

An evaluation of the Forge Centre and Shield: Support services for people in South Yorkshire infected and affected by HIV / AIDS and/or Hepatitis C

Aims and scope of the evaluation

This evaluation is a result of collaboration between Sheffield City Council's dedicated social work team at the Forge Centre, and a South Yorkshire charity, Shield. The two services commissioned Sheffield Hallam University to undertake the data analysis and report writing for their evaluation questionnaire. The findings are based on 50 responses to a self-completion survey sent to current and former Forge Centre and/or Shield service users (approximately 350).

The Forge Centre provides a specialist social work and counselling service for people infected and affected by HIV/AIDS and/or Hepatitis C. The centre:

- offers a wide range of services and information to meet individual and/or family/carer need;
- offers specialist advice, counselling and advocacy within a confidential setting;
- offers visits in hospital, at the Forge Centre, or at home;
- offers confidential counselling and arrangements for testing;
- can provide or arrange mainstream services, e.g. home support, adaptations to the home, or day care;
- can carry out carers assessments, provide support and/or arrange breaks for carers; and
- can give details of, and refer to, other agencies which can offer support, including voluntary organisations.

Shield began in 1985, as the Sheffield AIDS Support Group (Shield), becoming a registered charity in 1988. The organisation has paid members of staff, and volunteers, with centres in Sheffield and Rotherham. Its aims are to:

- Improve the quality of life for people affected by HIV and/or Hepatitis C
- Provide services that directly benefit service users and members
- Support, develop and promote better understanding towards HIV
- Build partnerships between public, voluntary and community based organisations.

Areas of strength

The majority of respondents were positive about the support they had received at the Forge Centre and/or Shield. A clear strength of both services was the **range of support** available, including:

- **Emotional support** and being "*listened to*", which often provided service users with comfort, confidence, and/or validation. Many respondents highlighted the value of having someone they knew they could talk to openly without being judged. This was important because some individuals chose (or felt forced) to keep their HIV status undisclosed elsewhere, or because friends, colleagues or family were not supportive.
- **Practical support**, including a wide variety, such as: information provision (e.g. around substance/alcohol use or new HIV treatments); support with setting up care provision; signposting/referrals to other agencies; advice and support regarding treatment/medication; help with housing issues; assistance with applying for benefit applications; financial assistance, food hampers and/or budgeting advice; IT training; arranging complementary therapies; help with transportation, and access to a gym. This portfolio of support is significant in highlighting the demand for extensive and up-to-date knowledge on the part of service staff/volunteers, the need for ongoing training on specific issues for staff/volunteers, and obvious budget implications for both services.
- **Social support**, whether facilitated by staff/volunteers, or offered from other service users (in the form of **peer support**). Networking activities included lunch groups and day trips. The importance of "*knowing others out there like me*" was explicit, with some respondents emphasising their social isolation outside of the Forge Centre and/or Shield. Both the emotional support received from staff/volunteers, and the strength gained from feeling part of a social group, appeared to facilitate a sense of belonging for some evaluation participants. To know you are "*not the only one with HIV*" is likely to help facilitate a more positive self-identity in a social context where stigma towards people with HIV is still strong.

"This is my only contact with the outside world and people like me. I think of Shield as a lifeline"

Impact of support

The vast majority of participants' comments were positive, and there was a clear sense of appreciation, or 'gratitude', for the services. Some expressed fears about the continuation of services should funding difficulties arise. In analysing specific ways in which services impacted upon service user's lives, the following themes emerged:

- **Dealing with depression** and the physical, emotional, practical and social issues that having HIV can

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precipitate. Services offered by the Forge Centre and/or Shield helped respondents to address some of these issues.

- **Building a “new life”** after being diagnosed with HIV. There was a clear sense that for some respondents the Forge Centre and/or Shield had helped to facilitate this, through offering a variety of support that combined to help improve respondents’ outlook on life.

