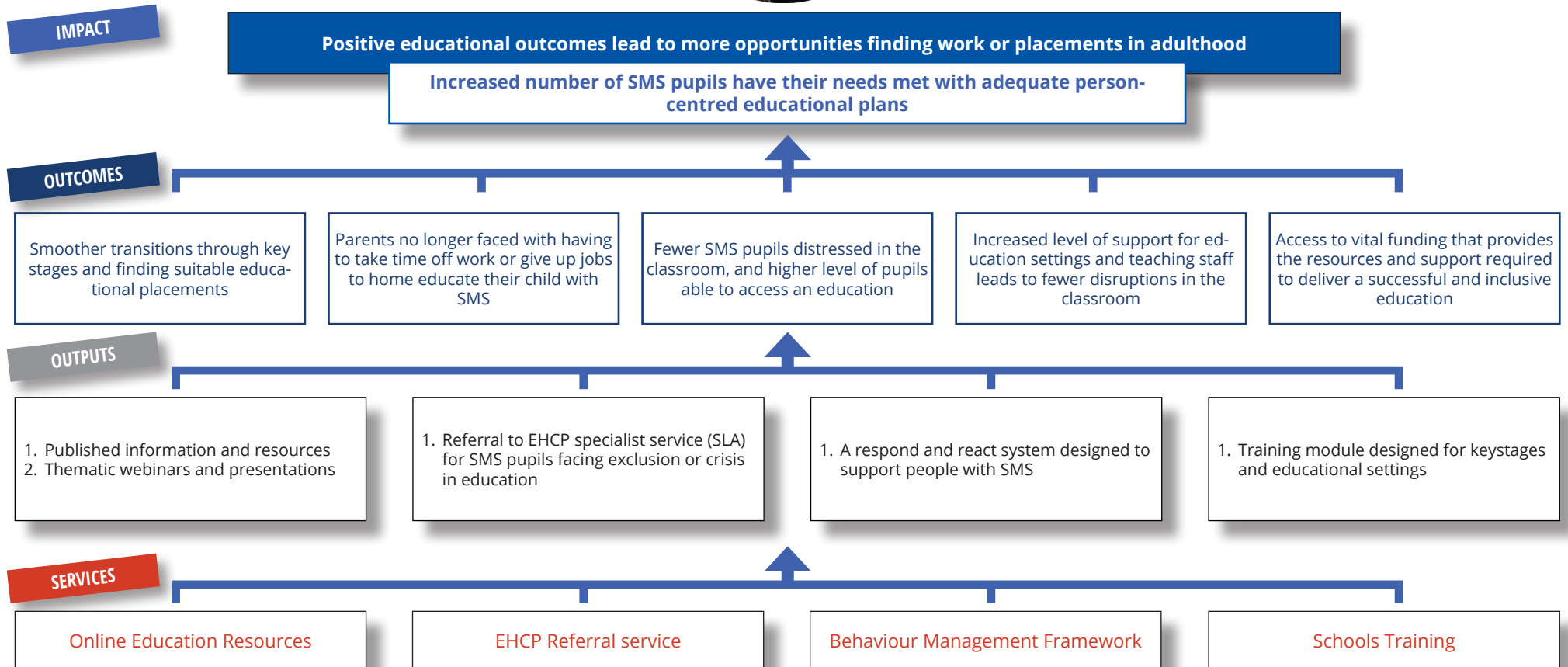
# PROGRAMME 01 : CARER SUPPORT SERVICE

People living with SMS have an improved quality of life through awareness, understanding, and a supportive community



# PROGRAMME 02 : EDUCATION SUPPORT SERVICE

People living with SMS have an improved quality of life through awareness, understanding, and a supportive community



# PROGRAMME BUDGETS OVER NEXT 5 YEARS

01

## CARER SUPPORT SERVICE



Online Education Resources:	£33,215.00
EHCP Referral Service:	£32,030.00
Behaviour Management Framework:	£25,100.00
Schools Training:	£52,750.00

