



Disability Sheffield

Centre for Independent Living

Advocacy and Information Service Report 2018-19

Introduction to Disability Sheffield

Disability Sheffield is a registered charity and a Disabled People's User Led Organisation (DPULO). DPULOs are organisations run by disabled people, for disabled people.

We are committed to and promote the Social Model of Disability. We believe that people with impairments are disabled by the barriers they face in everyday life such as inaccessible communication formats, people's attitudes or inaccessible buildings, and not by the way their minds and bodies work.

The majority of our dedicated team have personal experience of living with an impairment. We are therefore well placed to equip disabled people with the knowledge and confidence to address the challenges they face. Broadly we aim to work alongside disabled people to:

- Promote inclusion, choice and control
- Encourage Independent living
- Challenge Negative perceptions of disability
- Give a collective voice to one of Sheffield's lesser heard communities

General Overview of our work

The CCG grant enables Disability Sheffield to deliver an advocacy and information service to Disabled Adults in Sheffield – this work is at the core of what we do and forms the bedrock of our day to day work. Alongside it we are able to deliver a number of other projects which complement the CCG funded work.

In 2018-19 this included:

- PA Register
- PA training
- Sheffield Cycling 4 All
- MS Benefits Service
- Sheffield Voices Self-advocacy group
- Disability Hub and Sheffield Equality Hub
- Accessible Sheffield
- Autism Insight Training

The advocacy and information service underpins much of the other work that we do at Disability Sheffield; it brings us insight into the challenges for individuals in health and social care systems, and gives us connections with individuals, groups and services within the city. As a user led organisation we seek to influence policy and provision by making sure that the voices of disabled people in Sheffield are heard. We facilitate the Disability Hub for the local authority, and feed into a range of different forums where we seek to put people's experiences and views at the centre of policy making. The advocacy and information work that we do means we are well informed about how services are working for people.

Advocacy Service

This is the second year that our advocacy service has functioned as part of the Sheffield Advocacy Hub, which is led by Citizens Advice Sheffield. This means that along with the other Hub partners (Citizens Advice Sheffield and Cloverleaf), we are delivering statutory advocacy which is commissioned by Sheffield City Council. This is in addition to the 'generic' advocacy which the CCG grant funds - and although our generic work sits outside of the Hub in terms of commissioning, we have been able to use our closer working within the Hub to make significant improvements to this service.

Referrals can be taken directly by Disability Sheffield, but equally, staff at the Advocacy Hub are able to identify and take referrals for our service also. As different types of legislation has been implemented, the eligibility criteria for advocacy has become increasingly complex, – Hub staff are well trained in understanding these complexities, and are able to identify when someone might have a statutory right to advocacy, or when they might fall instead under one of the generic provisions.

The demand for this generic work is still there, and we believe it strongly compliments the work that we do as part of the Hub, allowing us to provide a much more joined up and complete service to individuals seeking advocacy. For example, it helps us provide advocacy consistently to individuals moving between care packages funded by social services, and Continuing Healthcare.

Advocacy team

Because of the increase in Hub work (particularly the rise in the need for Care Act advocacy), our staff team has grown. We are still by far the smallest partner in the Hub – we have balanced growth with our wish to keep in focus our position as a user led organisation and it remains the case that the majority of the staff and volunteers within the advocacy team have lived experience of disability.

Looking at the national picture, the provision of advocacy by grass roots and user led organisations is something which has become increasingly uncommon. We believe Sheffield can be proud that this provision is well-established in our city, and it sits well with the aim to become a Person Centred City. We also believe that for individuals accessing the service, it brings a greater depth of understanding of some of the barriers they face – for example our team includes people with lived experience of the barriers facing wheelchair users, and a deaf advocate who uses BSL to work with people in the deaf community work

Our team in 2018/19 consisted of:

- 1 Advocacy Manager – carrying small caseload, supporting and supervising team
- 5 paid Advocacy Workers
- 5 volunteer Advocacy Workers
- 2 social work student placements

All of our paid staff work part time, and the total paid posts amount to 3.6 full time equivalent posts. All paid staff split their time between CCG funded work and Hub (SCC funded) work. We also have a post working with the Deaf Community part funded by the Talbot Trusts and Sheffield Association in Aid of the Adult Deaf Community. The volunteers work primarily on the generic advocacy cases that we have.

