

Speak Out Advocacy Project

Annual Report April 2015 - March 2016



Report on independent and collective advocacy activity for people with learning disabilities or acquired brain injuries in South Lanarkshire

Speak Out Advocacy Project is a registered Scottish charity
No: SC044671.



Speak Out Advocacy Project provides professional and volunteer advocacy services for adults with learning disabilities and acquired brain injuries who live in South Lanarkshire. In addition, we provide outreach services throughout the area and facilitate a number of collective advocacy groups.

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Project Leader Report

2015-16 was a busy and tumultuous year for Speak Out. The major landmark was a significant cut in our core funding, which was reduced by 30% mid-way through 2015. This resulted in major restructuring within the service, redundancies, staff cuts and a move to a new location to keep the service viable and solvent.

Although there are a host of external funding opportunities available, applications are unlikely to be successful if the future of the core service remains questionable. We, of course, intend, as is our practice, to make funding applications, which, if successful, will support further development, and increase capacity across the service.

The Board of Trustees continues to work tirelessly to build solid foundations so that the service can thrive and develop. We would, on behalf of all of the Speak Out staff team, record our sincere thanks to all of the Trustees who have given up their valuable time and experience to support the project through this most difficult transitional period.

We are confident that with the Board's continuing support, the service will adapt to the difficult financial environment and rise to meet the challenges and opportunities that affect many services operating within the Third Sector.

Referrals

Referrals for the service are consistently high, and, we continue to receive service requests from a wide spectrum of resources and individuals. Increasing numbers of family members made referrals, and self-referrals continue to increase. Many self-referrals have been made through personal recommendations. Re-referrals are also increasing as various legislative measures such as SDS and welfare reform continue to impact upon the people Speak Out work with. Information about referrals and locality work can be found within the body of the report.

Development

As in previous years, a continuing growth area has been the increase in numbers of parents who have a learning disability and their need for support throughout Child Protection and Children's Hearing Systems. To equip us to face some of the challenges that this type of work presents, we successfully applied to the People's Health Trust to establish a peer support, advocacy and assertiveness training service for parents affected by learning disability in South Lanarkshire.

An area that requires increased development and investment is advocacy support for people with autism, particularly so for young people in the transitional phase between children and adult-

focused services. Most people with autism do not fulfil the criteria for services that are designed for people with learning disabilities or people affected by mental ill health and thus struggle hard to find the support and assistance that they so often need. The Scottish Government awarded Speak Out a small grant to test out demand for advocacy amongst people with autism, and we received some referrals that spanned a range of presenting issues.

We successfully applied for funding from SCVO's Community, Capacity and Resilience Fund to enable the service to support people who were adversely affected by welfare reform. This element of our service was a resounding success, with the advocates involved managing to secure significant amounts of money for those that we supported through this funding stream.

Our funding from NHS Lanarkshire through Patients' Rights Act monies have allowed us to provide advocacy to people affected by communication disorders without an associated learning disability. We have supported many people, who otherwise, would not have been able to access an advocacy service. One of the case studies in the main body of the report gives a valuable insight into the difference that advocacy has made, and the outcomes that we supported this family to achieve. We were able to take on this piece of work as a direct result of the additional monies.

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Collaborative work with NHS Lanarkshire continued throughout 2015-16, and we helped to facilitate work with members of Lanarkshire Ace and NHS Lanarkshire staff. This continuing partnership work complemented the work that we'd previously supported about making healthcare accessible.

Out-reach

We were forced to review our Out-Reach strategy, given the financial cuts and consequent reduction in our staff hours and capacity. Our Board of Trustees are committed to ensuring that the service continues to participate in the Cross Party Group on Learning Disability, The local Partnership in Practice Group, the local Autism Strategy Group, and the Adult Protection Committee. Sadly, the surgery services that we once managed to deliver in Lifestyle Centres and care homes that have younger adult units have had to be withdrawn.

Collective Advocacy

In conjunction with the members, we reconfigured the service as Lanarkshire Ace was too closely associated with Enable Scotland's Ace movement which was also undergoing change. The Speak Out

collective group is now aligned with the Scottish Learning Disability Alliance. Although it retains some local focus, it now aims to campaign on more strategic issues that affect people with learning disabilities across Scotland.

We strongly believe that people with learning disabilities should be active and full citizens and with members of the Speak Out Collective carried out a great deal of work to help people better understand the debate surrounding the Euro Referendum. We hosted briefings and electoral hustings that were attended by representatives of both camps and helped to stimulate questions and debate. Similarly, we hosted electoral hustings during the Scottish Parliamentary campaign, which was well attended and generated a great deal of discussion and many questions.

Other issues

Our move to High Patrick Street has not in any way diminished the increase in footfall through the office. Many people continue to arrive at the office seeking help and support. We have always encouraged an “open door” ethos, as we know that many of the people that we support often have doors closed to them, and thus we aim to be both accessible and welcoming.

