

Supporting Families Service Evaluation Report



Introduction

This is an evaluation of Centre 404's Supporting Families Service funded by the Cloudesley Legacy Fund.

Centre 404 is a charity that has been providing support and services to people with learning disabilities and their families in north London for over 65 years. Centre 404 is working towards a world where people with learning disabilities and their families have the support they need to enjoy the same rights, freedom, responsibilities, choices and quality of life as people within the wider community.

Cloudesley is an independent charitable trust that makes grants to people, organisations and churches within Islington. Cloudesley's 500th Anniversary Legacy Fund provided funding to supplement an existing Cloudesley-funded project. The original fund had been used by twice the number of people that it was set up to support. The Legacy funding runs from March 2018 to March 2020, and Centre 404 aims to support 185 family carers in the two year project. This includes one-to-one support and a range of activities, which are detailed in this report.

Healthwatch Islington is an independent organisation that gathers local people's views on the health and social care services that they use. Healthwatch Islington was commissioned by Centre 404 to undertake the evaluation.

During the period of the evaluation Centre 404 has been relocated temporarily. This has had some impact on resources and delivery of activities.

Aims of the evaluation

- ▶ To identify the strengths of the Supporting Families Service
- ▶ To identify key learning points and to suggest ways in which the service might be further improved
- ▶ To provide a report to promote the learning and good practice, and to help with future funding bids

Method

This evaluation is based on interviews with key stakeholders - primarily parents and carers, but also staff and those who refer or signpost to the service - and was conducted using one-to-one interviews, both face-to-face, and by phone. It also uses existing monitoring information.

The research was undertaken by staff at Healthwatch Islington. Participants were identified through talking to the manager of the service. This group was supplemented by individuals from the service's client list: these were all telephone interviews conducted from Centre 404's office to comply with data protection legislation and confidentiality. All had used some aspect of the service within the last two years, since March 2018. The report is based on data gathered from October to December 2019.

Who took part

The Supporting Families Service

- ▶ Support for families to claim relevant welfare benefits, including Universal Credit, Personal Independent Payments and related disability information. Transfers from Disability Living Allowance to Personal Independence Payments has been a significant area of work.
- ▶ Helping individuals to apply for specific grants for equipment and adaptations to the home.
- ▶ Providing independent information, advice and emotional support - around welfare benefits and local services.
- ▶ Advice and support to complete health and social care assessments for both the carer and the person being cared for.
- ▶ Family activities including trips out of London and cinema sessions at a local hotel.
- ▶ Encouraging the involvement of volunteers in activities so that carers can support each other.
- ▶ Support groups are an important part of the service, and a male carers project has been established.

Centre 404 holds a range of quality marks covering the different aspects of the service. These include the Advice Quality Standard, Investing in Volunteers, the UK Investing in Equality and Diversity (UKIED) charter mark, an established specialist equality, diversity and safeguarding quality assurance framework.

They are signed up to the Driving Up Quality Code for best practice within disability services, and are members of Learning Disability England and the British Institute of Learning Disability and STOMP, which works to prevent the over-medicalisation of services for people with Learning Disability.

29 people participated in the evaluation:

- ▶ 2 staff working directly on the project
- ▶ 3 teams from referring or signposting agencies in the borough
- ▶ 24 beneficiaries (family carers of people with learning disabilities living in Islington)

Equality monitoring data

The profile of participating beneficiaries is broadly in keeping with the profile of people who use the service as a whole. The high proportion of beneficiaries identifying as disabled is worthy of note, though the overall numbers are small, and the issue is not explored in this research.

Ages of participating beneficiaries

0-17	18-24	25-49	50-64	65-79	80+	No answer	Total
0	0	16	7	1	0	0	24

Sex of beneficiary

Female	Male	No answer	Total
23	1	0	24

Ethnicity

Arab	2
Asian/ Asian British	3
Black/ Black British	4
Mixed heritage	2

White British	7
White European	4
White Other	1
No answer	1
Total	24

Did beneficiary identify as disabled?

Yes	No	No answer	Total
11	10	3	24

You feel completely on your own when you get the diagnosis, it's really hard to find anyone who can help.