Advocacy Standards

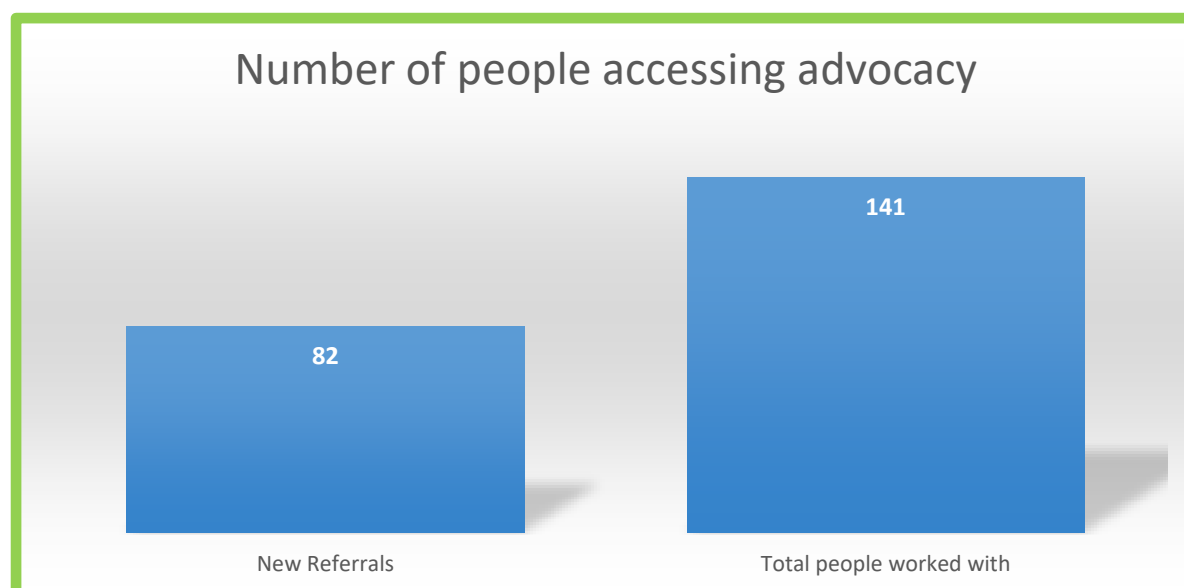
All advocates are trained to an appropriate level; our paid staff have completed, or are working towards, their Level 3 Certificate in Independent Advocacy. Along with our partners in the Hub, we are working towards a model where all advocates can work across all types of advocacy – this is to avoid situations where individuals get passed from one advocate to another as their needs changed.

All our advocate's, including our advocacy volunteers, work to the Advocacy Code of Practice, and in December 2018 our service attained the Advocacy Quality Mark.



