



Evaluation of Pacesetters Wave 1 Local Change Ideas

NHS Sheffield Disability Project

Pacesetters Information and Signposting Service. Coordinated by Inclusive Living Sheffield (ILS)

Evaluation Report prepared by
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Sheffield PCT Disability Project

Pacesetters Information and Signposting Service, coordinated by Inclusive Living Sheffield (ILS)

1. Context and Background

The initial idea for the project grew out of the recognition that the advocacy and information needs of disabled people in Sheffield were not well-served. This need was identified and discussed at a 'Partners for Inclusion' consultation event in September 2006. By February the following year potential funds had been identified through Sheffield PCT's involvement with the Pacesetters programme to undertake work around disability issues and by the end of 2007, total funding of £12,000 was confirmed for Inclusive Living Sheffield (ILS) to develop and run the project.

The project was launched at a 'Partners for Inclusion' event in December 2007. Its aim was to provide a signposting and information service for disabled people in Sheffield and for the service to be staffed by disabled volunteers. At around this time also, the first volunteers began to come forward.

2. Inputs & Activities

Through the early part of 2008 the groundwork for the project began, including the drawing up and approval of role descriptions and volunteer agreements. At this time the project was being coordinated by ILS Executive Director Jacquie Stubbs though the intention was to appoint a paid Information Officer whose job it would be to set up and coordinate the service. Val Bowen took up this ILS-funded post in July 2008.

On starting in the job, Val recalls how she needed to begin work immediately on the induction programme for volunteers and in developing processes and procedures for the service itself. She remembers her initial surprise at finding volunteers already recruited and ready to start work; however, both she and the volunteers feel that this resulted in a very participatory process and helped to develop a shared sense of ownership over the project.

In the weeks that followed her appointment, Val and the volunteers were extremely busy. In the early stages of the project Val worked closely with individual volunteers to identify both their expectations in working with the project and the skills and experience they brought to the role. She was also interested in finding out what skills or knowledge they hoped to develop through volunteering so that, wherever possible, she could match them to tasks according to those interests.



The Pacesetters Volunteer Team at their first team meeting

In reflecting on those busy months – it is clear that the time invested in developing the team and helping individual volunteers feel comfortable in their role is considered extremely valuable. The team appears to remember every team meeting and what they did at each and volunteers recall particular ice-breaker activities which put them at ease with one another and countered the potential stresses associated with taking up a new volunteer position on a new project. By this stage other volunteers had also joined the project. One of them, Sarah, recalls her initial interest and the fact that she had ‘not heard of anything like this before’.

As the process of setting up the service progressed Val supported volunteers through a series of training sessions familiarising them with existing databases and websites, both national and local, and how to access information through them.

Another major task for the team at this time was publicising and raising awareness of the service across the City. Leaflets and posters were designed, printed and distributed and the team had a stand at a conference event in Rotherham in October 2008. As a result of these efforts, the first enquiries started to come in.

3. Outputs

3.1 The Volunteer Team

As the service began to operate, staff and volunteers recall feeling overwhelmed by how much there was to do and the challenges of responding to public enquiries: ‘It’s mind boggling how much information there is out there if you know how to access it.’

A key priority for the project at this stage was to build and sustain the team in order that all volunteers felt secure and supported in their roles and able to work effectively. This was undertaken through a series of carefully planned and facilitated team meetings in which the team developed and signed up to shared objectives, processes and ground rules for delivering the service and working together. Volunteers began recording calls and enquiries on an enquiry form and also to keep reflective journals themselves, through which to keep track of their own learning and ideas relating to the project.

3.2 Respdng to Enquiries

Many of the achievements of the service are captured through the mini 'case studies' of enquiries they received. These appear to span a range of subjects, from health to housing to transport but, for the staff and volunteers many of them represent personal stories and powerful examples of the service offered.