**TOTAL BUDGET OVER 5 YEARS £143,095.00**

Community Wellbeing Service:	£46,700.00
Information, Activities & Events:	£50,025.00
SMS Clinics & Passport:	£37,600.00
Parent & Carer Training:	£16,100.00
Adult Care Home & Respite Training:	£16,100.00

**TOTAL BUDGET OVER 5 YEARS £166,525.00**



## EDUCATION SUPPORT SERVICE

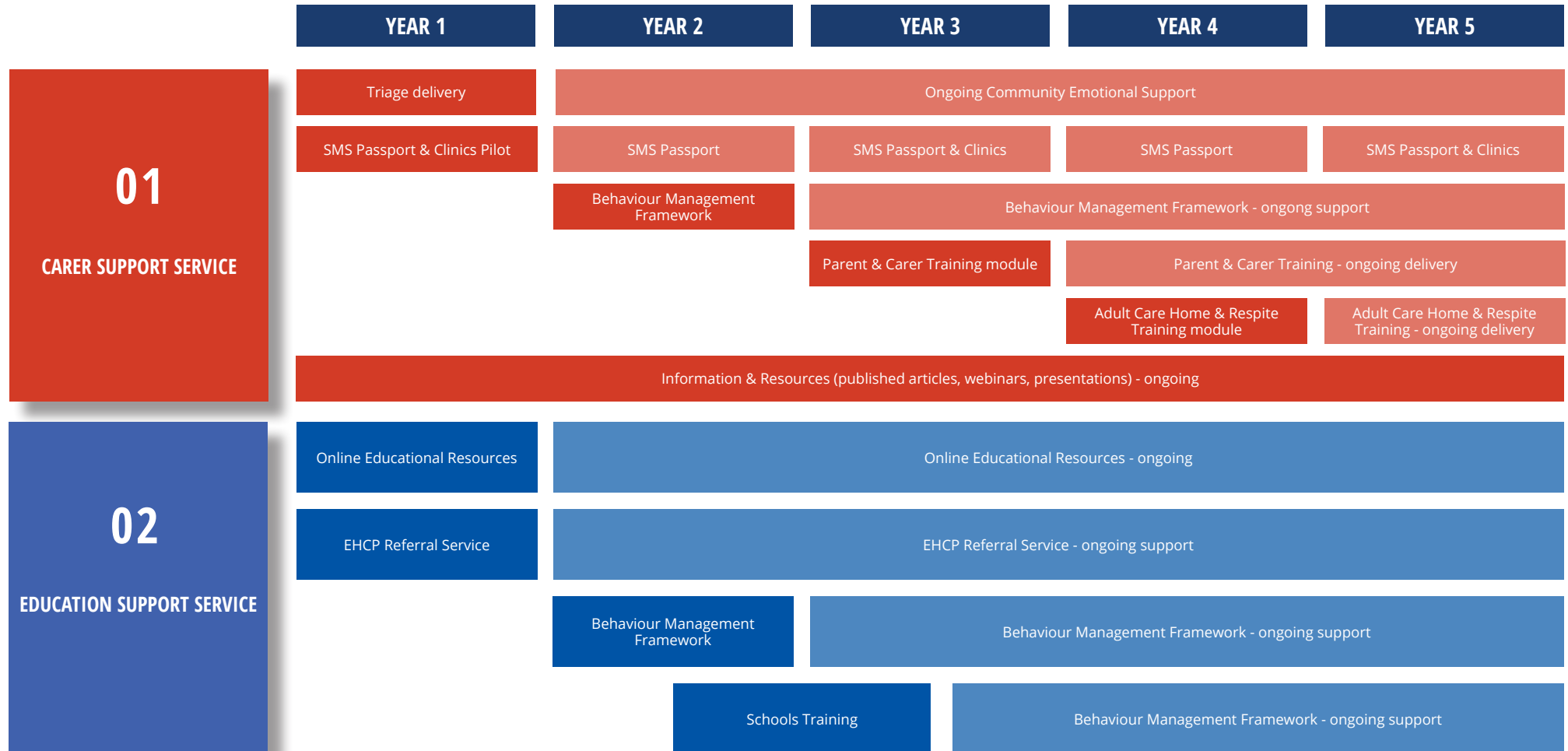
02



# PROGRAMME DELIVERY

Our charity is proud to be small and agile, as it allows us to quickly adapt the delivery of our projects and services based on our income. Our adaptability allows us to prioritise and execute programmes and services that align with our mission and values, while being mindful of our financial constraints. We are dedicated to making