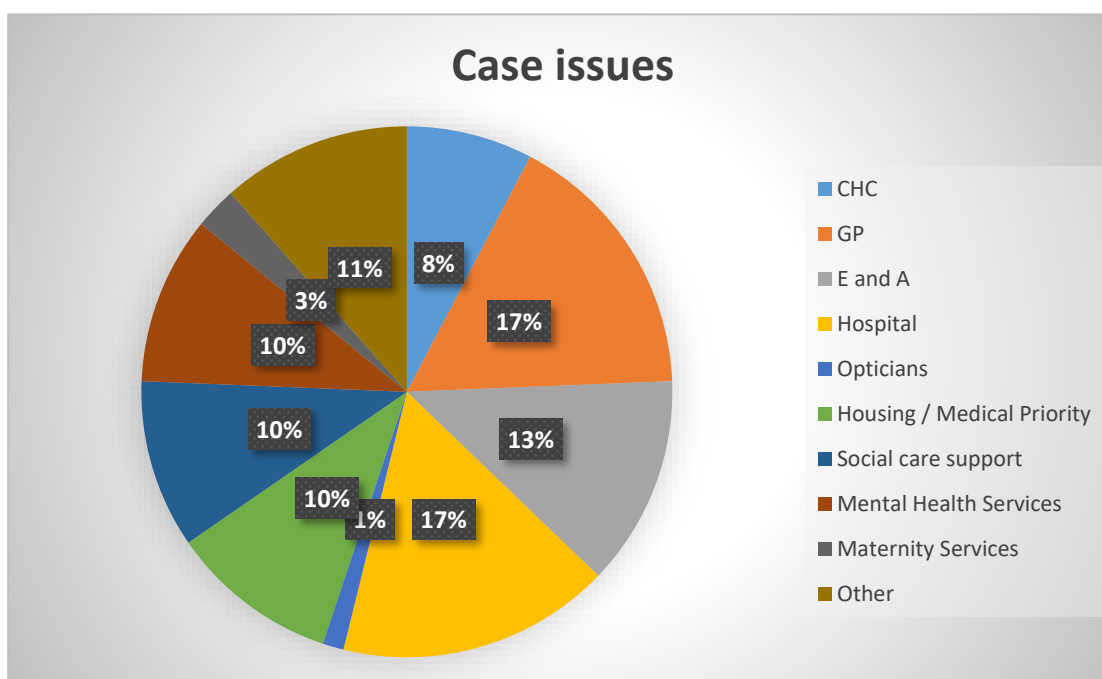
<https://qualityadvocacy.org.uk/>

Amount of advocacy delivered in 2018-19 under the CCG funding



Advocacy Issues worked on

Many individuals that access our service come with multiple issues needing advocacy support. A large proportion of our clients have multiple and complex health needs. Our focus for the service is taking cases where there is a health element or health outcome for the person, but we work holistically. For example, we might take on a case because someone feels their GP isn't listening to them, but if in the course of working with them it becomes apparent that they need to access social care, we will work with them on that also. The amount of work we do on social care issues under our generic work has declined because now we may often identify that someone is entitled to Care Act Advocacy and will work on this element of the case under the Hub provision.



