



*Empowering families of children
and young people with special
educational needs and disabilities*

Reaching Families Services

Making Sense Of It All: an extensive far reaching handbook for parents of children aged 0-14. Covers a wide range of vital subjects including diagnosis, handling stress, benefits and money matters, accessing support from education, health & social care, local leisure opportunities, etc. It also contains an extensive jargon buster and a directory of over 400 local and national organisations.

Making Sense Of Adult Life: a comprehensive handbook for parents of young people aged 14-25 making the transition to adult life. Covers a wide range of relevant subjects including further education, volunteering, training and work, adolescence and emotional wellbeing, housing & independent living, moving into adult health & social care, etc. It too contains a directory of local and national services and an extensive jargon buster.

Fact sheets: in partnership with Brighton based partners, Amaze, we have published a series of 37 fact sheets that provide both clinical and relevant local information to parents across a range of subjects including major childhood disabilities, and a miscellaneous range of issues including behaviour, benefits, bullying, mental health, preparing for adulthood, SEN support at school, sensory issues, sleep management, support for siblings, etc.

Training Roadshow: we currently deliver 24 workshops per annum at various venues and locations across West Sussex. Workshops include understanding anxiety in children, applying for benefits, understanding challenging behaviour, understanding sensory issues, handling stress & building resilience, SEN support at school, helping your child achieve better sleep, etc.

Umbrellas Support Group: we run 4 monthly support groups for parent-carers in Billingshurst, Haywards Heath, Littlehampton and Worthing. The groups help connect parents and share information via resources and guest speakers.

Facebook: our online support group has a membership of over 1,750 parents (now the largest in West Sussex). It is an excellent means of connecting parents, promoting our projects and services and sharing news, information and resources.

“ This service has been a light in the darkness of SEN! Extremely helpful and much appreciated. Thank you. ”



Executive Summary

Reaching Families are proud to present their impact report for 2017. This is the first report of its kind that we have compiled but our intention moving forward is to write and publish an impact report every year in order that parents, families, funders, partners and other stakeholders can evaluate our performance in achieving our mission – *“empowering, informing and caring for parents and families of children with special educational needs and disabilities in West Sussex”*.

We are immensely proud of all that the organisation achieved during 2017 and consider it to be our most successful year to date, not least because we met our targets across all areas of our service delivery. Given our meager human and financial resources this represents a considerable achievement.

Approval ratings of our services remain incredibly high – 87% of families said they would recommend our services to other families. Meanwhile, in our online annual survey, which was completed by 274 parents, 80% of parents said they valued that we are a parent-carer led charity, which we believe reinforces the need for organisations like ours in the provision of information, training and peer support.

“What a fantastic charity, has been essential in making me feel supported since my son's diagnosis”

Over the course of 2017 we helped more than 2,250 families across West Sussex on a budget of just £77,000. This represents £34 per family supported, by any measure significant value for money. However, it is worth noting that whilst we supported more than 2,000 families this represents less than 10% of the number of children and young people with SEND in West Sussex. It is therefore frustrating that we have been unable to secure meaningful investment from the local authority in order to reach a more significant percentage of families. In fact during 2017 we received no funding from the local authority.

Delivery

- 6,767 unique visitors used our website during the year
- 2,975 copies of our 37 fact sheets were downloaded from our website by parents and professionals (plus several hundred more distributed in hard copy)
- 2,250 copies of Making Sense Of It All and Making Sense Of Adult Life were distributed to parents including 250 copies in e-book or PDF format
- 416 parents joined our Facebook group, now the largest in West Sussex (1,695 members as of 31st December 2017)
- 257 parent-carers attended one of 24 training workshops
- 86 parents attended one of our four Umbrellas support groups



Outcomes

Reaching Families is an outcomes based provider that aims to measure the impact of our work by monitoring and evaluation of our service user's self reporting across a number of indicators (see below). In this way we are able to measure the distance travelled against outcomes using relevant indicators like improved knowledge, self-confidence, resilience, impact on family life, etc. This then enables us to evaluate where or how we need to adjust our service delivery in order to meet our targets. The four outcomes we work to achieve for parents are as follows: -

1. Disabled children and young people will have better chances in life as a result of their parent's improved access to information and training
2. Parent-carers will have improved self-confidence and life skills as a result of attending our training workshops
3. Disabled children, young people and their families will be healthier as a result of their parent's access to information, training and peer support
4. Families of children with disabilities will have improved resilience as a result of peer support from other families in a similar situation to their own

We use a series of indicators to measure our progress in achieving the outcomes described above. These are then built into 3 separate monitoring tools – training questionnaires (230 completed), book questionnaires (225 completed) and an online annual survey (274 completed). The

following results have been reached by aggregating scores from parents across each of these surveys.