the most out of our resources, ensuring that funds are utilised in a way that positively impacts our beneficiaries and creates meaningful change in our community. Over the next five years we have developed a flexible schedule of programme delivery that is prioritised based on our current finances, resources, and ambitions for growth.



# KEY POINTS TO STRENGTHEN OUR CHARITY

01

## ENGAGEMENT & BRAND

- Communication strategy
- Engagement strategy
- Corporate and brand guidelines and resources

02

## NETWORKS & COLLABORATION

- Build relationships with similar patient groups and umbrella charities
- Build relationships with medical, educational, and care professionals
- Identify gaps in our professional board and recruit new members
- Work with organisations and businesses that can help us deliver advice and support
- Tap into pro-bono support

03

## RESOURCES

- Overhaul volunteer programme
- Identify skills gaps and recruit new resources (volunteers and employees)
- Recruit short-term contractors to fulfill immediate needs, long-term employees as and when budget allows

04

## MEMBERSHIP

- Improve and increase awareness and reach
- Develop powerful incentives for families and professionals to join

05

## SUSTAINABILITY

- Implement fundraising strategy
- Strengthen fundraising initiatives via corporates, CSR programs, and investors
- Increase membership to our regular giving scheme
- Increase support and participation of community fundraising events and challenges
- Implement commercial strategy
- Implement training programme to generate income stream

# FUNDRAISING STRATEGY

We have a limited financial engagement with our community, beyond a small dedicated group of existing fundraisers who regularly participate in our challenge events. We have a very strong engagement and connection with our SMS community. However, despite the limitations on how much donations can be raised through individuals, this is a valuable income stream since it is 'unrestricted' and covers the overheads that tend to be attractive to large donors.

We need to maintain fundraising activities with existing donors and monitor donor fatigue. Community fundraising will not generate huge amounts of income for us but is the strongest connection we have financially to our SMS community and we need to continue to nurture this relationship via challenge events and community activities if we want to see this pool of income grow in the future. Stewardship of our supporters in this area is crucial, even if returns are small.

The future of our fundraising must increasingly focus on accessing funds from trusts and grants providers and look towards partnership working and collaborations on larger bids with other charities and universities in the future. Opportunities for research grants in collaboration with universities and other charities are currently being identified and should be a priority for the coming years.

The focus of our fundraising should largely be on trusts and grants funding. However, there are some existing products and programmes that are already generating some financial return for us, and with a few tweaks could potentially see an increase:

- Increasing engagement with our SMS 1711 Circle.
- Off the shelf fundraising packs to allow our community to run their own fundraising events within their homes, workplaces and schools.
- Legacies are a treasure trove of unrestricted cash reserves – they are our best vehicle for securing our long-term financial health but they will not be a quick win. We need an internal legacies 'champion'.
- The SMS online shop and our merchandise currently generates little return. We have identified a new focus on SMS living solutions, as a replacement for our traditional on-line shop front, using drop-shipping to fulfill orders.

