

"We are feeling infinitely more optimistic about the future. This is not just a Helpline, it is an essential lifeline to countless numbers of families. It provides hope for a better future and quality of life for those living with special needs."













This document is a summary of an External Evaluation - funded by The National Lottery Community Fund - to evaluate the Helpline and Face-to-Face Support Services provided by SNAP (Special Needs And Parents). The researcher and author of the report is evaluation specialist, Neil Smith, from Eastside Primetimers. Neil is a highly-experienced consultant with varied evaluation experience over more than two decades.

This professional external critical analysis and evaluation of these services was to assess if SNAP is making an impact with its families.

6 Based on a wealth of feedback from parents and carers, these findings tell a clear and consistent story of the real and lasting positive impacts that SNAP has on family life.



Produced with the co-operation and commitment of the SNAP Team, stakeholders, and more than 300 remarkable, inspiring and openhearted families. Their thoughtful input and patience is very much appreciated.

The parents & carers interviewed for this evaluation have engaged with SNAP for varying lengths of time, from a couple of years to more than 14 years.

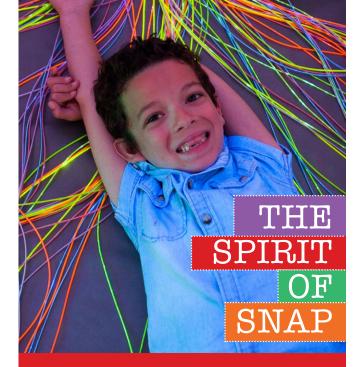
They were asked the main differences that Helpline calls and Face-to-Face meetings have made.

The responses to this question were the lengthiest and most comprehensive of all the questions, and the most consistent in content and tone. SNAP occupies a pivotal role in the lives of the families it supports. Parents & carers uniformly report that there is no other service like it and that these services and support are essential to their families. The difference made to parents & carers with much shorter associations with the charity is hardly less impressive – there is an immediate impact and a 'change of trajectory', as one parent put it.

# Neil fmith

The full Comprehensive Report and Data Analysis Appendix are available on request - please email s.clifton@snapcharity.org

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SNAP as an organisation has a strong ethos that pervades the building and the staff; this is what the inspiring SNAP Team refer to as the 'Spirit of SNAP'. This is not the only factor in the organisation's success: it is well led, it recruits effectively, many of the staff have direct experience of special needs children and adults, and the care of the building embodies the same spirit.

Perhaps the single strongest characteristic that marks SNAP out as a special charity is the degree of care and dedication that the SNAP Team consistently show to the parents & carers and children & young people. This is hugely valued by the SNAP families.

All parents & carers remember their first interaction with SNAP and the relief that came from meeting a team who understand them, do not judge them and have only their family's interests at heart.



Helpline

Face-to-Face

This evaluation investigated the impact of the Helpline and Face-to-Face support against five specific outcomes.

Parents & carers are highly consistent in their comments on how fraught their daily lives can be as they struggle with their child's problems and public services that they feel largely hinder rather than help.

Based on the answers taken from the parents/carers by phone and in person, these services undoubtedly make a huge positive difference to their lives, have saved relationships and kept families together, and in some cases even literally saved lives.

All remember their first interaction with SNAP and the relief that came from meeting a team who truly understand.

On a day to day basis, SNAP helps to support and empower parents & carers, provide services to the children & young people and provide a range of highly responsive and relevant family services and this is hugely valued by the SNAP families.

As a result of the support given through these two services, parents and carers...

**Confidence:** Have the confidence to try new strategies (with their child/ children) and advocate on behalf of their child. Confidence is also having faith in their judgements, skills and abilities to parent their child and feeling stronger and more resilient to cope with the challenges and difficulties of parenting a child with special needs.

**Understanding:** Have a better understanding of their child's needs, condition and how best to support them. **Supported:** Feel more supported and less isolated. They understand that they are 'not the only one' and that there is a wider support network with others who know what it is like to have a child or children with special needs.