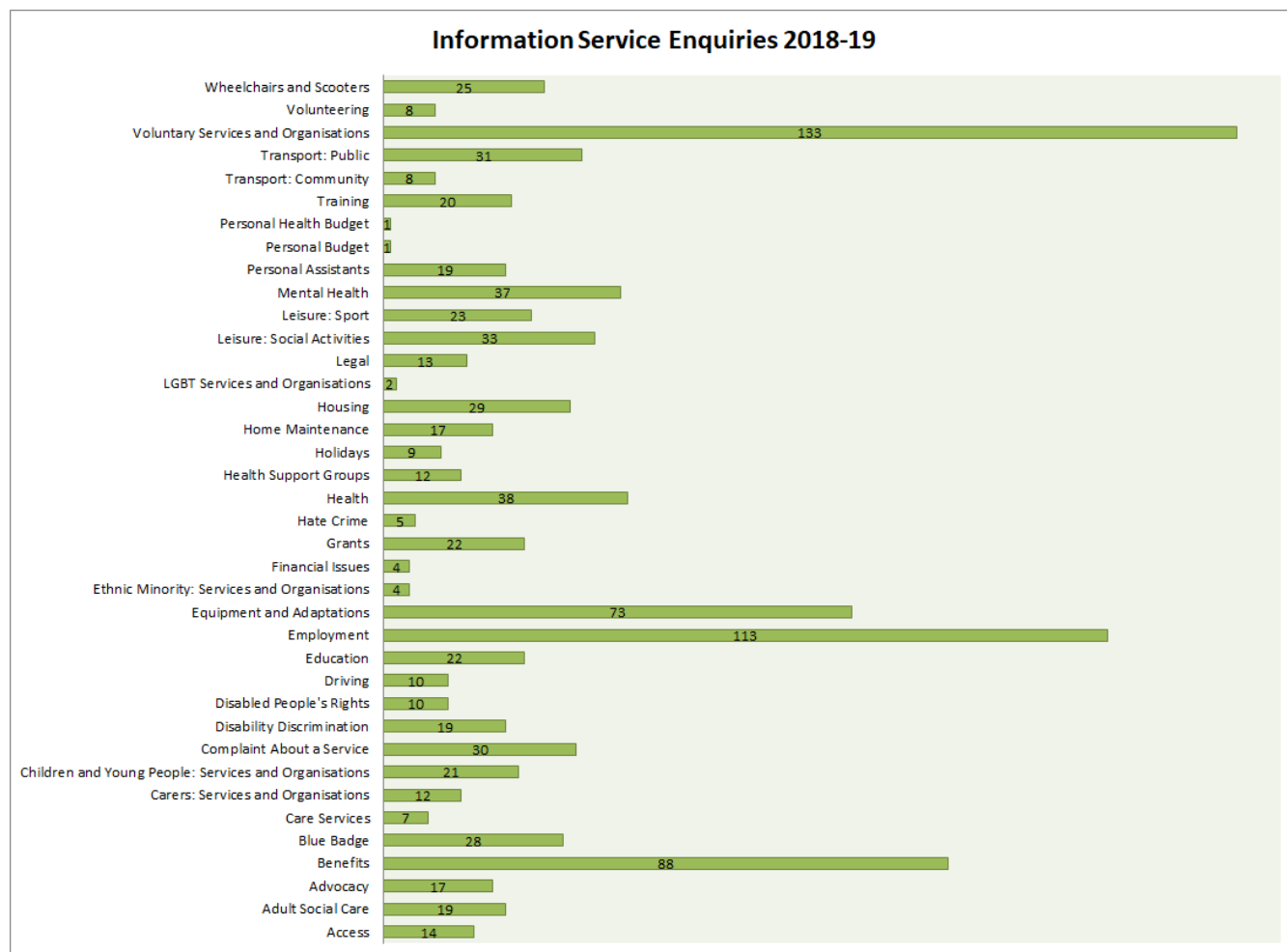
Information Service

Disability Sheffield information Service, supported by a part-time information officer, has a number of functions – the provision of a quality service providing a personalised response to enquiries on disability issues; producing and updating information factsheets based on frequently asked questions; supporting volunteers who have lived experience of disability to deliver the service; writing and news items and events on our website and posting out news bulletins to our members.

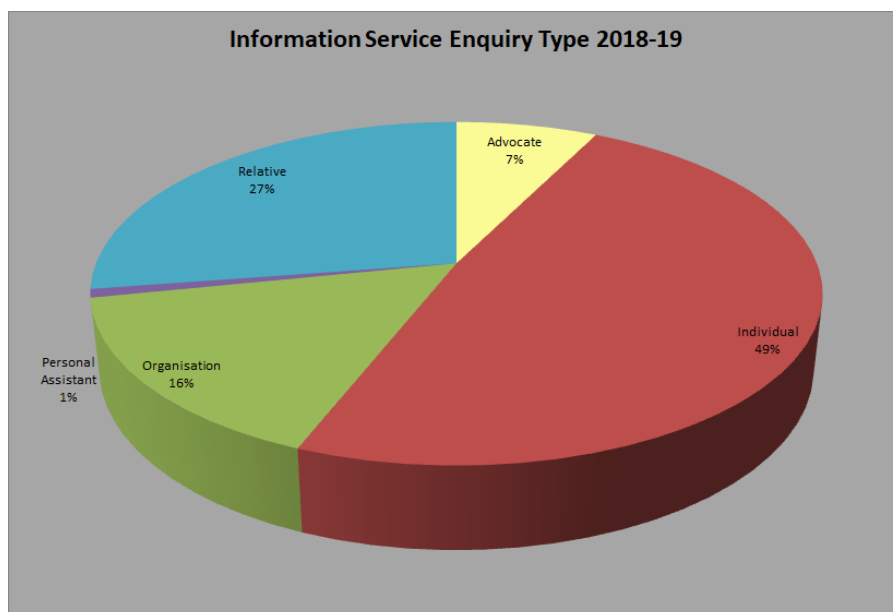
Enquiry Work

Disability Sheffield Information Service provides free, confidential information to disabled people, their families and friends, their personal assistants and carers and any other organisation or individual in Sheffield who needs information about a disability related issue.

In the past 12 months we have responded to enquiries on 979 different issues.



Almost half of all our enquiries came directly from individuals (49%) with a further quarter (27%) being from relatives of people with a disability or long-term impairment.



News Items 2018-19

We have written and posted on our website 230 news articles and 231 events this year which form the regular news bulletins to our members. Many of the local events are health specific and we promote local and national campaigns and surveys, for example Eye Health Week Event, Survey into Urgent Care Services in Sheffield. We regularly post news encouraging disabled people to be more physically active and get involved with leisure opportunities in the city.

We sent 132 Tweets and our average Twitter Impressions were 297 per day. Most of our Facebook fans live in Sheffield and tend to Like or Love our posts. People who view our Facebook page arrive there from a number of places including other Facebook pages of people/organisations, from an internet search or through our website.