- Parent carers will report improved knowledge in accessing support for their disabled child 90%
- Parents will report their disabled child accessing new services as a result of improved access to information and training 72%
- Parents will report improvement in their child's development as a result of improved access to information and training 75%
- Parents will report improvement in their self-confidence and skills ..83%
- Parents will report attending additional training as a result of attending one of our workshops...33%
- Parents will report an improvement in their child's health 72%
- Parents will report an improvement in their family's home life 76%
- Parents will report improved peer support 57%
- Parents will report an improvement in their family's capacity overcome difficulties 61%



Other Findings

The various surveys we asked parents to complete also provide other information on the challenges they face (see below) and other useful information in terms of the profile of the parents we support and the value of our services: -

- 64% of parents who completed our online survey have children with Autism (and other related conditions)
- 25% of parents said they have more than one child with SEND
- 42% of respondents have children aged 12-25 which suggests we are doing more to reach families of older children
- 80% of respondents said they value that Reaching Families is parent-carer led
- 24% of respondents said they have become less reliant on public services as a result of using our services
- 55% of parents said they would like us to develop work around counseling and emotional wellbeing
- 54% of parents said they would like us to develop work around volunteer befriending
- 45% of parents said they would be interested in volunteering for Reaching Families

“Our child was diagnosed 7 years ago and we have had very little support. We have had to pay for the help we receive and it wasn't that helpful. Feel completely let down.”

Challenges Faced by Families

A persistent theme of parent feedback throughout 2017 was anger, frustration and despair in accessing the support their children need. We noted it throughout the year on Facebook at training courses and from parents who attend our Umbrellas support group.

Whilst frustration has long been a common feature of the parent-carer experience we have never known it be this pervasive or acute. Typical frustrations include multiple problems with almost all stages of the EHC process, deteriorating relationships with professionals in schools and in health, huge delays in receiving diagnosis and trouble with accessing mental health services.

65% of parents in our annual survey said their biggest struggle is accessing services whilst 68% of respondents in training workshops said they were not receiving relevant services for their child. Meanwhile, 55% of parents said they faced challenges in getting support for their children at school.

Given this poor access to external support it is not surprising that almost two thirds of parents reported that they struggled to support their child's health and development and almost half reported they struggled to get the support they need to support their child at home.

Taken as a whole it is difficult not to conclude that the majority of children and young people in our community are not reaching their potential. Given what we know of the limited life chances of disabled adults this is a deeply worrying trend.



Making Sense Guides

Our Making Sense guides remain incredibly popular with parents and highly effective in improving their access to information and in understanding how systems work. Crucially, the guides are also vital in “walking you through what they need to know” as one parent described it. In our annual survey 90% of parents said they have or would recommend our guides to other parents whilst 87% of parents in our book survey said the same. This is consistent with research we carried out in 2016 in which parents ranked the Making Sense guides as their most popular information resource.

“It’s incredibly helpful and touching and so very well written; it really spoke to me around diagnosis in particular”

The quality of our guides has improved tenfold since our first edition, in particular as a result of our now commissioning a professional editor (who is also a parent-carer) to edit the books. We have also improved the accessibility of the books by publishing them in iBook and Kindle format and thanks to Big Lottery funding, making them available to parents free of charge.

Fact sheets

We received little in the way of qualitative feedback on our fact sheets in 2017 but usage of this resource was much higher than the previous year – 2,975 downloaded compared to 1,801 in 2016. In our annual survey 87% of parents said they would recommend them to other parents. Given

the relatively small investment in producing the fact sheets they have proved a highly cost effective means of information delivery. We therefore plan to review and add to the range in 2018.

“Just discovered the excellent fact sheets; great for the tricky wider family”

Training

2017 was a record year in our training delivery. Our target was to deliver 24 workshops to a minimum of 240 parents. However, 257 parents attended over the course of the year. 88% of parents in our annual survey said they would recommend our training to other parents.

“Please keep bringing these crucial workshops for parents”

Umbrellas Support Groups

The peer support parents can provide for one another is crucial to building self-confidence and resilience and as a user led charity, Reaching Families is ideally placed to bring parents together to achieve greater mutual support. Indeed, a common pattern of feedback on our training, support groups and Facebook group, is as one parent put it “a sense that they really know what it’s like for us a family”.



“ My local Umbrellas group has been an absolute lifesaver and especially the lady who runs it. She is so helpful, knowledgeable, kind, non-judgmental and just brilliant ”

89% of parents who attended Umbrellas during 2017 said they would recommend the groups to other parents. This is reflected in the high attendance of the groups, particularly in Littlehampton and Worthing. Meanwhile, 57% of parents who attended the groups said they have improved peer support and resilience whilst 61% said they feel better equipped to deal with problems as they arise.

Facebook

Facebook remains the most popular online community for parent-carers in West Sussex and for a small charity like ours, an excellent means of marketing, providing information, signposting and sharing resources. It also has a vital role to play in connecting parents with similar experiences and/or providing a gateway to the outside world for parents and carers who owing to caring responsibilities are socially isolated. In short as our monitoring information demonstrates it can help reduce social isolation, improve peer support and resilience.

