

RESOURCES FOR AUTISM

**An evaluation of Resources for Autism Project funded
by the Big Lottery Funding - Reaching Communities
Supporting the London Autistic Family**

Jane Shepherd
Maddocks Associates
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Contact details

**Author: Jane Shepherd
Maddocks Associates**

jane@maddocksassociates.org

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Abbreviations

AP	Alternative Provision
ASC	Autistic Spectrum Condition
CAMHS	Child and Adolescent Mental Health Services
EHCP	Education, Health and Care plans
FE	Further Education
IPC	Integrated Personal Commissioning
LGA	Local Government Association
PECS	Picture Exchange Communication System

Glossary

Direct Payments	Direct payments are cash payments made to individuals who have been assessed as needing services, in lieu of social service provision.
CAMHS	Child and Adolescent Mental health services
Early help	Intervention at the earliest stage of identification and is inclusive for children and families of all ages from birth onwards.
Education, Health and Care Plan	Education, Health and Care plans bring together multi-agency planning throughout childhood and to the transition to adulthood.
Integrated Personal Commissioning	Integrated personal commissioning is strategic local commissioning between local authorities and clinical commissioning groups to create the market conditions for personal budgets.
Local Offer	The Local Offer describes the services, resources and support in education, health and social care that is available inside and outside of the local area for children, young people and families.
Personal budgets	Personal budgets are made up of the funding allocation from social services, but may also include funding for health needs, access to employment benefits or equipment.
Targeted services	Targeted services provide support aimed at particular groups of children but often accessed from within universal (or mainstream) services. They are provided directly to children who have been identified as having additional needs.

RESOURCES FOR AUTISM

Short breaks

Short breaks provide opportunities for disabled children to have fun and become more independent. These are often weekend, after school or school holiday activities.

Specialist services

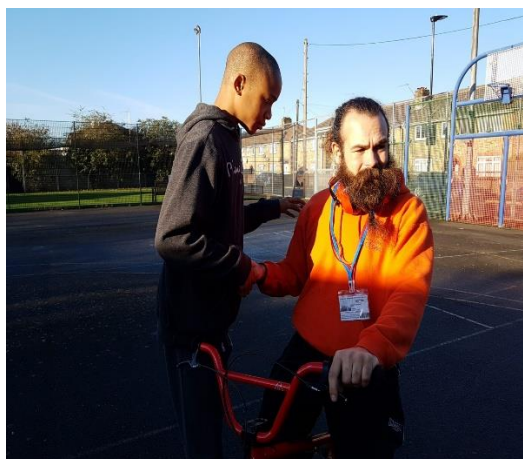
Specialist services are provided specifically for children with specialist, acute, complex or very high-level needs.

Universal services

Universal services are designed to meet the needs of all children; they include early year's provision, mainstream schools as well as health services provided by GPs, midwives, and health visitors.

100 hours scheme

The 100 hours scheme operates in some London boroughs. The allocation can be used for whatever families want but is based on 10 holiday days and some weekend provision.



Executive Summary

1. The evaluation examines the entire London service delivered by Resources for Autism. The organisation has grown geographically, in response to policy initiatives and increased demand. The organisation offers 'niche' services, provided for all ages and for people at all points on the spectrum.
2. The organisation shares its 'model of good practice' with other voluntary and statutory organisations and local networks. It is underpinned by an ethos of acceptance and inclusivity.
3. Waiting lists have increased by between 10% and 340% since the last evaluation of London services in 2015.
4. Local authorities continue to commission short breaks services although these have been challenging times for local government and cuts in provision have affected Resources for Autism.
5. The Transforming Care Programme, the government's second response to Winterbourne View intended to discharge all vulnerable patients in private hospitals with a learning disability or autism has been extended by another four years. Resources for Autism has the skills and the confidence to deliver on this agenda which does not have any quick-fix solutions but could be delivered on the 'model of good practice' developed over the years.
6. Resources for Autism offers, through practical services, a combination of social opportunities with skills for life for children, young people and adults living with an ASC. There are gaps in services particularly in adult social care and the potential to develop a 'drop-in' facility for adults who have become marginalised and are at home not engaged in anything productive.
7. Parents and carers continue to report that there are no other suitable services for their children other than Resources for Autism.
8. Local authority commissioners recognised the value of the services provided and they are positive about the excellent value for money that Resources for Autism provide.
9. One local authority area has the ambition to develop in partnership with Resources for Autism a Centre of Excellence – a single building providing

everything from information and advice; with professionals working together to support at the time of diagnosis, throughout childhood and into adulthood. This type of service should be made available in every local authority area. Parents and service users want to 'co-produce' a proposed centre and they are keen that any new innovation is 'user-led'

10. Resources for Autism have continued to provide the consistent approach, meticulous planning and key worker system that means that parents and carers can trust the highly trained, talented and resourceful staff to care for their children.
11. Resources for Autism do not use agency staff. They have a rigorous recruitment process. However, the biggest threat to the organisation is being able to retain staff because this relies on secure funding, which has been problematic throughout the past ten years of austerity and the regular re-commissioning of services. An innovative recruitment strategy that links to 'traded services' such as training and providing expertise in schools are required to retain staff.
12. Routine data collected showed that:
 - 100 % of service users enjoyed the service provided and felt they had benefited
 - 94% of service users felt that communication had improved
 - 95% felt that there had been an improvement in interaction
 - 96% felt that the service had benefited the wider family
 - 95% experienced an improvement in mood and a decrease in anxiety
 - 97% of children showed improved play skills including sharing
 - 96% expressed that they felt more self-confident
13. This is the third evaluation of the services provided in London by Resources for Autism and the findings show that since 2012 and 2015, in 2019, the standards have again increased with a higher percentage of people reporting satisfaction in the outcome measures despite government cuts in public expenditure.
14. Resources for Autism have during the last academic year 2018 – 2019 developed 'Orange House' which is a remarkable success story. Providing Alternative Provision (AP) for children with an ASC living in the London Borough of Newham. The local authority had a number of children who had not been allocated a secondary school place at the year 7 transition to secondary school

because there were insufficient special school places. This had led to a crisis where six young people with complex needs had all been out of school for more than a year. Orange House is now at the start of the second academic year and the service has been described as outstanding by the commissioners. The children from year one are now back in school.

15. Resources for Autism created an innovative and brand new service, a group for mums with autism. This is an extremely cost-effective service run by the mums to support each other. The stigma associated with autism can create barriers to mums with a diagnosis of autism seeking help from social care and this initiative has the potential to prevent children entering the care system.
16. In conclusion, Resources for Autism have grown in confidence. The 'best practice model' that has been developed has meant that in a range of different circumstances the organisation can galvanise very quickly when serious gaps in provision occur and they can step in and offer support services.
17. There is a growing recognition that Resources for Autism can provide emergency provision on both an individual and community basis. This has become increasingly necessary as statutory services often fail to provide help in an emergency. The organisation can also provide training and support to staff in the statutory and voluntary sectors which enables individuals with autism to access mainstream services.

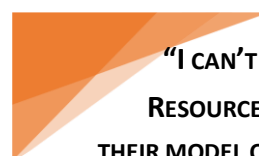


Introduction

‘Supporting the London Autistic Family’ is a project funded by The Big Lottery Fund. It is part of the range of essential services provided by Resources for Autism to families who are often isolated and at risk of breakdown as a result of having a family member with autism. This evaluation provides the opportunity to examine the entire London service delivered by Resources for Autism.