Information Service Volunteers

Our Information service has continued to support volunteers during 2018/19. One volunteer who volunteers twice a week and has been with us since October 2015 has taken on the new task of supporting us with our social media presence increasing our reach through tweets and Facebook with great success.

Our second volunteer joined us in September 2017 to help write news items after having to give up work due to his unpredictable neurological condition which affects his physical health and ability to communicate. He has this year been able to practice communicating with us in the office by using a speech amplifier recommended by his occupational therapist to improve his weak voice and declining ability to speak and make himself understood.

After staying with us for 2 years we are pleased to report that our volunteer who had lost confidence in her ability to focus in a working environment due to her mental health has set up her own business in February 2019 and is now self-employed.

We have recruited to the new role of 'administrator' two volunteers this year, one of whom was a past advocacy service user, who after gaining experience in this role also wishes to volunteer as an advocate. Our second volunteer in this role moved into full time employment after six months.

We recruited and trained a fourth volunteer who sadly could not continue in the role due to his declining health. However in the time that he spent with us he acquired the confidence to successfully apply for a job which boosted his self-esteem although he could not accept the full time role.

Sharing Knowledge through information resources

We apply our principles of sharing knowledge about information resources wherever possible with individuals and community organisations and regularly share our factsheets with local authority staff and teams.

Examples include Gareth Hayden, Community Project Officer in Sheffield City Council's Physical Activity and Sport Team who is involved with the development of the Council's 'Within Reach' website for disabled people. Gareth was very impressed by our Leisure Factsheet and asked how we gathered and knew about all of its content.

Pema Sherper, a physio working in the Learning Disability Team at the Council contacted us saying she had no resources to find information for her clients and she needed to signpost her clients to physical activities in the city. We supplied Pema with our Leisure factsheet and also highlighted our information service, other resources and other factsheets. Pema feedback that she shared the factsheet with her team saying it was her "go to sheet to find information on different activities."

Sharing Knowledge through training

Opportunity Sheffield is Sheffield City Council's employment and skills service. 'Sheffield's Working' is their dedicated employment support service designed to help to guide vulnerable and marginalised adults including disabled people and people with long term health conditions towards and into sustained employment. Programmes are delivered by local partners in the community. Service managers had identified that a more person-centred approach was needed to identify solutions and outcomes that work for the person during the assessment interview.

Voluntary Action Sheffield were commissioned to provide training to approximately 50 front-line workers from the partner organisations in order to improve their ways of working with people disadvantaged or marginalised through complex needs. Disability Sheffield was asked to provide expertise and input to these sessions to establish the meaning of 'person-centred' and to give an insight into the powerful changes this approach enables.

Our Information Officer used the experience and skills acquired through our person centred approach to delivering our services and her knowledge of employment issues to deliver one hour training sessions "An Introduction to Person Centred Planning" as part of a wider programme of training for 'Sheffield's Working' staff during the summer of 2018.

The participants also benefited from a number of our resources including Disability Language and Behaviour factsheet and Employment factsheet.

Christine Heeley, course leader VAS commented that "Feedback from participants has been deeply appreciative of the thought-provoking and practical approach of these sessions. In particular, even the organisations dedicated to supporting people with learning disabilities or mental health challenges felt that they had learned something new."

The impact of our advocacy and information service

The following provide examples of the different types of work carried out by the advocacy and information service over the past year and the impact that it has had on the people we work with.

Advocacy - Working holistically with different issues

Amelia is 63, she has experience chronic pain, especially in her legs, since childhood, following a series of tests and misdiagnosing over several years she was found to have a rare neurological condition, in addition to super hyper mobility syndrome and a number of other conditions which had developed as she got older. These conditions are incurable and some are difficult to treat. Amelia had several operations, which have had only limited benefit and her mobility is extremely limited.

The GP she knew for years retired and Amelia felt that her new GP, and even some hospital staff, were not listening to her and putting a lot of her problems down to her weight and/or mental health. Because her problems were worsening, Amelia requested further referrals to specialists by the GP but these were not made.

With advocacy help over the last 18 months Amelia now has a GP that she has a better relationship with, the referral she wanted have now been made and she, with our help, has seen a number of specialists and had updated tests which have led to a treatment plan.