Beneficiary , Supporting Families Service

I was going through a tough time with my boys, both with autism. Other organisations are more general, like Scope, the IMPACT team, and school services. The 404 leaflet was specific. I decided to go and see what there was.

Beneficiary, Supporting Families Service

They are quite different from other organisations. I feel like I belong. They understand parents' needs.

Beneficiary, Supporting Families Service

Findings

How and why do beneficiaries access the service?

Beneficiaries had found out about Centre 404 and the Supporting Families Service from a wide variety of sources. CAMHS (Child and Adolescent Mental Health Service) was the single biggest source of referrals, with five of the 24 beneficiaries who participated in the evaluation accessing the service via this route. Three were referred by the Northern Health Centre. Two were referred by family support services. Two found out about the service as a result of attending a Cygnet programme (a training course for parents of children with autism). Two heard from other family carers. Other routes identified included school, leaflets, friends, the council more broadly, a social worker, and happening to live close by. Several beneficiaries couldn't remember how they had first found out about the service.

Some beneficiaries said that they chose to come to Centre 404 because they wanted help with a specific issue, such as applying for benefits or getting a reassessment for their child. Others said they came because the service as a whole was recommended, either by friends or statutory organisations. Many respondents said they felt bewildered and isolated before finding Centre 404. There weren't any other services which offered the same kind of help.

Help with forms and benefit applications was the aspect of the Supporting Families Service that the largest number of beneficiaries had accessed (17 respondents). The opportunity to share experiences with parents in a similar situation, informally via coffee mornings, day trips and the like, was frequently mentioned (13 responses). Seven parents said they had accessed information and signposting. Six said that they attended the support groups. Other aspects of the service that were mentioned included texts and newsletters, help with letters, disability related help, and general support and encouragement.

What beneficiaries value about the service

The Supporting Families Service was generally seen as more attentive to service users than statutory services. This is something that comes up across Healthwatch Islington's evaluations of voluntary sector organisations, they know their audience and they offer patience, empathy and understanding that are sometimes less available within statutory settings. Staff across the organisation are praised for their approach, there is a culture of putting beneficiaries first.

'I always found them amazing. They are very friendly and they make you feel at home, and like you've known them for years. The same lovely lady helped me twice, and they don't forget something that you might have told them a year ago. It's like, they really care. It's not just a job to them, they really want to help you.' [Participant 20]

'[Statutory services] don't want to talk to me. You get five different answers to one question. Everyone passing the buck. I have no faith in the system.' [Participant 4]

'The Occupational Therapist has helped with letters too. But social workers just tell you where to go, don't actually help. You get that extra bit of support from 404.' [Participant 3]

They are helping me with Disability Living Allowance and to appeal. A staff member is coming to court with me. They come with you all the way through the process. They don't abandon you to the system.

Beneficiary, Supporting Families Service

At the autism support group meetings you get to share ideas of places you can go to with kids, what works well, sensory things. It helps us as a family to self care, and gets dads involved which is important.

Beneficiary, Supporting Families Service

You have to be a jack of all trades. It's a steep learning curve in this job. Quarterly, the team reflects to see if we can do anything differently. It matters. We are always keen to get feedback and we have a dedicated person who coordinates feedback.

Staff member, Supporting Families Service

The service was also valued because beneficiaries felt there was nothing else like it. When asked what they would have done if they hadn't come to Centre 404, nine beneficiaries said that there was nowhere else. Four beneficiaries said they would have approached their child's school for support and three said they didn't know what they would have done. One or two said they wouldn't have time to do anything, or would search the internet or ask Healthwatch. Only three beneficiaries identified alternative services that they felt might be able to provide support.

The beneficiaries described what they felt they had gained from accessing the service:

- ▶ Emotional support/feeling of not being abandoned/support for parents and children (11 respondents)
- ▶ Benefits/entitlements/help with applying for these (10 respondents)
- ▶ Meeting people in a similar situation/swapping ideas/social opportunities for kids (9)
- ▶ Information/good pointers (6)
- ▶ Understanding my rights (4)
- ▶ An opportunity to help other parents/empowerment (3)
- ▶ They are good (2)
- ▶ I can't do it on my own (1)
- ▶ I was able to get my son into a club (1)
- ▶ Sessions on how to deal with special schools (1)

What the service does well

From Centre 404's internal evaluation of its service, we know that they reach an ethnically diverse audience primarily aged between 30 and 60 from all across the borough of Islington.