“ I just want to thank you for your Facebook support group. I've gained a lot of knowledge and self help tips from it ”

Over the course of the year 416 parents joined our Facebook group, a far higher rate than in previous years. The group is now the largest in the West Sussex parent-carer community.

Outreach

Our three Outreach & Training Coordinators each work part-time and make up just 0.9 full-time equivalent staff. Despite their lack of time they are a highly effective team evidenced by exceeding targets set in training delivery and Facebook membership.

“ They are excellent. Breaks my heart when I meet people who are in need of help and don't know of them. I recommend them to the moon and back ”

However, one significant feature of feedback from parents, namely referral and signposting, suggests that parents hear of Reaching Families from other parents and voluntary organizations, and less so from statutory services who appear to lack a comparable knowledge or awareness of our service.

Whilst parent referral, as captured in the above quote and the 87% of parents who value that we are parent led, is immensely important, we recognize that more still needs to be done to improve signposting and referral from public services and plan to address this in our outreach during 2018.



Capacity Building

“They are a really professional organization who deliver high quality training and information”

Capacity building in small organisations is notoriously difficult to achieve. Meager resources do not make it easy for charities like ours to focus on infrastructure and organisational development as so much of our time needs to be spent on ensuring we meet the needs of parents and families.

However, despite the limitations posed by our resources, Reaching Families wants to achieve the highest possible standards in the quality of our delivery and we are therefore working towards achieving the voluntary sector quality mark, PQASSO. We hope that in achieving this highly respected accreditation we will not only deliver greater quality for parents but also demonstrate to funders we are an organisation worthy of investment. In 2017 we achieved around 40% of the development needed to attain PQASSO and aim to deliver the remaining 60% by the end of 2018.

Funding

From its inception Reaching Families has followed a best practice model of funding based on achieving diversity in our income. The rationale is by achieving diversity we are more likely to remain independent of any one funding source whilst also increasing our longer-term sustainability.

Our funding is made up of the following income sources – the Big Lottery Fund, charitable trusts and foundations, statutory income, earned income from book advertising and training delivery and donations from parents, small community groups and associations.

In pursuing this model Reaching Families has grown financially every year since 2009. However, our rate of growth and subsequent capacity to support more families has been slow, and whilst we have all but optimized the percentage of funding we can secure from the Big Lottery and charitable trusts and foundations, this has not been the case with statutory income from the local authority. In fact in 2017 we received no funding from West Sussex County Council.

It is worth making the point that almost a quarter of the parents who participated in our online annual survey (24%) said that Reaching Families had helped them become less reliant on public services. This represents around 500 families that we supported during 2017. Given the strain on the public sector meaningful investment in Reaching Families by the local authority and clinical commissioning groups could be highly effective not only in supporting more families but also relieving pressure on health and public services.

“An amazing service but not wide spread enough”



What Next?

“ More of the same please!! ”

The most important element in monitoring & evaluation is the learning it provides in adapting and developing service delivery. Qualitative feedback in our training questionnaires and online annual survey established a number of key themes that we will address in order to ensure we are responsive as resources allow to the needs of parents and families. These themes included greater depth and flexibility in our training delivery, improving awareness of our services and increasing the reach of our delivery.

In our online annual survey we also asked parents to give feedback on a number of possible options for new service delivery. Not surprisingly 55% of parents suggested we develop work delivering counseling and emotional wellbeing. Having at one time in our history delivered counseling we are wary of doing so again. However, we do want to explore other ways of supporting parent-carers emotional wellbeing and one way we think we can achieve this is through developing work around volunteer befriending, mentoring and outreach, which a further 55% of parents in our annual survey said they would be interested in us delivering. The benefit of this type of support is we can also address challenges we face in our outreach and signposting of parents to our service. Interestingly, 45% of parents in our online survey said they would be interested in volunteering for Reaching Families.

Over the course of 2018 we will therefore concentrate on making the following developments and changes: -

- We will review and add to our fact sheets series
- We will increase the number of training workshops that we deliver in the evening in order to improve access to our training for parents who work during the day or who have caring responsibilities
- We will increase the length of existing training workshops to allow for further depth of delivery
- We will work to raise funds to deliver more one day training workshops
- We will explore ways to provide parents with greater support in achieving more positive health and emotional well-being
- We will work to raise funds to recruit a volunteer co-ordinator and in doing so improve the peer support parents are able to provide each other
- We will undertake “professional outreach” to ensure more teams within social care and health know of our service and in doing so, improve signposting and referral to parents
- We will complete the work necessary to achieve PQASSO accreditation
- We will continue to make our case to the local authority for meaningful investment in our service

“ Great support, really useful information and a sense that they know what it's really like for us as a family ”

With many thanks to the following funders and partners who helped in the delivery of our services during 2017

Amaze

Autism and Social Communication Team (WSCC)

Autism Sussex

Bascule Charitable Trust

Big Lottery Fund

Co-op Community Fund

Henry Smith Charity

May House (WSCC)

Sussex Community Foundation

TSB Bank (Worthing Branch)

West Sussex SEND IAS (WSCC)

Wilmington Trust



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