Resilience: Are better able to cope, having a plan for the next stage in their child or children's lives as well as their own increased resilience and time to themselves.

**Empowered:** Are empowered by SNAP to engage more fully with the services on offer and frontline agencies. Empowerment is also helping parents and carers to feel informed and equipped with the necessary skills and knowledge to give the best possible support to their children.

#### GATHERING EVIDENCE

The data consisted of 267 Helpline or Face-to-Face evaluation forms analysing the progress of 249 individual parents and carers against 5 set outcomes over the period 18 October 2018 - 17 October 2019.

Support to parents and families via the phone Helpline and Face-to-Face meetings make a significant positive difference across all of the five outcomes - 89 per cent of parents & carers experienced improvement against these outcomes.



### SNAP STATS

SNAP has grown enormously since it was founded in 1994. From 2009 - 2019 the number of families SNAP actively supported almost doubled from 1,490 to 2,774. SNAP has also seen an increase in new families registering each year from 224 to 505. The Helpline has become essential for supporting families - In 2014 they supported 3,617 calls and emails. By 2019 that figure had almost doubled to 6,598.

66 Praise for SNAP is consistently very high.
A parent & carer will typically describe their experience of SNAP as essential, vital and lifesaving.

# SNAP provides 'light and hope'

Parents & carers who have children & young people with special needs find themselves in challenging, sometimes desperate situations. In addition to the pressures of coping with one or more children with a special need - being a 'member of a club that no-one wants to join' - they universally struggle with public sector processes that frustrate, and humiliate them. The evaluator has been shocked by the uniformity of this experience across the parents spoken to.

There are significant hurdles on the journey of a parent & carer who has children & young people with special needs such as getting a diagnosis, finding a school, keeping them in school, developmental stages such as toilet-training and puberty, finishing school and perhaps finding work or training. This list in no way does justice to the challenges involved in what can be difficult stages for the parents of all children, let alone parents of children with special needs. It is regrettable that the statutory provision struggles at meeting the needs of these families.

The impacts are significant for SNAP's parents and families: increased stress and frustration; anger and anxiety; confusion and despair, sometimes leading to depression and suicidal thoughts (including children); isolation and vulnerability. Parents/carers find that they must become the expert on their child/young person's condition(s), with many gaining relevant qualifications in order to care better for their children, and to better navigate through and negotiate with the public sector to secure the support they are entitled to. Too often, the

parents/carers have to fight at every stage for the help that their children & young people need.

In this context, SNAP provides 'light and hope' to so many desperate and isolated parents & carers.



## A PARENT'S STORY

## "The SNAP Team inspires confidence"

"It is a warm, welcoming, supportive, caring and non-judgemental safe space to discuss problems and work out possible solutions. We know we can whole-heartedly rely on this fantastically dependable service, (when we are frequently experiencing repeated failures, by professionals, to fulfil their assurances.) We are always treated with the utmost respect and given time to discuss the difficulties we are facing. The SNAP Team inspire huge confidence with their depth and breadth of special needs knowledge, as well as their professionalism and discretion in dealing with confidential matters. Following the call or email, we feel we have great advice and direction on taking action towards resolving our difficulty."



Following a Helpline call or Face-to-Face session Parents & Carers...

92% exhibited increased resilience.

SNAP reduces isolation, loneliness, anxiety and depression.

Parents & carers arriving at SNAP may be dealing with the shock of a diagnosis they suspected but did not want, or often in despair knowing that something is wrong but not yet having a diagnosis.

Often the consequences of these circumstances are isolation and loneliness as family, friends and school struggle to accept their child or children. These feelings are compounded by anxiety as the parents & carers fight to be understood, or as they realise that their future will be very different from that which they imagined. If they are lucky, they will be referred to SNAP, or will find the charity through a recommendation. Parents & carers are universal in their praise of SNAP and the

recommendation. Parents & carers are universal in their praise of SNAP and the welcome they receive and one of the early and major benefits of going to SNAP is knowing that they are not alone – other parents & carers are going through what they are going through, and SNAP is there to help.