Profile: Cicely – Breast Cancer Patient

Request: Cicely, aged 89 had just been discharged from Hallamshire Hospital after having both breasts removed due to cancer. Referred by an ILS Advocacy worker who was helping with practical support needs having requested information from the Pacesetters service on counselling and emotional support for her condition. Cicely looks well 'for her age' and feels this has disguised the pain and trauma she is feeling inside.

Action: produced an information sheet containing details of local and national support groups/helplines including Weston Park Cancer Support Centre. (The Centre had contacted the Pacesetters Service with details of their activity and therapy sessions and can arrange supported care in a day care setting if required.)

Feedback: "Highly delighted. Thank you."

Profile: Community Mental Health Team on behalf of young carer.

Request: 65 year old client with dementia is cared for by granddaughter who suffers from random epilepsy and is afraid to leave the house. Could we suggest any activities and/or support groups for her granddaughter.

Action: provided information sheet detailing local epilepsy support groups plus the Carers' centre and Young Carers' Association. Mailed Leisure and Social Activity Factsheets.

Feedback: "Thank you very much for your very prompt and useful information which I will pass on to the young lady in question."

Profile: Caroline, ILS Member

Request: Would like to try out an adult tricycle to improve her health.

Action: Signposted to 'Sheffield Wheel for All' Project.

Feedback: "What a positive day I've had today! Pacesetters put me in touch with a cycling scheme and I've just cycled over a mile in a trike. I feel proud of myself for doing this without feeling too 'different'. I feel very included.



Profile: John, Visually impaired

Request: Ongoing problems with various NHS services causing loss of confidence in treatment e.g. Hallamshire Eye Clinic refuse to send letters or email him in a font size he can read (Arial 24). He also cannot read prescription dosages.

Action: Signposted to ILS advocacy service to resolve communication issues and Wicker Pharmacy to deliver prescriptions labelled in requested font size. Sourced 'talking labels' product. As a result of advocate support the Eye Clinic identified a loophole in their computer appointment system and have promised to improve it. Through the course of the year John contacted the Service with further queried and information requests.

Feedback: "Thank you for your quick replies to my emails with the information I required."

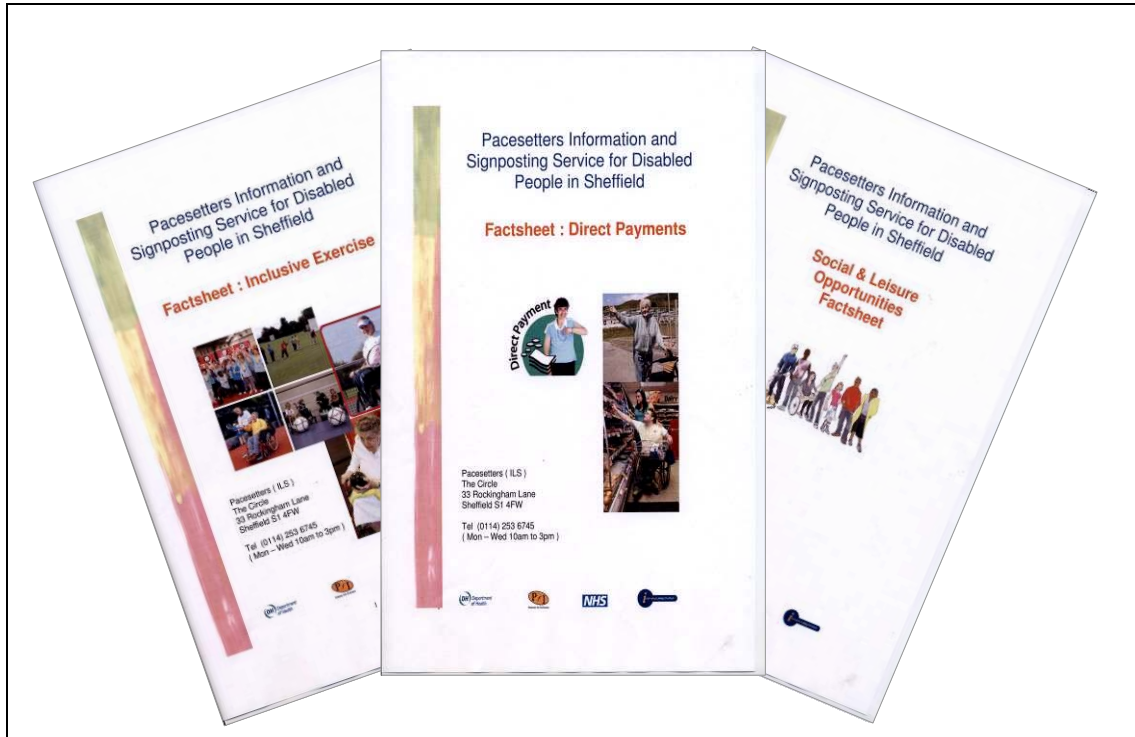
All enquiries received by the project are recorded in a database. A summary of that data is shown below and clearly illustrates the breadth of information the service has been required to find on behalf of callers:

| | | | |
|-------------------------------------|---------|--------------------------|-----------|
| Total Calls received as of 26/10/09 | | 142 | |
| Referred by: | Self 61 | Family 33 | Agency 47 |
| Enquiry Categories: | | | |
| Access | 12 | Advocacy | 5 |
| Blue Badge | 2 | Community Transport | 3 |
| Disability Discrimination Act | 5 | Direct Payments | 12 |
| Employment | 11 | Equipment | 17 |
| GP Charges | 1 | Grants | 8 |
| Health | 16 | Holidays | 2 |
| Housing | 13 | Independent Living | 2 |
| Immigration | 1 | Learning | 2 |
| Leisure | 5 | Mobility | 2 |
| Social Care | 5 | Social Groups/Activities | 15 |
| Support Groups | 8 | Support Services | 7 |
| Training | 2 | Travel | 8 |
| Volunteering | 7 | Welfare rights | 10 |

N.B Some enquiries fall into more than one category

3.3 Researching and producing information and factsheets

Towards the end of 2008 the team was starting to compile and distribute information sheets based on frequently asked questions and areas of recognised need. They had also identified their 'Top Ten Websites' for disability-related information and were putting together weekly e-bulletins of information and notices to be sent to members. This process of researching and editing available information and turning it into accessible resources is clearly seen by all as another important contribution of the project.



3.4 Raising public awareness and networking

During the year staff and volunteers have participated in several events, exhibitions and conferences, helping to raise the profile and public awareness of the service.



They have a mutually beneficial link with the ILS Advocacy Service which refers people to the Pacesetters service and vice versa and have also developed relationships with other agencies and services .For example the story of one of the Pacesetters volunteers, Dale Smith, and the Pacesetters project was chosen to feature in Sheffield Volunteer Centre’s “Diversity in Volunteering ‘ exhibition at venues across the city . The exhibition, highlighting the valuable contribution of volunteers from diverse backgrounds, was launched in the Gallery at The Circle on Rockingham Lane to mark the start of

National Volunteering Week from 1st – 5th June 2009. The exhibition reflects the Government's commitment to tackling barriers to volunteering. Sheffield First's Strategic Volunteering Manager who attended the launch will be working with agencies including ILS to progress a strategy to increase the number and diversity of volunteers in Sheffield. Evidence and experience gained on supporting disabled volunteers in the Pacesetters project will be shared and will contribute towards a Best Practice Guide for Volunteering.

The project has also participated in two focus groups arranged by ILS. The first of these, on 'Achieving Balanced Health ' was held on 26th August 2008 and the second, which took place on 20th May 2009 sought to gain ILS members' views on how NHS Sheffield can make their engagement and consultation activity accessible to all disabled people.

3.5 Weekly mailouts to ILS membership

A further output of the Project are the weekly mailouts of news items sent to disabled individuals and organisations on the ILS database of members. The project sees this as a key activity in meeting the information needs of disabled residents, ensuring they have regular updates of disability-related news and information.