Resources for Autism is a unique organisation established by the former MP Dr Hartley Booth OBE in 1997 as a direct response to the number of constituents seeking help and the level of unmet need amongst local families. The organisation continues to provide practical support to individuals with an autistic spectrum condition (ASC) because this is what families have consistently told Resources for Autism in their extensive consultation, that they need. The organisation has grown both geographically and in response to policy initiatives and continually increased demand.

Resources for Autism offer ‘niche’ services. These are services provided for all ages, from cradle to grave and for people at all points on the spectrum. The organisation is committed to providing ‘lifelong services’ even though local authorities and other statutory services often have an arbitrary cut off point or gaps in their provision.



“I CAN’T IMAGINE BARNET WITHOUT RESOURCES FOR AUTISM. THEY SHARE THEIR MODEL OF GOOD PRACTICE WITH ALL OUR MEMBERS.”

YOUNG BARNET FOUNDATION

Other voluntary organisations provide special needs after-school clubs and holiday schemes, but these are not exclusively for children and young people with an autistic spectrum condition. For many years families have reported that generic ‘special needs’ play and holiday schemes are not able to meet the needs of their children. The National Autistic Society and Mencap also provide specialist services to families and Resources for Autism share knowledge and accept referrals from these organisations when they cannot meet the need. The organisation shares and models good practice with other organisations and local networks, e.g. The Young Barnet Foundation, various multi-agency autism strategy groups. Resources for Autism is underpinned by an ethos of acceptance and inclusivity. The organisation prides itself on never turning

anyone away. Individuals using the services are some of the most marginalised in society and they have often been excluded from both mainstream and specialist services.

The context

The number of people diagnosed with autism continues to rise and what was once considered to be a rare 'disorder', in recent decades the numbers of those diagnosed on the wider 'autism spectrum' has massively increased to an approximated figure of 1 in 100. Not surprisingly the level of unmet need has also grown and the waiting lists have increased by between 10% and 340% since the last evaluation in 2015.

Ten years ago the Autism Act 2009 placed a statutory requirement on the Government to publish an adult autism strategy. Resources for Autism have been instrumental in working with local authorities to develop best practice and they also now provide groups for adults with an ASC, some of whom have been marginalised by society and become vulnerable because of the lack of support available.

The children's services policy context was changed with the introduction of The Children Act 2014. This is discussed in detail later in the report as the challenge of young people being excluded from school because they had not been offered a place at secondary school has led Resources for Autism to create an innovative new service in one London borough.

Although it is not a core activity, Resources for autism have helped people with an ASC into employment. This can be not only life-transforming for the person but makes enormous savings over that person's lifetime to public finances.¹ This is an unplanned

INTO EMPLOYMENT

"After a while S settled into working on the IT & Communications systems within HAIL, this is where he found his niche! It also became apparent that S has skills and knowledge that were a huge asset to us, and further, the quality and volume of work he undertakes are clearly saving HAIL time and money."

"We saw his value and knew we'd benefit as an organisation by employing S, we're delighted to say S is now a valued and well liked member of the team at HAIL. It's been a pleasure to watch S grow."

¹ THE AUTISM DIVIDEND Reaping the rewards of better investment; By Valentina Lemmi, Martin Knapp and Ian Ragan on behalf of the National Autism Project; Jan 2017

outcome brought about because the organisation nurtures talent, can spot potential and create opportunities.

Very little attention has been paid to the issues affecting older adults with an ASC. This will become a significant challenge in the future to ensure that adults with autism enjoy fulfilling and productive lives in old age and Resources for Autism will be well placed to provide support and services.

One of the aims of the organisation is to provide a resource base (a centre of excellence) for people of all ages from early years and diagnosis through the life span. There would have a number of benefits including;

1. Therapists (OT; Psychologists; Music and Art) could make holistic assessments of sensory, sleep, food-intolerance issues if professionals worked alongside each other.
2. For some adults with personal budgets and personal assistants, a physical base to go to is essential especially in the winter months, where there could be a range of activities for adults who have become vulnerable and marginalised.
3. Parents and service users want to 'co-produce' a proposed centre and they are keen that any new innovation is 'user-led'.

Resources for Autism offers, through practical services, a combination of social opportunities with skills for life for children, young people and adults living with an ASC. The organisation has grown over the years by using a model of practice that is tried and tested. It works not only when establishing new clubs, but also to set-up provision in other geographical areas or as shown during 2018, to provide at very short notice 'Alternative Provision' (AP) for young people who are not attending school.

The Transforming Care programme was the second response to Winterbourne View but despite the initiatives and although there have been people discharged from hospitals, even more, have been admitted. The 2019 NHS Long Term Plan will extend the timescale by another four years. There is no easy solution to moving people back into local communities, but Resources for Autism have the skills and confidence to deliver part of the solution. They have the 'model of good practice' and they could partner with a housing provider to be able to make a valuable contribution to this continued national programme.



The model of good practice

The model of practice is the building block of the organisation. It has been proved to be sustainable. It has led to more diverse funding streams as local authority commissioners have over the years recognised the value of the services.

To understand why the best practice model that Resources for Autism have developed works so effectively, it has been important to listen to service users of all ages and parents and carers who frequently report that there are no other suitable services for their children.

Parents and carers can easily identify what is different about Resources for Autism from their experiences of using other services. This came over in every single interview with parents and carers. They appreciate the consistent approach, the meticulous planning that goes into each session and having the same staff that they can trust to care for their children. The staff are all highly trained, talented and resourceful. They do not use agency staff and there are rigorous recruitment, training and retention of the staff.

Each group or session run by Resources for Autism has the same structure and consistency. The groups are well-staffed to ensure there are no accidents and children and young people have the same 'key worker'. Parents and carers are visited at home to assess a child's needs before they start and this is the start of building confidence

in the service, particularly when parents have experienced services that have not been able to meet their child's needs.

There is a range of groups and clubs and ideally, a child could start in a group or club for younger children and then move to the next age range. This does not always work in practice if there are gaps in the local authority provision. During the evaluation, it became apparent that one local authority did not provide for 5 to 8-year-olds and this was identified by many parents as a gap in provision.



When our son was 3 year's old he was diagnosed with autism. He had just started nursery and he went through a phase of hitting babies. We were mortified. We could not understand where this behaviour came from. We didn't know what to do and we were in a very dark place. I was so desperate for help and 'googled' Autism and found by chance, Resources for Autism. I telephoned them and they straight away said they would come out to see me at home. They came a few days later. The person who came was so knowledgeable and she identified our son's anxiety and helped us by working together to look at how we could help him. Then she made arrangements for us to have a service called Reach Out. A volunteer came for 3 hours every week and she took our son swimming. He absolutely loved spending time with her and would look forward to the time when she was coming. She became like part of the family. I cannot tell you how grateful we are to receive this ongoing support. When our son started school, the Behaviour Support Manager offered to go into school with me and work with the teaching staff on some of the strategies that she had helped me develop. By then I was really starting to gain confidence again and so I went into school to talk to the staff myself.

The Behaviour Support Manager knew how we could access the short breaks programme in our local authority area and that means that he can go to the clubs and holiday schemes run by Resources for Autism.

The most important thing is that we completely trust them all. They have always been there for me and my family and that has been absolutely amazing. We could not have managed this without their support. - Mother talking about her son and her family's experience of RfA.

Evaluation methodology

The evaluation used a mixed-method approach intended to reach all stakeholders, including young and older service users, parents and carers, volunteers, including those working on the 'Reach Out' Project and volunteers providing office support and working in the clubs. Local authority commissioners, social workers, a range of staff members including the management team, playworkers, therapists and fundraisers. Other funders were also included in the evaluation and organisations that Resources for Autism network and work closely with such as the 'Young Barnet Foundation'.