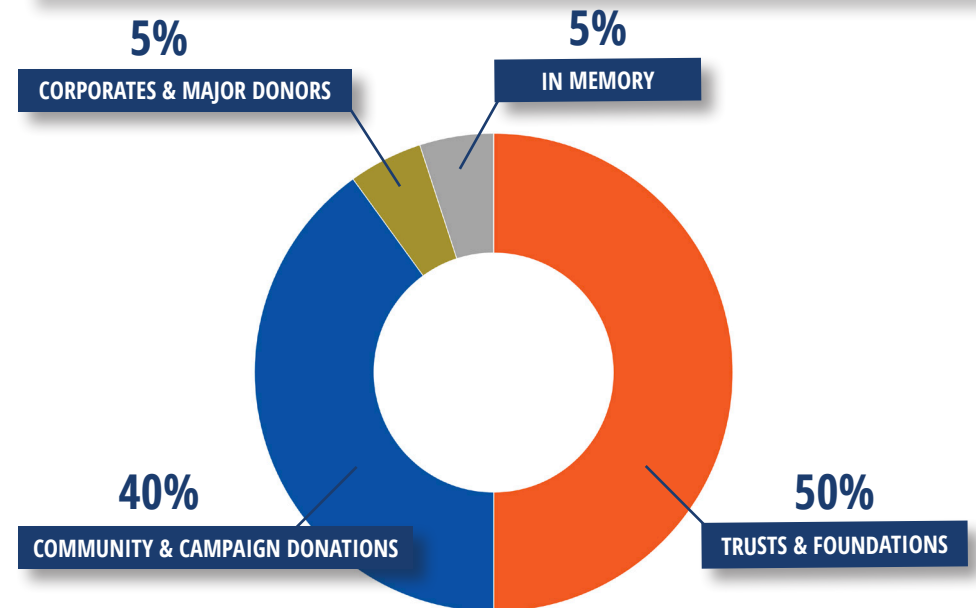
This means that community fundraising is the main feed into our unrestricted cash reserves.

We have developed a 5-year plan using a phased roll-out approach to deliver programmes and services to enable us to manage costs, seek funding opportunities, and recruit for the skills required to deliver projects.

We know that:

- Individual giving does not build reserves;
- Trusts and foundations generally give to projects;
- Corporate funding is normally restricted to projects;
- Statutory funding is normally project/service based.

**The fundraising strategy identifies trusts and foundations as a key source of income for us for the future – they are our financial mainstay and this line of income needs to be protected and prioritised.**



# COMMUNICATION STRATEGY

Our aim is to ensure that the right message is delivered to the right audience in a way that is effective and impactful. We need to carefully consider the needs and preferences of each audience, and tailor our messages to be relevant and meaningful to them.

## TARGET AUDIENCES

We have identified that our target audiences for key communications include our **SMS community, fundraisers, donors, volunteers, and partners**. Understanding their needs, interests, and communication preferences will enable us to tailor our messaging and outreach efforts for maximum effectiveness.

## CONTENT CREATION

We will develop high-quality content that is relevant, engaging, and aligned with our messaging and goals. Using a range of rich media we will create **stories of impact, testimonials, infographics, videos**, and other forms of content that effectively conveys our mission and impact.

## ENGAGEMENT

We will focus on strategies that **engage with our target audiences**, and **continue to strengthen stewardships** with existing donors and volunteer engagement programme. Sharing regular updates on projects and impact, and opportunities for feedback and input. Building relationships with our audiences will foster loyalty and encourage ongoing support.

01

02

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## CLEAR MESSAGING

We will develop **clear, concise, and compelling** messages that clearly communicate our mission, goals, and impact. Our messaging should be used consistently across all communications channels, including website, social media, emails, and marketing materials.

## COMMUNICATION CHANNELS

We will identify and prioritise the most effective communication channels to reach our target audiences. Our channels include **website, social media, email marketing, in-person events, and digital platforms** for activities (webinars etc.). As an agile organisation we must consider the resources available and focus on channels and activities that are feasible and aligned with the target audience's preferences.

