

Reaching Families

Impact Report 2018



Empowering families of children and young people with special educational needs and disabilities in West Sussex

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 well-being, 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 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.

Reaching Families are also members of the West Sussex Autism Pathway and deliver a number of one-day training workshops on Autism, ADHD and related issues.

Umbrellas Support Group: we run 3 monthly support groups for parent-carers in Billingshurst, 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 2,350 parents (the largest in West Sussex). It is an excellent means of connecting parents, promoting our projects and services and sharing news, information and resources.

“Your support has helped me keep my sanity. Especially as we can't access other support, so thank you”



Executive Summary

We are thrilled to present to parents, partners and funders our second annual Impact Report, detailing what we achieved for and learned from parents and families during 2018, our 10th anniversary year. It was defined by one overriding factor – an exponential rise in demand for all our projects and services. The table below details the growth in that demand:

	2017	2018	+%
Making Sense Guides	2,500	2,682	7
Fact Sheet Downloads	2,975	4,797	61
Training Attendees	257	348	35
Umbrellas Attendees	88	112	27
New Facebook Members	410	591	44
Website (Unique Visitors)	6,767	14,463	114

There are a number of factors that explain the growth in our delivery. Some of it is simply owing to the year on year improvement in our ability to reach parents and families. As an organisation that places huge emphasis on learning, we have always sought to apply what we learn to improve our services and as a result, have become increasingly effective in our delivery.

A more worrying reason for the growth in demand for our work might be what parents have told us about the challenges they face. In our 2018 annual survey of 281 parent-carers, 78% told us their greatest challenge was emotional stress, 62% told said it was supporting their child's health and development and 60% said it was accessing projects and services.^[1]

Each of these are alarming in terms of their prevalence – note the vast majority of parents who report they suffer from emotional stress – interrelated in terms of their effect on each other – parents who struggle to access services for their child will almost certainly experience an increase in stress – and endemic in terms of these

being persistent challenges that parents continually face, year after year.

The increase in demand for Reaching Families work is therefore directly related to the increasing difficulty parents have in supporting their child and the strain this takes on their emotional well-being. Elsewhere, in our annual survey parents told us their best source of support is voluntary organisations like ours. It therefore comes as no surprise that as external support becomes harder to access more and more parents turn to us.

That parents report organisations like ours, parent support groups and other parents generally as their best source of advice reflects a great strength in our community. The informal advice, support and understanding parents share with each other is of such high value that building on this strength will be a priority for Reaching Families in 2019 and beyond.

1. Parents were asked a series of multiple choice questions in our annual survey and could choose more than one option. The challenges cited are those ranked as the highest by parents.



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 evaluation tools – training questionnaires (249 completed), book questionnaires (175 completed) and an online annual survey (281 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 92%
- Parents will report their disabled child accessing new services as a result of improved access to information and training 61%
- Parents will report improvement in their child's development as a result of improved access to information and training 76%
- Parents will report improvement in their self confidence and skills 78%
- Parents will report attending additional training as a result of attending one of our workshops 55%
- Parents will report an improvement in their child's health 68%
- Parents will report an improvement in their family's home life 68%
- Parents will report improved peer support 80%
- Parents will report an improvement in their family's capacity overcome difficulties 77%

“A great service run in an effective and professional manner by friendly, knowledgeable and empathic individuals.”



Other Findings

- 83% of parents who use Reaching Families have children with SEND aged 0-11
- 85% of parents who completed our online annual survey said they value that Reaching Families is led by parent-carers
- 67% of parents who completed our online annual survey said they think Reaching Families should establish a counselling service for parents
- 58% of parents said they think we should establish a befriending service
- 47% of parents said they received no support when their child was first diagnosed (4% said they had received counselling, 4% said they had received key worker support)
- 77% of parents said their best source of information and support was voluntary organisations like Reaching Families (63% said other parent-carers, 40% said parent support groups)

What we learned from parents

“ I suffer from anxiety and this has helped me so much, its nice to know you aren't alone ”

The results of our 2018 annual survey (and other feedback) was characterised by three key themes – the emotional stress experienced by the overwhelming majority of parents, the poor experience they had of support during their child’s diagnosis and their continuing struggle to support their child’s health and development.

The results of our survey were very powerful. That 78% of parents said their greatest challenge is emotional stress speaks volumes of the unrelenting pressure they are under – the strain of their caring responsibilities, the endless battle for external help, the struggle to support their child’s health and development without access to the external expertise they need.