Using a combination of routinely collected data from questionnaires, telephone interviews with, local authority commissioners and staff, the evaluation looks at the strengths-base of the organisation and how it makes an impact in the communities where it works. Stakeholders were also asked to identify things that didn't work so well and this produced some ideas about how to involve service users and carers but there were few negative comments about the services provided. Any negative comments were directed at the fact that there are not enough clubs and holiday schemes. Single parents seemed to struggle with a lack of holiday provision. One parent commented

that the clubs were more enjoyable for her son because they were more age-specific than the holiday schemes which had a wider age range. These comments all relate to the need for more services to be provided by Resources for Autism.

The evaluation examined how effectively Resources for Autism works collaboratively with other organisations. This provided evidence that the organisation can prevent school exclusion, prevent social isolation and build resilience in communities. Resources for Autism engaged with statutory agencies to help train their workforce, including training school teaching support staff and working with staff in a local authority homelessness department to make contact with rough sleepers with successful results in getting people housed.

The evaluation examined the positive working relationships that are nurtured within the organisation and how the passion and knowledge of every member of staff and volunteer are recognised by other organisations and all the stakeholders.

The evaluation also considered how knowledgeable the parents and carers were about the true cost of the services, how affordable the services are (when commissioned by local authorities) and the mechanism and equity of how Resources for Autism are able to waive fees for those families who are suffering from hardship.



	Questionnaire	Interviews with families	Monitoring data	Interviews with commissioners	Interviews with staff	Document review	Referral data
No of services users		✓	✓	✓	✓	✓	✓
Level of satisfaction	✓	✓	✓	✓			
No receiving information pack		✓			✓	✓	✓
Type of service offered	✓	✓	✓	✓	✓	✓	
Groups and clubs running	✓	✓	✓	✓	✓	✓	

Data collection matrix

Audited accounts, an ‘Impact Report’ and management reports were also examined and a range of play, youth and adult groups and summer play-schemes were observed.

The impact of the project on the wider community has been explored through the evaluation questions. The buildings that are used by the clubs and playschemes have an impact on the quality of the services and can vary. Although there has not been time to visit all the venues across London, the cost and constraints of buildings have been considered and were discussed by local authority commissioners.

The evaluation questions have been framed as open questions such as, ‘What other changes have there been?’ ‘What else have you achieved?’ as well as incorporating the formal and routine data collection by the organisation; which benchmarks the quality of the service.

Organisation and aims

The purpose and aims of the organisation are to support the needs of people with autism and related conditions and to promote and protect the health of families and carers of people with autism and related conditions.

Specifically, the charity aims to:

- Improve the quality of life of individuals and families affected by autism
- Expand the opportunities for individuals with autism
- Improve the skills of individuals with autism
- Improve the emotional well-being of individuals with autism

The charity aims to establish a model for the provision of services that can serve as a model for replication either as a direct activity of the charity or through the action of other organisations.² This statement is an important acknowledgement by the Trustees that they are keen to share what has been learned over the years in developing the 'model of good practice' with other organisations. It is clear on a practical day-to-day basis that the staff at Resources for Autism work collaboratively and they know that there are many win-win situations when working with other organisations.

The evaluation considered to what extent the project had delivered on three outcomes identified in the lottery application:

- ✚ The extent to which group members with autism will increase communication and life skills and therefore become less isolated.
- ✚ The extent to which autistic individuals will gain improved strategies to reduce challenging behaviour.
- ✚ The extent to which autistic individuals will have increased independence through community-based support.

² Taken as a direct quote from the Annual Report and Accounts from April 2018 – March 2019

The Findings

Resources for Autism identified the targets to be achieved for each of the outcomes. The outcomes identified at the outset of the project were intended to be SMART; specific, measurable; achievable realistic and time-bound.

The impact of the project on the wider community has been explored through the evaluation questions.

Outcome 1	Autistic individuals will be better able to access at least one group activity per week.	250 people per year	Year one
	Carers/support staff will report improvements in communication.	200 people	By the end of the project
	Carers/support staff will report an improvement in money management and life skills.	100 people per year	Year one
Outcome 2	Carers/support staff will report a reduction in incidences of challenging or isolating behaviour.	40 people per year	Year one
	Carers will report a reduction in stress and isolation	180 people	By the end of the project
Outcome 3	Carers will report that individuals with autism are using community resources such as public transport shops and universal services.	250 people per year	50 by the end of year one
	Families will say that they are able to enjoy more family outings.	100 people	By the end of the project.

Outcome 1 Autistic individuals will be better able to access at least one group activity per week.

Carers/support staff will report improvements in communication.

Carers/support staff will report an improvement in money management and life skills.

Routine data collected by Resources for Autism showed that 92% of adults felt their overall skills had improved.

Interviews with service users and parents and carers were overwhelmingly positive.

One service user aged 18 years said that he loved going to the Wednesday club he attends and this had given him so much more confidence. He told me that the most important thing for him was that he had made friends. His dad said that he was 'wholly positive' about Resources for Autism. His son is about to start his first year at 6th form college and he felt that Resources for Autism had helped him with 'social engagement'.

"My son has had the consistent support which has allowed him to learn about himself in a non-judgmental way. He can be himself and can play without anxiety. He has learnt that people are all different and now has the self-esteem to embrace his autism and therefore his worth."

"I don't know what I'd do if I couldn't use RFA. It is the one place my son will leave the house for. The place is a godsend."

"This service works due to the quality of the staff. They are young and they have fun. My son can relate to them so he will listen to them as he sees them as friends. They are so professional, energetic, diplomatic and friendly which gives me the confidence to leave my son there, and to pick him up later looking so happy is great."

The routine data collected showed that 94% of service users felt that communication had improved.

Communication was often mentioned by parents and carers during the face to face and telephone interviews.

"It's not just about communication but our daughter was suffering from anxiety and depression and we found that there was simply no support through the local Child and Adolescent Mental Health Services (CAMHS). We have found that RfA is the one place where she can go and be herself. She can talk to the staff about how she is feeling and her social anxiety and she has opened up and become much more confident. This was starting to affect her school as she was becoming school phobic, but now we have turned a corner and she is so much happier." Mother of a 12-year-old girl.

"This is a safe space where she can go without worrying about 'social norms'."

The routine data showed that 89% of service users felt more independent. Although this does not specifically refer to an improvement in money management and life skills, independence is an important outcome of being able to learn life skills.

One parent put it very clearly when she said, “This is not just about having a good time at the club, which my son does have, but also about equipping him with skills for life. My son has learned about online dating, managing emotions and managing finance all through the clever ways that the staff arrange the activities. They don’t say, ‘today we are going to learn about money’, they have inspirational activities that really engage the young people.”

Outcome 2 Carers/support staff will report a reduction in incidences of challenging or isolating behaviour.

Carers will report a reduction in stress and isolation.

During the evaluation, families sometimes told heartbreaking stories about the damaging effect of excluding a child from school. This can quickly destroy a child’s confidence, disrupt their routine and escalate negative behaviour. The implications of school exclusion can be devastating. When professionals such as social workers do not have an understanding of autism, it can have grave consequences. It may result in a child being removed from their parents if challenging behaviour is interpreted as inadequate parenting. Resources for Autism always offer to work alongside teachers and support staff in schools; social workers and other frontline staff who may need advice, training or support.