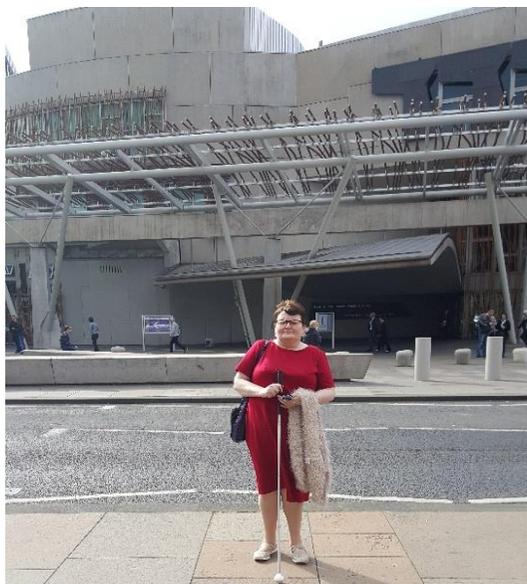
Much more information about the service is contained in the body of the report, but before we conclude the preface, we would like to take this

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opportunity to once again, thank all of our colleagues both in Speak Out and in Speak Out Collective for their continuing support, commitment and hard work. We would also once again thank the Board of Trustees for their dedication, time and support. We would also like to take this opportunity to thank South Lanarkshire Council, NHS Lanarkshire, Scottish Council for Voluntary Organisations, the Scottish Government and the Peoples' Health Trust for their financial support throughout 2015-16.

Patricia Kearns and Jim Walsh

Scottish Parliament - Cross Party Group on Learning Disability



Speak Out are active members of the above group. Gerardine Hand, a trustee, attends the group regularly. The issues that the group have discussed have included “The Keys to Life” Plan, Care Homes for Younger Adults, and most recently, advocacy funding.

SCVO – Community, Capacity and Resilience Fund

Speak Out secured £5,000 from the above fund to enhance our capacity to support people who required assistance to help with welfare benefit issues. This funding enabled us to organise workshops, to do training on money and financial literacy, and support individuals to attend tribunals and medical procedures. This project was a resounding success, with the project worker securing more than £100,000 for those who benefited from the service.

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New Project:

Speak Out for Parents Group

Speak out secured additional funding this year to provide professional and collective advocacy to parents living in South Lanarkshire who have a learning disability. This will help parents understand their rights and responsibilities and help them to understand their need for support to be an effective and competent parent.

The project will support a ‘community of interest’ – a group of people who have things in common and wish to come together to address something that is important to them. This will be done by holding small, locally-based groups that will be specific to parenting and will also provide peer support and knowledge and learning exchange opportunities. Advocacy skills and assertiveness training sessions will also be made available to enable people to become more effective self-advocates and increase their independence and confidence.

Since receiving the funding, we have promoted the new service in community resources throughout South Lanarkshire. We have also given out information to Children & Families social work teams, Learning Disability resources and local advocacy networks and fostering groups inviting

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them to nominate someone to participate in our steering group.

Our Steering Group is now up and running, and we have held several small groups to find out exactly what type of help and information parents would like us to provide.

Advocacy skills and assertiveness training sessions are currently being planned, and hopefully, will be offered to our members at the beginning of October.



Case Studies

The following case studies depict the range of issues that the service has worked on over the course of the past year.

Case Study 1

Presenting condition:

J is in his 30s and was involved in a car accident which left him with severe physical disabilities, brain damage and limited ability to communicate verbally. His recovery process has taken two years. He was recently discharged from hospital to a self-contained flat adjacent to his parents' house. There are several allied health professionals involved in his continuing care. The Brain Injury Team devised a plan of activities to improve his communication skills and exercises to improve motor skills. A support provider was engaged to provide care and support at various times throughout the day and some nights. He also has his own accessible vehicle.

Presenting advocacy issue:

J'S parents have Welfare and Financial Guardianship and referred him to the project to give him an independent voice. The family felt that the

level of support he was getting was patchy and inconsistent. The staff team did not seem to have the experience and expertise to stimulate J or encourage him to make progress. They did not always implement the Brain Injury Team plan. There had also been several incidents with staff being changed at the last minute and having to change hours of support.

Advocacy intervention:

The advocacy worker met with J at home and spent time getting to know him, gaining an understanding of his communication and talked through his support. He felt he was making some progress but not enough. He would like the opportunity to choose his staff team. He got on with all of the staff but thought that some were very young and inexperienced. He wants support to have a life, meet new people and be as independent as possible. The advocacy worker also met with J'S parents to discuss their issues with his care and support them to look at the budget provided by Social Work and how it could be used.

Outcomes:

The advocacy worker attended several meetings with Social Work, Occupational Therapy and the Support Provider Manager to discuss options. The provider continued to have problems recruiting and maintaining a stable team although they provided cover to give both J and his parents some respite. The support provider had experience of involving people who used their service in recruiting staff and

said that they would work with J to enable him to recruit his own team. However, this did not happen.