There were also some issues with her care package so we supported her to ask for a review from social services which led to a number of issues being resolved. We are also in the process of helping Amelia to obtain a motorised wheelchair which will give her more freedom and flexibility in her life. Although Amelia's physical health problems will always be severe, at least she now feels she is being taken seriously again as an individual and this is making her more confident to self-advocate at medical appointments.

Advocacy - Joining statutory and generic advocacy

David was having a social care assessment, and had support from an advocate under the Care Act, who helping him understand the process and express his views. Setting up his package was delayed because of problems with his equipment, and because he was not happy with what was being offered by wheelchair services; these things impacted on the type of care he would need. Under our generic health advocacy work, the same advocate was able to speak with wheelchair services on his behalf, and attend an appointment with him to help him express his views, which enabled the situation to move forward and be resolved.

During this year we have altered the way that we work with referrals coming in, to improve the responsiveness of the service to enable people to access advocacy support in a timely way. When a referral goes onto the waiting list, it is checked to see whether any work can be done immediately through email or phone support. There is one volunteer who focusses on this work, and they will endeavor to support the person to self-advocate by providing relevant information or explaining processes over the phone. If the person cannot self-advocate, the volunteer may make phonecalls on their behalf. This has reduced unnecessary delays for people.

Advocacy - Phone based advocacy to provide quick interventions

Surrinda phoned up the service, she was looking for support to get the right equipment and adaptations in her home. She explained that 'someone' had been out to see her, but she couldn't remember who. She had asked for alternation to her outside steps which had been causing her to fall – but she had been told by the worker that they couldn't provide this. She wanted advocacy support to try and get the adaptations she believed she needed, she didn't know where to start in challenging the decision. She didn't recall getting anything in writing about the decision. Our advocate spoke with Surinda and agreed that they would phone the Council on her behalf to find out more about who had made the decision and why. The advocate discussed the new information with her, and together, via email, they put together a list of the reasons why she felt the decision was wrong. With the advocates help, Surinda put this in a letter to appeal the decision which was successful and the adaptations were made.

Advocacy - Empowering to Self-Advocate

Jonathan is 52, he lives alone having recently seperated from his partner, who used to provide him with some care and support. Jonathan had a stroke many years ago which casued severe damage including affecting speech, co-ordination, mobility and memory. Wuth great deternination Jonthaan had rebuilt his life as far as possible but silll needs substainal help and support.

Jonathan can only process and retain information if it is presented in a clear, written format, well-spaced out and in bullet points or short paragraphs.

Jonathan had problems with his previous GP who insisted on communicating and providing information verbally, or in formal letters and documents which are difficult for him to understand. He recently changed GP, and had already had one unproductive appointment at that surgery as he felt the GP he saw did not understand what he wanted or was saying.

We met with Jonathon and worked at his pace in his way, helping him to word what he wanted to say to the GP.

We accompanied him in an appointment with a different GP at that surgery and this was much more successful. After a brief introduction by the advocate, the GP listed attentively to Jonathan, and from his response, it was clear that he understood and agreed to provide what Jonathan needed in the format that he needed it in. Jonathan says he now feels much more confident to go to further GP appointments on his own.

Advocacy - Using individual casework for group voice

Our service was coming into contact with a number of people who were struggling with Continuing Healthcare (CHC) processes. Our advocates worked with those individuals on a case by case basis, supporting them in line with advocacy principles. At the same time, as an organisation, we looked for ways to positively work with the CCG to try and address this on a more general level. We worked with Healthwatch who ran an event to bring stakeholders together and explore the themes and issues in relation to CHC and have maintained contact with key staff at the CCG to follow up and work on actions arising from this event. To improve understanding and working relationships, advocacy staff have

delivered an information session for CHC staff on advocacy, and CHC staff have in return delivered a training session for advocates on CHC processes and practice. This enable advocates to better support the individuals they are working with.

Advocacy and Information Working Together

George is a wheelchair user and has a low level of oxygen. George's initial referral to the Advocacy Hub was to get some support around his care for a care package that would aid his independent living, following his discharge from the Northern General Hospital. George felt socially isolated and wanted to learn how to use the internet, find out about social activities in his area, particularly Archery, and transport options. Our advocacy manager requested this information for George and on her next visit was able to take the booklet 'Your Guide to Living Well' in North West Sheffield for him to look through. We also provided an information sheet detailing free computer classes in his area, Archery for All, the Breathe Easy support group, Sheffield Community Transport, and the Travel Pass.