“My son used to go to groups that were too noisy, too sensory and too cold. His behaviour was always affected by the venue. Then we found out about Resources for Autism through a parenting course. His communication had become very difficult. I found with Resources for Autism that they know about everything you are going through and can offer support and advice. The RfA groups are brilliant. He likes the toys there and he loves the quiet, calm atmosphere and the sensory room. I feel supported by RfA and this has taken away some of the huge strain this has had on us as a couple. Our son really looks forward to his weekly club. He does not always want to go to the Sunday family group, but he likes it when he gets there and we (as a family) really look forward to it every two weeks.”

Two parents in separate geographical locations mentioned that as a result of the Resources for Autism clubs their children attended they had developed informal 'clubs' with other parents. An unplanned, but effective outcome of the RfA provision.

"My son just would not sleep and kept going throughout the day and night. I was at my wit's end. I felt as if I couldn't cope any longer and on one occasion after 36 hours without any sleep, I finally reached rock bottom. Eventually, the social worker got the funding arranged for a 10.00 am to 1.00 pm session each Saturday with Resources for Autism. Other than that there was no help for parents. I had to leave my job. Eventually, with the use of some medication and a lot of support from Resources, his behaviour started to be more under control. Now, he is no longer kicking and punching, he is going to school and he is calm and content. He is also starting to become a little bit verbal." Mother of a 14-year-old son.

Outcome 3 Carers will report that individuals with autism are using community resources such as public transport shops and universal services.

Families will say that they are able to enjoy more family outings.

The routine data showed that 96% of respondents felt that the service had benefited the wider family.

Resources for Autism have worked with the Metropolitan Police Independent Travel Programme to encourage young people with an ASC to learn to travel independently in London. As a life skill, this can be transforming, enabling young people to go to colleges and to enter paid employment.

"My son has so many opportunities through inspirational activities. He has been to see Captain Correlli's Mandarin and been to the Rose Theatre recently."

"He wanted to get the experience of volunteering and that has been possible to arrange because he has learned to travel independently. RfA has helped to find the venues and we are hoping that he can spend a few years doing voluntary work and then may be able to get into paid employment."

Parent of a young adult.

"We absolutely loved going to Go-Ape! We thought it might be difficult, but we all had a great time." Parent

Resources for Autism understands that people with autism require the same everyday services and support as everyone else; schools, colleges, health services, housing, transport and employment. When these services fail to meet the needs of people with an ASC, the consequences can be devastating and seriously impact by limiting aspirations and opportunities. Resources for Autism recognise the importance of working alongside statutory organisations like the NHS, schools and local authorities to enable children and adults with an ASC to be able to access the services provided for everyone. In addition, there are specialist resources that play an important role, special schools or autism resource units in mainstream school; CAMHS provision which is vital for many people on the spectrum who have a range of mental health conditions. Resources for Autism is able to work with the specialist providers to ensure everyone working with a child or adult works consistently.



Local authority commissioning

Local authority commissioners who are responsible for the provision of services in local areas sometimes fail to understand the lived experience of people with an ASC. This has sometimes been described as having a 'spiky profile' of abilities and capacities. Commissioners often incorrectly assume that verbal 'autistic people' are capable in areas in which they struggle, whilst those with less verbal skills are often incorrectly assumed to be lacking in skills, 'strengths', ability or potential. This can distort the perception of what is required in the area and lead to eligibility criteria that unintentionally create exclusion. This becomes apparent in the discussions with

parents of children and young people who have been described as ‘high functioning’ but who may have narrow interests and can suffer from social isolation and debilitating anxiety.

The views of commissioners were sought and there were a number of lengthy telephone interviews made during the evaluation. In some local authority areas, the high turnover of the staff made this task more difficult. Generally, local authority commissioners recognised the value of the services provided and were positive about the excellent value for money that Resources for Autism provide. This at a time when local authority budgets are under such a strain. The parents in some areas had identified gaps in provision, such as a gap between 5 and 8 years. Commissioners want to provide a full range of services and they recognised the need, but are cash impoverished.

As well as directly commissioning services local authorities are required to provide direct payments and personal budgets. This enables individuals to purchase their own care and support and Resources for Autism Home Support is not only popular with parents but also particularly valuable to provide practical support for some of the most vulnerable adults who are often living alone and struggle with autism and mental health issues..

One local authority area has the ambition to develop in partnership with Resources for Autism to establish a Centre of Excellence – a single building providing everything from information and advice; support at the time of diagnosis, throughout childhood and into adulthood. Resources for Autism recognise the value of having a team of therapists and other professional staff working together and being able to provide very high-quality assessments and to be able to work with families to prevent social isolation and exclusion.

This is a model that could be replicated by Resources for Autism once it has been established in one local authority area.

Later in the report, there is an account of a new project – Orange House in Newham. The commissioners of this project could not have spoken more highly of Resources for Autism. They praised the professional attitude and the effort and determination to create an outstanding service with virtually no lead-in time. The reason Resources for

Autism are able to do this is because of the model of good practice and the quality of the staff who all have belief in the values and the ethos of the organisation.

The Director of Resources for Autism and the senior team were singled out for their ability to make things happen very quickly. There were many comments about their energy, passion and drive. This gives local authority commissioner's confidence in Resources for Autism and pays dividends when commissioners discover that they have inadequate provision and need to quickly develop an alternative. They are very keen to look for a suitable building to continue to develop the services in Newham.

The staff and recruitment

The model of good practice starts with a recruitment process that is designed to be rigorous. This was observed through the evaluation as it coincided with the recruitment of staff for the summer schemes. A meeting was held following a group interview session that had been held on the previous evening. The staff gave feedback about each candidate and whether they would be called back for an individual interview. The assessment is intended to draw out a candidate's values and attitudes at this initial stage. The staff recruited on the holiday schemes were interviewed during the evaluation. Some of the comments were illuminating.

"I trained as a Lawyer but then I came to work for RFA and I love it! I don't ever want to do anything else. It can be hard work, but it is just so rewarding."

Team Leader

"I have worked as a teacher for twenty years and I have learned more about autism during the last week than I have done during all those years. I am really enjoying the work and I would like to stay with Resources for Autism if there was a role for me." Play Worker on a Summer Scheme



The interviews showed that the people who are attracted to the role and get through the rigorous interview process are often young professionals who are well qualified and could take up other more lucrative employment.

“I am a comedy writer and an actor, but I saw this role advertised and I am so pleased I applied. It is absolutely brilliant. Last week I worked with a young man and he was so energetic that after we had chased around all day I was exhausted, but I enjoyed my time here so much.” Play Worker

There is a serious problem with the retention of staff because of short-term funding of short breaks and regular re-commissioning of services. This uncertainty around funding means that retaining staff is a major problem. There is career progression and everyone working as a team leader or in any of the senior posts has worked their way up through the organisation. There is a very strong sense of loyalty and staff said over and over in the interviews for the evaluation how much they wanted to stay. Any recruitment strategy would begin by recognising that focussing on the retention of staff is a much more efficient use of resources because the interview process and the

training of staff is an expensive use of resources. The challenge for the organisation is to retain staff, yet many are from the EU and some talked about Brexit and how this might affect them in the future. The organisation is only as good as the staff and there are several key roles in the organisation that are pivotal. In order to expand or to establish new clubs or playschemes requires the input of three key post holders in the organisation, including the volunteer co-ordinator, behaviour support manager and the community support lead and the group and project lead that support the team leaders and playworkers.



Staffing is the biggest threat for Resources for Autism as irregular funding creates anxiety and forces the organisation to make temporary staffing arrangements. The evaluation took place just before the recruitment of summer workers, many of whom were highly talented and would be a great asset to the organisation. The reality is that for several years, local authorities and other public sector organisations have been forced into short term planning.