“I’ve known people from the Forge Centre for about nine years and they have helped me build a new life for myself”
“The Forge Centre and Shield have helped me regain my life, helping put finances and support in place to help live a better life”

- **The long term nature of support needs**, as highlighted above. It is likely, and significant to funding resources, that (re)building a sense of belonging and a more positive self-identity are gradual processes that require ongoing long-term support. Circumstances associated with living with HIV/AIDS may also change and create new or evolving support needs, such as changing health and subsequent care and housing needs. The importance of support services to irregular service users was also highlighted by the sense of security in knowing it was there for future needs: *“Through choice I do not access services as I’m fit and well, although it’s nice to know that Shield and the Forge Centre are there if I need them”*.
- **Empowerment**, linked to increased confidence and/or self-worth was also highlighted by some evaluation participants as a result of support received from the Forge Centre or Shield.
- **Efficient services** were emphasised by participants in their sense of gratitude, and comments made on the impact that support had had on their lives.
- **Issues around confidentiality** were key to some participants, demonstrated in their response to the survey (e.g. not being willing to use their own handwriting), and in how they accessed and experienced support. The importance of many of the themes described above were more explicit when respondents said that no-one else knew their HIV status so the support they received from the Forge Centre and/or Shield was the only support they received, highlighting the sense of isolation that many service users felt.
- **Invaluable services** for service users were illustrated in many different ways. Without the Forge Centre and/or Shield many of the respondents may have lived more socially isolated lives. Participants highlighted the guaranteed nature of the support (e.g. knowing that there was *“someone there to talk to if I need it”*), and the regularity of contact.

“Reassuring and excellent support from the Forge Centre. Couldn’t cope without it.”

“Like you’ve never known, they gave me the strength to keep fighting”

“I would have struggled without the assistance because I am very isolated in Sheffield.”

Areas for potential improvement

Whilst the majority of respondents were positive about their experiences of support, a number of issues raised can be considered as ‘areas for potential improvement’, including **access** and **organisational issues**:

- **Awareness of services** as a minority of respondents said that they knew people who had not heard of Shield or the Forge Centre. Some respondents suggested that more publicity was needed to address this, however there are resource implications, both in terms of the cost of advertising the services, and in coping with any increasing service user numbers.
- **Location of services** as it was clear from respondents that those living outside Sheffield felt that they did not have access to the same level of support as did those living within Sheffield. Respondents from Rotherham and Barnsley commented that they found it difficult to reach services being offered in Sheffield.
- **Resources**, i.e. the numbers of staff/volunteers available to support people wishing to access services. Issues raised included the difficulty of making appointments with social workers, phone calls not being returned, and staff shortages (either in general or through staff sickness or leave).

“Due to staff sicknesses it has been difficult to speak to someone at the Forge... calls are never returned”

“Sometimes getting through to Shield and the Forge is difficult, I know they are extremely busy and I know Shield only has one phone line and many clients”

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For some, this resulted in a sense that their support was restricted and/or in decline. Based on the evidence available (this survey), it is not possible to say with certainty whether services are stretched, or whether specific respondents had unique and unfortunate experiences in trying to access services. For a vocal minority there were issues about declining services due to increasing service user numbers, sometimes directed at specific groups accessing services. It is evident that this may be causing some feelings of resentment on the part of service users who had been in contact with the Forge Centre and/or Shield for longer periods of time:

"In the last 12 months I have seen the support I received from the Forge crumble due to increased numbers of people receiving support and I have relied on Shield for additional support"

"I now find Forge workers overstretched and unavailable... it seems that priorities have to be made and if you are not in imminent danger you are not a priority anymore"

"Shield has an inclusive policy which is good and they do say that they are there to support people affected by HIV and not asylum. I am concerned that although they say they are supporting people living in South Yorkshire... too much of their services are going to support failed asylum seekers"

- **Service delivery methods**, tending to focus on issues of communication or the organisational set-up of the service. Respondents particularly raised organisational issues when discussing Shield. More (in-depth) research is needed to understand this further, e.g. to see how widespread these feelings are, or if they were from a minority who perhaps did not like the nature of the service. It could be, for instance, that in comparison to other services, an organisation that uses many volunteers (rather than a small number of paid staff) may appear to be less organised. Alternatively, it could be a result of scarce resources, for example a lack of paid staff to co-ordinate volunteer activities.

"Shield chaotic"

"Shield not helpful to me. Left to own devices, no direction or welcome"

"I think Shield can be a bit hit and miss with its service"

- **Confidentiality** concerns were clearly important to respondents. Ways to improve services in terms of confidential entrances and/or waiting rooms could be explored, however this needs to be balanced with ease of finding the service, and being careful not to appear to stigmatise HIV.