\* More difficult to measure with one interaction as it often takes parents/carers time to build up their knowledge.

demonstrated reduced feelings of isolation and increased awareness of

wider support networks.

showed improved understanding of their child's needs, condition and how best to help.\*

93% showed increased empowerment.

90%
demonstrated improved confidence.

#### PARENT/CARER QUOTES

"SNAP has introduced us to other families - we are meeting socially now. We've made friends with people in the same situation as us."

"Whoever you speak to makes you feel like you are not alone. That they are there for the duration and will be on your side." "You feel like you are not alone. You feel like, in time, things will be ok again."

Parents/carers report that SNAP empowers them to help their child by advising on how to deal with the public sector: knowing their rights, knowing what to say and who to say it to; signposting to help with important benefits such as Disability Living Allowance (DLA) or Personal Independence Payment (PIP); supporting parents to get an Education, Health and Care Plan (EHCP); providing training and information so that the parents can understand their child's problems and communicate this to professionals; and, providing strategies to help them manage their child and their family more effectively.

At a time when many parents feel powerless – in the face of a diagnosis they didn't want or knowing there is something wrong but not being taken seriously or having the diagnosis and feeling 'let down' by the system – SNAP enables the parents to find power through knowledge, skills and through building confidence.

Parents value the advice they get from external professionals and from SNAP staff, building their knowledge of conditions,

management strategies, treatments and relevant vocabulary. Parents find that they must become an advocate for their child in the public sector in order for them to access the right education provision, healthcare and support. Parents report that this support helps build their resilience and strength, something they need day to day, but also for the longer battles with public services.

Parents & carers report that SNAP has facilitated stronger social networks. This has also led to parents organising activities for their children & young people away from SNAP. When parents & carers find SNAP, they talk a lot about feelings of relief and release.

#### PARENT/CARER QUOTES

"SNAP never gave up and offered practical, constructive advice and support, and as well as a welcoming and kind environment at a time when it felt that nobody else wanted to know."

"Moving to school is where the problems get really emphasised; you are judged as a parent. I was empowered by SNAP, given confidence, and I built a better relationship with the school." "Each contact with SNAP is positive and you feel empowered, emboldened and powerful." "When you talk to SNAP they really know what they are talking about and can give really specialist and directed advice."



#### PARENT & CARERS QUOTES

"Our initial contact with SNAP was via the helpline. It takes courage to reach out and ask for support on the phone and we made this contact at a time when, as parents, we felt we had nowhere else to turn.

"This is where this amazing helpline comes into its own, empowering and equipping parents with the information they need to underpin their pursuit for support for loved ones.'

"Nothing is too much trouble - the phone service is always cheery and always helps (no run-around)."

"I can ring anytime and then breakdown! Lots of emotion, Don't think twice about calling; they don't judge even when I rant."

## The best thing about SNAP's **Helpline and Face-to-Face services**

**66** The SNAP Helpline is the first point of contact with SNAP for many parents, either following a diagnosis or when they know something is wrong and are desperate for help. Available five days a week during office hours (9:00am until 5:00pm Monday to Thursday, and 9:00am until 4:00pm on Friday), the Helpline is managed by a team of dedicated Family Support Advisers who will call parents back if need be. Importantly, parents are not sent from person to person but helped as soon as possible by the person that answers the phone. Parents attest that the phone service is responsive and personal.

A Helpline call often leads to a Face-to-Face meeting so that the parent's situation can be explored in more detail, or so that issues highlighted in the phone call can

be addressed. It also provides an opportunity for the parent to see the facilities at SNAP, such as the information library and the play Together, these two services are pivotal to the day-today support that SNAP provides, alongside the other services and the support given to parents who turn up at the centre unannounced. No-one is turned away.

What difference do these services make? They provide a mix of emotional and practical support direct to the parent and family – support provided without judgement and with warmth and understanding.