The findings of the evaluation show that most if not all the staff are well qualified and experienced and have a strong sense of loyalty to the organisation. The demand for services continues to rise amongst families and there are extensive waiting lists.

Resources for Autism should develop an innovative recruitment strategy that focuses on the retention of staff. It should also consider:

- How to make the roles more attractive for potential employees who don't have the experience and qualifications now, but are looking for the opportunity to gain experience of autism. This may involve developing stronger links between the local colleges and universities, offering work placements and providing opportunities for some people to make the first steps and gain practical experience.
- Promote flexible contracts that can be made to fit around family life or other commitments such as studying at university.
- Provide leadership opportunities. Some of the playworkers are highly trained professionals who have the talent and ability to step up and drive the organisation.
- Work smartly and more strategically with local mainstream and special schools. They often struggle to recruit experienced teaching support staff. Some teaching assistants are already employed by Resources for Autism in 'After school clubs and during the holidays. This could be extended and formalised as part of a 'team around the child' approach and by formally sharing resources.
- School-based mental health support teams are being developed in all schools from September 2019 and although these will have a wide remit, there will be a growing need for the 'support teams' to have far more than a basic awareness of autism spectrum conditions. Resources for Autism could establish themselves as a provider of the 'expertise' the support teams will require. They could recruit trainers and begin to develop 'traded services' as an additional funding stream.
- It would be a completely detrimental step for the organisation to use agency staffing, but there may be limited scope for a 'bank' of staff. Some volunteers or former employees might be willing to work 'as and when' necessary and particularly at times when the organisation might be expanding. This is important because they will be the people who already understand the culture and ethos of the organisation.

- The development of Alternative Provision is an opportunity to employ teachers. There are some trained teachers amongst the staff group and they should be engaged and leading developments around further AP in other areas,

Empowering service users

Resources for Autism empower service users in all of the activities. An example of this was given by a parent as part of the evaluation. In total twelve young people supported by Resources for Autism were recipients of the Jack Petchey Achievement Award in recognition of outstanding effort. She described how her son had been supported by the staff at the club he attends to enable him to make his own decisions about how to spend the award to do something he enjoyed, but also benefitted the club as a whole.

The clubs and holiday schemes equip children and adults to become part of their local community. When the club leaders and staff take young people to the shops to buy ingredients to make snacks and meals, people in the local community get to know and accept the young people.

Although many of the parents and carers that took part in the evaluation spoke of the daily struggle and the sense that they had to fight for services to meet the needs of their children, there were also parents who wanted to become involved in the development of the organisation.

Accessing everyday services

Resources for Autism understands that people with autism require the same everyday services and support as everyone else; schools, colleges, health services, housing, transport and employment. When these services fail to meet the needs of people with an ASC, the consequences can be devastating and seriously impact by limiting aspirations and opportunities. Resources for Autism works alongside statutory organisations like the NHS, schools and local authorities to enable children and adults with an ASC to be able to access the services provided for

RFA ARE BRILLIANT! THEY RECENTLY HAD A SESSION WHICH WAS ALL ABOUT ON-LINE DATING WHICH IS ABSOLUTELY ESSENTIAL FOR MY 23 YEAR OLD SON. HE REALLY WAS VERY ISOLATED AND DID NOT KNOW HOW TO MAKE FRIENDS AND SO I WORRIED ABOUT HIM MAKING INAPPROPRIATE FRIENDSHIPS ON-LINE. IT IS SO

everyone. In addition, there are specialist resources that play an important role, special schools or autism resource units in mainstream school; CAMHS provision which is vital for many people on the spectrum who have a range of mental health conditions. Resources for Autism is able to work with the specialist providers to ensure everyone working with a child or adult works consistently.

Promoting tolerance in the local communities where Resources for Autism have clubs and holiday schemes cannot be under-estimated. Successive governments have the ambition of moving people who are living in private hospitals back to their own local communities. Building community resilience is essential to the four year NHS strategy to develop local services. The opportunities that will present are around the 'Winterbourne View' programme of work as individuals move out of private hospitals which have failed to deliver on time because the local infrastructure is not in place.

Continuous improvement

The evaluation looked at the range of services provided by Resources for Autism. The challenge is to maintain the very high quality of service as the organisation continues to grow. The findings of the evaluation show that since 2012 and 2015, the standards have increased with a higher percentage of people reporting satisfaction in the outcome.

This being the third evaluation of the services provided in London by Resources for Autism created an opportunity to measure progress against the two previous evaluations.

The findings show the consistency of the quality of the services that have been achieved by the organisation over a period of seven years a time that has coincided with government cuts in public expenditure and austerity measures that have created problems for the organisation to be able to plan when local authorities are concerned about the short-term.

In 2012

- ✚ 85% of parents and carers reported their child was more self-confident after using a service
- ✚ 86% reported improved interaction
- ✚ 87% of respondents reported an improvement in making friends and relationships
- ✚ 83% of parents and carers reported an improvement in the mood of their child
- ✚ 100% of parents and carers agreed that the service had benefitted them
- ✚ 100% reported that the client had benefitted from the service