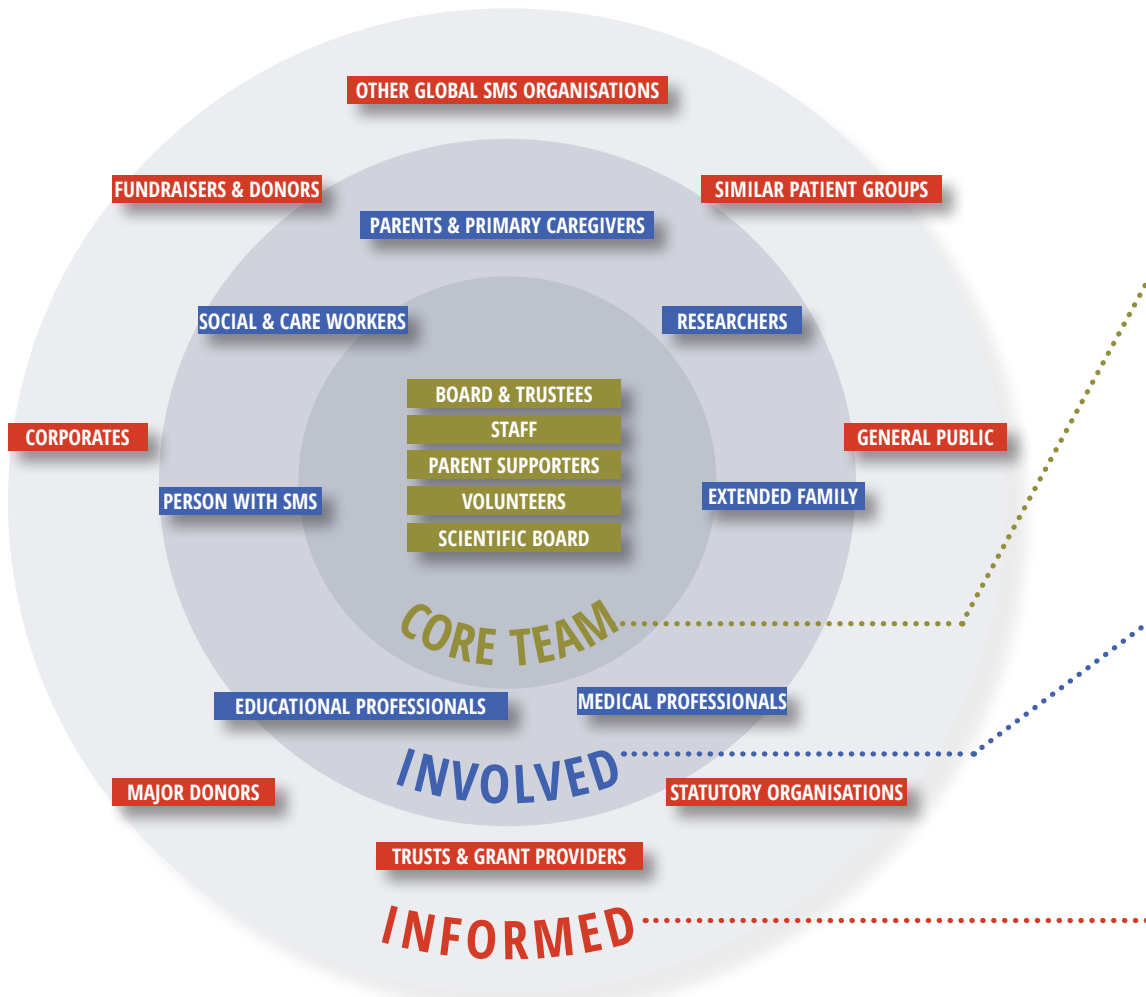
## BRANDING

We will continue to establish a consistent visual identity, including **logos, color schemes, fonts, and other design elements** that reflect our brand personality and values. We will make brand assets available to the core team to ensure that our branding across all communications materials helps to reinforce our credibility and professionalism.

# COMMUNICATION STRATEGY

Our goal is to influence how our audiences **think** about our organisation and our work, as well as how they **feel** about it. We want them to feel connected to our mission and motivated to take action. Our communication efforts need to:

- Inspire and empower
- Promote positive thinking about our work
- Convey a sense of connection and purpose
- Encourage action in support of our initiatives
- Join us and get involved



Our **core team** need a clear understanding of our mission and goals, as well as the strategies being used to achieve them. They should be aware of our financial situation and fundraising efforts, and have a good understanding of our community and how to best serve them. Our tone of voice should be professional and respectful, fostering a sense of teamwork, collaboration, encouragement and honesty.