The Personal Assistants Network is a Department of Health funded website which provides information and guidance for Personal Assistants, people who would like to become a P.A. and people who already employ a P.A. or would like to. PANet also provides information on Individual Budgets, Direct Payments and the Personalisation agenda. You can join PANet at <http://www.panet.org.uk/> (membership is free)



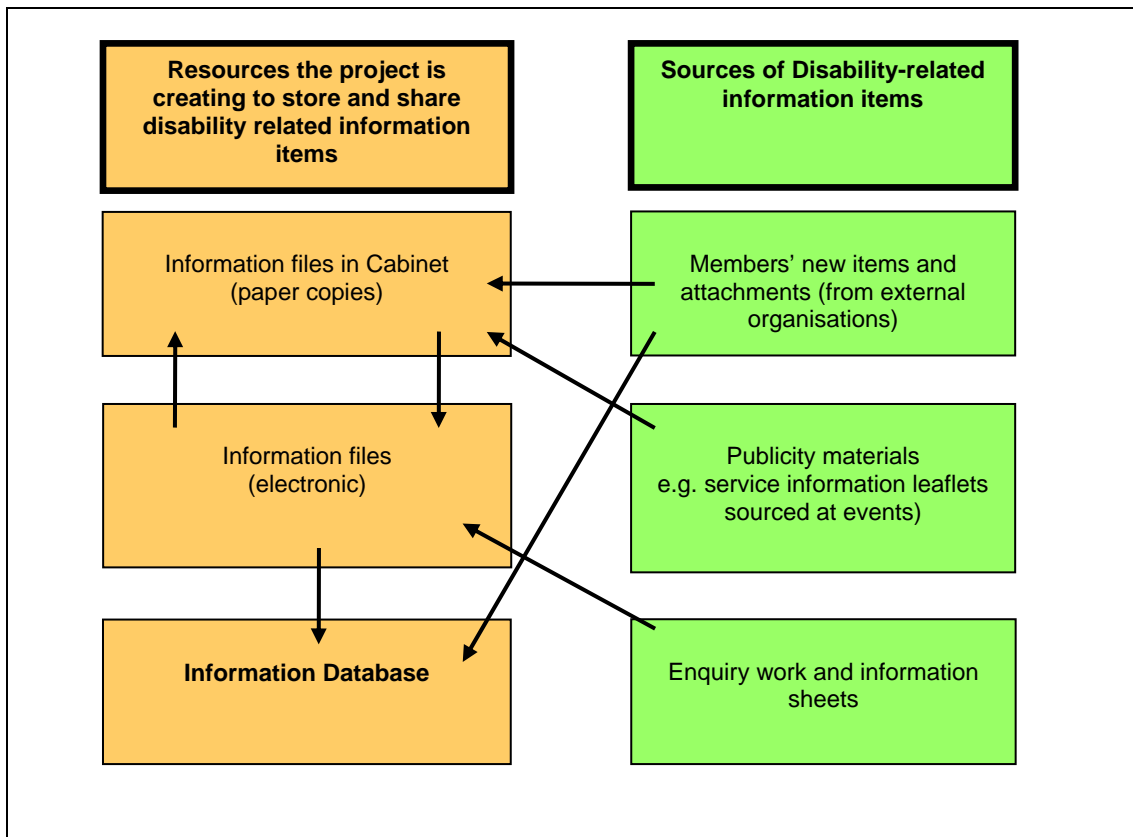
Joanne Richardson is the new Information Officer at the Sheffield M.E. Group. The group help with queries on health issues, local services and facilities or anything to make living with ME/CFS easier. You can visit their website at www.SheffieldMEgroup.co.uk or tel/fax (0114) 253 6700 from 10-12 and 1-4pm Tuesday to Friday. Their Listening Ear Helpline (0114) 258 014 is weekdays from 5 - 6 pm. Alternatively e mail the group at info@SheffieldMEgroup.co.uk

Some examples of news items from mailouts

3.6 Information Management Systems

A final important output of the project are the systems they have put in place to source, record and disseminate information. This lies at the very heart of what the project was created to do and has had to be managed in a clear and systematic way in order for the service to be able to operate effectively.