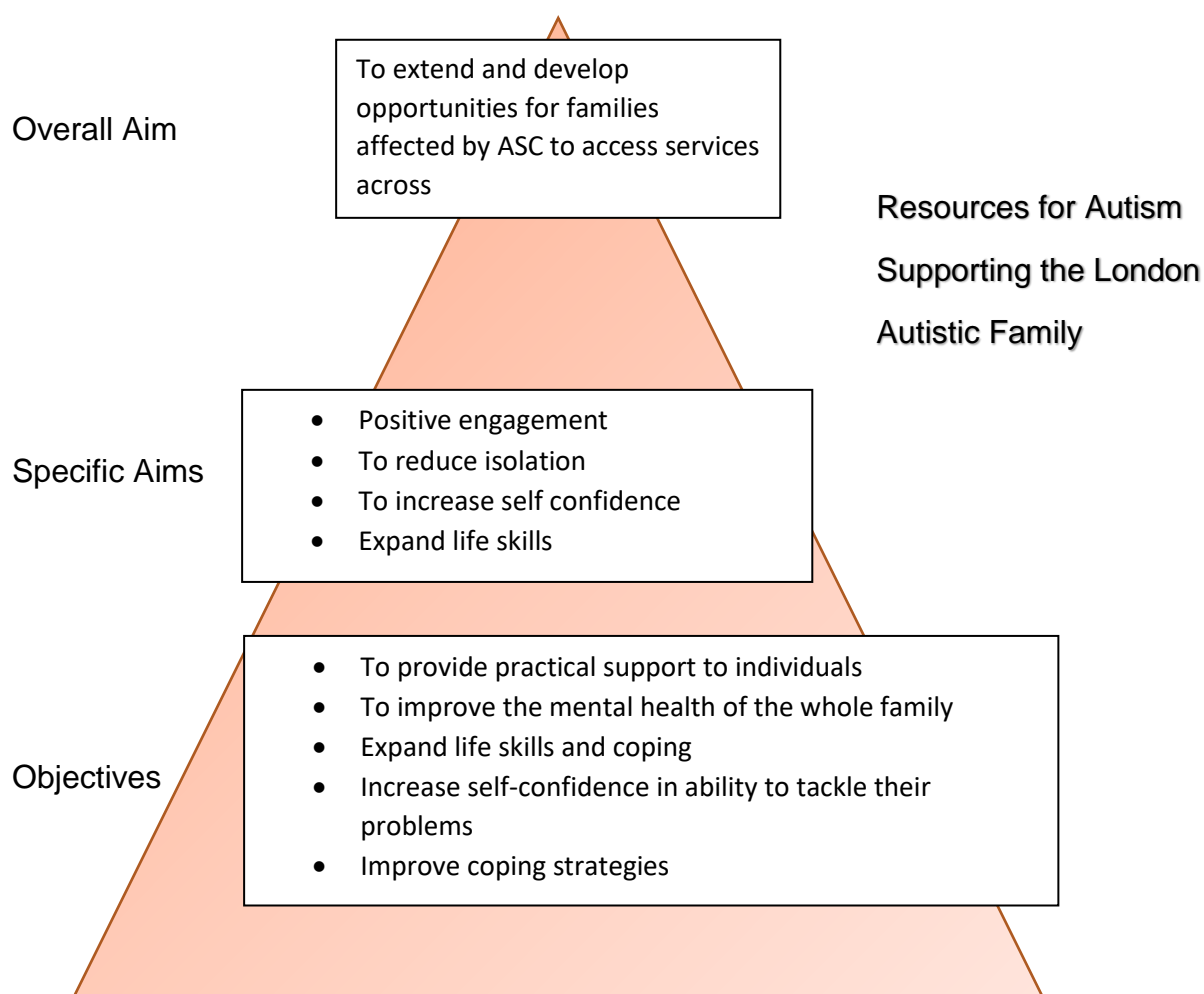
In 2015

- ✚ 94% of parents and carers reported their child was more self-confident after using a service.
- ✚ 96% reported improved interaction
- ✚ 91% of respondents reported an improvement in making friends and relationships

In 2019

- ✚ 100 % of service users enjoyed the service provided and felt they had benefited
- ✚ 94% of service users felt that communication had improved
- ✚ 95% felt that there had been an improvement in interaction
- ✚ 96% felt that the service had benefitted the wider family
- ✚ 95% experienced an improvement in mood and a decrease in anxiety
- ✚ 97% of children showed improved play skills including sharing
- ✚ 96% expressed that they felt more self-confident
- ✚ 89% felt more independent
- ✚ 96% felt better equipped to make friends and relationships
- ✚ 92% of adults felt their overall skills had improved

A continuum of services and lessons learned from the evaluation



The purpose and aims of the organisation are to provide practical support to the most isolated families affected by an autistic spectrum condition. The organisation has grown both geographically and in the number; type and volume of services. The success has been partly due to the Big Lottery funding that has enabled the organisation to use their model of best practice to start-up new weekly clubs and holiday schemes.

Resources for Autism has the 'feel' of a small organisation and families frequently report that they have found the organisation extremely approachable; often at their lowest point; where a child has recently been diagnosed or who have reached a crisis point. Resources for Autism also works on a small scale in communities. Staff go to people's homes and offer a personalised response.

The demand for services continues to grow and in comparison to 2015 when the last evaluation was completed the increases are stark. Although waiting lists are a useful measure of both the need and the success of the services, behind the numbers there are families who are desperate to be able to access services. During the evaluation parents and carers, in particular, commented on the often lengthy wait for services.

		2015	2019
Play services	10%	1217	1345
Reach out	40%	890	1371
Adults	40%	447	591
Therapy (Music & Art)	223%	283	630
1:1 paid community support	354%	125	442

The waiting list for therapeutic services has increased by 223% and currently stand at 630 people waiting for art and music therapy.

The increase in the waiting list for 1:1 paid community support is up by over 350% although the increase in numbers was anticipated once personal budgets came into wider use.

Summer Schemes

The feedback from parents and carers and from young people themselves was overwhelmingly positive. One or two parents said that they would like if possible to know whether their child had a place and the dates. This is something that Resources for Autism is well aware of but often in the hands of local authority commissioners. Many parents said that it would be great to have longer than a week, but they are generally grateful for any summer play schemes.

Recruiting staff to run the schemes is a challenge, but the staff who took part in the evaluation all enjoyed working for Resources for Autism and some were keen to stay with the organisation.

Reach Out

Reach Out is a service provided by volunteers and is extremely popular with families. The waiting list for the service is high and has risen by 40% in the last four years. It is a very popular service amongst local authority commissioners because it is run by

volunteers but it is dependent upon paid staff to recruit, train, retain and match the volunteers to the families.

During the evaluation, the volunteer co-ordinator talked about it becoming more difficult to recruit volunteers. This is for a number of reasons:

1. There are now more people working on 'Zero-hours' contracts but these often require people to be available to work at short notice and so they are unable to commit to a regular time to volunteer. Reach Out is a service that requires the volunteers to be highly reliable and commit to the same three hours each week.
2. The organisation has historically had many European volunteers and Brexit has meant that more are returning to their home countries.
3. There are more people in part-time employment or with more than one job and this impacts on their availability.

One way forward that is actively being considered is for the service to act as a 'rapid response', rather than families waiting for a long time on the waiting list. Often the first contact with Resources for Autism is at the point of diagnosis, or at a crisis point. The benefit of responding to a crisis is that it can have the most impact on the individual and the wider family.

A good example of the importance of being able to make instant decisions that make a massive impact on an individual's life by making an immediate intervention was evident during the evaluation. In early August 2019, a social worker from a London Borough telephoned the Resources for Autism office for help. He had placed a non-verbal boy with an ASC with a foster carer in an emergency on the previous day. The child's mother was a single parent and she had at the time been suffering a serious mental health crisis, hearing voices and acting in a manner that put herself and her child at risk. The police used their powers to place the child under an immediate Child Protection Order. The child did not understand why he was being placed with strangers and what had happened to his mum and became extremely distressed. The foster carers did not have any experience of working with children with an ASC and were unable to calm him. Whilst the Director of Resources for Autism was still on the telephone to the social worker, the behaviour support manager put together a box with a range of sensory toys and activities and went out immediately to meet the foster

carers to support the boy and his carers. The group and project leader responsible for the running of the playschemes immediately made the necessary arrangements to move staff in order to create an additional place for the boy at a nearby holiday scheme. Resources for Autism are able to do this because with some donations and funding through the Big Lottery it allows the organisation to act with flexibility.

Many families experience a cycle of despair as they try to get help and support for their child from statutory services and they find a system that has lengthy delays; chronic lack of resources and often has staff who do not have the knowledge or expertise to be able to identify difficulties and offer support. This makes it even more important that Resources for Autism can offer immediate services or advice and assistance.

Home Support Services

The home support service is paid for by individuals using personal budgets. There is often a shortfall between the hourly rate paid by local authorities and the direct payments or personal budgets and the actual cost of providing the service, but overall this service pays for itself. The service is recognised by those who use it to be far more reliable than other organisations who may use agency staff. The home support service provides autism specific specialist support for children and adults with an ASC but is especially beneficial for vulnerable adults who may live alone and be struggling with autism and mental health issues.

Art and music therapy

Art therapies excite imagination and creativity. They have the ability to soothe or to stimulate the senses and both art and music therapy can have a positive impact on people with an ASC.

In London Resource for Autism have offered art and music therapies for children for many years. This usually lasts for up to six months. The therapists are registered with HCPC and provide individual sessions after an initial four-week assessment. There is also a well-established art group for adults that meets every Monday afternoon. This group is invaluable to the small group of adults who use it and provides a calm safe space where through art, the group leaders are able to focus on the painting without

direct, face-to-face interaction which can cause acute anxiety in some people with an ASC. Problems and other life events that are causing distress are picked up and the individual can be offered help.