The **involved audience** are seeking information about the syndrome. Many want to connect with other families so we need to share information about our regional support groups (RePS). Key messages should include information about support, services, impact, the resources we offer and how to access them. We need to encourage those in crisis to reach out and provide information on self-care and tips on how to manage stress. Our tone of voice should be caring, empathetic, understanding, and respectful.

The **informed audience** need clear, consistent, and accurate information and resources. Key messages should provide an understanding of the services we offer and the impact that support is having on our community. They should know our mission and how their support is helping to achieve it. Other messages include events, campaigns, and how their funding is being used. Our tone of voice should be appreciative, engaging, inspiring, and convey a sense of excitement about our achievements.



# NETWORK & PARTNERSHIP STRATEGY

In order for us to achieve our goals and objectives we will need to collaborate with other organisations or individuals. We need to identify potential partners, assess the value of the potential partnerships, and to establish guidelines and expectations for working together. Partnerships should be closely tied to our overall goals and objectives and align with our mission and values.

## COMMERCIAL PARTNERSHIPS

Commercial partnerships will provide us with the support required to achieve our goals and enable us to make a bigger impact on our community. Advantages include financial support, increased visibility, and access to new resources and expertise like technology, logistics, and marketing resources. A partnership should be mutually beneficial, gaining positive exposure and reputation by association. Commercial partners will bring fresh perspectives and new ideas enabling us to innovate, grow, and reach new audiences. We have identified the following potential strategies for commercial partnerships:

### **SMS living solutions.**

Focusing on products and solutions that improve and enhance the lives of those living with SMS. Using visual info-graphics and storytelling to sell the benefits. Through commissioned affiliation links we will partner with suppliers of a wide range of products that support the health and wellbeing of our SMS community. Sponsored content will offer further opportunities to

generate income through commercial partners.

### **SMS branded merchandise.**

The sale of products through our website shop is minimal and not cost effective. It is recommended that we switch to using drop shipping as a retail fulfillment method instead. Advantages include low startup costs, lower risk, flexibility, location independence, scalability, and potentially higher profit margins.

## RESEARCH PARTNERSHIPS

Research partnerships offer us an effective way to advance our mission by leveraging expertise and resources to better understand and address the issues our community face.

The advantages of research partnerships include advancement of knowledge, increased credibility, access to new resources, shared goals/objectives, increased impact, and cost savings due to collaboration. We already have some excellent research partnerships in place including:

- The Cerebra Network
- Umbrella charities
- Rare syndrome support groups/charities
- The International SMS Hub
- Universities (Keele, Aston, Cardiff)
- Community research delivered by our core team and family members

We need to focus on developing these partnerships, finding new opportunities for collaboration and campaigning. Currently untapped research partnerships that could be advantageous for us include:

- Organisations that focus on supporting some of the syndrome symptoms (sleep, weight, behaviour).
- Local community organisations that provide support and services to the wider disabled community.

## PARTNERSHIP STRATEGY

1. Identify potential partners who can help us achieve our goals for example healthcare providers, government agencies, advocacy groups, and other organisations working with individuals with SMS or similar rare diseases.
2. Assess partner compatibility aligns with our goals and objectives.
3. Develop a partnership plan that outlines the specific goals and objectives of the partnership.
4. Establish communication channels to ensure that everyone is updated and on the same page.
5. Evaluate, adjust, and track progress to ensure continued success.
6. Foster a culture of collaboration by creating opportunities for partners to work together, providing resources and support, and celebrating successes together.

# ORGANISATION & RESOURCES

As a small and agile charity, we understand that adaptability is crucial in the dynamic landscape of the third sector. There may be occasions where external factors or unforeseen circumstances require us to adjust our timelines for project delivery. We are committed to being responsive and flexible in such situations, as our ultimate goal is to ensure the successful implementation of our projects and services for the benefit of our community. We believe that being adaptable allows us to effectively navigate challenges and seize opportunities that arise along the way, while staying true to our mission and values. Our focus remains on delivering meaningful impact while remaining accountable to our stakeholders.