In the first year of the service:

- ▶ 92 families were helped with welfare advice and benefits applications
- ▶ 28 were supported to apply for grants, bringing in an additional £11,570.87 across those families
- ▶ 161 families attended cinema sessions hosted by a local hotel
- ▶ 95 families took part in four trips which included a zoo and the seaside

The centre has a garden space with accessible facilities and has hosted a number of summer events to bring families together. Carers report being satisfied with the support offered in year one:

- ▶ 92% of carers found it easy to make an appointment
- ▶ 96% of carers felt their issues were listened to
- ▶ 96% of carers who received welfare benefit support found it helpful
- ▶ 87% of carers said support was good or very good
- ▶ 100% found the information they were given from Centre 404 helpful
- ▶ 96% of carers said help from Centre 404 made a positive difference
- ▶ 100% of carers report they have a chance to forget about their problems and think about themselves for the duration of the activity

I needed some extra help filling in my first Disability Living Allowance application. With the help I got with the first application, I was able to do it myself in subsequent years.

Beneficiary, Supporting Families Service

There are lots of useful talks to help me understand the diagnosis and the system. You can access the talks afterwards, which is really great. There is still a way to get the information if you can't physically get to the event.

Beneficiary, Supporting Families Service

If clients need more than a generic carers wellbeing service, then we always refer them to Centre 404. Primarily around accessing benefits, but also for the peer support that 404 offers and which we think is very helpful. All we're concerned about is who is best placed to support. If there was a better service, we would refer them. But there isn't.

Head of services for carers, referring agency

The staff are valued as experts by partners and beneficiaries. Though the staff team is small they have a great deal of expertise. Staff get beneficiaries their entitlements (benefits, assessments, support) including things that beneficiaries were unaware of, or unaware they were entitled to.

'They helped me to claim the low rate mobility component of Disability Living Allowance. I didn't realise I would get that, they helped to find out. Helped me to think about what I could get.' [Participant 21]

The organisation strives to deliver what is of most use to beneficiaries. The team holds regular meetings to discuss casework trends and families' needs in Islington. Over time staff have noticed an increase in the number of people needing additional support with matters that are not related to disability; including council housing applications, non-disability benefits such as Housing Benefit and Job Seekers Allowance, and legal advice. As is typical of smaller, grass-roots, specialist organisations, they support beneficiaries with multiple issues and offer a person-centred approach.

The organisation manages staff time and resources well to prioritise clients' needs. This approach was reflected in beneficiary feedback that staff try to deal with your needs as urgently as they can. Cases are allocated weekly on a Friday and staff will shuffle appointments around if necessary to avoid missing key deadlines that clients have to meet. The caseworkers also make some evening appointments available to help carers in need of welfare advice.

What they offer depends on the family situation. By empowering those who can support themselves, they are able to offer more support to those who need more, but without others feeling abandoned. Almost all respondents emphasised how supportive the service is, including those given the tools to help themselves.

'The people are so kind at 404. There's warmth and so much support here. They do as much as they can for you. They go the extra mile!' [Participant 22]

'I now know my rights and what I am entitled to.' [Participant 8]

The service is flexible to people's needs and recognises that attendance can be difficult because of caring responsibilities. They share written information, for example, from learning sessions to make the information available to more people.

The service links well with other organisations. Centre 404 has identified a lack of information in schools about learning disabilities and autism, and about the support available to help teachers and parents to support children. Over time they have developed their model and are now sharing learning with schools. This helps prepare parents who have an appointment with the service. The family caseworker has also worked with Islington Council to design guidelines and plan a good support network for people moving to Universal Credit.

There are parents that attend [the support groups] regularly who are quite vocal and some parents have found it difficult to express themselves.