Almost half the parents surveyed (47%) said they received no support at all during their child’s diagnosis. Of those who had received support just 4% said they had been provided with counselling, 9% had received training on their child’s condition and 34% had received information. Expressed another way the vast majority of parents when receiving news with life long implications and consequences for their child, themselves and their family leave the room empty handed.

It is difficult to express how we as an organisation feel about findings like these. On the one hand we are shocked and alarmed, on the other not in the least surprised as it is consistent with what we see and hear every day. The challenge of getting support to parents during this most vulnerable period was a driver behind establishing Reaching Families and an issue we feel compelled to return to in the coming year.

The road ahead for parents after diagnosis appears to be characterised as an ongoing struggle to access help in support of their child’s health and development. 62% of parents in our annual survey said this was their biggest challenge. Meanwhile, 68% of parents who attended our training workshops said they received no support on the subject



covered in that workshop. If we needed an explanation for the surge in attendance at our training workshops during 2018, then simply put, when parents cannot access the external expertise they need, they will do their best to acquire the skills and learning for themselves. Our training is therefore a crucial intervention in this respect.

One other characteristic of the parent-carer experience that our families reported on during 2018 is the incredible primacy and high value they place on the support they receive from other parent-carers. 77% of parents said their most valuable source of support is parent-carer led organisations like Reaching Families, 63% said other parent-carers generally and 41% said parent support groups. When asked the value of support from other parents 91% of respondents said they understand their situation, 90% cited sharing skills and experience and 86% said emotional support.

Looking ahead the challenge for Reaching Families is trying to address the challenges parents face around emotional well-being, diagnosis and supporting their child's health and development by leveraging peer support in the parent-carer community. To that end our Umbrellas support groups, Facebook group, and crucially, a new befriending service we will pilot in 2019 in partnership with Amaze, are important steps in creating a structure in which we can optimise the support parent-carers can give to one another.

Making Sense Guides

“Receiving this book from yourselves when my son was diagnosed was so helpful and made things less stressful”

It was business as usual in 2018 for our two making sense guides, both of which are still incredibly popular with parents. We were thrilled to publish the 2nd edition of Making Sense of Adult Life in 2018, which included significant new content to reflect changes in local service delivery. We were also delighted at the number of parents who have made use of the option to download our books in either Kindle or iBook format. Given the cost of printing the books (over £5,000 per year), the easily accessible e-book versions provide a highly cost effective means of distributing the guides to the optimal number of parents at minimal cost.

Fact sheets

“Excellent bite-size information, sometimes just what you need”

The huge increase in unique visitors in our website during 2018 translated into an exponential increase in the number of parents who downloaded factsheets from our website – 4,797 compared to 2,975 in 2017. Our aim in 2019 is to up-date and add to this small library of resources with a particular focus on the diagnosis series and related subjects.



“The training workshops were fantastic and so helpful. I have recommended them to my child's school”

Training

2018 was a record year for Reaching Families training delivery as we delivered 33 workshops across two programmes to 348 parents. 24 of the workshops were delivered as part of our lottery funded programme, the other 9 (one day workshops) were delivered through the West Sussex Autism & ADHD pathway.

A key feature of the increase in demand for our training delivery was the percentage of parents who attended workshops that reported they were in receipt of no relevant services to the issue at hand (68%). Combined with the number of parents in our annual survey who said their greatest challenge was accessing services and supporting their child's health and development (62%), it is little wonder our training workshops are in such high demand.

As with 2017 one consistent piece of feedback from workshop attendees was that whilst the workshops are highly valued, parents would prefer they were longer. This entails obvious cost implications but Reaching Families is committed to exploring how we can increase the length of workshops.

“Just wanted to say the support and advice on Facebook is unreal, thank you”

Umbrellas Support Groups

A key theme running through our work in 2018 was the vital importance of peer support, the value of information and advice parents share with one another, and the informal networks of support they create with each other. This is best exemplified by our three Umbrellas support groups, which experienced a 27% increase in attendance and participation during the year. We were particularly pleased at the growth of the Billingshurst Umbrellas group, which despite being in a sparsely populated area has become firmly established as a means of support to parents in mid Sussex.

“Without your support I think I would have probably felt overwhelmed and given up. But attending Umbrellas has helped at every stage and I now feel we are making slow steps to helping my daughter”

Facebook

The importance of Facebook in connecting parents, sharing information and resources cannot be overstated. In a virtual sense, it is where parents meet. Our group experienced huge growth during 2018 and is now firmly established as the largest in West Sussex (almost 2,500 members).