Information - Blue Badge: Service Complaint

Request: Kathleen aged 68 , receives Pension Credit and has a chronic condition affecting her spine and her ability to walk, angina, asthma and kidney problems and a hearing impairment, was struggling to get her Blue Badge renewed and asked for our help.

Issue: When Kathleen took in her application form to the Hillsborough office she handed over her form and evidence including medical evidence but staff denied receiving the proof of eligibility. After complaining Kathleen received a letter stating that her application was being reviewed. Kathleen received a phone call from a physiotherapist asking about her ability to walk which due to her hearing impairment and the caller's language difficulties caused her further anxiety about not giving an accurate picture of her impairment and circumstances and losing her Blue Badge. The call was completely unnecessary.

Outcome: We summarised her complaint to the manager of the Blue Badge team at Sheffield City Council pointing out her qualifying eligibility from her PIP assessment. We have established a very good relationship with the service manager who investigated the circumstances and reported back to apologise acknowledging their error and thanking us for bringing the matter to their attention. The application was quickly completed and the £10 charge waived. Kathleen's 'with carer' travel pass was also speedily authorized.

Client Feedback: Highly delighted as she had almost given up hope of renewing her Blue Badge and was dreading going through the complaints process. Client promised to contact her MP regarding our support.

Information - Education

Request: Tom has a heart condition and is immunocompromised. He has some adjustments in place at school but his mother contacted us to find out what further support is available.

Issue: Unaware of her son's rights and which services could help, if any.

Outcome: We provided information about how to obtain an Education, Health and Care Plan and signposted Tom's mother to Sheffield SEN and Disability Information, Advice and Support Service and the Sheffield Parent Carer Forum. We also highlighted the Department for Education's SEND Guide for parents and carers and education specific support/helplines from national charities including IPSEA, Contact and the British Heart Foundation's online information for Children and Young People

Client Feedback: "Having the knowledge that organisations like you exist made me feel supported and like I wasn't alone. I think what you do is really important and the information you gave me led to me and my son receiving the support we both needed."

Information - Influencing Service Delivery

Request: Carol's mother contacted us in the New Year hoping to find support for her autistic adult daughter whose health is seriously affected by noise levels in and around her home.

Issue: Her daughter was refused a medical priority for rehousing following poor and inappropriate conversations with staff who she felt did not understand her condition or know how to communicate with her appropriately. Her mother's impression after contacting a number of services we signposted them to was that *"We are asking them about something which they have given no thought to and can't really begin to think about because they just envisage it costing money - people just say sorry we can't help, some friendly some less so."*

Outcome: We have kept in touch with Carol's mother and brought this comment and other subsequent ones to the attention of the Autism Partnership Board and to the Sheffield City Council's Housing Policy Officer and Senior Managers. When we were notified that Carol had been awarded Medical Priority C following an appeal, we queried the necessity of an appeal and the ongoing lack of support with a senior Housing manager asking if the stress for Carol and her mother could have been avoided. The Manager replied offering to meet to discuss the issues that Carol and her daughter had raised and the wider issues and implications regarding applying for medical priority rehousing, and the limitations of the allocations policy in terms of their decision making. We are currently facilitating a meeting and further deliberations of the issues raised at the Autism Partnership Board.

Client Feedback: "I really have appreciated your input - from my ringing round and emailing you were the only person I managed to find who has really taken an interest and been supportive - it has made a great difference to me to be able to communicate with you - I haven't felt so alone with the problem, and I have been able to say to my daughter - I'll get back to Val because she is listening and is able to contact people."

Information - Access Complaint

Request: Naomi is chronically ill. Although she has an adapted car with a lift for her scooter Naomi feels excluded by the lack of disabled parking bays in her community and asked for our support with her campaign for better provision city wide.

Issue: Naomi finds it very difficult to access vital services, particularly her pharmacy and feels socially excluded from venues where she can meet her friends which affects her wellbeing.

Outcome: We provided a listening ear, supporting documentation and feedback/suggestions for her ongoing correspondence with council officials. We posted news relating to her campaign and connected her to the wider work of our organisation e.g the Disability Hub.