Referring agency

They need more activities for the children themselves, while the parents are at 404. Your child distracts you and you can't make best use of the time.

Beneficiary, Supporting Families Service

I can't get to the workshops, I don't have the time to breathe. Maybe they could do something else to help us get the answers we need.

Beneficiary, Supporting Families Service

Learning for Centre 404

Generally beneficiaries were very pleased with the support offered and the empathetic, holistic way they are treated at Centre 404. Several could not think of anything to improve their experience of the service. The organisation's 'Unique Selling Point' is that it is so truly person-centred.

Comments that focused on ways making the service more accessible were not a surprise to Centre 404 who had heard similar feedback through their own channels. What was suggested would generally require additional resources.

- ▶ Seeing people more quickly (though people appreciate that Centre 404 does not rush them once they are being seen)
- ▶ Provision of a crèche when activities are being run for parents
- ▶ Offering housing support (currently people are referred to the council for this, although Centre 404 has a new project funded by Cloudesley that includes limited housing support - providing information, advice and help filling out medical forms)
- ▶ Broadening the offer to include other disability groups

Some of the suggestions focused on the activities and timings:

- ▶ Stronger facilitation in certain group settings (some parents found it difficult to express themselves at support group meetings)
- ▶ A list of activities on offer, and who they are suitable for as children can have very different needs
- ▶ Varying the times of activities for parents who work (though we note for example that family trips take place at weekends, and the Family Carers Reference Group hold an evening meeting at least once a year for working parents, and that day time activities are also needed for those who can only attend when their children are at school)
- ▶ Varying the types of activities for different aged children including adult children
- ▶ More trips and activities in general
- ▶ Making more use of the garden that the centre has
- ▶ Promoting their service more heavily with CAMHS (Child and adolescent mental health services), particularly in the waiting areas

There was lots of variety in the responses, depending on individual needs. Other miscellaneous suggestions included:

- ▶ Not relying on volunteers for some activities
- ▶ Providing more information outside of workshops
- ▶ Offering a course in all aspects of autism
- ▶ Offering counselling

They need more staff to put on different activities, but mainly to shorten the wait. You used to be able to drop in, but with fewer staff, you have to wait. This can cause problems with deadlines, which are often short.

Beneficiary, Supporting Families Service

Parents trust the 'brand' of Centre 404.

Head of services for carers, referring agency

They are amazing and I couldn't fault them in any way. I'm so proud of the support I've had and I want to give back so much. It's a shame a charity has to do this and not the government. Centre 404 is able to offer support to such a wide range of needs. They, the workers, also need help.

Beneficiary, Supporting Families Service

Why the Supporting Families Service is needed

People with learning disabilities find it harder than others to learn, understand and communicate. This affects their health and wellbeing, with the impact increasing with the severity of the person's disability.

As defined by Carers UK, a carer is someone who, without receiving a wage, provides help and support to a partner, child, relative, friend or neighbour who could not manage without their help. Up to 40% of carers experience psychological distress, or depression. Carers have an increased rate of physical health problems. One in five carers gives up work. More than half fall into debt as a result of caring. These costs damage the health and well-being of individual carers and their families, and can impact upon their ability to provide care.

According to Islington Council's Evidence Hub from which the borough devises its Joint Strategic Needs Assessment, Islington has a statistically higher percentage of pupils with a special educational need, both with and without a statement, compared to other areas with similar population characteristics (statistical neighbours), in London and England. As of July 2015, one in five children in Islington schools had an identified special educational need.

Nationally, there is consistent evidence that people with learning disabilities experience poorer health than their non-disabled peers, this impact increases with the severity of the disability. People with a learning disability, and people who are carers, are more likely to experience common social determinants of poor health including poverty, poor housing, unemployment, social isolation and discrimination. For carers this can also impact on their ability to provide care. Therefore, streamlined services providing clear and accessible information for parents and carers, such as this one, can prove invaluable.