The component parts of this system and the relationship between them are illustrated in the diagram below.



4. Outcomes

Looking back over this period – the team reflected that the project had come a long way and listed a number of key achievements. The first of these is the development and operation of a service which is clearly appreciated by those who have used it and has the potential to grow and cast its net still wider. Volunteers, in recounting examples of the queries they have responded to and the people they have helped speak of this as ‘genuinely rewarding’ work.

Another achievement recognised by the team is the way in which the project has recruited, trained and supported a team of disabled volunteers. Not only has the volunteers’ personal experience of disability enriched their understanding of, and response to enquiries from the public – but the project has also clearly developed their skills and confidence, supporting them in their transition into work (voluntary or otherwise), training or education.

This achievement is evidently important to the team and they have, through the project, gathered a wealth of information, experience and advice on supporting disabled volunteers. Many of the volunteers have personal stories to tell of how their involvement with the project has impacted on their lives. Some of these are recounted below.

Neil Simpson

Neil Simpson is 54 years old and has been a volunteer with the Pacesetters project since it began. Neil suffers from minimal cerebral palsy and is also a carer for his elderly disabled mother.

Describing himself as at 'the upper end of disability' he adds, *"People at the upper end of disability often have no contact with disability support groups at all"*. This was part of his motivation to volunteer and he has been on the executive of the local Cerebral Palsy Association for 10 years.



Working 1 day a week for the Pacesetters project, Neil is involved in collating information for databases and also undertakes research in response to enquiries. Through the project he feels he has developed a range of new skills, particularly internet research and online survey skills. *"Having not worked in an office for 25 to 30 years, I've also picked up basic office skills as well."*

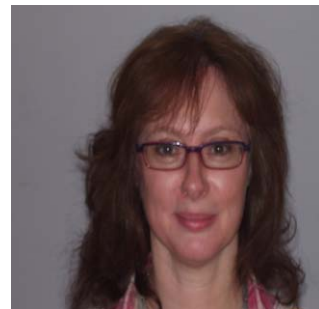
Neil is committed to the project and driven by a desire to help address the information gap in relation to disability issues. Reflecting on the years he spent not realising he was entitled to Disability Living Allowance, he feels people often don't know where to turn for information. *"The stuff's out there. You've just got to know where to look for it"*.

His enthusiasm for the work has recently prompted him to switch from the part-time English degree he was studying for when he joined the project, to a course in 'Community Studies'. On a personal level, Neil has also benefitted directly from the information service offered by the project; he recently sought information and advice in relation to his elderly mother's rehabilitation. *"One of my claims to fame is that I was logged as the 100th enquiry received by the project"*

Dale -Smith

Dale is 46 years old and was diagnosed with Aspergers Syndrome 5 years ago. She has been a volunteer with the Pacesetters project for the last 8 months.

Dale recalls the difficulties she experienced in holding down jobs in the past, prior to her diagnosis. *"I've always found it difficult to deal with people and relationships...I became ostracised and alienated in the workplace"*. After she was diagnosed, Dale was struck by how little support was available – particularly for adults on the autism spectrum. *"There's nothing in place for people, there's no back-up. Once you've got your diagnosis – that's it. You're just told to go away – there's nothing there"*.



Her own interest in accessing and sharing information on Autism prompted her to look for volunteering opportunities and eventually led her to the Pacesetters project. *"I wanted to do it because it was about information and I thought I could perhaps throw new light on it from an autistic perspective"*.

Dale works one day a week with the project and undertakes a variety of tasks including putting the newsletters together, updating the Newsboard and information sheets, and researching enquiries. She would like in the future to become more directly involved in dealing with enquiries. *"I'm not particularly good on the telephone, but I'd like to build up to that. Once I've built my own knowledge and experience, then I can perhaps talk about it a bit"*

more fluently over the phone.”