**Face-to-Face meetings** are a good opportunity to work with the parent to support them with strategies for navigating the system: education, health/medicine, mental health, the Department for Work and Pensions and benefits and housing. Parents frequently reported to the evaluators that 'the system' uses a language that they have to learn and processes that are complex. SNAP provides the expertise to get the system working for the parent and child, and the emotional support to help build their resilience.

SNAP also provides strategies for supporting the child or children better e.g. their behaviour, or less obvious things like dealing with the child's reaction to change. For example, losing teeth can be a traumatic experience for an autistic child; SNAP can help parents to anticipate and manage this change.

Parents are very unlikely to receive this sort of support from the public sector.



## 'Always a plan of action'

'The best thing about the helpline is knowing you always have someone you can call when you are having a bad day and just need someone who understands, to listen. It feels like having a security blanket, a safety net, a cuddle when you need it. Your family can be very quick to judge you; no one judges you at SNAP. Friends don't always understand your difficulties, but those at the end of the phone at SNAP do, and they can reassure you that you are doing a good job, and always offer solutions to try and help your situation.

The Face-to-Face service gives you the opportunity to talk through how to move forwards and how to improve things for your family. There is always a plan of action on both parts, so you come away feeling empowered and understood. You feel listened to and cared for. You feel like you're not alone. You feel like, in time, things will be ok again."



### The stakeholders perspective

**66** Seven SNAP stakeholders were interviewed; these are people external to SNAP with a different perspective to the parents & carers. Stakeholders were defined as people who have an external connection to SNAP, or an informed external perspective e.g. health professionals or other providers of services to parents & carers.

The extent to which these people engage with SNAP's services varies, the way they understand the difference SNAP makes to the parents & carers or the length of time they have been involved. Their feedback on the difference SNAP makes is very similar to the feedback of the parents & carers. They hold SNAP in high regard. The package of care that SNAP provides is described here by a stakeholder who regularly observes SNAP services in person.

"I see the journey that young people take over time. I see increased confidence and reduced isolation. Parents can stay and get support alongside this, providing contact with other parents which they might not otherwise get.

Again, this provides reduced isolation and a sense of shared common ground. SNAP uniquely encompasses the whole family and supports them. Advice and support is vital, especially immediately after diagnosis when parents are left on their own. Lots of information and resources are available, signposting internally or externally and help for parents who do not yet have a diagnosis. I have met parents at both ends of the journey.

My perspective is that SNAP's success is based on the founders starting from a point of crisis themselves as parents with SEN children, with nothing available. The ethos is 'we know what it's like, we want to help, and we can help you.

They have been on the same journey. Passion for helping families; lots of empathy; passion passed on to staff. No judgement. Specialist Talks and Workshops for professionals and parents helps to pass on what they have learnt."

The obvious concern is securing sufficient funding to maintain the existing services and building, let alone expanding services as many would like to see SNAP do. Stakeholders see demand and uncertainty increasing both short and long-term, but are generally optimistic about SNAP's future:

"SNAP are well established, and they have a diverse funding base. They do their own fund raising, they are in a reasonable position."

"Financially, I am less optimistic for the future, but as far as the team are concerned I am more optimistic because there is effective planning."

Other concerns in relation to all parents & carers: "I worry more outside of SNAP for parents and their capacity to parent with increasing pressures."

However, the same stakeholder has a lot of faith in SNAP: "The parents will get the help they need, despite the boundaries and limits of the SNAP services.



#### WHAT MAKES SNAP SO EFFECTIVE?

**The SNAP Team:** For a good number of the staff, there is lived experience of raising a child with special needs and they want to make a difference by helping families. Others have had more circuitous routes into SNAP, such as studying psychology or having volunteered at The SNAP Centre or having worked as a teacher and moving into special needs.

There is a strong sense of a close team with a shared set of values that they put into practise. They reported that they pride themselves on providing a high level of care that focuses on the parents/carers. Also, they are willing to go over and above because they have a passion to help families.

We have taken on board the observations from this report and will action the following in the coming months.