Cloudesley used its Legacy Fund for this Supporting Families work from Centre 404 because in 2017 there was more demand than the organisation could meet with Cloudesley's existing funding. That demand has continued to grow with fundamental changes to the Welfare System meaning more regular benefit assessments and appeals. Since October 2019 the organisation has had to alert those needing help of longer-than-usual waits (over two weeks, though with priority given to anyone at risk of homelessness or where there is a safeguarding concern).

Considerations for Islington Health and Wellbeing Board

Islington Health and Wellbeing Board is a committee charged with promoting greater integration and partnership between bodies from the NHS, public health and local government.

The Board is made up of local councillors, directors of public health, adult social services and children's services; the clinical commissioning group; and Healthwatch. Collectively, they take the lead on improving health and wellbeing outcomes and reducing health inequalities in Islington and are responsible for identifying current and future health and social care needs.

As the Board will be aware, small community organisations' funding is increasingly less stable. The Supporting Families Service is offering good value and vital support for vulnerable families, both those with a learning disability and/or autism and their family carers, who may also be experiencing inequality.

This service is currently funded by Cloudesley. This 'one-off' funding stream comes to an end soon, although the need continues and is growing. Hopefully Centre 404 can find further resources to support these family carers to support their families.

With such drastically reduced resources from central government, local authorities have limited resources to go round, but the fact that this service is preventative, and brings families much needed support and financial resources, could save the local authority money in the longer term.

It is also important that commissioners are confident that there is sufficient statutory provision within the borough to meet the support needs of these families if further funding for the Supporting Families Service is not secured.

Recommendations for Centre 404

1. Keep going the extra mile – beneficiaries report feeling well supported and Centre 404 offering a much-needed listening ear. Participants really valued the empathy of Centre 404 staff, and not being rushed when talking through their needs. They also valued hearing an independent point of view.
2. Be clear about who can engage and benefit from service delivery. The website is clear about the services offered, though could include a line of text for each service stating 'Who this service is for'. However, because many people hear about the centre and its services from other carers, making sure that they are up-to-date is also important.
3. Generally the right people seem to be getting support, but some felt that there was more support for people with autism over learning disabilities, and some felt there was more support for certain age groups than others. It would be useful to review which services are being used by which age groups and see if anything can be done to create specific activities for age groups currently offered less support, if the review finds this is the case.
4. Talk to other local partners who run service-user-led initiatives. For example, Islington Mind run several types of peer-led sessions, with various amounts of staff support. Mind provide the space, refreshments, and some support to advertise and contact others. Similarly, Manor Gardens Welfare Trust run a project for mothers from migrant communities who find it difficult to access support. They offer peer support groups aimed at breaking down social isolation, allowing women to share knowledge, build confidence and develop long-term support networks. It is to be hoped that local partners can learn from each other, however it must be acknowledged that the impact may be limited for carers who already have very limited time.
5. Most referrals come from the Northern Medical Centre where children go for their Special Educational Needs assessments, and where the Child and Adolescent Mental Health Service is based. The Centre is also linked to the borough's Autism Hub. As Centre 404 has greater demand than capacity it might not be appropriate to promote the service more widely at this stage. There has been a lot of work with GP practices, GPs and Practice Managers to highlight the offer.

Future funding

Whilst Centre 404 is in the advantageous position of having a range of income sources, this can be a barrier to securing funding for bespoke projects such as the Supporting Families Service.

The organisation could review whether they could build some capacity into larger scale bids or consider hosting a smaller organisation for bidding for this kind of work. Healthwatch Islington will provide a list of suitable potential funders in partnership with Red Pencil (marketing, fundraising, brand and communications specialists), based on Centre 404's current funding sources and plans for the future.

Acknowledgements

Healthwatch Islington would like thank the Supporting Families team at Centre 404 for their generous support for this evaluation. Thanks too to the interviewees who gave up their time to talk candidly about their experience, in particular the family carers who are the beneficiaries of the project.

For further information please contact Centre 404
404 Camden Road, London N7 0SJ
020 7607 8762
general@centre404.org.uk
www.centre404.org.uk



Copyright © Healthwatch Islington 2020
200a Pentonville Road, London N1 9JP
020 7832 5814
info@healthwatchislington.co.uk
www.healthwatchislington.co.uk
 @hwislington