As well as providing an opportunity to build on and develop her existing IT skills the project has enabled her to access valuable information and consultation opportunities, allowing her to advocate effectively on behalf of adults with autism. The experience, she feels, has been a positive one, increasing her awareness and understanding of a range of disabilities – and, she hopes, helping others to better understand hers.

Dale was recently nominated and selected for an exhibition celebrating ‘Diversity in Volunteering’. Describing the challenges she has faced and what she has gained through volunteering, she wrote:

“As a female on the autism spectrum, voluntary work has helped me to progress my interaction with people in the wider public since my diagnosis five years ago. I have had to overcome years of alienation in settings of that nature due to misunderstandings of communication and behaviour. Working as a volunteer for ILS is a personal challenge and a chance to prove my worth.”

A number of other volunteers have also benefited from their experience of working with the project. One of these, Sarah, has successfully applied for a part-time administrative post at Sheffield Teaching Hospitals NHS Foundation Trust, drawing on the experience and skills acquired through the Pacesetters project.

Another volunteer, Janet, is also an ILS Director/ board member. As a result of her Pacesetters volunteer role she now takes a more in depth, ‘frontline’ understanding of the project to board meetings. Janet’s enquiry work skills are very strong and she has a long-standing involvement with Sheffield Carers’ Centre and also sits on the North Sheffield Grants Panel for the South Yorkshire Community Foundation. Although clearly bringing a wealth of relevant experience to the project, she too feels that she has learned a great deal about disability issues from the wider perspective afforded by volunteering for the project. She now also participates in the NHS Expert Patients’ Programme.