Decisions and direction come from our board, who now meet monthly, and a subcommittee is in place for finance. Any decisions or key changes to our delivery plan, or other important decisions, are put to our board who are able to convene meetings at short notice if necessary.

Our core capabilities include service development, fundraising, communication, partnership building, financial management, legal compliance, governance, human resources, and impact measurement. Over half of the board and staff also bring a wealth of knowledge as highly experienced parents to a person with SMS.

Our current staff resources include an Operational Lead, Programme Lead,

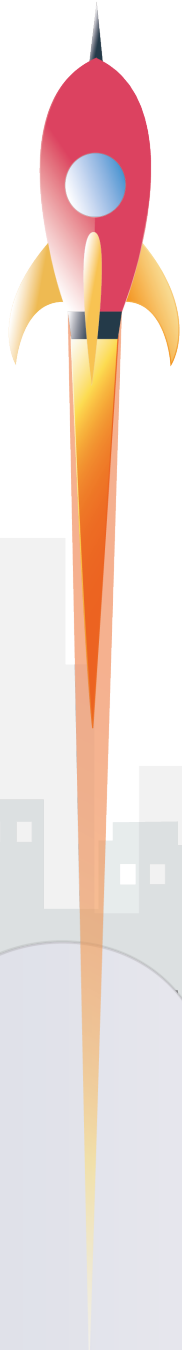
Fundraising Lead, and Research and Engagement Manager. The strategy has already outlined the need for extra fundraising resources to increase our income streams and fund our initiatives. The current staff head-count will not be sufficient and we will need to grow to deliver our programmes.

More experience comes from our Parent Supporters (all SMS parents) and pro-bono volunteers. These are highly engaged volunteers who commit time to furthering our aims.

A recently developed volunteer strategy will enable us to fulfill some gaps, growing and developing our volunteer support base. However, we cannot entirely rely on pro-bono support particularly where tasks require specialist skills and are time consuming. Efforts to increase head-count should be focused on plugging gaps that are critical to the delivery of services or increasing our income. We will need to take a blended approach to resource fulfillment using a combination of short-to-medium contractor/temporary roles and outsourced services. We will only recruit permanent employees when we are financially stable and reserves are sufficient. Programme resources should be carefully planned and recruited in-line with the delivery of our five year programme using our blended recruitment approach as above.



# MEASURING SUCCESS



We will measure the success of our development strategy through several key indicators and metrics that align with our mission and goals. These will include:

- **Setting specific fundraising goals.** Success will be measured by tracking progress towards these goals and evaluating whether they are being met or exceeded.
- **Impact on beneficiaries.** Success will be measured by tracking the outcomes and impacts of our programmes and services. We will achieve this through data collection, monitoring and evaluation, and feedback from beneficiaries.
- **Programme effectiveness.** This includes evaluating programme design, implementation, and delivery, as well as measuring outputs and outcomes. Success will be measured by the extent to which programmes are achieving their intended results and making a positive difference in the lives of beneficiaries.
- **Donor engagement.** Success in donor engagement will be measured through indicators such as donor retention rates, donor satisfaction surveys, and donor participation in events or activities. Strong donor engagement can indicate that the charity is building a loyal donor base that is supportive of its mission and programmes.
- **Financial sustainability.** We need to ensure long-term financial sustainability. We will measure success in financial sustainability by monitoring financial indicators such as revenue growth, diversification of funding sources, expense ratios, and overall financial health. This will help us ensure that we are managing our resources effectively and on track to achieve our long-term financial goals.
- **Stakeholder satisfaction.** Success can be measured by conducting stakeholder surveys or feedback sessions to assess their level of satisfaction with our performance, communication, and overall impact.
- **Public relations and brand awareness.** We need to increase public awareness by raising our profile, attracting more supporters, and generating greater impact. We will measure success through indicators such as social media engagement, website traffic, media coverage, and brand recognition.