People with an ASC can benefit from art therapy as an alternative way of unlocking emotion. Compulsive behaviour, sensory hypersensitivity, communication and social interactions can often be improved with the use of art therapy. Art can be an alternative means of communication by drawing

Music therapy has a number of potential outcomes for children and adults with an ASC. It can help to stimulate language development through songs. It allows children to listen, improve concentration and provides a means of self-expression.

The waiting list for art and music therapy is always long and there are currently 630 people waiting for the services.

Orange House - Newham

Orange House is a remarkable success story. It is providing Alternative Provision (AP) for children with an ASC living in the London Borough of Newham. This is the most recent and innovative project and 'Orange House' has succeeded during the academic year 2018-19 in getting six extremely vulnerable children back into education. After more than a year without a school place, all the children had dysregulated behaviour and were initially unable to concentrate at all on learning. After a few weeks of specialist input by the staff at Resources for Autism, they were able to provide a safe space for the children to attend and to put in place behaviour support plans and strategies to engage the children so that they were able to learn.

Resources for Autism are also preventing children with an ASC from being excluded from school by training teaching assistants and working in schools and at home with parents and carers to provide a consistent approach which aims to keep children with an ASC in school.

An earlier evaluation had recommended establishing AP as part of the range of services offered, In 2018, Newham found that they had a number of children with an ASC who had not been allocated a secondary school place at the year 7 transition to secondary school because there were insufficient special school places. This crisis had led to six young people, five boys and one girl being identified who were not in

school. All had been out of school for more than a year and all had complex needs that could not be met in a mainstream school. They were all at home without any meaningful activities, structure and routine and missing out on socialisation and friendships as well as formal education.

Local authorities must arrange for AP, which is education for pupils who, because of exclusion, illness or for other reasons, would not otherwise receive a suitable education.

Resources for Autism stepped in and in September 2018 they started Orange House. The local authority identified a building called 'The Shipman Centre'. This is a youth service building that was not used during the daytime. Although the building is not ideal, it is set in a local community and there is a park nearby and a small area outside where the young people can offload their excess energy and have a meal before settling down to work with tutors provided by the local authority.

The commissioners in the local authority could not speak highly enough of Resources for Autism. They intend to significantly enhance the service in Newham for the academic year 2019 - 2020. They also want to develop a 'hub' model so that Resources for Autism can work with schools. Their approach is to have an early intervention approach with Resources for Autism working alongside other services.

The commissioner said, "The service was up and running very quickly and went from strength to strength. They have a service level agreement with clear outcomes and they have exceeded all the planned outcomes and they have more than achieved those outcomes and done so much more. They are an amazing service. I have never come across an organisation that is anywhere near as good as this."

School can be an overwhelming place for autistic children – things like bright lights, sudden noises, unclear instructions or other children's unpredictable behaviour can trigger extreme levels of anxiety. This can lead to behaviour that seems naughty or disruptive but is actually an indication that they are overwhelmed, anxious or distressed. Resources for Autism is working in schools with Heads, SENCOs and teaching assistants to prevent children and young people from being excluded. Some schools in London have problems recruiting suitably qualified and experienced staff.

Playschemes and clubs

The playschemes and regular clubs provide a wide range of activities to cater for different abilities and age ranges. There was an immediate gap identified in one London Borough by parents and carers for children between 5 and 8 years. Once parents had managed to get their child into a playscheme, they were usually able to move up to the next age group and staff helped them to make the transition. Some parents explained that this had been very difficult but they acknowledge that transition is part of life.

The staff are all highly trained, talented and resourceful. The clubs and holiday schemes equip children and adults to become part of their local community. The needs of girls are met with some adjustments although one parent told me that her daughter who she described as having 'narrow interests' and because of this suffered from social isolation and debilitating anxiety was equally happy spending time with boys at her club because she was more interested in spending time with people who had similar interests.

Adult groups and other provision

Transition to adulthood is a notoriously difficult time for young people with an ASC. The Young Barnet Foundation worked with Resources for Autism on a project that was specifically addressing the vulnerability of young people with an ASC in the transition to adulthood. They focussed on one particularly important aspect of the transition stage, which was the disruption to friendship groups as young people disperse into further education, employment etc. They identified that young people are often in desperate need of friendship and particularly vulnerable at that stage of their life. They secured a small grant from the Young Londoner's Fund to work with these uniquely vulnerable young people.

Adults with autism are almost twice as likely as their typical counterparts to have diabetes, high blood pressure and heart disease, for instance. As a result, they die, on average, 16 years earlier than typical adults matched for gender, age and country of residence, according to one study.³

³ Br J Psychiatry. 2016 Mar;208(3):232-8. doi: 10.1192/bjp.bp.114.160192. Epub 2015 Nov 5. Premature mortality in autism spectrum disorder. Hirvikoski T1, Mittendorfer-Rutz E2, Boman M2, Larsson H2, Lichtenstein P2, Bölte S2.

The adult art group which has met at Finchley Road for many years now supports vulnerable adults. Although the activity is art, the group supports its members in what is happening in their home life. People know each other very well and they trust each other.

An innovative new group for mothers with an ASC

Resources for Autism has recently started a very innovative service; a brand new group for mums with an ASC. This is a space where for the first time mums who have themselves a diagnosis of autism can discuss their particular issues as parents and gain support from the other mums. The group is specifically for mothers; whether or not their children have a diagnosis. This is somewhere where they can discuss the particular issues they face, for example, around social interaction. Mothers with an ASC often say that they have difficulty interacting with other mums at the school gates. There are other issues such as being unsure how tightly to cuddle their baby. Mums with autism can also experience mental health issues that are often undiagnosed.

Although there is a paucity of research into the wider implications of autistic mums not receiving appropriate support, a survey found that twice as many women were undiagnosed compared with men (10% against 5%).⁴ In an article in the Guardian newspaper,⁵ one mum described how she felt that she interacted with professionals and the potential seriousness of a misunderstanding occurring. "I understand that my autism makes me a difficult person to deal with: I don't know when to back off when I know I'm right. Maybe I can't always look people in the eye, so perhaps I come over as being shifty. Autistic people do hyper-focus, but they mistook my obsession as a sign I was unstable". There is a need for research and awareness raised amongst professionals about the specific issues faced by autistic mums. The high rates of surveillance by social services suggest there may be discrimination towards mothers with autism.⁶ There is a stigma associated with autism and this can create a barrier to seeking help from a social worker and a need to develop more and better-tailored support. This group is providing the 'space' for mums with a diagnosis of autism to support each other and to discuss the issues that they face.

⁴ National Autistic Society Survey; 2017

⁵ The Guardian Newspaper; 21st May 2017

⁶ The Guardian Newspaper 21st May 2017

The challenging political and policy context

The evaluation has taken place at a time of national political uncertainty and policy inertia. This is important to understand because it has impacted on recruitment; morale and has the potential to disrupt the organisation and local communities.

‘Think Autism’ was produced in 2014. A review of the National Autism Strategy is due to be published in 2019. The consultation period ended in May and the results are being analysed but the review will for first-time cover children as well as adults.

Progressive reforms to the way services are provided should be a good news story. The Children and Families Act 2014 introduced the framework for children and young people with special educational needs or disabilities (SEND) to have Education, health, and care plans (EHC plans) up to the age of 25 years. The reform was in recognition of the problems commonly faced by young people and their families in the transition to adulthood. It also introduced personal budgets, so that families could have greater control of the support they received.