The advocacy worker provided information and support for his parents on Direct Payments and the responsibilities they would have to undertake. J and his parents realised the choice and control that a Direct Payment would give them. However, they felt that in the current circumstances they would try to get the right support from the provider. Problems with the staff continued, and the Support Provider gave 4 weeks' notice of withdrawal of service. This was a severe blow to J and his parents.

The Social Work Department was able to put a Direct Payment in place fairly quickly, and the parents worked with Take Control to recruit a new team for J.

The staff team is now in place, and J is happier and feels more in control of his support. His parents have confidence in the new staff members.

Case Study 2

SDS & Transition Services:

This is not just one individual case study; it is an overview of how our transition based referrals have changed since the Council started to use the Self-Directed Model of assessment.

As an advocacy service, we have always had a high volume of transition based referrals over the years. We have been able to provide support during this

process and help individuals become aware of their potential options, allowing them to be in an informed place to make choices and decisions about those options.

This has never been a straightforward process for people with learning disabilities or autism as leaving a school or college environment is always a big change and challenge. Having our advocacy service involved has usually meant that someone is there to explain & explore potential new options or at least make people aware of what resources might be available. A huge piece of this work was completed before people moving to a school for example and enabled people to have a look at their options and become familiar with what they might experience in the future.

What we are experiencing now with our transition based referrals is quite different. We are still receiving referrals from people who are preparing to leave school and move on to new resources.

The difference and indeed the challenge for our service is that we are not in a position to support someone to look at potential options until a "Budget" has been agreed through the Self-Directed Support Assessment. This has impacted on our role as we are not able to help individuals to explore options unless we are confident that a budget will be awarded allowing them to afford the option in question.

This has been very frustrating so far for our transition based referrals as budgets have not been

agreed early enough for people to explore options while still at school. This has caused a lot of distress and confusion for our advocacy partners and their families.

As advocacy workers our role has now changed from helping people to look at potential options and instead we are now supporting people to request if their assessments can get completed as quickly as possible.

This is going to be a very difficult ask as so far none of our current referrals has managed to get budgets agreed in time for leaving school. Another negative from this process is that it is then too late for potential new providers to shadow school staff who have a wealth of experience and knowledge of our advocacy partners.

To summarise there is still a huge need for advocacy support during the transition but the actual delivery of the support has had to be adapted to comply with the Self Directed Support Assessment.

Case Study 3

S had completed her training at the Coal Yard and was anxious to find paid employment. The Coal Yard had supported S to seek help from a Disability Employment Adviser at Job Centre Plus who referred her to Remploy, Hamilton.

S came to Speak Out advising that Remploy had supported her to complete a CV but had been unable to find paid work for her. She asked me if I could support her to raise her concerns with her Remploy adviser.

The Remploy adviser explained that she had searched but had been unable to find a paid position for S.

S and I talked at length about her training at the Coal Yard. She spoke about the work experience she had completed her training. S agreed that we should contact the work experience placements to see if they had any openings. At S'Ss request, I spoke to the manager of the care home where S' work experience had been particularly successful. The manager was very positive about S' former placement and promised that as soon as a post became available, she would get in touch.

S and I met with the DEA to find out how this would affect her benefits. He advised that providing S works for no more than 16 hours and earns no more than £107 per week she could do permitted work for a year and still keep her current benefits. After a year if she continues to work, there are other benefits to which she should be entitled. S lived with her family which meant that housing benefit was not an issue. S and I discussed this information at length to enable her to make an informed choice about whether she should work or not. S decided that on balance she had far more to gain than to lose by accepting the paid position at the care

home. The manager offered S a paid position at the care home. The manager and the DEA worked together to ensure that S'Ss income and benefits were maximised. Six months later S continues to be gainfully employed.

Case Study 4

J was referred to advocacy due to falling health and having to use a wheelchair as this resulting in him having greater support needs. He had multiple issues, housing, support, health and transport.

Many meetings took place, and things moved slowly. Support came from the local authority managing the budget, but there were problems with provider reliability, the result being he was left without social support on many occasions and the personal care issues were only resolved when the authority's care provision was put in place.

Health issues were resolved, transport issues resolved, care plans changed to meet J's changing needs. The only issue that has not moved forward is suitable accessible housing. With other issues, there were always the different option to explore and reach resolution, but housing or lack of it was always going to negate any progress made in other areas. J is still stuck in a house that is totally unsuitable and for him and about 90% inaccessible.

The Speak Out Team:

Patricia Kearns – *Project Leader [job share]*

Jim Walsh – *Project Leader [job-share]*

Greig Skeffington – *Project Worker*

Helen Clark - *Project Worker*

Linda Campbell – *Project Worker [Physical
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Sandie Carnegie – *Project Worker [Parenting
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Jordan Womersley – *Administrative Worker*

Trustees:

Sinclair Laird

Madge Clark

Kathleen Gilgunn

Gerardine Hand

William Learmonth

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