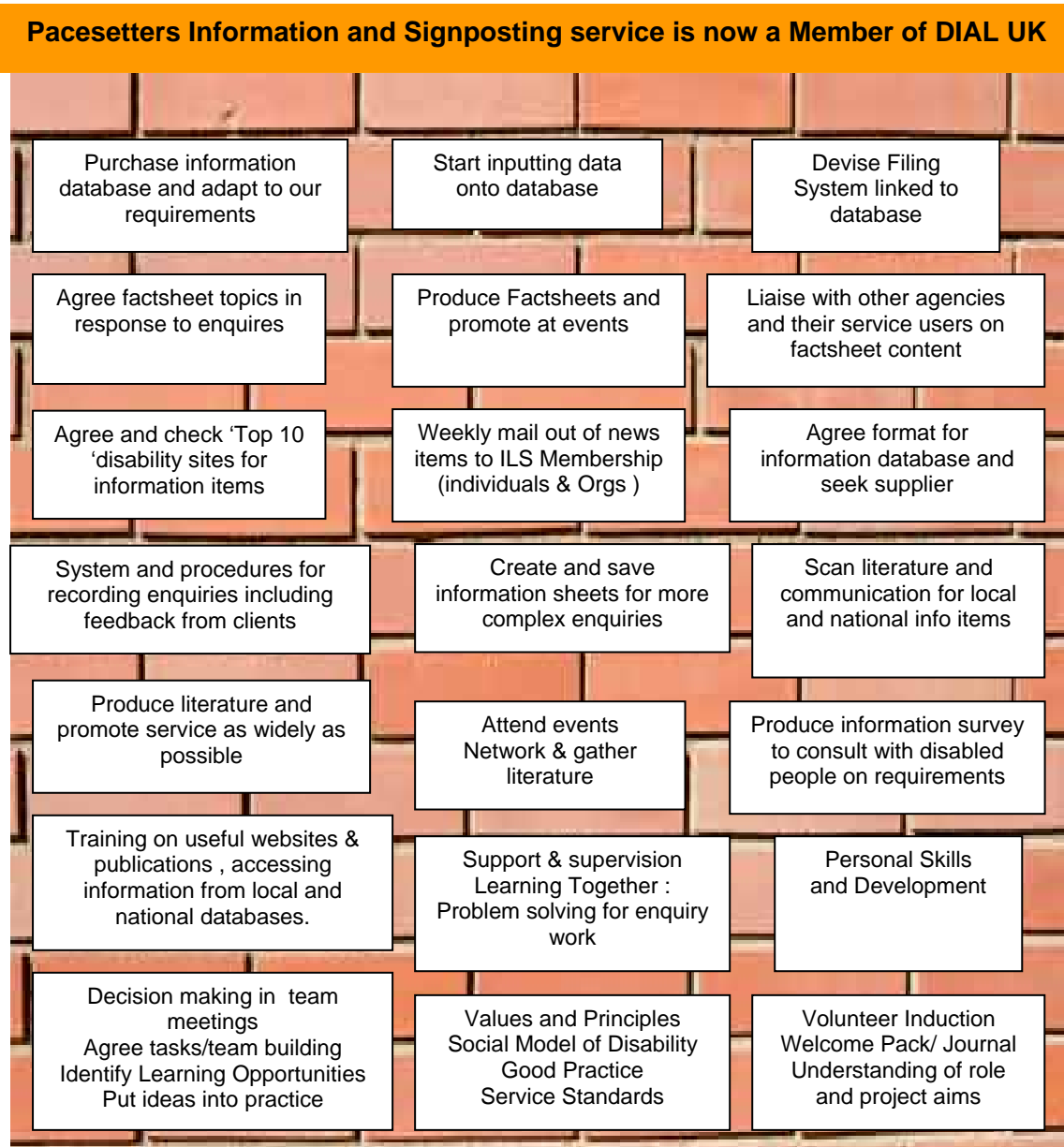
5. Key Learning

In accounting for the evident success of the project the volunteers acknowledge and praise the **crucial role played by the project coordinator** in guiding and supporting their work. They see this role, and the individual who performed it, as the key to their success. Having someone at the helm who is calm, supportive, organised and systematic in their thinking has enabled them to perform their roles flexibly and without the stress that often accompanies responsibility.

Val herself describes the progress of the project and her approach to the work in terms of ‘building blocks’. Crucial to the success of the project, she feels, was **getting certain foundations in place so that the service could develop in a systematic and sustainable way**. Some of those tasks and the

way in which they were sequenced and became mutually supportive are illustrated in the figure below:

Building Blocks of Service Development



Each set of tasks generated learning and led to the acquisition of new skills and awareness. However, underpinning the entire structure is the sense of team spirit and a culture of collaboration and partnership.

Several of the volunteers speak of how they 'look forward' to their allotted days at ILS. Val, in turn, praises **the commitment and enthusiasm of the volunteers**. The project has lost very few over the period since it began; one or two have had to leave due to illness or the limitations of their disability, but the majority have been with the project throughout – and show no signs of leaving.

Success is also attributed by the team to **the role of ILS as the 'host organisation'** for the project. In supporting and providing an infrastructure for the service – as well as an established profile and network of contacts, ILS has played a key role in getting the project off the ground. Although there is, perhaps inevitably, uncertainty over continued funding for the service – the team themselves are full of ideas and plans for the future.

6. Next Steps

Building on the success of the 'story so far', the project has a number of objectives for consolidating and improving the service in the future.

- To work towards the DIAL quality standard for information and advice giving.
- To look into achieving the Legal Services Commission quality mark for general advice giving work.
- To secure funding to support further training and development for volunteers, particularly around Welfare Benefits and peer-support for personal budgets.
- To secure funding for outreach work with disabled and older people requiring support with disability and health related issues.
- To gather evidence to lobby the statutory sector to support the organisation to further develop the NHS-funded Inclusive Sheffield Advocacy Service.
- To secure the future of the service to become a Disability Information Service for Sheffield operating within a Sheffield Centre for Inclusive Living.
- To improve accessibility and awareness of the service through the redevelopment of the website and publicity materials.
- To improve the information and materials, making them accessible in alternative formats to include easy words and pictures for disabled people with learning difficulties.

Report prepared by:

Sarah Thomas, on behalf of and in partnership with the Project Team
October 2009