- ✓ Identify and protect the values and beliefs that sustain the
- Continue to set a first class standard of evaluation of our services.
- ✓ Develop more online information resources for parents & carers.
- ✓ Extend SNAP's reach by empowering parents & carers to pass on their learnt knowledge to others families.

- **Living** the Strong, good quality leadership: Living the values and ethos, 'walking the walk', setting the tone
  - Good recruitment and employing people who have been there themselves, or have very good empathy with the parents & carers
  - Genuine and enduring dedication to the work staff are prepared to go above and beyond
  - Care and warmth towards the parents & carers and children & young people
  - Constantly striving to improve
  - Resourceful e.g. doing so much with relatively little money
  - Genuine concern and compassion
  - Passion and ambition in wanting to keep things going in the right direction
  - The quality and dedication of the volunteers.



# HELP'S AT HAND IN SO MANY WAYS

SNAP - Special Needs And Parents - is an Essex charity that helps families with children and young people who have any special need or disability.

SNAP's Helpline and Face-to-Face Support are just two of a wealth of services and activities for Essex families.

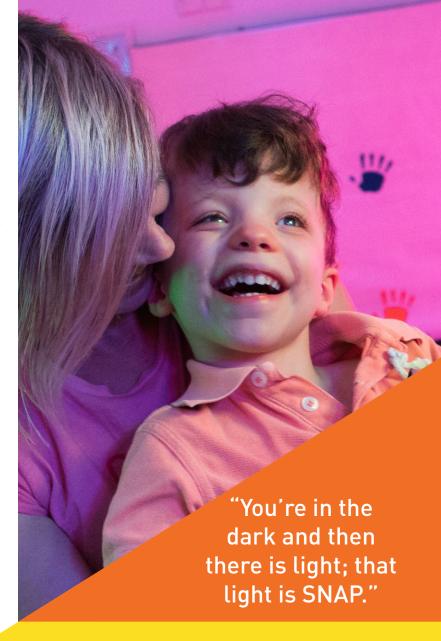
SNAP offers a helping hand to thousands of families who need support in a variety of ways. No formal diagnosis or professional referral is necessary to access SNAP services, which is available to families of children and young people aged 0 to 25.

SNAP is currently offering a wide range of services remotely to meet the needs of its families.

- Helpline and Online Face-to-Face Parent Support
- Specialist Talks and Workshops
- Online Directory and Information Network
- Online Counselling, Benefit and Educational Advice
- Library of Specialist Books and DVDs
- Parent and Pre-School Children Sessions
- After-School and Holiday Sessions for Children and Young People
- Sibling Support

"We are overwhelmed by the results of this report and would like to thank all of those who provided feedback, participated in interviews and group discussions. A very special thank you to Neil as well, for his critical analysis and guidance. As a result of this report, we will continue to evaluate and develop all of our services in response to the needs of SNAP families."

Karen Boath, **SNAP Executive Director** of Family Services



### A PARENT'S STORY

# "SNAP never gives up on our children"

"Our child's mental health was continuing to take a downward turn, had lost hope, with limited learning opportunities and lack of access to therapeutic support. SNAP provided not only a safe learning venue, but access to SNAP counselling, our child had something to look forward to at last and began coming out of themselves. At crisis point, when our child felt suicidal, and neither education nor health were able to provide the urgent support our child so desperately needed, SNAP stepped in with solutions which literally saved our child's life.

As a family, we were at breaking point, with myself and my husband battling both the Local Authority and the Health Service to enlist support without success. Each service was 'passing the buck' to the other. Under considerable strain, the upturn in our child's mental and physical health saved ours too and enabled us to continue battling!

After 18 months of endless emails, meetings, phone calls, and repeated drafting and redrafting of our child's EHCP, we finally secured a commitment from the Local Authority to provide 25 hours of tuition a week. Without SNAP's support we could not have achieved this, and our child would have lost access to education altogether!"

"SNAP never, ever, give up on our children. They genuinely see all the potential and positivity in them. They try different solutions repeatedly, and consistently, to give our children the best possible chance of the most favourable outcome. If an intervention doesn't work, they help us to think of something else until something works."