The continuity of support beyond 18 and up to 25 for a young person and the new duties placed Further Education colleges to ‘use their best endeavours’ to secure special educational provision should have seen significant numbers of young people being able to access FE colleges.

The Care Act 2014 places a strong emphasis on preventing and delaying the need for care and support by making sure that there are appropriate information and advice for people, support for carers, and promoting integration between social care and health care services.

A Government report published in 2016 into the progress on ‘Think Autism’ shows that local authorities have improved their data collection and now have strategic arrangements in place to work in partnership with other agencies and voluntary sector providers.

Beneath the headline, is a backdrop of ten years of austerity and the impact this has had on many front line services. There are some stark statistics;

- ✚ 4,500 pupils with statutory rights to special needs support were awaiting suitable provision or being home-schooled – this is likely to be an under-estimation as it doesn’t include children without an EHC plan.

- ✚ More than 1.2 million children, or about 15% of all students in England have some kind of special educational need, but only about 253,000 have ECH plans.
- ✚ Tower Hamlets; Newham; Hackney and Islington had the highest child poverty rates among British local authorities.
- ✚ 320,000 homeless; 1 in every 200 people in Britain are homeless. In London, homelessness is even higher with 170,000 people – equivalent to 1 in 52 people who are homeless.
- ✚ CAMHS have long waiting times for their initial assessment. Only 30 per cent of children were assessed within four weeks of referral, with 4,309 children waiting more than 18 weeks, and 992 waiting for over a year.

The government response to Winterbourne View

In 2011 the Winterbourne View scandal shocked the nation. Six staff were jailed and five given suspended sentences after the abuse of people was filmed by the BBC Panorama programme. And yet a recent Panorama programme has revealed a similar situation at Whorlton Hall, a 17-bed private hospital where patients were shown being mocked, taunted and intimidated by the staff and repeatedly restrained. A report by NHS England in 2014⁷ acknowledged that a pledge made in the wake the Winterbourne View scandal – to enable people with learning disabilities and/or autism inappropriately placed in the hospital to move to community-based support by June 2014 had failed. In 2019 and another scandal later, there is still insufficient progress. The report in 2014 recognised the need for workforce and skills development. They also recommended that this must happen alongside the development of community facilities. This is what Resources for Autism do every day and they have the specialist knowledge and expertise to make some real inroads in this policy area.

⁷ WINTERBOURNE VIEW – TIME FOR CHANGE; Transforming the commissioning of services for people with learning disabilities and/or autism - A report by the Transforming Care and Commissioning Steering Group, chaired by Sir Stephen Bubb – 2014

Conclusions

Resources for Autism have grown in confidence. The best practice model that has developed over a number of years has meant that when a local authority identified a serious problem in their area of some young people being out of school because the local special school did not have enough capacity, Resources for Autism were able to step in and offer to support those young people. They set-up the service within weeks and they have met all the aims and objectives that they promised and more. Orange House is a very successful project and one that has sparked an interest in setting up a Centre of Excellence in the borough.

Resources for Autism have a clear understanding of the range of voluntary sector providers and charities that provide 'short breaks' or holiday activities for children and young people in the local areas where they operate. They are always willing to work strategically. For example, the Young Barnet Foundation is an organisation with 185 members. As part of the evaluation, they reported that Resources for Autism have worked with youth groups to upskill their workers. Resources for Autism work well collaboratively with statutory agencies and with large and small voluntary sector organisations.

The staffing structure at Resources for Autism is fairly flat and there are a number of key posts that are crucial to the ongoing work and the quality of the services. These include the volunteer co-ordinator; the behaviour support manager and the reach-out co-ordinator. It is only by having these members of staff who can pursue a rigorous volunteer recruitment campaign; develop and support both paid staff and volunteers and provide high-quality training, this means that the organisation can continue to empower individuals and for families to develop strength and resilience.

Resources for Autism continues to provide very high-quality services that are highly valued by service users, their families and commissioners. Most local authorities have autism strategies that aim to provide support to people over the whole life course, from birth to old age. This means that the ambition to provide a Centre of Excellence with a wide range of services and help, assessment and advice throughout the whole of life should become achievable.

Some, but not all children and young people are in contact with professionals because they may be allocated a social worker to access short breaks through the Children's

Disability Team. Resources for Autism will always attempt to work with and alongside professionals and parents by providing practical advice or solutions to social workers and school staff. For parents, there is very little research, support or services to support families with complex difficulties around neuro-disability including poor mental health, with different ways of thinking and processing information, mental inflexibility and the need for extreme control to manage anxiety. Access to Child and Adolescent Mental Health Services (CAMHS) nearly always involves lengthy waiting lists

The impact of austerity and cuts to public spending means that access to Child and Adolescent Mental Health Services (CAMHS) and other publicly funded services have been severely curtailed and CAMHS, Special Schools and local authorities all now refer to Resources for Autism. This presents challenges and opportunities for the organisation as it grows. These include nurturing the culture of the organisation; managing cash flow; delegating and keeping up with an ever-changing public policy agenda. It also means that Resources for Autism has to be ready to step into the school mental health support team initiatives in school to offer the 'expertise' that they will require around autism, rather than waiting for the fall-out of the services when they are overwhelmed by the needs of pupils. Resources for Autism has the solutions and needs to be at the forefront of new initiatives in schools.

Resources for Autism provides a consistent model of best practice which has enabled them to plug gaps in statutory services, work with other professionals to upskill them, to actively engage in multi-agency strategic planning and to engage with other groups and learn from them. The organisation works with some of the most disadvantaged people in society, yet it empowers people living with an ASC by offering opportunities for volunteering, or helping people into paid employment.

Resources for Autism can respond to need in a crisis. Many statutory organisations are no longer able to provide any response, given the cuts in services, yet the long-lasting cost of failing to prevent a family breakdown has not been calculated.

The aim of establishing a Centre of Excellence in one local authority area to be able to provide everything in one place to support families is entirely achievable with support from a local authority and by developing other income streams.

Resources for Autism is an amazing organisation that is well placed to deliver on a challenging policy agenda as this eventually climb back up the political agenda. During

the evaluation in most of the interviews with parents when commenting about the staff by far the most frequently used word to describe Resources for Autism and the staff was 'brilliant !'

Recommendations

1. Resources for Autism is a specialist resource with the knowledge and skills base to be able to train staff in specialist areas; e.g. School Learning Support staff, other public sector organisations as well as the private sector.
2. The organisation should consider developing a 'traded services' arm to the organisation which could provide training to groups of staff.
3. The mental health support teams being developed in all schools will require specialist input and Resources for Autism can offer this to schools across the local areas where they operate and beyond.
4. Winterbourne View and Whorlton Hall are scandals that will repeat unless the government achieves the closure programmes it announced. Resources for Autism has the expertise to develop the workforce and skills development that NHS England recognises are needed to create the local infrastructure.
5. Resources for Autism is well placed to recreate 'Orange House' in other areas. Some of the staff are trained teachers and could help to develop the model to provide the learning support.
6. Very little attention has been paid to the issues affecting older adults with an ASC. This will become a significant challenge in the future to ensure that adults with autism enjoy fulfilling and productive lives in old age and Resources for Autism will be well placed to provide support and services.
7. There is much work to be developed with adults who are at home and marginalised and who need a base to use especially during the winter.
8. A Centre of Excellence is a model that could be replicated by Resources for Autism once it has been established in one local authority area.
9. Resources for Autism should develop an innovative recruitment strategy. This should promote the retention of talented staff and also recruit based on the new developments of the organisation that have proved to be so successful – e.g. Orange House.