"I live in Sheffield and am unable to access Shield because I feel somebody will recognise me"

"When I visit the Forge Centre there is no specific waiting area, only a few chairs in the entrance. This is not confidential and feels like I am in a goldfish bowl. I also feel that the area can be a little intimidating as there is always (on my visits to the centre) a high volume of staff/visitors coming in and out and although I am not ashamed of my HIV status I would prefer that all Social work department staff and Forge Centre staff didn't know/assume by seeing me there in full view that I was in fact HIV positive"

Suggestions for improvement

When asked how services could be improved, respondents offered a wide variety of suggestions, including:

- introduce name badges for staff and volunteers at Shield
- more joint/closer working between the two organisations to offer a more 'integrated' support experience
- longer and/or clearer and more consistent opening hours, particularly outside of normal working hours
- only provide support to HIV+ people, and run more specific support groups e.g. gay men and young people
- improve communication between staff and volunteers in relation to service user casework
- keep appointments with service users and return people's calls
- provide more financial aid
- continue/increase consultation with service users
- move or provide additional locations (e.g. in Barnsley)
- provide more and/or more varied social support, and vary the staff involved more
- provide specific asylum and immigration support
- have more follow-up of service users, and have outreach to people's homes
- improve hygiene standards at Shield
- introduce a (hard copy) weekly events listing and an overall directory of services which could be mailed out to service users so that they are clear what is happening on each day, where, and at what time.

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Specific support

An issue that emerged in the evaluation is connected to a debate about whether or not HIV support services need to specifically cater for particular groups, or whether 'generic' support is sufficient and/or desirable. There was a strong split in opinion amongst respondents. A number of Shield users specifically identified the general / non-specific nature of the support available to the "whole community" as appealing. However, two forms of specific provision were also often requested: a gay men's support group, and a group for HIV+ people from Africa.

"I don't want to go anywhere where peoples' needs are pampered to... We all have HIV in common and anything else is irrelevant. All groups should be based around this, not people's skin colour or sexuality."

Conclusions

There was an overwhelming sense from the evaluation data that there is a need for a variety of forms of support, including practical, emotional, and the facilitation of peer/social support in order to help combat the plethora of issues that people infected/affected by HIV may face – both in terms of the actual virus, and the social prejudice that can relate to it. Services can fulfil a 'fire fighting' role, such as helping with immediate problems around medication, housing or care, but can also (over the long-term) help facilitate a more positive self-identity, a sense of belonging and/or a 'new life' with HIV. The evaluation highlighted the sense of stigma surrounding HIV still feared and/or experienced by many respondents: this emphasises the need and importance of service confidentiality.

A clear theme emerging from the survey results was the wide range and volume of the support currently offered by both services. For many evaluation participants this support was invaluable in combating isolation and/or a negative self-image. The practical information and assistance offered was also crucial for many in helping deal with statutory bodies, for example in relation to benefit entitlements. There was a clear need for both 'professional' support, and peer support from other service users.

Recommendations

1. Explore strategies for effective information exchange between services and service users, and awareness-raising initiatives for service users around expectations and diversity/equality issues (e.g. in newsletters or on waiting room notice boards).
2. Investigate resource and staffing issues with regard to service user dissatisfaction on inability to make appointments, staff failing to keep appointments, staff being unable to respond to telephone calls more routinely, and lack of back-up for staff illness or holidays.
3. Consider dedicated staff and/or hours of operation for telephone numbers so that service users know when there should be a response and/or when messages might be returned.
4. Consider the need for, and implications of, planning and resourcing regular and ongoing training for staff and volunteers on service aims, service user expectations, confidentiality issues, communication skills, etc.
5. Attempt to combat access issues by expanding locations and/or the hours of service offered, particularly in Barnsley and/or outside of normal office hours.
6. Consider the demand and feasibility of more and/or more specific support groups to facilitate peer/social support e.g. for African service users, gay men, and young people.
7. Explore ways to make some people feel more at ease with service confidentiality e.g. through altered entrances and/or waiting rooms.
8. Consider providing a 'Suggestions box' in waiting rooms for ongoing consultation/feedback from service users.
9. Investigate the need and/or feasibility of increasing advertisement of services.
10. Ensure the case for the necessity of long-term funding is clear and consistently promoted. This will ensure both continuity of care for service users, and confidence in their continuity of care.

Further information

For a copy of the full evaluation report please contact the Forge Centre or Shield. The authors would like to thank the respondents for their involvement in this evaluation. Ben Willis and Claire Wolstenholme from Sheffield Hallam University were also involved in the data analysis.



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