Like Umbrellas our Facebook group is an important vehicle in enabling parents to provide each other with peer support. In fact our Facebook group has become increasingly characterised



by this function, so much so the trustees have taken the decision to change the status of the group from open to closed in 2019, thus allowing greater privacy for parents to share their stories and experiences.

PQASSO

“Fantastic organisation. The workshops are so well run and informative. The books are an invaluable resource”

Over the course of 2017 and 2018 Reaching Families, with the support of the Big Lottery Fund, has invested significant resources in building the capacity and infrastructure of the organisation. This has included work on governance, management and policy development.

Our aim when first starting on this work was to use the PQASSO quality framework (now called Trusted Charity Mark) to build the infrastructure of our organisation. The process of achieving this standard is hugely demanding on small organisations like ours. However, we have made significant progress in strengthening our infrastructure and are confident we can achieve Level 1 of the Trusted Charity Mark during 2019.

Funding

2018 was also landmark year in our exceeding £100,000 in income for the first time. This included a very welcome increase in funding from the local authority who awarded the charity over £28,000 towards

the delivery of our outreach, training delivery and the development of a new befriending service. We hope this level of support continues. With it, as our track record attests, we are able to leverage the investment to attract other funding from outside of West Sussex. Without it small, user led voluntary organisations like ours struggle to survive. Given our impact, the trust parents have in our service delivery and the financial leverage we can create, we are confident the local authority will continue to see the value in investing in our work.

What Next?

As an organisation that places huge value on learning, the feedback we get from parents has been vital in informing the way we adapt and develop our service delivery. Each of our projects and services has been developed based on the expressed needs of parents and adapted over time to optimise their accessibility and impact.

“Just keep being you!!”

In our 2017 Impact Report we laid out the plans and aspirations we had for the following year, the vast majority of which we were able to progress, for example, securing funds to recruit a Volunteer Co-ordinator who we appointed in June 2018, undertaking “professional outreach” to raise awareness of our services amongst teams within health & social care, and adjusting our training delivery to provide more workshops during the evening.



Sadly, we were unable to make progress with all our aims for 2018. We have yet to secure the funds we need to lengthen the duration of our training workshops and as explained previously, still have work to do to complete the process of achieving Level 1 of the Trusted Charity Mark. Our aspirations for 2019 therefore include some targets we were unable to action or complete during 2018 but which we remain nonetheless determined to achieve:

1. We will pilot a new befriending service for parents of children undergoing or who have recently undergone diagnosis
2. We will update and add to our Fact sheet series with a particular focus on diagnosis and related subjects
3. We will continue to seek the funding necessary to lengthen the duration of our training workshops
4. We will develop a bespoke training workshop designed to inform and empower parents of children undergoing diagnosis
5. We will complete the process of achieving the Level 1 Trusted Charity Mark
6. We will carry out an independent evaluation of Reaching Families and the support needs of parents with particular focus on diagnosis, emotional resilience and peer support
7. We will change the status of our Facebook group from open to closed to ensure parents have greater privacy and freedom to share their challenges and experiences with one another

How to Support Reaching Families

As a small voluntary organisation with limited resources we depend on the support of a wide range of people to ensure we can reach the optimal number of families. There are a number of ways you can support Reaching Families, including:

1. Make a donation - if you would like to make a donation to Reaching Families you do so via our Local Giving page. For further details, please visit localgiving.org/charity/reachingfamilies.
2. Fundraise for us - are you the kind of person who likes a personal challenge or is great at organising events? Maybe you could use your daring and skills to help raise money for us.
3. Volunteer Befriender - are you a parent-carer who wants to support other families? Perhaps you might be interested in training as a volunteer befriender and help support parents of children undergoing diagnosis.
4. Outreach Volunteering - can you help us reach more families? We need help distributing information and resources particularly in smaller towns and villages in West Sussex.

For further information on any of the above suggested ways of supporting Reaching Families please contact our project manager, Brian O'Hagan at brian@reachingfamilies.org.uk. Thank you.

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

Partners & Funders

With many thanks to the following funders and partners who helped in the delivery of our services during 2018:

Amaze
Albert Hunt Trust
Autism & ADHD Pathway
Big Lottery Fund
Co-op Community Fund
Earnest Kleinwort Charitable Trust
Garfield Weston Foundation
John Lewis (Chichester)
Autism and Social Communication Team (WSCC)
Sussex Community Foundation
TSB Bank (Worthing)
West Sussex County Council
West Sussex SEND Information Advice and Support Service (WSCC)



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