Client Feedback: “Disability Sheffield’s information service has provided invaluable support in my attempt to influence the Council as well as crucial encouragement to pursue the issue” More disabled parking bays will be provided in her community and there is a commitment to looking at further provision across the city.

Information - Invisible Disability Awareness

Request Elaine Goddard, Libraries and Community Services Manager (Health and Wellbeing) requested guidance on raising awareness of hidden disabilities for her work in a staff wellbeing group , looking at how staff can increase their physical activity.

Issue:To prevent assumptions being made about a person’s “willingness” to have involvement in some of the initiatives

Outcome: We provided information about invisible disabilities including our [news item](#) about a new sign used in supermarkets. We also highlighted our [Leisure Factsheet](#).

Client Feedback: “This is really helpful! “ Elaine recommended that similar simple signs are placed in the lifts and outside the accessible toilets and will use our factsheet to complement their information on physical activity for staff. Will also take our information to their Staff Equalities and Inclusion Group to consult with staff on whom this impacts.

Feedback

We regularly collect feedback from people who have used the advocacy and information service. All clients who provided feedback said that overall they found the service helpful and 95% said that they were very satisfied with the way the advocate involved them to have a say in the issue they were providing support with.

The following is a selection of comments we have received:

"I wouldn't be where I am without the help of the service" Advocacy Client

"Gave me confidence to apply for help I thought I may not get" Advocacy Client

"The advocate went through all the questions with me and was able to clarify some of the meanings I may have dismissed" Advocacy Client

"We send you our thanks for the undoubted time and effort you put into putting all the information together for us. We appreciate that much of what you sent us wasn't off the top of your head and you had put a great deal of time into putting it all together." Information service enquiry

"Very helpful given the outcome of the application. Certain points were put forward which I would not have thought of" Advocacy Client

"No matter what the problem they tried to help as much as they could" Advocacy Client

"The feeling that I had support from someone experienced and confident at a difficult and stressful time" Advocacy Client

"Thank you so much for this extremely helping and detailed message. I appreciate all your work and I know my daughter will too" Joanna, Information Service Enquiry

"Thank you so much! Your factsheets will be so useful for the work I do in Triage" Joanne Hayles. SOAR Community

"The information you provided gave us a focus for the conversations with my client– helping us to look at the options available and getting our client to home-in on what was most important to him." Jennifer Bedford, Focused Reablement Team

"Thank you. We shared the information you gave us with the client and his family – this information supported the client to seek the employment opportunities he is looking for" Learning Disability Team

"I really appreciate your comprehensive and speedy response about accessible volunteering opportunities, where to find them and what that means. I'll hopefully find something appropriate for my client soon" Jody Sill, Asset Coach

"Thanks so much for this information about accessible communication formats - this is a great help and much appreciated. The links will be a big help to us as we go forward to produce our report." Catherine Elphee, Communications Officer, Social Work England

The Future

This year we celebrated 10 years of the Advocacy and Information service with an event held at Virgin Lounge for staff, volunteers, partners and past clients. As part of the celebrations we developed a video promoting the work of the advocacy service:

[Disability Sheffield Advocacy and Information Service](#)



During the coming year we will continue to look at how we meet the increasing demand for advocacy to ensure that we respond to requests for support quickly and effectively. As part of this we have introduced an 'advocate of the day' system so that there is always an advocate available each day to respond to requests for advocacy support. We will also look to expand the in- depth advocacy support we are able to provide via phone as well as using email to support individuals in self-advocacy where possible, using resources such as our fact sheets.

Advocacy has become an increasingly professionalised area of work; whilst recognising the value of consistency of standards and the need for accountability, we would like to make sure that this doesn't 'squeeze out' the original advocacy values of peer support. By creating different routes into the role we hope to widen it out as an opportunity to individuals who may have experienced barriers entering the job market. Alongside this we will continue to support information service volunteers to develop their skills in advocating on wider issues that impact on individuals.

Over the coming months we will be looking to recruit new volunteers to support our advocacy and information service as some existing volunteers move into paid employment. One volunteer has used their experience to gain employment as a paid advocate of a partner organisation within the Advocacy Hub.

As a small disabled people's user-led organisation, the Advocacy and Information Service will continue to be integral to the wider work of Disability Sheffield. We have worked to ensure that our projects complement each other. We will look forward over the coming year to continuing to provide this work, which makes such an impact on people lives.